Patient Nexus Typologies and Care Management Behaviors:
A Case Study of Youth with Cystic Fibrosis

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Abstract

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This study applies and expands Mark Tausig's patient nexus theory to examine how social support systems influence chronic illness management in youth with Cystic Fibrosis (CF), a life-limiting genetic disease requiring intensive daily care. While social science research recognizes the role of social context in health, less attention has been given to how disparities in social resources shape care management and health outcomes. Patient nexus theory, which views the "caregiving social network around the patient" as central to care behaviors, offers a framework for addressing this gap. Drawing on 21 virtual dyadic interviews with children with CF and their parents across three U.S. care centers, this study explores daily care routines, support systems, and experiences navigating CF. Qualitative analysis reveals five distinct patient nexus typologies: unique configurations of support, agency, and trust in care teams that shape adherence. Youth with greater support and agency demonstrated stronger care management behaviors, while those with limited support and lack of agency faced more challenges. These results underscore the importance of designing interventions that extend beyond individual-focused models to address the broader social and relational contexts impacting care. This is the first empirical application of patient nexus theory to pediatric chronic illness management.

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I. Introduction

Although social science health research has supported greater understanding of the interconnection between the individual, their environment, and their health behaviors, there has been “insufficient discussion” of the “types of networks that support or undermine self-care” and day-to-day management of chronic illness (Rogers et al., 2011). For chronic illness management in particular, there has not been much discussion of the connection between disparities in social resources, disparities in self-care management and adherence, and disparities in morbidity and mortality (Tausig, 2013). Indeed, much of the conversation of chronic illness management has focused on internal aspects that impact adherence, such as self-efficacy and agency. Although self-efficacy and agency can be impacted by one’s social context, there is a lack of conversation in chronic illness management research about this connection between the social context and associated level of efficacy and agency (Franklin et al., 2023). Self-efficacy, understood as the confidence one has in themselves “to perform a behavior” such as maintaining a consistent care routine, has been labeled an important factor to predict self-management of chronic illness (Parcel et al., 1994). Self efficacy impacts one's agency, defined as one’s actual ability and persistent motivation to independently manage and regulate their health behaviors (Sousa et al., 2005; Heckhausen et al., 2019). While internal aspects such as agency are known to be vital in understanding chronic care management, there is a growing conversation to also include the social context of the individual.

An important dimension to better understanding social context is the notion of adherence. Adherence is a critical aspect of chronic care management, understood as how much an individual’s health behaviors (i.e. taking medications, following dietary recommendations, making lifestyle changes) coincides with their care team’s recommendations (Haynes et al., 1979). Adherence is described as one of the “most frustrating problems” for providers and researchers in medicine, from prevention to treatment (Chesney, Morin, and Sherr 2000; Lutfey and Wishner 1999; Pescosolido, 2006). If an individual fails to adhere to their treatment plan and provider recommendations, the blame is placed on the patient and “the individual is seen as failing” due to their own ignorance or lack of initiative (Tausig, 2013). To combat this blame-placing on the individual, recent research has argued for greater responsibility to be taken by the healthcare system to ensure that they provide adequate support and services to facilitate successful chronic care management and adherence (Tausig, 2013; Allegrante et al., 2019). However, health intervention success to maintain or improve patient adherence cannot rely on an educational intervention alone, but must be multifaceted with a behavioral component and possibly self-management and organizational strategies to assist individuals in their particular contexts (Dean, Walters and Hall 2010, Lemanek et al. 2001). To develop such an intervention, there is a need for greater understanding of the social contexts of individuals with chronic illness and the types of support and resources that are available to them. The terms used to describe the kinds of support and resources that are available to an individual in managing their health include those such as "social support systems," "social context," and "patient nexus." While I will use all of these terms interchangeably throughout this paper, my focus for this study is on the latter of the three.

Tausig's patient nexus theory, described as the "caregiving social network around the patient" offers a launching pad to understand an individual's patient support network, the types of support and resources their network offers, and what influencers and barriers currently exist within their context that impact their care management behaviors for chronic illness (Tausig, 2013). With patient nexus theory, Tausig argues that chronic illness management is not "self-care," but rather it is care management that is made up of the self along with the household, social network, and community surrounding the individual (Tausig, 2013). Each patient nexus, made up of family, friends, and "other ties" that have an impact on care management behaviors, is unique with its own social capital and set of resources attached to it, which impact the individual's ability to adhere and adapt to care recommendations, which Tausig argues that providers should take into account when working with their patient (Tausig, 2013).

This study applies and expands upon patient nexus theory using a case study of youth with Cystic Fibrosis (CF), a chronic disease that impacts the lungs, pancreas, and other organs. CF is the most common life-limiting autosomal recessive disease in Caucasians, with about 40,000 children and adults in the United States (O'Sullivan et al., 2009). Although there are some recent studies that discuss patient nexus theory and its potential in understanding barriers to chronic illness management, they do not apply the theory in their methodology or analysis (Boucher, 2022; Boucher et al., 2022; Brahim, 2019). No other study, to my knowledge, has applied patient Nexus Theory in a case study of any group. As such, this study is the first to apply patient nexus theory, and the first to do so with a case of youth who have CF.

Patient nexus theory is especially helpful in relation to management of CF as the theory specifically refers to the management of chronic illness, and it aims to understand the support system an individual possesses and the resources that exist within it. The typical CF care recommendations, which will be described in the following paragraph in greater detail, can be challenging for some (depending on the resources attached to their social context) to implement in day-to-day life due to the time and ability to consume a high-calorie diet, the economic cost to support the CF diet, and the time and energy needed to complete breathing treatments and other care management behaviors. I focus my analysis on youth as adherence in youth with CF is particularly poorly understood due to an over-reliance on adult-only models, lack of consideration of the multitude of influencing factors, and a "lack of synthesis of research, clinical practice, and policy implications" (Oates, 2015). Applying patient nexus theory to a case study of youth with CF will allow for scholars and practitioners to have a better understanding of the different types of patient nexuses in youth with CF, and how care management behavior tendencies differ across them. With this increased understanding, interventions can be developed to prevent and treat adherence challenges with acknowledgement of differing social contexts and disparities of resources available within them.

II. Literature Review

Social Science Influence on Chronic Illness Research

From Anselm Strauss' work in the 70's to today, sociological research has suggested that in order to understand and improve upon how individuals navigate self-care of chronic illness, greater focus must be placed on understanding the social contexts of patients with chronic illness and their associated resources and abilities (Rogers et al., 2011). The idea that patients are set within a particular context that have varying impacts on health behaviors which has an eventual effect on health outcomes has become more widely recognized with continued sociological health research, although large-scale implementation of its importance is still yet to be fully realized today (Pescosolido, 2006; Oates, 2015).

Social sciences have been involved in chronic illness research since the 1950's, with community surveys assessing "the need for medical and social care," which documented in the process the nature of social support in chronic illness and "the impact of illness on family and working life" (Bury, 1997; Patrick & Peach, 1989; Anderson & Bury, 1988). To understand patient behavior, psychologist Kurt Lewin created the equation $B=f(P,E)$ in 1936, which describes behavior as a result of the person (P), and their environment (E) (Lewin, 1946). Early social health research embraced Lewin's equation and focused efforts on understanding the differing impact of the individual versus the environment in determining health behaviors (Ong et al., 2014). While this work initiated the dialogue between social sciences and medical fields, the innovative work of sociologist Anselm Strauss solidified sociological influence in chronic illness work as he drew attention to the connection between public health and chronic health conditions, with implications that lead to the "development of health services" (Strauss, 1975; Corbin & Strauss, 1988; as cited by Taylor & Bury, 2007). In 1988, Strauss and Corbin argued that the challenges of chronic illness must be understood "from the perspective of those with chronic illness," and have asserted that the healthcare system must be constructed in a way that it is harmonious with the reality of the day-to-day experiences and promotes a greater quality of life (Corbin & Strauss, 1988).

While social and sociological health research up to this point has supported greater understanding the interconnection between an individual and their environment, which has an effect on health behaviors, Rogers et al states that there have been "insufficient discussion" of the "types of networks that support or undermine self-care," and that new interventions can be developed with increased understanding of how differing environments can have varied health outcomes (2011). Indeed, Ong et al also notes that while there have been some advances with theories such as Health Behavior Change Theory, not enough attention has been placed onto understanding social context impacts on chronic illness management (Ong et al., 2014). There has also been little discussion on the disparities within social contexts, and the connection between disparities in social resources, self care management, and in morbidity and mortality (Tausig, 2013).

Patient Nexus Theory

Mark Tausig’s patient nexus theory provides a theoretical platform to explore the connections between the social resources one’s support system provides and their chronic care management behaviors. Tausig’s patient nexus theory is described as the “caregiving social network around the patient” (Tausig, 2013). As Tausig states, “the risks of chronic illness and the resources available to deal with it are socially (and unequally) distributed,” which must be accounted for in intervention work to minimize disparities of “risks and resources” that impact an individual’s ability to fulfill treatment recommendations (Tausig, 2013). The patient nexus serves as a critical component in understanding the social context of chronic illness management, as these networks provide both tangible and emotional support that can either facilitate or hinder an individual’s ability to manage their care. Tausig elaborates that the resources within this social network, such as access to information, financial and emotional support, and practical help, can significantly alter an individual’s approach to self-care (Tausig, 2013).

He further argues that internal motivation to engage in care management behaviors is deeply influenced by these social ties and the resources associated with them (Tausig, 2013). This motivation is not just a personal or individual drive but is shaped by the expectations, assistance, and encouragement provided by those within an individual’s social circle. For example, family members may provide emotional support that boosts an individual’s confidence in managing their illness, while friends or peer networks may share valuable coping strategies. Additionally, Tausig discusses how these networks can create a sense of responsibility or obligation, which may either promote greater engagement with care or, conversely, add stress and strain depending on the dynamics of the relationship (Tausig, 2013). Thus, social ties are not merely external influences; they play an integral role in the cognitive and emotional processes that underlie self-care decisions and behaviors.

The goal of using patient nexus theory is to capture a better understanding of an individuals’ “patient support network,” the types of support and resources their network offers, and what influencers and barriers currently exist within their context that impact their care management behaviors. This greater understanding of their social context allows for more successful intervention implementation to support care management behaviors (Tausig, 2013). While recognized as a novel approach to understand patient social context and barriers to chronic care management, there are currently no known studies that apply patient nexus theory to an actual case study of any group. The demand for research on support systems and chronic care management has gained traction in recent years, with Cornwell and Waite describing the in order to “limit the health consequences” of long-term illness, there must be a greater understanding of how to practically manage chronic health conditions in everyday life, which includes an in-depth understanding of the type of social support system an individual possesses (2012).

Individuals with chronic illness use social support to assist them in managing their health and in carrying out their day-to-day lives (Edwards & Boxall, 2013). I utilize Rogers et al.’s broad definition of social support, which is categorized as a “network of networks,” which can be made up of family members, friends, colleagues, neighbors, and more (Rogers et al., 2011).

Using a broad definition of the social support system is described as advantageous in order to fully comprehend the varied and complex types of social support in “illness-related work” and how these vary in their impacts in chronic care management and treatment adherence (Rogers et al., 2011). Understanding challenges with adherence in chronic health conditions is important, as lack of consistent management can increase the risk of hospitalizations, cost of care, and risk of mortality (Sokol et al., 2005; Rasmussen et al., 2007).

Application of Patient Nexus Theory in Individuals with Cystic Fibrosis

While there have been studies exploring social factors that influence self management behaviors and treatment adherence in other chronic conditions “such as asthma and diabetes,” research on the social factors associated with self management behaviors and treatment adherence in individuals with cystic fibrosis is underexplored (Parcel et al., 1994). There is also a lack of research on the “typologies” of support care systems in chronic care management. Studies that exist on support system types for individuals with cancer or HIV describe the different types of people that create the support system for the individual, such as friends, family, or healthcare professionals, rather than defining specific different “types” of patient support systems and the barriers and influencers associated with each type (Cheng et al., 2022; Brashers et al., 2004). There are no current studies, to my knowledge, on different typologies of support systems for individuals with CF. In fact, there is an underwhelming amount of research in just understanding the day-to-day care management experiences of adults and children with CF and the “structural, cultural and attitudinal challenges faced by adults with CF” (Edwards & Boxall, 2013). Cystic fibrosis, also known as CF, is a progressive, genetic, chronic disease that impacts the lungs, digestive system, and other organs of approximately 40,000 children and adults in the United States, and an estimated 105,000 people across 94 countries (CFF 2024a). CF has the greatest impact on the lungs, where the mucus can clog airways and grow bacteria which creates greater risk for “infections, inflammation, respiratory failure, and other complications” (CFF 2024a). Though treatment adherence is vital to successful chronic care, only half of individuals with CF are adherent to their treatment regimens (Quittner, Espelage, Ievers-Landis et al. 2000b, Stark 2003; cited by Oates, 2015).

Especially for individuals with CF, treatment adherence is critical as it is these treatments that assist in slowing down the progressive disease that would ultimately lead to an early death (Oates, 2015). Failure to adhere to treatment recommendations is the “single greatest cause of treatment failure” in those with CF (Oates, 2015). Inconsistent care management behaviors can lead to resistances or reactions to drugs, decreased quality of life, and increased morbidity and mortality (Pai & Drotar, 2010). Research has found that individuals with CF have decreased rates of adherence as they enter adulthood due to decreased parental supervision, increased responsibility and lack of perceived importance, and embarrassment or interference with social life (DiGirolamo et al., 1997; Modi et al., 2010; Llorente et al, 2008). Transfer of care from pediatric to adult medical staff was also found to decrease adherence rates, due to a potential “lack of confidence between patients and adult medical” with the new relationship (Llorente et al, 2008). Additionally, having a lung transplant was associated with decreased adherence rates as individuals may feel overall healthier and perceive treatment as no longer necessary, even though medical staff advise against stopping treatment after lung transplant (Llorente et al, 2008). Adherence is particularly poorly understood in children with chronic illness, and there are few interventions that include understanding of the types of social support systems in children with CF and how they vary in their impacts on care management behaviors (Oates, 2015).

Individuals with CF may receive varying levels of support throughout their life. Williams et al examined the spectrum of caregiver-care-recipient relationships in those with chronic illness and found that as a child with chronic illness ages they take on a more active and independent role with their care management, with the caregiver providing decreasing levels of assistance and supervision (Williams et al., 2007; Nguyen et al., 2016). While the progression of independence and increasing responsibility can occur with age and increasing maturity, an individual's social context determines the level of support an individual receives, the level of trust within the support system, and the types of routines and structure in the individual's environment (Williams et al., 2007).

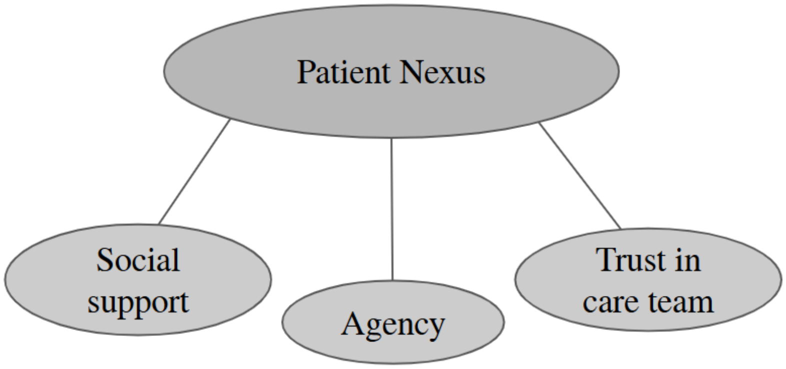
Previous research has shown that having a larger network as a resource while managing a chronic illness is associated with higher self esteem, a greater sense of belonging, and the confidence and sense of control one has over their environment (Cohen 1988; Cornman et al. 2003). In other words, individuals with larger resource networks have a greater sense of agency. Additionally, individuals with chronic illness who possess "larger and more diverse networks" have reduced rates of hospitalization, progression of disease, and mortality (Brummett et al. 2001). As mentioned earlier, an individual's agency and ability to manage their own health can be impacted by their level of self efficacy, or the confidence one has in themselves "to perform a behavior," such as maintaining a consistent care routine (Parcel et al., 1994). The links between self efficacy, agency, and self management all ultimately determine health outcomes in individuals with CF (Oates, 2015).

The strength and size of the social support of an individual with CF may vary - some support systems can serve as resources for health-related information and promote healthy behaviors such as exercising, limiting sugar intake, or meditating, which can act as a buffer to health risks and mental stress (Thoits. 2011). Not all support systems are equal in terms of the resources impact they offer to an individual with a chronic illness, and a well-resourced support system is particularly important during the transition between childhood to young adulthood due to the many adherence challenges that can take place during this time (LLorente et al., 2008). CF is a complex disease that appears differently across individuals and over the life-span (CFF 2024b), and life expectancy is increasing for individuals with CF, which means many will spend more time managing their health and navigating care recommendations (Hugo, 2007). Indeed, management of chronic illness later in life can be challenging in different ways, as stressful events such as "retirement, bereavement, and the advent of health problems" begin to increase (Cornwell & Waite, 2012).

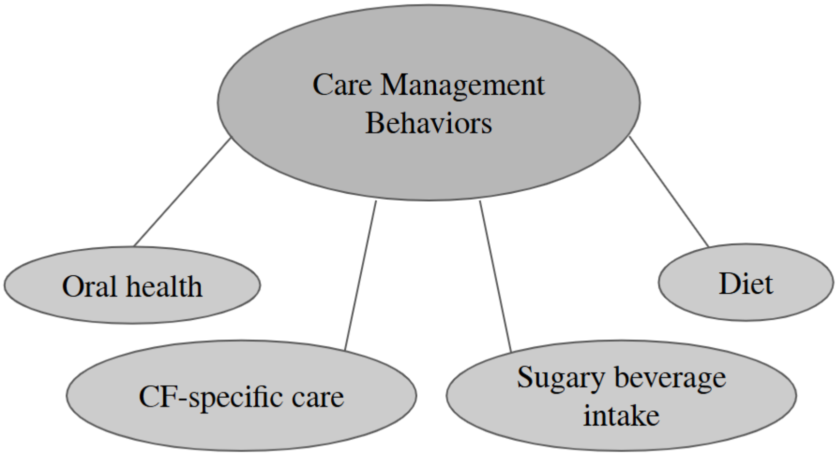
Gaining a greater understanding of the patient nexus an individual is exposed to early in their life with chronic illness, and the adherence challenges and advantages associated within each patient nexus type, allows for implementation of preventative interventions that can support successful care management throughout an individual's lifetime with CF. My research aims to achieve this greater understanding by applying Tausig's patient nexus theory to a case study of youth with CF. Application of patient nexus theory in chronic care research is so far limited, as there have been no studies known to apply the theory specifically to individuals with CF. This research study focuses on care management behaviors such as CF-specific care tasks (daily medication and airway clearance), oral health behaviors, and diet. I will describe the specific care recommendations for individuals with CF in the following section.

Patient Nexus Dimensions & Care Management Behaviors

As stated, I am applying patient nexus theory to frame my analysis of interviews with youth who have CF to understand what typologies of support systems exist among participants, and how care management behaviors vary among them. Below, I have created a visual model to define the different dimensions of the patient nexus. Tausig describes the patient nexus as the resources that come with the support network of family, friends, and any other ties that impact care management behaviors (Tausig, 2013). He also states that internal motivation to engage in care management behaviors is impacted by these social ties and the resources associated with them (Tausig, 2013). With this understanding of the patient nexus, I have defined dimensions to include one's social support system, the level of agency the individual has, and their trust with their CF care team. I include the level of agency and trust in the care team as these two dimensions have been shown to impact treatment adherence in previous research of care management in chronic conditions, and I consider them vital to creating a fuller picture of one's social context (Llorente et al., 2008; Jones et al., 2012).



The care management behaviors I aim to capture amongst participants include oral health behaviors, CF-specific care, sugary beverage intake, and diet.



Care Management for Cystic Fibrosis (CF)

Individuals diagnosed with CF have specific care recommendations for maintenance and preventive care, such as respiratory therapy treatments, a specific diet regimen (high-calorie, high fat, and high protein to maintain weight and encourage weight gain), and medications. In the past thirty years, the life expectancy has increased for individuals with CF due to medical care improvements and better individual care management (McBennett et al., 2021). The 2019 FDA approval of TriKafta, a modulator-therapy drug, has also helped to ease symptoms and will likely further increase the life expectancy for individuals with CF who are eligible to take the drug (Heijerman et al., 2019). With this recent increase in life expectancy, health concerns such as diabetes and obesity have become more prevalent in populations with CF. The risk of diabetes and obesity in individuals with CF has resulted in the evolution of CF dietary recommendations to become more sustainable for long-term health. Additionally, current oral health research has identified oral health diseases impacts on respiratory health and initiated the conversation of the importance of oral health in individuals with CF (Chi & Rosenfeld et al., 2018). While there are no current oral health recommendations for individuals with CF in the United States, ongoing research may lead to the greater importance placed on oral health in regular clinic visits and oral health recommendations for individuals with CF to consider.

During this time of evolving care recommendations, specifically for diet and oral health, it is important to consider how individuals with CF are able to implement current and evolving recommendations within their unique daily life. Through 21 qualitative interviews with children ages 12 to 17 with CF, this research study aims to use patient nexus theory to analyze and identify different nexus typologies of youth with CF, and how their care management behavior tendencies vary across them. This research specifically examines dietary and oral health behaviors as recommendations in dietary and oral health are currently evolving with ongoing research. The findings of this research study are important not only to improve support for youth with CF in realistically applying care recommendations to their daily life as they age into adulthood, but also for other chronic care conditions and treatment plans. At some point in life, every individual will visit a doctor and will likely receive a care plan on how to maintain or improve their health and they will need to fit their care plan within their day-to-day life. This case study of care management in youth with CF contributes to the growing sociological health research on the impact that one's social context, and the unique resources and barriers of that social context, has on one's ability to successfully implement care management tasks within daily life and thus adhere to treatment recommendations.

Daily treatment for CF is typically a combination of airway clearance therapy to loosen and rid built-up mucus, inhaled medications to open airways and thin mucus, enzyme supplements to absorb nutrients, modulator therapies such as TriKafta, and a fitness plan (CFF 2024a). The traditional CF diet has a greater focus on weight gain and weight maintenance, and thus are recommended to eat up to "twice the amount of daily calories as others who are of similar age and weight," with an additional 500 calories if necessary to gain weight (CFF 2024d). Furthermore, the CF diet prioritizes foods that are high-salt, high-calorie, and high-fat foods, and are often recommended to consume supplemental beverages, such as Ensure, Pediasure, or Boost, as needed (CFF 2024d). This focus on weight maintenance and gain is because of the increased risk of malnutrition for individuals due to "inadequate intake, increased energy expenditure, and malabsorption" (Harindhanavudhi et al., 2019; Culhane et al., 2013). Research has also found malnutrition to be associated with poorer lung function, yet when BMI is within a "healthy range," it is associated with better lung performance (Stephenson et al., 2013). However, improved lung function has not been associated with overweight and obese individuals after a certain BMI threshold (Solís-Garcia, 2024).

With the introduction of modulator therapies and the impacts they have had on increasing life expectancy in individuals with CF, diabetes and obesity have become a greater concern (Quick et al., 2013; Snowball, 2023). Modulator therapies allow for an easier time absorbing nutrients and a better ability to maintain and gain weight (Mailhot et al., 2023; Bailey et al., 2022). The traditional "legacy CF diet," however, can contribute to "excessive weight gain," after being placed on modulator therapies as children and adults with CF are are often advised and have become accustomed to "consume an unrestricted high calorie diet," with minimal attention given to nutrition quality due to limited ability to absorb nutrients and the goal of weight gain or maintenance (Bailey et al., 2022; CFF 2024a). Indeed, fewer individuals with CF are in need of additional nutritional support to gain weight, and in fact many are asking for guidance on how to either lose or "prevent further weight gain" (Snowball, 2023). While there have been concerns about weight and nutritional support due to the malabsoprtion issues caused by CF, the introduction of modulator therapies has led to better overall health and nutritional absorption for many individuals with CF (CFF, 2023). Consequently, during the last five to 10 years (especially after the widespread availability of modulator therapies) there has been an increased focus on managing weight more carefully to prevent excess weight gain in individuals with CF (Gramegna et al., 2023).

While the benefits of weight gain on pulmonary function are strong, the impacts of being overweight or obese in children and adults with CF as they age are not yet fully known (Mailhot et al., 2023). To prevent further health complications in later life for individuals with CF, there is a recognized need to “promote healthy eating guidelines,” even more so than the general population as the CF population has historically had “lower quality dietary patterns” due to the recommended “legacy diet” (Snowball, 2023). Additionally, the high-calorie nutritional needs can be financially challenging for many to meet (CFF 2024d). As a result of this, food insecurity is a common issue amongst children and adults with CF, reported at “three times the national average” (Seyoum et al., 2023).

As for oral health recommendations, the long-standing view since the 1970’s has been that individuals with CF are at a lower risk for dental caries (tooth decay), due to chronic antibiotic use that “protects against cariogenic bacteria” (Jagels et al., 1976; Primosch, 1980; Kinirons, 1983, 1989, 1992; Ferrazzano, 2009). However, research has found that during adolescence a respiratory bacteria shift occurs which requires a different antibiotic treatment (Strausbaugh & Davis, 2007; Van Westreenen & Tiddens, 2010; Bals et al., 2011). The switch to this new antibiotic does not have the same protection against caries as the original antibiotic used. In fact, it is possible that the new antibiotic may place youth with CF at greater risk of caries, however this hypothesis has not yet been fully tested (Chi, 2013). Individuals with CF are at greater risk for caries not only potentially because of this, but also because of frequent carbohydrate intake, secondary to conformity to the “legacy diet,” altered saliva, and gastric reflux (Arquitt et al., 2002; Smyth & Walters, 2012; Catalan et al., 2011).

Recent and ongoing research has shown the increasing importance of oral health in individuals with CF due to the connection between oral health and respiratory health, and the possibility of oral bacteria infecting the lungs (Chi & Rosenfeld et al., 2018). However, there are currently no specific oral health recommendations and guidelines for individuals with CF on the United States Cystic Fibrosis Foundation website (CFF 2024A). As research on the connection between oral health and respiratory health continues, it is hopeful that oral health recommendations will be included in future iterations of CF guidelines. Adherence to CF dietary and oral health recommendations is dependent on an individual’s self-management behaviors. Self management is understood as “the interaction of health behaviors and related processes that patients and families engage in to care for a chronic disease” (Modi et al., 2012). The social context of the individual thus impacts their self management behaviors.

III. Current Project

We know from previous social science health research that social context can have an impact on chronic care management behaviors, however, we do not know what types of social contexts support or undermine care management behaviors (Rogers et al., 2011). In this analysis, I use patient nexus theory to frame my analysis of two waves of interview data of children with CF to illustrate ideal typical cases of patient nexus typologies and the care management behaviors across them. My central research questions are as follows:

1. How does Mark Tausig’s sociological theory of “patient nexus" apply to care management for youth with cystic fibrosis, and how can Tausig’s theory be further expanded upon to improve understanding of care needs for youth with CF?

2. For youth with CF, what types of patient nexuses exist, and what are the care management behaviors across each nexus type?

   Note: for this study, care management is understood as CF-related care tasks (such as taking medication and doing breathing treatments), dietary behaviors and sugary beverage intake, and oral health behaviors.

3. How can the findings of this research study be applied to support individuals with CF in meeting changing recommendations around diet and oral health?

Analysis for this paper focuses on twenty-one dyadic interviews with child participants, ages 12-17, and their parent/guardian. These interviews occurred as part of the larger project in waves one and two of qualitative data collection. Analysis of child interviews will allow for better understanding of different types of nexuses in children with CF and its impact on care management, which is poorly understood in children with chronic illness (Oates, 2015). Future analysis will explore differences in social contexts/patient nexuses across adults with CF and how these nexus types may shift in the transition to adulthood.

IV. Data and Methods

Project Background

This research study project is a branch of an ongoing larger five-year parent project which examines the relation between oral health diseases and respiratory health. The overall hypothesis of the parent project is that oral diseases are potentially modifiable contributors to lung disease in CF. Ongoing research has shown that oral bacteria associated with oral diseases such as caries and gingivitis can infect the lungs in individuals with CF at high concentration (Mantovani et al., 2019). The link between oral diseases and CF has never been evaluated prior to this larger parent study, which is the largest and first longitudinal CF oral health study to date with a total of 205 participants, ages 12-30 years old at three CF care center site locations the University of North Carolina (UNC), Seattle Children's Hospital (SCH), and the University of Alabama (UAB). Site locations were selected for their representativeness of the U.S CF population. The study focuses on individuals with CF ages 12-30 years old as this age range is a high-risk group with accelerated lung function decline and higher caries prevalence than younger patients. In addition, the lower end of the enrollment age range reflects the age at which individuals have all permanent teeth and oral diseases begin to increase in prevalence.

The mixed-methods parent study has three aims: the first of which is to describe the prevalence of oral diseases in adolescents and young adults with CF, and to identify corresponding risk factors and possible interventions to improve oral health behaviors. The second aim evaluates oral diseases' association with respiratory outcomes in CF, while the third aim explores the microbiome pathways that link oral and respiratory health. The qualitative portion of the study falls under the first aim of the three, which includes three waves of semi-structured qualitative interviews with children and adults with CF. Each wave of qualitative interviews allows for analysis, reporting, and revision of interview protocol to delve deeper into relevant topics uncovered in the previous wave. Findings from the larger study so far have described poorer oral hygiene in adolescents with CF than non-CF adolescents (Alkhateeb et al., 2024). In this paper, I analyze two of the three waves of child interviews. The parent projects research questions and analysis focus on which oral health behavioral risk factors are modifiable to intervention, and what feasible intervention methods are available.

Recruitment for Qualitative Interviews

The population of interest for this research study is youth with CF ages 12-17 years old who receive CF care at either the University of Alabama Birmingham (UAB), University of North Carolina (UNC), or Seattle Children's Hospital (SCH). Adults and children ages 12-30 at these institutions were asked if they would be interested in participating in an oral health research study about CF, with a total 205 participants in the parent study. All 205 participants were also asked if they would be interested in participating in a qualitative interview about their oral health behaviors, and 98 individuals expressed interest. These 98 individuals who expressed interest represent the sampling frame from which the sample size of 45 adult and child participants was drawn through recruitment efforts which included three rounds of phone calls, emails, and text messages. Analysis was conducted on the 21 child interviews, with the final sample size by site represented in Table 1. Method of contact was determined by the participant's marked preference on the interest survey, which was completed when a participant agreed to be contacted about the qualitative study. The tables below show the number of participants at each site who first expressed interest in participating in the study, the number of participants at each site who were contacted, and finally the number of participants at each site who completed a qualitative interview.

Table 1. Participant Recruitment for Qualitative Interviews

	SCH	UNC	UAB	Total
Participants ages 12-30 expressed interest	36	40	27	103
Participants ages 12-30 contacted to participate	12	30	19	61

Participants ages 12-30 participated in qualitative interview	11	26	8	45
Participants ages 12-17 participated in qualitative interview	8	9	4	21

Interview Protocol

Protocol construction

The first version of the interview protocol, used during the first wave of the study, from October 2022 until February 2023 for the first 11 participants, was designed by the qualitative research team which included myself, another graduate student researcher, Magali Sanchez, and one behavioral research scientist, Barbara Baquero. The initial interview protocol was developed based on constructs from the Health Belief Model (HBM) and the Extended Parallel Process Model (EPPM). The HBM states that beliefs, attitudes, and knowledge are key factors that impact how individuals make health behavior decisions, while the EPPM describes that behavior change occurs when there is a balance between a perceived threat and efficacy (Rosenstock, 1974; Witte, 1992). Previous studies of the larger project have supported using both the HBM and EPPM constructs to understand care management behaviors. This initial protocol developed from these models was then finalized in collaboration with the CF Stakeholder Advisory Group, which included a focus group of individuals who have CF.

The interview questions inquire about dietary habits, experiences with CF medical care teams, oral health behaviors, and support systems. After reviewing the first wave of interview data, I took the lead in revising interview questions to understand each topic with more depth for the second wave of ten interviews. For example, questions about dietary habits were adapted to probe in greater detail for social or environmental influence on diet, changes to diet over time and the contextual reasoning for dietary changes, and the level of difficulty in making dietary adjustments. Greater attention was also given to understanding the participant’s relationship with their care team, changes in dietary recommendations over time, barriers to accessing dental care and challenges to maintaining dental hygiene, and additional probing questions on if and how the participant seeks support from others and their comfort level in seeking out support. The importance of these topic areas became clear throughout the first wave of interviews, as participants frequently discussed their experiences navigating dietary recommendations, the barriers and influences on diet and oral health habits, and the participant’s relationship with their care team. Revisions were presented to the qualitative research team, and the phrasing of interview questions was finalized. Interview questions for participants under 18 (who were interviewed as a dyad with a parent or guardian) were adapted to use simpler terms for ease of understanding.

Data Collection

Data collection included virtual qualitative interviews over Zoom with children between the ages of 12 and 17 who have CF. Dyadic interviews (interviews with both the child and parent/guardian) were conducted with all participants, though all were given the option to interview separately if they chose to do so. I independently conducted all but one of the total 21 qualitative interviews with children and their parent/guardian. The other graduate research student on the team, Magali Sanchez, stepped in when I was unavailable to take an interview. In addition to interview data, participants who agreed to participate in the larger CF study completed a REDCap survey which included demographic data on participant's age, sex at birth, race and ethnicity, and insurance type. I use these demographic data from the survey for participants who completed a qualitative interview.

Data & Analysis

Data for this study included 21 qualitative dyadic interviews of children with CF and demographic data from the REDCap survey. Interview audio files were typically about one half hour in length and were transcribed within a week of interview completion by myself and undergraduate research assistants as part of the larger project. Personally identifiable information was omitted from the transcriptions to ensure privacy of all participants. I conducted quality checks on the transcriptions as lead interviewer on the project. Interview audio files and transcriptions were securely stored on a SharePoint server only available to the research team members granted access.

Demographics of Child Participants

Most child participants were assigned female at birth (n=14) while the remaining seven were assigned male at birth. However, one participant assigned female at birth used he/him pronouns during their interview. All other participants used their assigned at birth pronouns at the time of the interview. The majority of participants identified as white (n=20) while one participant identified as American Indian or Alaskan Native. One participant ethnically identified as Hispanic or Latino while the remaining 20 did not. Most participants had private insurance (n=11) or public insurance (n=8), while the two remaining participants had military insurance.

Table 2. Demographic Factors of Child Participants with CF (N=21)

	n	%
Age		
12-14	9	42.85
15-17	12	57.14

Sex		
Male	8*	38.09
Female	13	61.90
Race		
White	20	95.23
American Indian or Alaska Native	1	4.76
Hispanic or Latino		
Yes	1	4.76
No	20	95.23
Insurance Type		
Private	11	52.38
Public	8	38.09
Military	2	9.52

*one participant used he/him pronouns

Coding and Analysis

Interviews were conducted in English and were audio-recorded, transcribed, and thematically analyzed in Dedoose. A grounded-theory coding approach was used to analyze interviews such that codebooks were systematically and iteratively revised based on emerging themes. Grounded theory is a practice of collecting and analyzing qualitative data that is both “systematic, yet flexible” in order to “conduct theories from the data themselves” (Charmaz, 1). A grounded theory approach to research means repeatedly returning to the data and analysis to uncover emerging themes. This process also includes iterative revisions to interview protocol after review of initial data to understand what areas could be further explored during data collection. This study is strengthened by the grounded theory approach by the flexibility of revising interview protocol and repeated return to raw interview data. This approach allows for a rich understanding of participant’s experiences and actions.

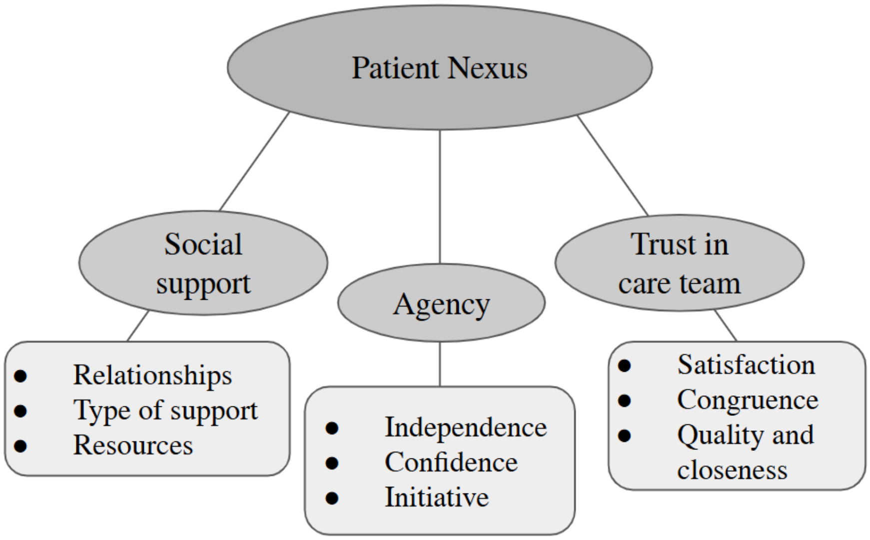
Coding in Dedoose began after the first wave of interviews was completed. A preliminary codebook was developed to include overarching categories of dietary and oral health behaviors, experience with the care team, and support system. Each overarching category had codes to capture the experiences of participants for that category, such as dietary support the child receives, what their oral health behaviors and reasonings for these behaviors are, and how the participant seeks and receives support from those around them. This codebook, with a total of forty codes, was the first step to sort relevant quotes into "buckets" to later inductively code and gather themes from. The preliminary codebook was tested on a small batch of initial interviews, which was then revised and used for the remaining interviews.

Once all 21 interviews were coded using the codebook, the excerpts were then exported into a large spreadsheet, with each tab representing one of the forty codes. A second pass of open coding was done for each of the forty codes, which identified major themes amongst participants for each code (i.e. The majority of participants describe their oral health as "pretty healthy;" most participants expressed feeling proud of themselves in "not letting CF stop them from doing things they want to do"). A codebook was not developed for this second pass of coding, as codes were generated from participants' excerpts. Codes that repeatedly appeared across participants were then identified as a major theme for the category. A thematic summary across all participants was written for each category after the second pass of coding.

After this general analysis across all participants was complete, participants were then mapped across different support dimensions that I conceptualize as the patient nexus. As mentioned, I expand on Tausig's patient nexus theory to include the social support network, the participant's level of agency, and trust with their care team. I measured the level of support a child has from family and friends by observing the support the child receives with their diet and care management (do their parents prepare and plan all of their meals or are most meals prepared and eaten independently? Do their parents check in with the child about their care management behaviors?), the support the child receives from friends (are they comfortable sharing with others about their CF? Do they have stories about their friends helping them in times of need? Do they have experiences being bullied?), and the amount of resources available to the child (i.e. do financial issues, lack of time, or other barriers come up during the interview? Are there other family members that are mentioned that care for the child? Do they mention other resources that support care and awareness for and about CF?).

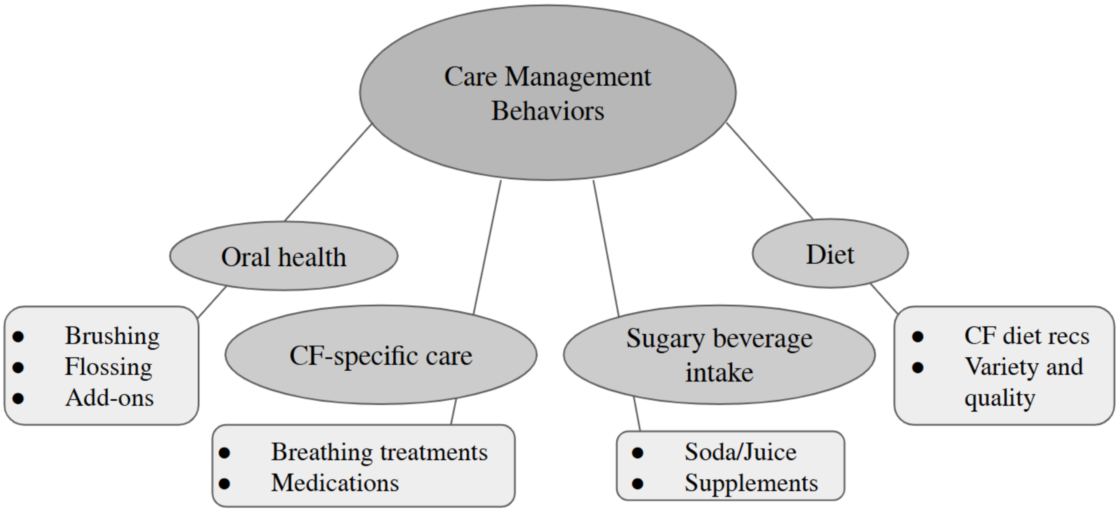
To measure the level of agency a child has in their care management, I observe how independent the child describes themselves in managing their health (do they remember to take their medications and do their treatments consistently, or do they require assistance and reminders?), how confident and positive the child is in their abilities to take care of themselves (do they speak proudly about their care management, or do they seem unsure about what to be proud of, or not proud at all?), and how much initiative the child takes in managing their own health (is taking on more responsibility an effect of the child's own volition, or was it something that had to be encouraged repeatedly from their parent?).

Finally, I measure how much an individual trusts their care team, I observe the level of satisfaction the child and parent feel in their experience receiving care, how congruent their "health beliefs" are with that of the care team (particularly around dietary and oral health recommendations), and the quality of the relationship self-described between the child/parent and their care team (does the child/parent describe their relationship with the care team as close and long-term, “like family," or have there been issues of turnover or lack of feeling connected to the team?). Participants were mapped across the three categories (trust in care team, support system, and agency) using the thematic codes that appeared after the second pass of coding.



As mentioned, the goal of applying patient nexus theory to frame my analysis of interviews with youth who have CF is to understand what typologies of support systems exist among participants, and how care management behaviors vary among them. As described earlier, patient nexus theory defines the caregiving social network surrounding a person with chronic illness, emphasizing how social ties, such as family, friends, and community, provide tangible and emotional resources that shape an individual’s ability and motivation to manage their care. These networks influence not only access to support but also internal drive, as expectations, encouragement, and even obligations from others directly affect self-care behaviors and outcomes. During the analysis process, five different typologies of patient nexuses began to appear, which I will describe in greater detail in the Findings section. After each participant was categorized across the five types, a short summary was written for each nexus type by describing participant trends across the patient nexus dimensions. Along with this, each participant was summarized by describing their social context, care management behaviors, and relevant quotes around diet, oral health, social support, agency, and their relationship with their care team.

Participants' care management behaviors (oral health, CF specific care, sugary beverage intake, and diet) were then analyzed and summarized to identify care management behavioral trends across the patient nexus types. Oral health behaviors of participants were observed by how frequently participants reported brushing and flossing their teeth along with any additional oral health behaviors, such as using whitening products. Participants’ adherence to CF specific care, which includes breathing treatments and medications, was measured by how participants and their parents described how successful the child is in managing their habits, what they are proud of in terms of managing their CF, and what they feel they could improve on. Sugary beverage intake was measured by participant's report of how much soda, juice, and supplemental beverages (such as Ensure, Pediasure, and Boost) that they consume, while dietary habits were observed by the participant's ease of adhering to CF dietary recommendations (i.e. consuming all the calories required, adding fat to meals, etc.) and the variety and quality of dietary choices (i.e. pickiness levels, if the meals are homemade, frozen, or from a restaurant).



Narrative Analysis

After all participants had been categorized into one of the five nexus types that emerged through data analysis, I completed a narrative analysis for one ideal typical case from each nexus type. The participants who were selected to be narratively analyzed were chosen because of the richness of interview data, and to best represent that nexus type and care management behavior tendencies of that type. Narrative analysis is a storytelling methodology used in the social sciences where "the story becomes an object of study" through analysis of observation and interviews (Mitchell and Egudo, 2003). Narrative analysis offers a tool to explore the social context of "complex problems" and address the "ambiguity, complexity, and dynamism of individual, group, and organisational phenomena" (Mitchell and Egudo, 2003; Webster and Mertova, 2007). As this study aims to understand the social contexts and lives of the participants, narrative analysis felt appropriate in order to fully capture the "capture the complexity of meaning embodied within stories" (Mitchell and Egudo, 2003) Especially for sociological research, narrative analysis reveals greater detail about "social life or culture, as culture speaks through a story" (Mitchell and Egudo, 2003).

In the following section of findings, I describe each nexus type and their care management behavior tendencies in greater detail alongside an ideal typical participant case that fits within that nexus type. Names have been changed to protect the privacy of participants.

V. Findings

The Five Nexus Typologies

Utilizing patient nexus theory to frame my analysis, five different typologies of patient nexuses (i.e. the caregiving social network around the patient) emerged from our interviews with children who have CF and their parents or guardians. As mentioned, I expand Tausig's conceptualization of the patient nexus by including the following three dimensions: the level of trust the child and parent have with their care team, the level of support available and received by the child, and the level of agency the child possesses. The five nexus types, as shown below in the table, vary in level across each dimension and are color coded to represent their level (green for high, yellow for mid, and red for low).

Table 3. Five Nexus Types Across Dimensions

Nexus Type	n	Trust in Care Team	Support System	Agency
Strong Safety Net	5	High	High	High
Maternally Motivated & Supported	4	High	Mid	Mid
Suffer in Silence	4	High	Low	Low
Hyper Independent & Concerned	5	Mid	Mid	High
Unresourced & Unmotivated	3	Low	Low	Low

As mentioned, I have selected ideal typical cases of each nexus type to illustrate the five different nexus typologies among this sample of youth with CF and their care management behavior tendencies. I begin with the first nexus type, Strong Safety Net.

Strong Safety Net

The first patient nexus type is the "Strong Safety Net," made up of five participants (four females and one male) that have high trust in their CF care team, multi-pronged/directional support, and high agency. Individuals in this nexus type describe strong trust in their care team and support from both parents, extended family, and have a strong social support system of friends. Participants with this nexus type desire continued support from others and understanding. While some parents mention some incongruence with dietary recommendations made by the care team and their own health beliefs, this does not impact their high level of trust in their care team. Participants describe feeling comfortable discussing their CF with others, especially when gaining new friends. They feel comfortable reaching out to trusted individuals when they are in need of support and are becoming independent with their care management habits.

Table 4. Strong Safety Net Nexus Type

Nexus Type	Trust in Care Team	Support System	Agency
Strong Safety Net	High	High	High

Table 5. Demographics of Strong Safety Net Nexus Participants

	n	%
Age		
12-14	3	60.00
15-17	2	40.00
Sex		
Male	1	20.00
Female	4	80.00
Race		
White	5	100.00
American Indian or Alaska Native	0	0.00
Hispanic or Latino		
Yes	0	0.00
No	5	100.00
Insurance Type		
Private	2	40.00
Public	2	40.00
Military	1	20.00

One participant that fits the Strong Safety Net patient nexus type is Rebecca, a white 14 year old female who is privately insured. At the start of the interview, Rebecca and her mom, Sarah, sit together in front of a bright window-lit white wall at their dining room table. They both appear alert and energetic, and in their brief introductions, Rebecca says that she enjoys playing volleyball and hanging out with her friends, and Sarah describes being busy with some renovations they're doing on the house.

Rebecca is homeschooled and her mom prepares most of her meals. Sarah describes Rebecca's meals as following a similar routine; "we're pretty structured breakfast, lunch, and dinner. We don't really do a lot of snacking." Rebecca's meals are focused on getting high protein and vegetables, with a "solid rotation of broccoli, kale, and peas." Before taking TriKafta, Sarah notes that Rebecca's diet was high in fat, and higher in sugar than Rebecca would like, describing the conversations they've had with Rebecca's care team about CF-related diabetes: "I think they've always been a little concerned about the sugar because of that." Since taking TriKafta, Sarah and Rebecca have made an effort to make adjustments. Rebecca notes, "her breakfast was, like, Nutella on pancakes because of high fat. Yeah, it was also high in sugar. She's really done a good job of phasing that out, just because TriKafta has made such a difference for her."

Even with the structured dietary support her mom provides her with, Rebecca describes the challenge of navigating some of these dietary changes since starting TriKafta: "I have to be like, no, you're trying to be healthier, make a smoothie. I have to tell myself to not, like, make unhealthy choices, but it's getting easier." Rebecca also describes that she has a stanley cup that she uses daily to drink plain water, drinking about two full cups of the 40oz bottle everyday, along with tea in the morning.

Sarah describes some incongruency with the dietary recommendations for CF, which are typically focused on efficient ways of "packing in calories and keeping weight on." Sarah notes the differences between these recommendations and her own health beliefs: "at times we've been, you know, encouraged to pick up an Ensure or a Boost. And that just doesn't really jive with what I believe to be good food." Instead, Sarah opts to make Rebecca a smoothie for a snack, as Sarah notes that they "haven't been that desperate for calories and she hasn't had that problem where she needed something that fortifying."

Although Sarah notes these differences between the recommendations she receives from her care team, it doesn't impact the strong bond she and Rebecca have with them; "I feel like we have the best medical care we could possibly ask for. We honestly see them more than we see a lot of our family - they are like our family. I mean, we just adore them." Sarah describes feeling satisfied with how responsive the care team is, and their awareness and concern about CF related diabetes; "they've always been a little concerned about the sugar because of CF related diabetes, but we've never had that problem either. They are just true A+ type professionals, they don't let anything slip or slide."

When it comes to everyday care management for her CF, Sarah notes that Rebecca is great at being independent and in being an advocate for herself when she needs more support.

> Rebecca: *I have to stay on top of my meds, I have to do my treatments, I have to sterilize my nebulizer, which I need to do a better job of doing but... yeah. Treatments, meds. nebs.*
>
> Sarah: *She's a really good advocate for herself when it comes to something going on, too. She usually alerts me like, hey, I've had this cough for a couple days now.. .just because now she's kind of at that age where, you know, if she's not down here for dinner or doing something, she's in her room.*

Sarah explains that Rebecca has had this high level of agency from a young age, showing a natural inclination to take control and manage her health:

> Sarah: *She's always just stepped up. And she started sterilizing her own nebs probably at like...I don't know, 12.*
>
> Rebecca: *It was before that.*
>
> Sarah: *Before that? 10? I don't know. She just has always wanted the increasing responsibility and ownership of her, you know, care and processes and all that stuff. So. It's just kind of happened naturally.*

Though she manages her health independently and successfully, Rebecca still feels comfortable in reaching out to her friends for support, and doesn't mind talking about her CF with them: “usually CF comes up in like the first couple months. Usually the first month. If they're a good friend, I think all of my current friends know I have CF.” Both of Rebecca's parents are involved in her care and they make decisions as a team, although her mom manages most of her diet and day-to-day support; “I mean, my parents and I. They don't make decisions without me and I don't really have any power to make decisions without them.”

Care Management Behaviors of Strong Safety Net

The table below summarizes the following themes for care management behaviors of participants in the Strong Safety Net nexus type.

Oral Health: All participants in this group have good oral health behaviors, brushing one to two times a day and flossing occasionally. All participants in this group described their teeth as healthy.

Care Management: All participants in this group describe being proud, serious, and consistent about their care regimens (taking their medication and doing their breathing treatments). Participants also described being proud of how far they have come and not letting it stop them from living their lives.

Sugary Beverage Intake: Most participants in this group typically drink juice every day, milk frequently, and sweet tea or soda occasionally. Two participants in this group drink soda once a week. Four participants drink juice everyday, with one drinking juice all at once with a meal, typically with their medication, and the other three described sipping juice throughout the day. Some participants mentioned drinking water regularly.

Dietary choices & support: Two participants in this group are homeschooled and have a greater level of structure around meal-times and support from their caregiver. For participants that attend school, they have independence for breakfast and lunch, whereas dinners are eaten with the entire family at the kitchen table. Dietary decisions are made by the entire family, such as making food calendars together at the beginning of the week and planning grocery trips. Parents are involved in what their child eats and actively try to meet dietary recommendations. Two participant caregivers described navigating some recommendations that do not fit their personal preference (i.e. sugary supplemental drinks) and revising their child's diet to ensure a best fit with personal health beliefs while meeting dietary requirements. Child participants describe taking greater ownership in what they eat and in making healthier, aware choices. Participants in this type describe having a wide palette and enjoyment of a variety of foods, notably different types of vegetables.

Table 6. Care Management Behaviors of Strong Safety Net Nexus Type

Care Management Behavior	Strength	Reasoning
Oral Health	Strong	Brush 1-2x daily, flossing occasionally
Care Management	Strong	Consistent, serious, and proud
Sugary Beverage	Average	Juice daily
Dietary support	Strong	Interdependent & Expansive

Maternally Supported & Motivated

Though participants that fall under the next nexus type, "Maternally Supported & Motivated," also possess high levels of trust in their care team like those in the Strong Safety Net type, these Maternally Supported & Motivated individual's support systems are made up of primarily maternal support rather than both parents, and their agency level is in the mid-range rather than the higher levels found in the Strong Safety Net type. Individuals that fall under the Maternally Supported & Motivated type (three females and one male) have fairly strong social relationships, especially amongst female child participants, who describe their friends from school as being protective and coming with them to the nurse or doctor appointments. The one male child participant described having strong online relationships through CF support groups.

These individuals need some reminders or motivational support from others to keep on top of their routine. There can be a lack of support in some areas, such as being independent in what they decide to eat during the day as their parents may describe themselves as not cooking as much. These individuals have a strong relationship with their care team and do not mention strong incongruence around dietary recommendations.

Table 7. Maternally Motivated & Supported Nexus Type

Nexus Type	**Trust in Care Team**	**Support System**	**Agency**
Maternally Motivated & Supported	High	Mid	Mid

Table 8. Demographics of Maternally Motivated & Supported Nexus Participants

	n	%
Age		
12-14	0	0.00
15-17	4	100.00
Sex		
Male	1	25.00
Female	3	75.00
Race		
White	4	100.00
American Indian or Alaska Native	0	0.00
Hispanic or Latino		
Yes	0	0.00
No	4	100.00
Insurance Type		
Private	1	25.00
Public	3	75.00

Military	0	0.00

Laila, a 16 year old white female who is publicly insured, falls under the Maternally Supported and Motivated nexus type. Laila and her mother, Caroline, sit closely side-by-side at their kitchen table in front of a window with the curtains drawn. The interview is conducted in the evening after Laila has come home from school. Laila is wearing a zip-up sweatshirt with the hood up, and her mom sits beside her in a comfortable T-shirt. From the start of the interview, Laila's dry sense of humor and dead-pan delivery makes her mom chuckle while trying to answer the interview questions.

Laila describes her typical breakfast as cinnamon toast sticks or corn muffins, and her lunches at school vary day-to-day depending on what they have. "Sometimes I eat burgers or a peanut butter jelly sandwich, but the past two days I've been eating Chick-Fil-A waffle fries and empanadas." Laila's diet is fairly independent in what she chooses to eat, until Laila comes home from school and Caroline typically prepares a meal for the both of them. The night before the interview, Laila ate the spaghetti her mom made for dinner; "I don't have a choice. Dinner's whatever my mom eats." Caroline counters this by stating Laila does get input in what they eat for dinner, and describes trying to make food that Laila enjoys; "She does get a lot of – you get a huge amount of input for dinner. She gets a lot of input." Caroline also describes the impact that Laila's school schedule, timing, and hunger levels has on Laila's diet.

> Caroline: *Her day starts really early. She's up by 6:30. She's eating breakfast by a quarter to 7, and it's hard for her to eat that early on school days. Her lunch is at 10:30 in the morning, so it is hard for her to eat that early again. And then when I pick her up, she is really hungry. And so that's when you see the fast food, because I'm taking a break from work and we stop and get Wendy's because she's really hungry on the way home. Then we try to make dinner, and I try to make something she loves. She loves rice and gravy.*
>
> Laila: *I want rice and gravy tonight.*

Laila's diet also is dependent on her cyclical food cravings, as Caroline describes:"When she finds something she really likes, she eats it over and over again. And then she gets sick of it and then never wants to eat again." Laila expresses some pickiness and hesitates around certain foods, particularly vegetables: " I think onions are dumb and awful, and they need to die." Caroline tries to balance these cravings and pickiness with the CF dietary recommendations to ensure Laila gets enough fat and calories.

> Caroline: *She's always had to have, like, a high fat, high calorie diet. One of the medicines she's on, she has to make sure she has lots of fat in the morning. So I do try to augment. We try to add something like a sausage or bacon or something in the morning with fat.*

Laila: *The sausage is bad, so I don't really eat it.*

Caroline: *Well, we've now determined that she doesn't like sausage.*

For snacks, Laila typically munches on chips or cheese balls. “We know they are bad. The dentist said those are bad,” Caroline explains. “At school, I eat hot Doritos,” Laila adds. Laila’s diet has greater variation on the weekends when Laila does not have school. “Weekends are different. She sleeps until, you know, noon. We may try to go out to eat, but for the most part, her first meal is lunch, but then she has multiple dinners.” When Laila and her mother go out to eat, Laila may order a soda, her favorite being cheerwine. Caroline allows Laila to drink 1-2 sodas per week, typically on the weekend, although Laila prefers to drink soda daily and is trying to get her mom to allow her to have more soda.

Laila: *I'm working up for one soda per day. But because this woman listens to the doctors - this woman had an idea, brought it up to this old man doctor, and because he's an old man, he said yeah.*
Caroline: *We’ve switched to lemonade instead of soda. Everybody knows sodas are bad.*

Laila: *I love soda. It keeps me up and it makes me tolerate people more.*

At times when Laila was younger, Caroline would supplement Laila’s diet with Ensure and Pediasure, but more recently Laila has developed a deep distaste for them, despite having loved them in the past.

Laila: *You wouldn't catch me dead drinking Pediasure now.*

Caroline: *She loved it.*

Conversations around diet do not happen regularly during Laila’s appointments with her care team, but rather when there is a specific need, such as Laila’s glucose being high or if she is losing weight: “When she does lose weight, just making sure that she eats breakfast and doesn't skip meals and that type of stuff. It's just more about quantity instead of, they don't really focus too much on what.” Despite Caroline acknowledging that there is a focus on quantity over quality, this doesn’t impact her trust and relationship with Laila’s care team: “A lot of people kind of think they should focus more on what [quality]. But they're all, I mean, it's always been very good.” The relationship that Caroline and Laila have with their CF care team is overall positive, describing feeling comfortable and trusting with them.

Caroline: *She does trust her doctors, and she feels very comfortable asking her doctors questions.*

Laila: *They know not to mess with me.*

> Caroline: *They've just known her for a very long time and they let her have her crazy sense of humor.*

While Laila and Caroline's relationship with their care team is positive, their relationship with their dentist is not quite as strong. "I don't even know if this dentist really, some dentists when she was younger, knew she had CF. But I think at this point the dentist might not even know, then they probably won't even know anything about CF," Caroline explains. Laila's dental health has recently improved, particularly due to her own improved brushing habits, however when she was younger it was a greater issue, which Caroline believes to be due to some of the medications Laila was taking at the time."All the inhaled medicines, and then the masks and stuff, I think took a toll on her teeth. her teeth were not super great then." Caroline describes the dentist appointment that Laila had as part of the participation with this CF study as being particularly helpful for her dental health:

> Caroline: *They [the dentists in the CF study] talked to her a lot better than the dentist ever had, and I've seen a big improvement in her working on her teeth. We've always gone to the dentist every six months, and it always seemed crazy the amount of stuff that builds up in the six months. But, she doesn't really do her inhaled medicines anymore so that could have also helped.*

Although COVID has put a pause on Laila's transition into adult-care, Laila has taken on greater responsibility at home for managing her health in recent years: "She was 12 or 13, you know, middle school, when she started being home by herself and having to manage her own enzymes and making her own food when I would be at work." Caroline has a deep sense of pride in her daughter for navigating her health "with strength and bravery," Caroline says, "she has always been like that, even since a little girl. She's just always done it, you know, joking around and goofing around and being brave. It's just wonderful." In addition to having a positive outlook and attitude towards her health, Laila's support system is robust and she feels very comfortable telling others about her CF.

> Laila: *All my friends know I have CF. If I ever start coughing, they do their best to make sure everyone is not near me while I'm doing that. So that way no one else gets worried.*
>
> Caroline: *She just changed schools, so it's not quite the same support system, but when she was at other schools, kids were definitely very protective of her.*
>
> Laila: *And even in my online friend group I have a strong support system.*

Caroline notes that while Laila does have a strong support system, the changing of schools has been a little challenging and she notices Laila is not quite as open as she was in the past, especially with transitioning into high school. Caroline further explains, "I don't think she is open… not that she hasn't been as open, but she literally just started high school, and it's the new big high school." With that being said, Laila typically sees the one person she trusts most and goes to for support as her mom, Caroline. Caroline agrees with this, stating "you know, I'm gonna go out on a limb and say I am the one she would go to first if she needed help."

Care Management Behaviors of Maternally Supported & Motivated

The table below summarizes the following themes for care management behaviors of participants in the Maternally Motivated & Supported nexus type.

Oral Health: The majority of participants in this group have good or or great oral health behaviors, with only one having just okay behaviors, brushing only once a day. Majority of participants in this group describe their teeth as healthy, with only one describing their teeth as not very healthy.

Care Management: Most participants in this group describe being proud of themselves for persevering through hardships and not letting it stop them from living their lives. Half of participants described feeling proud of managing their care regimens, such as taking enzymes, and being more "in charge" of their health.

Sugary Beverage Intake: All participants in this group drink sugary beverages either everyday or every other day. Three of the four participants in this group drink either gatorade, sweet tea, and ensure every day. One participant drinks soda every other day.

Dietary Choices and Support: Participants in this group have a great deal of freedom in deciding what they eat and drink throughout the day. There is much more leniency, especially around breakfast and lunch, and the child is free to eat whenever they please or they feel hungry. Dinner is typically eaten with their maternal figure and what is eaten is decided by both mother and child, but heavily impacted by the child's pickiness and desires. Tight schedules with school impact dietary decisions, such as skipping breakfast and eating two dinners - once when arriving home, and another late at night. Fast food is common in this group, especially after school when hunger is high. Independence of food choices ranges slightly in this group - with about half of participants having much more freedom in all of their dietary choices (including dinner). The variety of food for participants in this group is not as wide as the Strong Nexus Type, as there are more "patterns" and "phases" of eating the same thing over and over again.

Table 9. Care Management Behaviors of Maternally Motivated & Supported Nexus Type

Care Management Behavior	**Strength**	**Reasoning**
Oral Health	Strong	Brushing 1-2x a day
Care Management	Strong	Consistent & proud

Sugary Beverage	High	Soda daily
Dietary support	Average	Leniency and schedule challenges

Suffer in Silence

The next nexus type, “Suffer in Silence,” also has trust in their care team, yet they lack the social support and agency that both the Strong Safety Net and Maternally Supported & Motivated types possess. Individuals in this type (three females and one male) may have familial resources and support, but lack social support from friends and describe significant experiences of being bullied. Participants in this group describe a desire for additional support, yet have difficulty in asking for help and have a low level of agency. Though they lack social support, they have a strong relationship with their care team. However, they frequently need reminders to keep up with care habits.

Table 10. Suffer in Silence Nexus Type

Nexus Type	**Trust in Care Team**	**Support System**	**Agency**
Suffer in Silence	High	Low	Low

Table 11. Demographics of Suffer in Silence Nexus Participants

	n	%
Age		
12-14	4	100.00
15-17	0	0.00
Sex		
Male	1	25.00
Female	3	75.00
Race		
White	4	100.00
American Indian or Alaska Native	0	0.00
Hispanic or Latino		

Yes	0	0.00
No	4	100.00
Insurance Type		
Private	2	50.00
Public	1	25.00
Military	1	25.00

One participant that falls under this nexus type is Annabelle, a 12 year old white female who is publicly insured. Annabelle and her mom, Freya, lay down in Freya's bed as they participate in the interview. They join the Zoom call through Freya's cell phone, with Freya in the forefront of the frame and Annabelle tucked in on Freya's side. Annabelle often whispers or mumbles a response to the interview questions to her mom, but perks up from behind and speaks up at moments when she has something particularly important, or a salient personal experience, that she would like to share.

Freya does most of the grocery shopping and cooking for Annabelle, although Annabelle typically has greater freedom in deciding what to eat for breakfast and lunch.. Before school in the mornings at about 5am, Annabelle eats oatmeal or bagels with cream cheese. For lunch at school, she describes eating peanut butter and jelly sandwiches, chicken sandwiches, or tacos. Though during school days her diet is fairly consistent, on the weekends Annabelle's routine is more lenient: "Usually on weekends, I just eat whenever I'm hungry." The majority of her meals are eaten at home or school, which Annabelle explains is for her parent's financial reasons: "they're trying to save up for stuff." For snacks, Annabelle eats cheese, different types of chips such as takis or goldfish, pretzels, and sweets like cookies and nutella. She rarely drinks soda, instead typically drinking water or milk. Her dinners consist of many different types of noodle dishes, such as ramen, macaroni and cheese, or spaghetti-o's. Annabelle's diet is heavily influenced by her pickiness, as Freya explains how Annabelle frequently requests to eat the same foods, such as chicken nuggets:

> Freya: *She's not a big protein eater, but she'll eat chicken nuggets, patties, and hot dogs.*
>
> Annabelle: *Yummy.*
>
> Freya: *She'll do ground beef in like spaghetti and tacos. But fish - she won't touch. The fried fish fillets don't count though. I mean, they count, but they're not healthy fish. You don't eat healthy fish. But I mean, chicken nuggets, the spicy chicken patties. That's about the most protein wise that we can get her to eat.*

> Annabelle: *I do like hard boiled eggs.*
>
> Freya: *Yeah, she does like hard boiled eggs. That's a good source of protein too. Protein is important, yeah.*

Although Annabelle is picky, Freya notes that she enjoys eating broccoli, green beans, black eyed peas, and lima beans. Freya emphasizes that Annabelle does indeed eat some healthy options: "I want her to know that you do eat some healthy stuff when you choose to*."* Still, Annabell's diet is often influenced by friends and cousins, Freya explains:

> Freya: *If her cousin would be like, oh, that's gross, then she would just automatically say the same thing without even trying it. Or friends at school, same thing, would say something looked gross and then she'd quit eating it. So, I think it was outside influences that helped to make her picky.*
>
> Annabelle: *I'm so scared to eat watermelons cause one of my friends said, you know, if you eat a seed and watermelon will grow in your stomach if you drink water.*

The dietary recommendations that Annabelle's care team provides push for greater focus on weight maintenance, Freya describes: "she is on the smaller side, so they've given us tips on things that we can do to add calories to help put on weight. Obviously, trying to eat healthy fruits and vegetables and proteins and things like that. But you know, every once in a while if you want to swing through a drive through and get chicken nuggets and fries, that's okay. That adds extra calories to her diet." Annabelle's care team also provides monetary support through the form of gift cards, which Freya uses to support their regular grocery trips and get "treats" for both Annabelle and her older sister, who also has CF.

> Freya: *They really do a lot for not just our kids, but for all of their patients. So, I'm very pleased with it. We'll do normal grocery shopping, but we're like 'girls, this is for y'all to get what you want with,' you know, obviously some healthy stuff too, but you know… it helps more than they probably realize it does.*

Freya's work schedule puts limitations on how frequently Annabelle can see her care team, she explains: "we had to change the day that we go based on my work schedule. It's not his typical clinic day. So, I don't think the whole team is there with him on that specific day." This has resulted in Annabelle no longer being seen by certain members of her care team, such as one of the pulmonologists. Despite this, Freya describes being happy with their care team and their efforts to support them, especially in times of urgency.

> Freya: *In a way, they are always there if, you know, they always have a pulmonologist on call. You may not always physically get to see them for their support, but they are always there. A message through our app or a phone call to the hospital. I mean that they are*

> *always there. I can say that, yeah. I mean the whole team, I've, I've never had any complaints. Her team is great.*
>
> Annabelle: *[INAUDIBLE]*
>
> Freya: *I know you don't like the blood work, but it's necessary.*

Work schedule limitations also create a barrier for how frequently Annabelle visits the dentist, with it being more than a year since Annabelle has last gone in. Though their current dentist knows that Annabelle has CF, Freya shares that she feels the need to find a new dentist because of their scheduling conflicts: “It's hard for me to take off during the week and, you know, on Fridays I work a 1/2 day, but her dentist is closed on Fridays. His practice has gotten more busy, and we've sat there for two hours waiting to be called back.” Annabelle’s dental routine has improved as she has gotten older, but Freya mentions how challenging it was to motivate Annabelle to take care of her teeth and her lack of communication about tooth pain she was having:

> Freya: *When she was smaller, we struggled. It was almost to the point of us forcing her and us brushing her teeth. She had to get 8 silver teeth due to how bad her cavities were. I mean, yes, you had an infected tooth because it chipped and you didn't tell me.*
>
> Annabelle: *I do brush them. But my mom just points out that I'm not brushing them long enough, and my gums are starting to turn red too. She's like, ‘look at my gums. They're pink. You need to start brushing more. Yours need to be pink or else that's really bad.’*

One of the biggest reasons that Freya was motivated to participate in this research study was due to her newfound awareness that individuals with CF can be more prone to cavities and gingivitis. She explains that in 2020, when Annabelle had to get her silver teeth, the surgeon noticed calcium deposits on Annabelle’s teeth. “She has two spots, one on the top tooth and one on the bottom, and it's a calcium deposit. She actually explained it to me. She said that she has actually had patients in the past with CF that have that same anomaly on their teeth.” Freya goes on to explain that Annabelle frequently gets bullied because of these spots on her teeth: “The dentist that did the research study said if we were interested, she could possibly get her in to help, ‘cause we hate it for her. She gets made fun of for it. And I know that kind of affects her mental health too… people think she doesn't brush her teeth because of those spots, but she does.”

Along with trying to improve her oral health habits, Annabelle is working on creating a more structured routine with her CF care management. At the time of the interview, Annabelle had been battling off a case of strep throat and Freya described feeling proud that she had been taking charge of fighting it off: “She's still on antibiotics, but she's actually fixing her own medicine and taking it.” However, Annabelle tends to have difficulty in being consistent with some of her treatments, especially her airway clearance.

> Freya: *Her airway clearance vest - we struggle with her doing that. But she is active. She runs around a lot, she likes to go outside. I joked with her doctor that she and her sister scream a lot. And he's like, well, to be honest with you, that does help rattle the lungs some, so that does still count a little bit. Still not an excuse to scream that much, but the airway clearance vest is the main thing that we struggle with getting her to do.*
>
> Annabelle: *I don't like sitting there.*
>
> Freya: *She doesn't like to sit there for 30 minutes.*

When asked what she feels most proud of in how she manages her CF, Annabelle responds by feeling unsure if she feels proud of anything. Freya feels proud of Annabelle for when she uses her airway clearance vest when she is really sick, but caveats it with that she wishes Annabelle would use it more consistently all of the time. In terms of medical decisions for Annabelle's care, Freya has been trying to include Annabelle in these conversations more: now that she's getting a little older, we try to include her and get her opinion on, you know, how do you feel about this if they want to prescribe a medication or try something. We do try to include her in the decision making now too."

Annabelle's support network, outside of her parents and older sister, includes some of her friends, but many of them are not aware that she has CF as she doesn't speak about it much. "most of the time they ask 'why weren't you here?' If I have an appointment they ask, like, 'are you feeling OK? Why did you have to go?' or like, 'why weren't you there that day?' And I always tell them like, what's wrong with me. And they're like, 'oh wow. I never knew that about you.'" Freya expands on this to say that Annabelle has struggled at times with building a strong support system at school: "At times she does struggle. Sorry to bring this up, but she was bullied last year at school and initially we didn't know about it. It was kind of thrown as if it was an accident, but it actually wasn't. So, in that aspect, she struggles a little bit." Annabelle at times also has difficulty in asking for help with academics, which can feed into the bullying she experiences.

> Freya: *Last year, a lot of teachers were commenting on report cards and progress reports, saying she doesn't really ask for help a lot.*
>
> Annabelle: *And then as soon as my parents read that, they're like 'honey, if you really need the help, you should start asking for help.' But I struggle with that, because I feel like last year I felt really put down. People will start making fun of me if I need help on something.*

When asked if there is anything else that Annabelle wishes others would do to help her manage her CF, she describes wanting more support just in case she ever needs it: "Honestly, what I wish is that they could always be there if I ever needed them for anything."

Care Management Behaviors of Suffer in Silence

The table below summarizes the following themes for care management behaviors of participants in the Suffer in Silence nexus type.

Oral Health: Half of the participants in this group have okay oral health behaviors, brushing only once a day. The other half have either good or great oral health behaviors, as they have improved their care habits to brush once or twice a day along with fairly regular flossing. Most participants in this group describe their teeth as healthy or pretty healthy, with some describing it as improving as it used to be worse.

Care Management: The majority of participants in this group describe not being proud of themselves in managing their health. However, their parents described some of their care habits as improving, such as completing airway clearance with their vest or taking enzymes. One participant described being proud of themselves in pushing through the challenges of having CF.

Sugary Beverage Intake: Majority of participants in this group describe drinking water regulalry. Half describe drinking sodas and juices infrequently with meals, while the other half drink soda and juice every other day with a meal. One participant described drinking a supplementary beverage such as ensure or pediasure every day.

Dietary Choices and Support: The majority of participants in this group make dietary choices depending on what others around them provide them with, or what is available for them to grab-and-go in their home. The level of structure around meals varies across participants, with one participant having a very structured and organized diet provided by their parent and other supportive figures (such as their nanny, father, and relatives), while other participants have fairly unstructured dietary patterns. (i.e. eating whenever they are hungry, most meals eaten independently). Participants in this group describe struggling with some pickiness, either having difficulty with consuming the amount of food to fulfill CF dietary requirements, or becoming particularly susceptible to the dietary choices and beliefs of those around them (i.e. a friend of the participant expressed distaste for a certain food, which now becomes the participant's belief).

Table 12. Care Management Behaviors of Suffer in Silence Nexus Type

Care Management Behavior	**Strength**	**Reasoning**
Oral Health	Average	Brushing once a day, improving
Care Management	Weak	Inconsistent & not proud
Sugary Beverage	Average	Soda & juice every other day
Dietary support	Average	Pickiness and inconsistent structure

Hyper-Independent & Concerned

While the previous three nexus types have fairly high trust in their CF care teams, the "Hyper-Independent & Concerned" type has mid-trust in their care team. These individuals (two females and three males) also have hyper-independent traits and show high levels of agency. While their support systems can include family and extended family, the individual may not reach out for support and prefer to manage their care on their own. Participants in this nexus type are able to maintain habits independently often to a fault (i.e. not asking for help, or express discomfort in sharing with others about their cf). Family members of participants in this type express some concern of the child's independence going into adulthood, as they fear they may not reach out for help when they need it. Family members of participants in this type describe mistrust of their care team due to some recommendations not matching their own beliefs surrounding healthy behaviors, or a lack of conversation about concerns such as diabetes or weight gain.

Table 13. Hyper Independent & Concerned Nexus Type

Nexus Type	**Trust in Care Team**	**Support System**	**Agency**
Hyper Independent & Concerned	Mid	Mid	High

Table 14. Demographics of Hyper Independent & Concerned Nexus Participants

	n	%
Age		
12-14	2	40.00
15-17	3	60.00
Sex		
Male	3	60.00
Female	2	40.00
Race		
White	4	80.00
American Indian or Alaska Native	1	20.00

Hispanic or Latino		
Yes	0	0.00
No	5	100.00
Insurance Type		
Private	4	80.00
Public	1	20.00
Military	0	0.00

A participant that falls under the Hyper-Independent & Concerned nexus type is Sean, a 15 year old white male who is privately insured. Sean and his mom, Kelly, sit beside one another on a fabric couch in their living room. Kelly wears jeans and a flowy blouse, while Sean wears basketball shorts and a t-shirt. Sean responds to the questions in a lighthearted, kind manner while Kelly chimes in with additional details in an often self deprecating way. Sean is fairly independent in what he decides to eat, typically eating what is available in the house or easy to make, such as a bowl of cereal for breakfast, a bagel with cream cheese and chips or fruit snacks for lunch, which is typically at school. For dinner, Sean describes eating “just a good fattening meal, I guess, like pasta or pizza, something like that.” Sean is not very picky, which makes it easier on Kelly to plan meals: “I’m just not the best cook, so I do try to get some of his favorite things, and so he'll eat it. He's never been a picky eater. So that is very lucky, like I feel like I can put anything down.”

To get more protein and extra calories, Sean will at times drink a protein shake with Orgain, a dietary supplement to gain weight recommended by their CF care team, or he will add turkey to the bagels he eats for lunch. Kelly explains that the dietary requirements they received when Sean was younger still influence Sean’s dietary choices to this day: “it was drilled into me to try to get a high fat, high salt diet. So I try to do that. But now he's getting older and he's doing a lot of this stuff on his own.” Sean describes wanting to eat a slightly “healthier” diet, with “ foods like tomatoes or something,” While she and Sean do tend to eat out at restaurants on a regular basis, Kelly adds that she does “try to incorporate as much healthy stuff as I can. There's a lot of good variety.”

Sean does not typically drink soda on a regular basis, unless they are at a restaurant, during which he’ll order a Coke, otherwise, he drinks mostly milk.

> Kelly: *He definitely is not like a soda drinker. If he's at home, he would drink milk. We go through about 4 gallons, it’s a lot, I know, a week. He drinks water mostly when he’s working out or something.*

Sean: *I don't really drink that much water to be honest.*

Although Sean doesn’t drink a lot of sugary beverages, Kelly does feel concerned about the level of sugar in Sean’s diet, mostly coming from breakfast cereals and occasional candies: “We all need to, we all need to watch the sugar intake, so that's been a new thing for me. I was just really thinking, how can I taper that down since I was the one that allowed it.” Recently at Sean’s care visits, the care team has been doing glucose testing to ensure he isn’t at risk for developing diabetes “he saw an endocrinologist because he was on a borderline for one of his glucose tolerance tests. So that was something that concerns me, because having CF has the potential for elevated, for diabetes, and we don't want to get to that point.” While they have recently been doing glucose testing, Kelly notes that conversations about sugar and diabetes weren’t always a priority amongst all members of the care team: “one of the other doctors wasn't talking about sugar as much. They were saying like, oh, it was ok…. But the more we looked into that, that can cause other problems.”

Sean and Kelly’s relationship with their care team has been impacted by this inconsistent dietary advice as well as provider turnover, particularly with providers that have been with them for a long time going into retirement: “One of our nurses, she just retired. She's been there since he was little. Even one of the respiratory therapists who was there for a long time, he retired a year ago.” This rotation of providers from the care team leads to the feeling of having to “start from scratch,” in building a sense of trust, as Kelly describes: “it's kind of hard and it's a little sad when the people you kind of depend on leave, even though you go every three months, you get to see the same person, and they know who you are, and you know who they are.“

In conversations with Sean’s care team, dental health never or rarely comes up, as he describes: “they've never asked about it.” Despite this, Sean has taken his oral health into his own hands and describes them as having improved in recent years. He mentions not brushing at all during his time in middle school but now taking greater care of his teeth: “pretty much all throughout middle school, I feel like I very rarely brushed my teeth, to be honest. But now I've started realizing I should actually probably do that. So I'd say as of now, they’re pretty healthy.” His motivation to brush his teeth came internally, as Kelly describes not placing much emphasis on brushing or flossing: “we've never been very good at instilling flossing. I'm even a sort of random flosser.” Though he had previously consistently gone to the dentist every six months, the COVID-19 pandemic made it difficult for Sean to visit the dentist on a regular basis. Kelly explains further, “it's been almost 2 years, which is really strange for us, because we were doing it every 6 months, and so that is on our agenda for me to get that appointment for both of us.”

In managing his care, Sean expresses that he feels lucky in how having CF has minimally impacted his day-to-day life, stating “I still play sports and do everything I want. It's just the routine of having to, you know, take medicine and do all that, that really affects me, but that's not too hard.” Sean manages his CF by doing his breathing treatments and taking his medication daily, which Kelly describes feeling proud of: “when I hear him doing his breathing treatments, and taking good care of himself and seeing the importance of it.” On the same note, Kelly expresses her admiration for Sean in his optimism while having CF, and not letting others' comments impact him: “when you're a kid, especially in high school, middle school, you have to take enzymes and everyone’s asking, ‘Why are you taking medicine?’ but he's never… he’s just been like ‘this is just what it is,’ and so I'm very proud of his attitude.”

Sean’s independence in taking care of himself at times can be a double edged sword, with taking on everything himself and not wanting to ask for help. However, Kelly describes this as being a strength so that he is aware of how to take care of himself after he moves out:

> Sean: *I don’t really… I mean, I have all the help that I need, so I don't really think they could do anything more. I mean, I guess you can, but as I want to be more independent, it's not always wanting to ask for help.*
>
> Kelly: *Sometimes we allow, as parents, for them to fail so that they have the repercussions and understand why. I think if you don't let them fail, then they come crashing down when they get older when they leave us.*

Sean’s support network consists mostly of his mom, Kelly, as he lives primarily with her. However, his father is involved and is “fairly aware of his routines,” Kelly notes. “Because I make the appointments, and I do most of the follow ups and that sort of thing, and like medicine ordering, no one is probably going to know about it too much. But I should get that all written down. Growing up, Sean used to be “a lot less comfortable” and even embarrassed about his CF, especially at school: “I would kind of try to hide it.” Though he shares that now that embarrassment has diminished as he’s gotten older, he still struggles with feeling like a burden to those around him, describing only asking for help if “it's not too much of a burden or anything. So I’d just say, like nothing really.”

Care Management Behaviors of Hyper-Independent & Concerned

The table below summarizes the following themes for care management behaviors of participants in the Hyper-Independent & Concerned nexus type.

Oral Health: The majority of participants in this group have good or great oral health behaviors (brushing at least once or twice a day and flossing). Only one participant had okay oral health behaviors, and all participants in this group describe their teeth as healthy or very healthy.

Care Management: All participants in this group described feeling proud of themselves for persevering through hardships, taking charge of their care, and for advocating for themselves. They also described achieving tangible goals such as being consistent in taking medications and gaining and maintaining weight.

Sugary Beverage Intake: Three participants in this group drink some kind of sugary beverage daily, such as soda, supplementary beverage such as ensure or pediasure, and juice. Only one participant described sipping on their sugary beverage (soda) throughout the day, while others described drinking it all at once with a meal. Three participants also described drinking milk every day. Majority of participants described drinking water every day, except for one participant who described rarely drinking water.

Dietary Choices and Support: Participants in this group have a mix of independence and interdependence with their diet. They typically make their decisions around breakfast and lunch on their own, and some will make their own dinner as well (depending on if the parent/guardian cooks on a regular basis). Parents and guardians of this participant type are typically fairly aware of the dietary recommendations for CF and work with their child to get these needs. However, participants in this group can often have greater independence over their diet, especially if they have more of a "hands-off" parent/guardian that allows the child more freedom in their dietary choices.

Table 15. Care Management Behaviors of Hyper Independent & Concerned Nexus Type

Care Management	**Behavior**	**Reasoning**
Oral Health	Strong	Brushing 1-2x a day, flossing daily
Care Management	Strong	Consistent & proud
Sugary Beverage	High	Soda & juice daily
Dietary support	Average	Mix of independence & interdependence, modifying to fit recommendations

Unresourced and Unmotivated

The final nexus type, “Unresourced and Unmotivated,” differs from the previous four as they have low trust in their care team, low social support, and display low levels of agency. These individuals (one female and two males) have low trust in or feel disconnected with their care team due to needs not being met and incongruence with dietary recommendations and their own health beliefs. They are uncomfortable asking for support and in sharing with others about their CF and lack a social support network of friends. While they may have familial and extended family support, most of their support is from their maternal figure. The maternal figures of these participants express concern with the child moving into adulthood and having to manage their own health. Child participants in this type are often either highly independent or highly dependent in managing their own care and diet - either cooking the majority of their own meals and managing their care routines without much check-in or guidance from their parental figures, or they are completely dependent on their caregiver and do not take a personal stance in managing their care. They often lack resources and access to care, such as regular dental appointments.

Table 16. Unresourced or Unmotivated Nexus Type

Nexus Type	**Trust in Care Team**	**Support System**	**Agency**
Unresourced & Unmotivated	Low	Low	Low

Table 17. Demographics of Unresourced or Unmotivated Nexus Participants

	n	%
Age		
12-14	1	33.33
15-17	2	66.66
Sex		
Male	1	33.33
Female	2	66.66
Race		
White	3	100.00
American Indian or Alaska Native	0	
Hispanic or Latino		
Yes	1	33.33
No	2	66.66
Insurance Type		
Private	2	66.66
Public	1	33.33
Military	0	0.00

One participant that falls under this nexus type is Chris, a 16 year old white male with private insurance. Chris and his mom, Rachel, join the Zoom call through separate video cameras, though they are in the same house. Chris is in the basement of the house at his desk, with his bed in the background, while Rachel joins from the kitchen dining room table. Chris answers the interview questions briefly with low energy, and Rachel comments as needed, usually with a sassy attitude about Chris's behaviors. Chris's diet is very independent, as he orders his own food, typically frozen meals, through the InstaCart app on his phone and prepares them himself.

> Chris: *Well, like Mom said earlier, it's just mainly, I just have the Instacart app, and I just add stuff to the grocery list and then it comes here.*
>
> Rachel: *Yeah, I would say 90%, he decides. And then I might change something, but pretty much he decides.*

Because Chris is recommended by his care team to eat so many calories, Rachel says it is easier for him to order his own groceries and eat what he wants:

> Rachel: *He orders his own groceries, and he has a separate fridge, so he has the most control over that, so he doesn't eat a lot of, like, fresh food. So we, I mean, he doesn't order it because he doesn't eat it. It was just easier to say, 'OK, just what will you eat?' Get that and eat that and then he takes vitamin stuff.*

Chris typically eats alone in his bedroom whenever he feels hungry, rather than on a strict structure with his mom, with his most common meals being frozen pizza, fish sticks, fries, and chips and gummies for snacks throughout the day:

> Chris: *It's not very strict. I kind of just eat whatever I have, but what I do have is, I've been trying to change it, but just frozen foods, just easily, just oven stuff.*

Throughout the interview, Chris expresses a desire to change his habit of consuming mostly frozen foods:"I wish that I was eating more properly cooked foods, not just like frozen stuff." He also describes his pattern of eating as strange, explaining "I kind of eat weird. I don't do a lot of snacking, I kind of just don't eat for a long period of time, and then just eat one thing. I don't think that's good, but." Chris' limited diet is partially due to his pickiness, particularly around vegetables.

> Chris: *I don't love spinach, but it's probably the best out of them, broccoli. It all just depends on how it's cooked. Maybe anything just steamed, like just sauteed stuff. That's pretty easy to get down.*

> Rachel: *Yeah, I can't think of any vegetables that he does like although he does ask if I have spinach.*

Chris's tendency to eat easy-to-prepare meals is also related to the infrequency that his family cooks and eats together:

> Rachel: *I don't make dinner very often anymore, but if I made dinner, he probably wouldn't eat the vegetables.*
>
> Chris: *I'd probably eat the vegetables.*

Chris consumes sugary beverages on a daily basis, sipping three bottles of gatorade throughout the day, though he wishes to consume more "we made the switch to Gatorade Zero because my blood sugar was starting to get really high. If I wasn't pre-diabetic, it would be orange Fanta."

Provider turnover and retirement has impacted the strength of Chris and Rachel's relationship with their care team, as they are not even sure what some of their names are or who their current physicians are due to changes:

> Chris: *My mom would definitely know more about the other people because I'm bad with names.*
>
> Rachel: *The nutritionist just retired so I don't know who our new nutritionist is. It feels like people have really changed in the last, like, 3 or so years. The PFT people change all the time, so I never know… and we don't go with him when he does that, so I don't recall their names usually.*

Chris' perception of the dietary recommendations his care team provides is different from that of his moms, as he is fairly unsure of what they recommend, but guesses that they would advise he eat "healthy stuff," whereas Rachel believes they have historically advised fairly unhealthy foods:

> Rachel: *They were saying it doesn't matter what he eats as long as he eats lots of calories and fat and not to worry about eating anything worthwhile because he wasn't processing the vitamins from them anyways. We sort of went round and round on that, but ultimately, that's sort of how we've done it, but his weight has, he's never been underweight. There was one point where he actually got too heavy, and they told us, the GI doctor at the time, to back off a little bit. But mostly the conversation has been just about calories.*

Chris describes his oral health as "not great" due to not having a strong routine of brushing or flossing his teeth, and he is unsatisfied with the overall appearance of his smile. Rachel adds that she has seen Chris struggle to have a consistent oral health care routine, and how it even has impacted his ability to get orthodontic care:

> Chris: *Well, typically in a day, I don't do it, that's the main thing. But on the days that I do decide to be semi-responsible, I just do normal brushing, electric toothbrush. That's it.*
>
> Cassandra: *I would say he just doesn't, it's just non-existent mostly. He's never been… we've never really got him to focus on that, and both his dentist and his orthodontist have said that he's really doing a poor job of it. His orthodontist wanted him to get some sort of apparatus, and they said there was no way they would do it until he started taking better care of his teeth.*

Though his oral care routine is lacking, Chris does go to the dentist every six months for regular cleanings. However, every time he goes to the dentist, they make a note that he struggles with plaque build-up on his teeth. While his dentist hasn't discussed any details on how CF is related to oral health, the orthodontist did advise the importance of good oral hygiene to prevent bacteria from entering the lungs:

> Rachel: *The orthodontist did. The dentist no. The orthodontist just talked about how the bacteria, you know, that it was more important for him because of the bacteria getting into his system from his teeth.*

In addition to not having a consistent oral health care routine, Chris describes not feeling proud of how he takes care of himself on an everyday basis for CF: "not a lot honestly, just cause I'm not very proud of how I do it in general." Rachel, however, is proud of Chris' consistency in taking his daily medications, though he struggles with consistency in managing his care overall: "we've been trying to turn stuff over to him as he's getting older. And he seems to have taken the pill thing on the best of all the stuff." When discussing his care management, Chris tends to distance himself from his CF and center his mom's knowledge and experience with it:

> Chris: *They've been trying to turn it over to me for stuff like that. As of right now, it's just my mom because she knows a lot more about it than I do, she has more experience than this.*
>
> Rachel: *We have the exact same amount of experience.*
>
> Chris: *Oh that's true, yeah.*

As far as a support system, while Chris has family members that are aware of his CF and try to look out for him, Chris describes not going to anyone for help besides his care team. Rachel chimes in that in Chris' support system, she possesses the most information about his CF:

> Chris: *Just the care team, honestly. because I don't really reach out to anybody for specific help.*
>
> Rachel: *I would say too, that outside of me and his dad, like other family members are aware of enzymes and will ask about that and also are conscious of if he's not feeling*

> *well, or making sure he's wearing a mask when they go out. But I would think me, I probably have the best grasp of, like all of it, I think I have the most information.*

When thinking about what others could do to support him in his CF care management, Chris does not desire any further support as he feels they have "done enough," to which Rachel agrees:

> Rachel: *I'd like us to do less.*
>
> Chris: *No, wait…*

Care Management Behaviors of Unresourced & Unmotivated

The table below summarizes the following themes for care management behaviors of participants in the Unresourced or Unmotivated nexus type.

Oral Health: The majority of participants in this group have poor oral health behaviors. However, most of them describe their teeth as "healthy," with only one describing them as "not very healthy."

Care Management: All participants in this group describe not feeling proud of themselves in their health management. However, their parents describe feeling proud of their child for taking their medications and persevering through the hardships.

Sugary Beverage Intake: All participants in this group describe drinking a sugary beverage every day, such as gatorade and juice. One participant used to drink soda every day but recently made the switch to gatorade due to becoming pre-diabetic. Two of the three participants describe drinking soda 2-3 times a week in addition to their daily gatorade or juice. One participant describes sipping on their sugary beverage (gatorade) throughout the day, while the other two describe drinking their sugary beverage all at once, typically with a meal.

Dietary Choices and Support: Dietary behaviors in this group are mixed, with one child participant being fully independent in their dietary choices, while the other two participants in this group have at least one meal cooked by a parent. Their parents are typically aware of dietary recommendations and try to support meeting those. However, pickiness impacts dietary choices, and in some cases can make the child more independent in their dietary decisions. Participants who are more independent with their diet rely on frozen foods that are "easier and faster" to cook.

Table 18. Care Management Behaviors of Unresourced or Unmotivated Nexus Type

Care Management Behavior	Strength	Reasoning
Oral Health	Weak	Brushing once a day or irregularly

Care Management	Weak	Inconsistent & not proud
Sugary Beverage	High	Juice daily, soda every other day
Dietary support	Weak	Pickiness and full independence

Care Management Behaviors by Nexus Type

Below are the care management behaviors examined as part of this research study (oral health behaviors, CF specific care, sugary beverage intake, and dietary habits) for each nexus type. The care management behaviors are classified and color coded to represent what is considered strong (green), average (yellow), and weak (red) care management behaviors. Classification was done according to the number of strong, average, or weak behaviors for each nexus type.

Table 19. Care Management Behaviors by Nexus Type

Nexus Type	**Care Management Behaviors**
Strong Safety Net (n=5, four females, one male)	Strong oral health behaviors Strong CF care management Average sugary beverage intake Strong dietary habits
Maternally Motivated & Supported (n=4, three females, one male)	Strong oral health behaviors Strong CF care management High sugary beverage intake Average dietary habits
Suffer in Silence (n=4, three females, one male)	Average oral health behaviors Weak CF care management Average sugary beverage intake Average dietary habits
Hyper Independent & Concerned (n=5, two females, three males)	Strong oral health behaviors Strong CF care management High sugary beverage intake Average dietary habits
Unresourced & Unmotivated (n=3, one female, two males)	Weak oral health behaviors Weak CF care management High sugary beverage intake Weak dietary habits

The Strong Safety Net nexus type is the only type of the five to have strong care management behaviors. Interviewees who have high trust in their care team, a strong support system, and a high level of agency tended to have stronger care management behaviors. Both Maternally Supported & Motivated and the Hyper Independent & Concerned nexus types have average care management behaviors. Participants who demonstrated a moderate level in two of the three dimensions of the patient nexus typically had average care management behaviors. Participants who had a low level of support and low agency also tended to have poor care management behaviors, such as those in the Suffer in Silence and Unresourced and Unmotivated nexus types.

Although high trust in the care team is important, those who had strong trust did not necessarily tend to have strong care management behaviors. For example, in the Maternally Supported & Motivated nexus type case, while Laila's care team's dietary recommendations focused more on quantity vs quality, Caroline, Laila's mother, does not find an issue with this and it does not impact their care relationship: "a lot of people kind of think they should focus more on what [quality]. But they're all, I mean, it's always been very good". However, having a trusting relationship does not necessarily mean that the recommendations that one receives from their care team are always the most consistent or current recommendations with changing research about dietary and oral health recommendations for individuals with CF. As mentioned, the shifting dietary recommendations due to TriKafta are now leaning towards considering the quality of food rather than solely on quantity for weight-maintenance purposes. Therefore, while having a trusting relationship can have a positive impact on care management behaviors, it is dependent on the quality and consistency of recommendations received.

The importance of having a trusting relationship with the care team should not be disregarded, however, especially for those who already possess low levels of agency and lack a strong support system. For example, Stephanie, a 14 year old female who is publicly insured and also falls under the Unresourced and Unmotivated nexus type, has a notably challenging relationship with her care team. Stephanie's mom, Cassandra, also has CF and is able to compare her experience with her own care team to that of the experience with Stephanie's:

> Cassandra: *I've worked with lots of different pulmonologists, and I actually go to a different center. I feel like the center I go to is much more compassionate and understanding. I feel like sometimes [*Stephanie's care team*] rushes us or they like, don't fully listen. I find that kind of annoying but… yeah, I just think, there's probably better people out there.*

Cassandra also expresses dissatisfaction with the quality of dietary recommendations. She describes going to Stephanie's care team in search of specific recommendations for daily water and calorie intake, to which she felt frustrated with the general feedback she receives:

> Cassandra: *It was like every person I asked gave me a different number, and some of them didn't make any sense. So it was like can I just have a reasonable response where*

> *I'm not playing a guessing game? I feel like in general, sometimes when I ask questions, I get a basic response or like, we're not sure. And if I asked my care team something like that they would give me a more definitive answer that actually made sense. I'm like, well, why don't you guys know more. Or like, why can't you give me a better answer? I find that frustrating.*

Indeed, compacted with low social support and low agency, participants who have mistrust with their care team tended to have poor care management behaviors.

Post-Hoc Analysis & Findings

Care Management Behaviors by Sex

The table below shows the care management behavior across all participants (n=21, 13 females and 8 males).

Table 20. Care Management Behaviors by Sex

Care Management Behavior	Female Participants	%	Male Participants	%
Strong Care Management	4	30.77	1	12.50
Average Care Management	5	38.46	4	50.00
Poor Care Management	4	30.77	3	37.50
Totals	13	100.00	8	100.00

The majority of all participants in the study tended to have average care management behaviors, with five females (38 percent of female participants) and four males (50 percent of male participants). Across male participants, only one of the eight exhibited strong care management behaviors, while across female participants, four of the thirteen exhibited strong care management behaviors. Indeed, average and poor care management behaviors were exhibited more often in male participants, while female participants were more evenly distributed in strong, average, and poor care management behaviors.

Care Management Behavior by Insurance Type

The table below shows care management behaviors by insurance type.

Table 21. Care Management Behavior by Insurance Type

Care Management	Private	%	Public	%	Military	%

Behavior	Insurance		Insurance		Insurance	
Strong Care Management	2	18.18	2	25.00	1	50.00
Average Care Management	5	45.45	4	50.00	0	0.00
Poor Care Management	4	36.36	2	25.00	1	50.00
Totals	11	100.00	8	100.00	2	100.00

In this study sample, there are no notable differences of care management behaviors across insurance types, therefore individuals of a certain insurance type do not tend to have certain care management behaviors. While insurance type has been used in previous studies as a proxy for income level, new research has found that this can cause misclassification of socioeconomic status of participants and bias in research findings (Monteaux et al., 2024). As this study does not have income data for our sample, I am unable to draw conclusions about care management behaviors across income levels.

Data Limitations

Social context also includes demographic factors such as race/ethnicity, gender and sex, age, socioeconomic status. All of these demographics can impact health and one’s ability to apply treatment recommendations. For example, Black and Latino individuals are less likely to have a primary care provider, let alone a trusting relationship with medical providers (MHQP, 2025). Populations with low socioeconomic status are also likely to have consistent care or may experience food insecurity (Hill et al., 2022). Women with CF have lower life expectancy than men with CF, while many studies have linked this life expectancy to biological factors such as decreased lung size, research on social factors (such as gender roles, gendered care, and gender discrimination) have been limited (Harness-Brumley et al., 2014).

While the data of this study includes race/ethnicity, sex, and age, the study does not have data on gender identity. It is critical to distinguish between sex assigned at birth and gender identity. Sex assigned at birth refers to the biological characteristics (such as chromosomes) that are used to classify an individual as male or female at birth, while gender is a socially constructed concept that encompasses the roles, behaviors, and identities that societies assign to individuals based on their perceived sex (WHO, 2023).This distinction is especially important in health research, as gender can influence how individuals experience their health, navigate the healthcare system, and adhere to medical recommendations. For example, women with chronic illnesses such as cystic fibrosis (CF) may face different challenges in managing their care due to gendered expectations, caregiving responsibilities, and even biases in the healthcare system.

Since this study lacks data on gender identity, we are unable to explore how gender may have impacted participants in their navigation of CF care recommendations. Further research is needed to explore how gender, alongside other social determinants, influences the life expectancy gap and other health outcomes for individuals with CF. This would help us understand how social, cultural, and systemic factors, rather than biological differences alone, contribute to disparities in CF care and outcomes.

This study lacks direct income data of participants, however it does have data on insurance type which has been used in previous research as a proxy for socioeconomic status. However, as mentioned, recent research has found that using insurance status as a proxy for income can misclassify socioeconomic status (SES) of participants (Wu et al., 2024). As this study lacks direct income data, caution is necessary when interpreting SES-related findings based solely on insurance type. As such, I am unable to draw direct conclusions about how a participant's socioeconomic status impacts their ability to navigate CF care recommendations. Although this study does not have participants' income level, participants at times touch on the monetary challenges that come with fulfilling CF care recommendations.

The sample for this study is also majority white participants, so I am unable to draw conclusions of how race/ethnicity may impact care management behaviors. However, about 90% of individuals with CF are Caucasian, which is similar to our sample representation of about 95% white participants (CFF, 2022). Still, it must be noted that there are racial and ethnic disparities for diagnosis of CF, which could misrepresent the actual racial and ethnic makeup of individuals with CF (Wu et al., 2024). Further research is needed to better understand the specific challenges of getting diagnosed, treated, and management of CF for BIPOC individuals.

Discussion

This study advances research on social disparities of chronic illness management by examining the care management behaviors and social support systems of youth with CF. First, I find five patient nexus typologies that represent the support systems available to participants that impact their care management behaviors. Of these five nexus typologies, participants who fell under the Strong Safety Net nexus type (characterized by having strong levels in all three patient nexus dimensions: high trust in their care team, a strong support system, and a high level of agency) were the only individuals who tended to have stronger care management behaviors in oral health and dietary habits and adhering to CF treatments and medications. The study results also revealed that individuals in the Maternally Motivated & Supported and in the Hyper Independent & Concerned nexus types (characterized by having "moderate" levels in two of the three patient nexus dimensions) tended to have average care management behaviors, such as having high sugary beverage intake and average dietary habits, but strong oral health habits and adherence to CF treatments and medications. Lastly, I find that participants in the Suffer in Silence and Unresourced & Unmotivated nexus types (characterized by low levels of social support and agency) tended to have poor care management behaviors, such as having average or weak oral health and dietary behaviors, average or high sugary beverage intake, and poor adherence to CF care management.

Findings from this study show that individuals with greater social support, higher levels of agency, and higher trust in their care team tended to have stronger care management behaviors in oral health, dietary habits, and adherence to CF treatment and medications. Of the three patient nexus dimensions, the level of social support available and individual agency tended to impact care management behaviors most. Despite having high trust in one's care team, participants without strong social support or high level of agency tended to have poorer care management behaviors. While there has been some recognition of social contexts impacting health behavior, implementation of these findings has yet to be fully realized, and there is a lack of discussion on the typologies of patient nexuses and their impacts on care management (Pescosolido, 2006; Oates, 2015; Rogers et al., 2011). Because no prior study has, to my knowledge, identified patient nexus typologies of children with CF, this is the first study to understand how differing types of social support systems impact care management in children with CF (Oates, 2015).

In this study, I also evaluated care management behavior tendencies by sex and found that the majority of all participants, regardless of sex, tended to have average care management behaviors (with 38% of female participants and 50% of male participants). However, across male participants, average and poor care management behaviors were more common, while female participants' were more evenly distributed across strong, average, and poor care management behaviors. Further research should explore care management behavior differences across sex and gender to better understand the gendered life expectancy gap in individuals with CF, as research thus far has mostly focused on biological differences rather than the gendered social differences of CF care management (Kazmerski et al., 2020; Tluczek et al., 2006). Continued research on the gendered differences in chronic care management would assist in health intervention development to lessen this gap with improved health outcomes for women with CF.

Finally, it is critical to discuss these findings considering the evolving CF dietary and oral health recommendations. The introduction of new CFTR modulator therapies such as TriKafta has led to significant improvements in lung function and overall health for individuals with CF. However, these advances also present new care management challenges, including the need to adjust dietary guidelines to accommodate changes in metabolism and nutritional needs. Additionally, ongoing oral health research has highlighted the increased risk of dental issues, such as cavities and gum disease, that may arise as individuals with CF live longer lives. The combined impact of these factors requires healthcare providers to develop more comprehensive and individualized care plans to support patients in adapting to both the physiological and lifestyle changes that accompany these therapies. This study highlights that the ability to apply care recommendations to one's day-to-day life varies immensely depending on an individual's social context and the resources and barriers attached to those contexts. Provider awareness of these challenges is essential in order to support the individual in meeting their dietary recommendations in a way that is applicable to their life. Self-advocacy of the individual patient is also of great importance, as the individual is the only one who can share the reality of their situation and how they plan to work within their means to manage their health. Medical professionals should pay close attention to patients who fall under the “Suffer in Silence” and “Unresourced & Unmotivated” nexus types, as these individuals lack both a strong support system and agency. Through targeted intervention and a trusting care-team relationship, individuals in these nexus types can work with their providers to build a strong support network and rebuild their agency to manage their health.

Future studies on CF care management, and care management in general, should include patient nexus theory in methodology and analysis to better understand how care management behaviors are impacted by one’s social context and the resources available within it. Further research is also needed to understand how to build a trusting, long-term provider-patient relationship, a strong support system, and a high level of agency. Further research is needed on the social determinants of the gender life expectancy gap in individuals with CF, and for racial, ethnic, and income disparities for diagnosis, treatment, and management of CF. Particularly in a time of evolving care recommendations for CF regarding diet and oral health, it is also vital for providers to be consistent in their messaging and recommendations to patients. Additional studies are needed to better understand CF care team dynamics, their perception of the current and evolving state of recommendations, and how consistent provider messaging is within CF care teams.

Conclusion

This is the first study to apply patient nexus theory in a case study and to identify patient nexus typologies of children with CF and their differing care management behavior tendencies. Although other social health research has shown the connection between social context and chronic care management behaviors, this is the first study to document greater understanding of the different care management behavior tendencies across different social network types with varying levels of social resources. I show that individuals who possess greater social support and agency tend to have better care management behaviors, while those who lack social support and agency tend to struggle. Taken together, this study provides greater understanding of the impacts that one’s social context has on their ability to adhere to recommendations and manage chronic illness, and describes specific patient nexus typologies that could benefit from targeted intervention.

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