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AN EXPLORATORY SURVEY OF FACTORS AFFECTING SATISFACTION WITH EDUCATIONAL EXPERIENCES FOR PARENTS OF CHILDREN WITH CYSTIC FIBROSIS

A Dissertation

Submitted to the School of Education

Duquesne University

In partial fulfillment of the requirements

for the degree of Doctor of Philosophy

By

Rebecca Perry Keenan

December 2018

AN EXPLORATORY SURVEY OF FACTORS AFFECTING SATISFACTION WITH EDUCATIONAL EXPERIENCES FOR PARENTS OF CHILDREN WITH CYSTIC FIBROSIS

By

Rebecca Perry Keenan

Approved October 22, 2018

Kara McGoey, PhD
Professor of Department of Counseling,
Psychology, and Special Education
(Committee Co-Chair)

Ara Schmitt, PhD
Associate Professor of Department of Counseling,
Psychology, and Special Education
(Committee Co-Chair)

Launcelot Brown, PhD
Professor of Department of Educational
Foundations and Leadership
(Committee Member)

ABSTRACT

AN EXPLORATORY SURVEY OF FACTORS AFFECTING SATISFACTION WITH EDUCATIONAL EXPERIENCES FOR PARENTS OF CHILDREN WITH CYSTIC FIBROSIS

By

Rebecca Perry Keenan, MSEd

December 2018

Dissertation supervised by Kara McGoey, PhD and Ara Schmitt, PhD.

Consumer satisfaction has been studied extensively as it relates to service seeking behavior, positive perceptions of services rendered, and measurable benefit as a result of service delivery. Furthermore, numerous studies have explored the importance of a strong, collaborative home-school partnership for student success. Additionally, previous research has identified children with chronic illnesses as a special population frequently requiring individualized accommodations and modifications to promote success in the educational environment, and therefore testing the limits of the educational system to adequately meet their needs. Finally, research has described the common sequelae of Cystic Fibrosis, including wide-ranging physical, behavioral, and functional consequences. However, these various contributing factors have not yet been synthesized to inspect their impact on parent satisfaction with educational experiences for children with Cystic Fibrosis. The proposed study aims to characterize the demographics of parents of children with CF, describe their responses to questions regarding various aspects of satisfaction, and determine the predictive value of the survey questions for measuring parent satisfaction.

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Chapter I: Introduction

According to the American Academy of Pediatrics (AAP), it is estimated that 10 to 20 million children in the United States are affected by a chronic health condition or impairment, and 1 to 2 million of these children have conditions severe enough to impact daily living (Majors, 2003). A chronic illness is a disorder with a lengthy course that can be progressive and fatal or associated with a relatively normal life span and causes significant impairment during periods of acute exacerbation requiring intensive medical attention (Coyne, 1997). Chronic illnesses affect 10% to 15% of school children in the United States (AAP, 2004), and this unique group of students encompasses a wide range of diseases with dramatic variation in disorder severity. Examples of chronic illnesses include diabetes, epilepsy, sickle cell disease, asthma, cancer, and cystic fibrosis.

Cystic fibrosis (CF) is the most common fatal genetic illness amongst people of white European descent, and primarily impacts the functioning of the lungs, pancreas, digestive, and reproductive systems. Treatment is frequently complicated by a host of co-occurring conditions and can be time-consuming, as well as financially straining (Quittner et al., 2009). According to the national patient registry of the Cystic Fibrosis Foundation (CFF, 2012), 30,000 people are estimated to be living with CF in the United States, and more than half of those living with the disease are children under 18. Medical and technological advances over the past half-century have drastically improved the quality of life as well as the life expectancy of children diagnosed with CF. Over the past 50 years, the median predicted survival has increased from school age in the 1950s to nearly 40 years at present, and continues to rise (Quittner et al., 2009). Additionally, more than 95% of children with CF born after 1992 have survived into their teenage years (CFF, 2012). More children with this disease are living longer, healthier lives, increasing the likelihood that educators and school personnel will come into contact with a child diagnosed with CF (McCance & Huether, 2002). For this reason, investigating the interactions of children with CF and educational systems is important.

As the number of children living with CF and other chronic health conditions grows, it is important to understand the extent of these children's service needs and the barriers to delivery of those services, which may vary widely. Schools face many challenges in attempting to meet the needs of children with chronic illnesses within legal and ethical guidelines, but little research exists on the functioning of these children in the school setting, the effectiveness of interactions between the school and health care systems, or the school experiences of parents with chronically ill children (Aruda, Kelly, & Newinsky, 2011).

One challenge schools face is the lack of standardized protocols for accommodating students with varying chronic illnesses (Irwin & Elam, 2011). In the realm of special education, some qualifying disorders have well established behavioral and academic profiles with widely researched intervention and management strategies, allowing students in need of support to be identified with relative ease and educators to design instructional programs with a plethora of evidence-based interventions specifically formulated to remediate the common sequelae of these disorders. On the other hand, evaluation teams must consider if academic difficulties are directly tied to the characteristics of a seemingly endless number of pediatric health conditions and if the difficulties are significant enough to warrant special services. Despite the necessity of weighing each incidence of chronic illness on a case-by-case basis, there are several common psychoeducational implications of health conditions identified in the literature.

The serious health consequences associated with chronic illnesses are highly likely to influence educational outcomes, necessitating individualized evaluation and programming.

Although acute illnesses, injuries, and family crises can impact the educational course of a student at any given time, chronic illnesses tend to have more prolonged, pervasive effects. Children with chronic illnesses face challenges in school beyond maintenance and management of health needs, including academic struggles, problematic internalizing and externalizing behaviors, and difficulty participating socially with their peers (Quittner et al., 2009).

Cognitive and Developmental Consequences

Regarding general cognitive ability, children with chronic physical health conditions are likely to fall within the average range (Clay, 2004), and more specifically, CF does not have any known cognitive sequelae with IQs of affected children being normally distributed (Lawler, Nakielny, & Wright, 1966; Grier & Bradley-Klug, 2011). Despite this fact, chronically ill children experience academic difficulty and failure at higher rates when compared to typically developing peers without health concerns. Several factors may contribute to the higher incidence of academic difficulty among chronically ill children, including decreased physical well-being, poor attendance, negative treatment effects, and poor psychological adjustment, including limited motivation and social difficulty (Power, McGoey, Heathfield, & Blum, 1999).

Physical Consequences and Treatment Effects

The physical symptoms of an acute illness such as the flu or a sinus infection may interfere with academic performance and behavior for typical children, but the frequency and intensity of symptoms in children with chronic illnesses may be even more pronounced. Chronic illnesses often follow relapsing-remitting patterns, with periods of acute exacerbation interspersed among periods of relatively good health. Some students might vacillate between states of health frequently, while others may experience long periods of stability between health crises. Furthermore, one student may experience rapid and extreme fluctuations in health status, while another students' variability in health status is more gradual and constricted. For these reasons, the impact of chronic conditions can be underestimated and even invisible at times, thus decreasing the likelihood that the need for services is recognized and a plan is in place prior to a crisis.

The ICD-10-CM (2016) reveals that patients with CF may experience a variety of respiratory, digestive, and general physical symptoms. Children with CF experience frequent respiratory infections, resulting in coughing, wheezing, and in extreme cases respiratory distress, arrest, or failure. These symptoms range from distracting and treatable at school to debilitating and requiring removal from the educational environment to obtain medical attention in more severe cases. Another common physical consequence of CF is digestive system disturbance, including diarrhea, constipation, cramping, and even bowel obstruction, which may necessitate frequent excuses to leave the classroom or emergent medical care. Finally, many children with CF experience body-wide musculoskeletal pain or headaches as a side effect of their other physical symptoms. During these symptomatic periods, children may have limited physical endurance, seem less energetic and more irritable, or demonstrate lack of attention and concentration, thus limiting the ability to benefit from instruction in the educational environment.

By extension of the physical symptomatology associated with CF, an obvious educational side effect of being diagnosed with this chronic health condition is absenteeism. Research shows that 58% of children with chronic illnesses routinely miss school and 10% are absent more than one quarter of the school year (Thies, 1999). Furthermore, a survey conducted by Wildhagen and colleagues (1996) found that children with Cystic Fibrosis miss an average of 19.5 school days per year, compared to a healthy child who misses an average of 3 days (Shaw & McCabe, 2007). The reasons for absences vary from routine preventive healthcare visits to acute health crisis. Additionally, several more complex factors may also contribute to these higher rates of absenteeism such as the child's attitude toward school, adult caretaker's perceptions of the relative importance of school, and the availability of school resources to meet the health and safety needs of the child (Aruda, Kelly, & Newinsky, 2011). For instance, when a child is prescribed a rigorous course of treatment, parents are not always confident in the ability of the child's school personnel to adhere to the regimen, and may keep the child home to retain more control over the therapeutic regimen, in spite of the child being in a state of health suitable for attending school. Infection prevention may also serve as a barrier to attendance for children with CF, who may not attend school when illness is prevalent among peers to avoid contamination (Sexon & Madon-Swain, 1995). Regardless of the specific reason for missing school, the cumulative effects of lost instructional time and missed opportunities to practice academic skills could contribute significantly to academic difficulty.

Another common factor that school children with chronic illnesses must contend with is the treatment effects of medications and therapies prescribed to improve or maintain health. Some treatment regimens are time consuming, taking 30 minutes or more multiple times per day to deliver medications or physical therapies and potentially taking time away from learning or social activities (Cystic Fibrosis Foundation, 2006). Other medications have neurochemical side effects, or "behavioral and emotional toxicities", such as decreased concentration, fatigue, depressed mood, or sleep and eating disturbances (Thies, 1999; Brown et al., 2009). Naqvi and colleagues (2008) found that more than 70% of children with CF reported daytime sleepiness and demonstrated poorer sleep than controls. Any of these side effects or a combination of several could contribute to increased absences or decreased ability to fully attend to instruction in the educational environment.

Behavioral and Emotional Consequences

In addition to the physical aspects of illness and treatment effects which are known to impact school performance, children with chronic illnesses are also known to be at increased risk for behavioral and emotional problems (Hysing, Elgen, Gillberg, & Lundervold, 2009). Blackman et al. (2010) posited that children with chronic health conditions were more likely than their typically developing peers to experience behavioral difficulty in the school setting due to a number of factors including limited coping skills and inconsistent limit setting. Contending with the day to day consequences of a chronic illness or intermittent health crisis can exhaust the coping resources of an ill child, leading to poor social and emotional adjustment in the school setting (Power et al., 1999). Finally, environmental factors related to the changing settings in which chronically ill children receive care may contribute to behavioral difficulty during adjustment periods due to differing expectations and goals. For example, the goals in an acute care hospital setting are often survival and patient comfort. Support for coping is high, structure may be limited, and expectations of emotional control are relaxed. Conversely, the goals in an educational setting include academic learning and peer socialization. Support for coping is not typically emphasized and the environment is highly structured, with more rigorous expectations of appropriate behavioral and emotional control. Thus, inconsistent behavioral expectations, including limit-setting, and support for coping across settings may create difficulty when the child is transitioning from one setting to another (Hysing et al., 2009).

Blackman et al. (2010) found that children with chronic illness were three times more likely than their typical peers to experience emotional, developmental, and behavioral (EDB) difficulties. These included trouble with learning, communication, emotional regulation, and behavior. Furthermore, when chronic pain was a symptom of the illness, the prevalence of EDB was eight times the prevalence rate in the general population. Additionally, the rate of attention, concentration and hyperactivity problems was twice as high among children with chronic health conditions as with typical children. Problems tend to increase with age, likely due to the cumulative physical and psychological effects of the illness.

Another issue chronically ill children may face is social anxiety related to body image concerns, particularly if an illness has caused visible physical changes (Harris, 2009). Children with CF are typically of short stature and thin build and may experience delayed onset of puberty and late development of secondary sex characteristics (Bradley-Klug et al., 2006), making them appear younger and less physically mature than healthy peers. These children may also have noticeable indications of treatments received, such as intravenous (IV) lines for antibiotics or feeding tubes for supplemental nutrition. Additionally, some medications have physical side effects such as drowsiness, causing a child to fall asleep during class, or water retention, causing swelling. The near constant cough that many CF patients have may draw unwanted attention or cause distraction during inopportune moments. Physical differences may lead to teasing and internalizing problems like anxiety and depression, common in adolescents with CF (Quittner et al., 2009).

In addition to physical limitations and social difficulties, children with chronic illnesses may experience emotional problems related to traumatic stress. In 1994, APA noted that learning of a life-threatening illness is a traumatic event and treatment of chronic illness and associated complications may constitute repetitive trauma (Santacroce, 2003). According to the DSM-V (2013), symptoms of Post-traumatic stress disorder (PTSD) may include: reliving trauma through nightmares or flashbacks, perseverative thinking, avoidance of places or people associated with trauma, and emotional lability, seeming overexcited, irritable, restless, or unfocused.

Additionally, PTSD may be related to social and behavioral difficulties such as intense separation anxiety and psychosocial regression. Children with chronic illness may experience "pediatric medical traumatic stress" (PMTS), a broader and more inclusive cluster of post-traumatic symptoms including arousal, re-experiencing, and avoidance specifically linked to medical events such as diagnosis and treatment (Kazak, Schneider, & Kassam-Adams, 2009). Given the potentially severe health exacerbations and subsequent treatments, children with CF may be affected by PMTS or PTSD, which could interfere with both school attendance and performance.

Social Consequences

Socially, children with chronic illness often experience problematic interpersonal and group relationships with peers. Issues include social withdrawal and isolation, peer exclusion and rejection, and limited social problem solving and conflict resolution skills. Chronically ill children may miss out on social experiences as a result of not being able to fully participate in the day-to-day dynamics of the social environment due to restrictions from certain activities or interference of treatment (Power, DuPaul, Shapiro, & Kazak, 2003). Aside from missed opportunities to engage with peers, ill children often contend with "contagion misconception" or other children's fears of contracting infection due to misinformation or lack of knowledge about an illness, which may lead to social stigma and relational aggression such as shunning and exclusion (Bradley-Klug et al., 2006). Finally, chronically ill children often struggle to get along with peers because children with chronic illness may no longer identify with the interests and concerns of same-aged typical children (National Cancer Institute, 2013). Adolescents with CF may encounter the unique psychosocial issues related to organ transplantation and contend with concerns about death or dying, including provision of advanced directives and making choices regarding end-of-life care (Quittner et al., 2009). After confronting such serious matters, the relative importance of age-typical social issues may be diminished. Despite this potential for disconnection, peer social support has been found to be related to increased quality of life for CF patients (Graetz, Shute, & Sawyer, 2000), which in turn is linked with more positive physical outcomes, thus adequate social integration may be critical for these students.

Appropriate Service Provision and Potential Barriers

Given all of the aforementioned potential consequences of Cystic Fibrosis for school children, access to appropriate academic, behavioral, emotional and social supports may have far-reaching consequences for these chronically ill children. Despite the obvious benefits of adequate service provision to this population, the difficulties presented by appropriately categorizing children with chronic illness and developing suitable educational programs are frequently compounded by inconsistent and sub-threshold demonstration of need, presenting another barrier to service delivery.

The costs of a school's failure to provide adequate services to children with chronic illness cannot be understated. Delivery of appropriate services is known to influence educational attainment, which has been correlated with healthy lifestyle choices (such as diet, exercise, and avoidance of illicit drugs) and treatment compliance (Fennell, Leitz, & Fantuzzi, 2009). Additionally, children with chronic illness are already at higher risk for school absenteeism and dropout than healthy peers. These two factors in conjunction make it highly likely that children with chronic illness may have much lower educational attainment than their healthy, adequately supported peers, and this may be related to negative health outcomes such as decreased life expectancy. Therefore, maintaining an appropriate and supportive educational environment has potentially critical long-term health consequences for children with chronic illness. Research demonstrates that a collaborative problem solving approach undertaken by a multidisciplinary team is most effective in improving student outcomes when the team accurately defines a student's problem, clearly identifies a goal, and reliably collects data to indicate the student's response to intervention (Telzrow, McNamara, & Hollinger, 2000). Important for all children, this collaborative problem solving practice is critical for students with chronic illness, including those with CF.

Home-School Collaboration

In addition to the difficult nature of identifying and providing the appropriate services for students with chronic illness, the impact on and needs of families must be considered. Most school age children are not yet legally or developmentally capable of making critical decisions regarding healthcare and education, thus those responsibilities fall to parents and guardians. For this reason, it is imperative that professionals approach working with children with their minds open to working with families, too. One important but often overlooked characteristic of high-quality care includes giving adequate support and respect to the family. Family-centered care is the standard in the field of medicine, but what about education?

Research suggests that parents who describe the medical care received by a child as family-centered report a greater sense of partnership and shared decision making, greater satisfaction with care decisions, greater adherence to treatment plans, and more positive health outcomes for children (Murphy et al., 1995). Echoing the sentiments of the Maternal and Child Health Bureau to provide family centered care in a medical home, a policy statement from The American Academy of Pediatrics (AAP, 2002) defined a "medical home" as a physician or team of healthcare workers known to the child and family and "family-centered care" as a partnership characterized by mutual responsibility and trust. Furthermore, The AAP noted that care should be coordinated with schools in such a way that the family, the physician, and other service providers work as an organized team to meet the needs of the child. Similarly, the Cystic Fibrosis Foundation's (2012) primary recommendation for the improvement of care is to include patients and their families as full members of the CF care team. By extension, ensuring a high quality educational experience for chronically ill children and their families necessitates that school personnel and families work as an organized team, forming a home-school partnership.

A collaborative home-school partnership is characterized by the efforts of both parents and school personnel to establish effective communication and inclusive practices. School personnel must demonstrate to parents that their children are safe and supported, and that they are well informed and involved in decision making. Parents must demonstrate concern to school personnel about the child's educational success and dedication to promoting a positive attitude towards learning and school (Canter, 2004). Although a strong home-school partnership is important for all children, it is especially important for children receiving special services due to the increased responsibility of all parties to exchange information and plan extensively to ensure the students' safety and success. By extension, this family-centered practice is perhaps most critical for those who experience concurrent medical and educational challenges since the communication and planning can have grave health consequences. Given this information, a family-centered approach to educational planning and intervention could lead to several positive outcomes for families and children living with chronic illness, including increased engagement, satisfaction, treatment compliance, and positive child outcomes, including educational outcomes.

Engaging and including families in the school community is the most basic tenet of family-centered practice as it relates to education. Family engagement has been a long-established goal of educators, evidenced by a decades-old policy statement of the National

Educational Goals Panel (U.S. Department of Education, 1994) specifying that schools must promote partnerships that increase parent involvement and participation to support the social, emotional, and academic growth of children. For many years, school personnel have been charged with the responsibility of building relationships with students' families to facilitate communication and provide support for continued learning outside of the classroom, and evidence supports that family engagement has far-reaching implications for student achievement.

Christenson et al. (1997) highlighted the critical nature of family involvement in education, finding that family process variables, or the specific things families do to support learning, predict up to 60% of variance in achievement, while status variables (such as social class and family configuration) predict about 25% of variance. Outcomes of this research suggest that families who are able to offer support and guidance to students beyond that provided by educators during the school day have a distinctly positive impact on student success. The ability to support learning is heavily influenced by the family's familiarity with the staff and curriculum, and willingness to offer this support is dependent on parents' overall perception of the relevance of the curriculum and educational philosophy of the school. When parents feel that both the quality and relevance of educational services are aligned, the result is satisfaction.

Parent Satisfaction with School Experience

Satisfaction refers to the extent to which people feel their needs are fulfilled to a satisfactory level and in a suitable fashion. As it relates to schools, parent satisfaction refers to the extent to which children's needs are being met in an agreeable manner, though few studies have explored the factors that lead to parental school satisfaction or the school and district characteristics associated with the construct. One of these studies, conducted by Friedman, Bobrowski, and Markow (2007), measured satisfaction by asking parents to grade their child's school using a ten point scale and indicate whether parents were proud of their child's school and would recommend the school to other parents. The researchers identified three factors, school communication and involvement afforded to parents, the adequacy of school resources, and the effectiveness of school leadership, as accounting for 63% of the variance in satisfaction ratings. Furthermore, results of a study conducted by the National Association of School Psychologists (NASP) indicated that parents felt provision of information on how schools function and time for face-to-face interaction between parents and educators to share information about children, school requirements, and family needs were among the greatest areas of need with regard to strengthening home-school partnerships (Christenson et al., 1997). Given that communication and involvement were endorsed as contributing heavily to satisfaction, enacting the principles of family-centered practice could lead to increased parent satisfaction with their child's educational experience.

Further support for increasing parent satisfaction was provided by Christenson and Sheridan (2001), who noted a bi-directional relationship between satisfaction and involvement. The researchers found that satisfaction shapes involvement and involvement influences satisfaction. Parents who are satisfied with a child's educational programming are more likely to be involved in the child's education both at school and at home. Likewise, involved parents are more likely to express satisfaction with the educational experiences being afforded to the child. Research emphasizing the critical nature of parent involvement in education has demonstrated an association between parent involvement and greater academic achievement at all grade levels, greater teacher perception of the child's social competence, lower grade-retention and high school dropout rates, and fewer years spent in special education (Fantuzzo, Perry, & Childs, 2006). Parent involvement is believed to influence a child's school performance through two main mechanisms, social capital and social control (Hill & Taylor, 2004).

Aruda and colleagues (2011) surveyed parents of CSHCN between the ages of 3-22 to determine how parents perceived the adequacy of communication between medical and educational providers and what significant unmet healthcare needs they perceived for CSHCN in the school setting. Results of the study revealed that although most families ranked communication between settings as "good" or "adequate", open-ended responses indicated that communication and the mechanisms required for successful coordination are still developing. Many parents perceived that their role was to act as an intermediary between the settings, though nearly one third felt uncomfortable in this role. Parents also indicated that lack of primary care support was a barrier to this critical communication. The majority of unmet needs were related to the availability of high quality services and the lack of palliative care, defined as "services addressing the medical, psychological, social, and spiritual needs of children and their families living with chronic illness, life-threatening episodes, or terminal conditions" (Aruda et al., 2011, p. 211).

Significance of Problem

Parent satisfaction with the home-school partnership is critical for student success. When children experience medical and educational setbacks as a result of chronic illness, parents must be comfortable and confident in clearly communicating the child's and family's needs and service desires to other team members involved in the care and schooling of the child. Families need to feel empowered, believing that parent input is valuable and influential in the decision-making and planning processes. Poor communication, limited information sharing, lack of respect for each other's expertise, and disagreement regarding appropriate educational goals may lead to a deep sense of dissatisfaction and mistrust between families and educational teams, potentially negatively impacting student outcomes.

Important to determine is if parents of children with Cystic Fibrosis are satisfied with the partnerships established between and among the members of their child's care team because strong home-school partnerships are known to be influential in the educational success of these children with far reaching implications. If it is determined that parent satisfaction with the home-school partnership is generally low, future research could explore strategies and interventions to improve relationships and communication. On the other hand, if satisfaction is generally high, future research could identify factors contributing to this relative success that might be useful in developing consultative strategies and treatments for the families of children with and without other disabilities.

Theoretical Bases

Head and Abbeduto (2007) found support for a systems approach to the assessment and treatment of school children with complex needs, acknowledging that the experiences and wellbeing of other family members can impact outcomes for children with disabilities. Shortly thereafter, Grier and Bradley-Klug (2011) introduced the biopsychoeducational model, incorporating the child, family, medical, and educational systems with an emphasis on communication and shared responsibility for problem solving and decision-making. Power et al. (2003) posit that it is imperative to link the healthcare, education, and family systems of children with chronic illness to resolve problems, promote competence, and ensure optimal health and education outcomes.

The biopsychoeducational model seeks to integrate administrators, medical service providers, teachers, students, family members, and community members and emphasizes collaborative problem solving, using a stepwise approach for identifying and analyzing a problem, formulating an intervention, and evaluating the effectiveness of the selected intervention. The biopsychoeducational model guides team members to develop hypotheses by examining ecological factors related to the child, family, educational setting, medical treatment, current health status, etc. Analysis of assessment and other data collection procedures are used to test hypotheses, and interventions are developed and prioritized based on the information gathered (Grier & Bradley-Klug, 2011). This model also emphasizes the importance of recognizing the parent as an "expert" relative to family and personal issues, another tenet of family-centered practice. Developing relationships with families by discussing and weighing their experiences is important in building trust and cultivating open, honest communication between parties and promoting satisfaction (Borrell-Carrio, Suchman & Epstein, 2004).

Statement of Purpose

The available research suggests that improvements could be made in the areas of timely identification of need, appropriate service selection and provision, and strengthening home-school partnerships regarding the educational services rendered to children with chronic illness. Head and Abbeduto (2007) suggest "translating a systems approach into practice requires incorporating 'family-centered' policies and practices into services throughout the diagnostic and treatment process" (p. 294). This research aims to validate the biopsychoeducational model by obtaining information about the subjective experiences of parents of school children with CF and determining if communication, involvement, mutual respect of expertise, shared responsibility for problem-solving and decision making contribute to subjective ratings of satisfaction, as well as discovering what, if any, barriers exist regarding effective home-school collaboration in this specific population. This information will add to the sparse literature base to inform policy and practice and improve the educational experiences of children and families living with CF.

Research Question 1: Research Question 1: What relationships exist among Overall Satisfaction, Child Age, Likelihood of School Recommendation, Satisfaction Sum, Family Factors, Child Factors, and Illness Severity?

Hypothesis 1: Overall Satisfaction is related to each of the component parts identified in the research literature, but the component parts are independent of one another.

Proposed Analysis: Pearson correlation coefficients were computed to assess the relationships among overall satisfaction, child age, likelihood of school recommendation, satisfaction sum, family factors, child factors, and illness severity.

Research Question 2*:* Are parents satisfied with the educational experience provided to their child(ren) with CF?

Hypothesis 2: Responses are bi-modally distributed.

Proposed Analysis: Frequency counts and descriptive statistics were calculated for the survey items pertaining to the variable "parent satisfaction."

Research Question 3: How can data collected regarding the following variables be used to accurately predict educational satisfaction for the parents of children with Cystic Fibrosis: illness severity, child-centered partnership factors, family-centered partnership factors, provision of information, suitable communication, suitable service provision, perceived ability to accommodate needs, perceived commitment to child, likelihood of recommending school to others with CF?

Hypothesis 3: The data collected regarding the above listed variables contributes significantly to the accurate prediction of educational satisfaction for parents of children with CF.

Proposed Analyses: The proposed analyses included multiple regression conducted using variables computed from survey responses as predictors and overall satisfaction as the dependent variable to determine which factors are significant predictors of overall satisfaction. A second analysis was proposed using Logistic regression with dichotomous (Y/N) satisfaction as the dependent variable and the above listed categorical and continuous predictor variables.

Chapter II: Literature Review

The American Academy of Pediatrics (AAP) has defined a chronic illness or health impairment as one expected to last longer than three months and including limitation of age appropriate functions, disfigurement, dependency on medical technology, medication, special diet, more medical care than is usual for the child's age, or special ongoing treatment (Majors, 2003). These children require well-coordinated care that is community-based, culturally competent, and family-centered (Knapp, Madden, & Marcu, 2009). The fundamental values of family-centered care include establishing the family as the focus of services, supporting and respecting the family as decision makers, and implementing interventions designed to improve the functioning of the family system (McBride et al., 1993). Six core outcome measures have been identified by the Maternal Child Health Bureau of the United States Department of Health and Human Services to insure these care requirements are met: (1) families partner in decision making, (2) chronically ill children have a medical home, (3) chronically ill children have adequate insurance, (4) chronically ill children are screened early and often, (5) community based services are well organized and easy to use, and (6) adolescents receive services needed for adult transition. The term 'medical home' describes care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective, delivered by professionals who engage families in a partnership characterized by mutual responsibility and trust between parties (AAP, 2002). Access to medical insurance has been addressed at the federal and state levels through the Affordable Care Act and the Children's Health Insurance Program (CHIP) and adolescent transition planning is already a tenet of the Individuals with Disabilities in Education Improvement Act (IDEA) followed by all schools receiving public funds, but the remaining objectives can be addressed directly by service providers such as educators and healthcare professionals, who share in the continuum of care and education of a child with complex healthcare needs.

Chronic conditions typically bring about significant changes in the life of the child and family (Wilson-Hyde, 2009) and may interfere with a child's ability to attend school regularly and participate in community activities. Survival rates of children diagnosed with chronic illnesses have increased dramatically with advances in medicine and technology, leading to more children with these conditions entering and re-entering the educational system and increasing the burden on schools to provide appropriate educational and social services (Shaw & McCabe, 2007). Potential educational implications of chronic illness include impact on physical and cognitive development, heightened stress, and redefined life expectations and outcomes. Through the course of a multidisciplinary evaluation, it may be determined that a chronic illness substantially limits the child's ability to benefit from the general educational environment. Individualized planning, programming, accommodations and modifications may be needed to meet the unique educational needs of these children, depending on the extent to which their illnesses affect their school performance and participation. These far reaching consequences of childhood chronic illness are likely to affect how a family interacts with their child's school system and educational team.

Cystic Fibrosis

Cystic Fibrosis (CF) is an inherited, autosomal recessive genetic illness, occurring approximately once in every 30,000 live births, predominately in children of European descent (Cystic Fibrosis Foundation, 2012). Cystic fibrosis is inherited when both parents carry the recessive CF gene, and each passes a copy to their offspring. If both parents are carriers of the gene, there is a 1 in 4 chance that each child will have Cystic Fibrosis. The disease results in defective ion transport due to faulty encoding that leads to structural abnormalities in the cystic fibrosis transmembrane regulator (CFTR) conductance protein; because chloride ions cannot pass through channels properly, patients develop thick, sticky mucus, which coats the digestive and respiratory tracts, leading to limited absorption of nutrients and increased susceptibility to infections (McHance & Heuther, 2002). Cystic fibrosis is a progressive, fatal illness and there is currently no cure, though treatments exist to target symptoms and complications.

Historically, children with CF were classified as failure to thrive infants. Later, it became clear that there was digestive and respiratory involvement and the disease was distinguished from Celiac Disease in 1938; at this time, it was believed to arise from abnormal mucus secretions blocking exocrine ducts and death typically occurred from lung infections; average life expectancy was six months. The sweat electrolyte marker, an excess concentration of sodium and chloride in the sweat of CF patients, was identified in 1953, and the sweat test became the standard diagnostic tool in 1959 (Cystic Fibrosis Foundation, 2012). Medical clinics were subsequently established to aggressively treat the symptoms of malnutrition, airway blockage, lung infections, and inflammation, increasing life expectancy into the teenage and early adult years by the 1980's. Decoding of the human genome led to the discovery of the CF gene on chromosome 7 in 1989, and gene therapies have since been the focus of biomedical research. Median survival now extends well into the 30's (Davis, 2006).

As treatment has progressed, many more children with CF have been able to live lives that approximate those of their healthy peers, including going to school, joining sports teams, and enjoying leisure activities (McCance & Heuther, 2002). Despite advances in medical care and quality of life, children with CF still become seriously ill and require extensive medical care and hospitalization far more often than typically developing children. In addition to the respiratory and digestive complications that are hallmarks of the disease, commonly co-occurring conditions include diabetes (about 1/3 of patients develop CF related Diabetes, or CFRD), bone disease and joint problems, sinusitis, gastroesophageal reflux (GERD), asthma, liver disease, and distal intestinal obstructive syndrome (DIOS) (Cystic Fibrosis Foundation, 2012). More than 20% of adults with CF experience depression, a prevalence rate similar to other chronic conditions. Even for those who do not require hospital care, treatments remain a time-consuming part of every day life. Children with CF take oral pancreatic enzymes to replace naturally occurring digestive enzymes, perform breathing treatments to thin mucus, receive percussive therapies to keep airways clear, and attend regular clinic exams to insure optimal health management and treat infections as they occur. Considering the physical limitations posed by the illness itself and the aforementioned treatment regimen, this disease could have myriad implications for a child's home and family life as well as school performance and experience.

Effects of Chronic Illness on Parents and Families

With the delivery of a diagnosis of CF, parents are faced with integrating that diagnosis into a future not previously envisioned for the child and family. Facing the reality of the limitation posed by an illness can lead parents to redefine their expectations and reevaluate the relative importance of certain aspects of their child's life. Some parents will experience grief that is very similar to the process associated with loss, these parents are, in fact, grieving the loss of their "typical" child, or experiencing an "ambiguous loss" (McCabe & Shaw, 2010). Unlike grief associated with death, however, this process is ongoing and may repeat each time the family encounters a new limitation or revised expectation associated with the stages of disease progression (diagnosis, treatment, acute crisis, and end-of-life) or with their child's failure to meet developmental and social milestones (e.g. talk, drive a car, or attend the prom). As it relates to education, revision of parental expectations may diminish the relative importance of schooling in the face of a health crisis (Harris, 2009).

In addition to grief, parents and children often experience uncertainty about the future, particularly for children with life-threatening illnesses or complications. Uncertainty has several dimensions including ambiguity about the illness state, overwhelming complexity or lack of information about the illness, its treatment, side effects, and management, establishing trusting relationships with healthcare providers, and the unpredictability of a child's prognosis, quality of life, and ability to function (Stewart & Mishel, 2000). Uncertainty has been associated with high levels of emotional distress, reduced quality of life, and poor psychosocial adjustments as parents and children fear and prepare for the worst (McCabe & Shaw, 2010). This can interfere with parents' ability to perform essential duties such as monitoring the child's health, applying consistent behavioral expectations, and promoting independence and self-management (Santacruce, 2003). Parents often cope with uncertainty through information management, which includes intense pursuit of information related to their child's illness and careful evasion or disclosure of the negative aspects of the illness to others (Clay, 2004).

Coupled with uncertainty directly related to the child's health and disease management, parents of children with a disability may be challenged with the financial and social implications of the illness, further compounding their stress and taxing their coping resources (Floyd & Gallagher, 1997). Some parents cope with uncertainty and grief through denial, refusing to accept their child's prognosis or alter their expectations. In combination, grief, uncertainty, and ineffective coping can lead to depression and maladjustment. The parents of children with chronic illnesses are more likely to experience major depression, generalized anxiety, panic disorders, post-traumatic stress, and marital discord (McCabe & Shaw, 2010). Increases in parental psychological distress are linked to less optimal parent and family functioning, greater perception of disease severity and poor health-related quality of life, and poorer physical and social-emotional outcomes for children with CF (Carpenter, Mullins, Wolfe-Christensen, & Chaney, 2008). Additionally, parents of children with CF report struggling with the strain between the traditionally established family roles and roles associated with accomplishing tasks related to illness management and treatment (Berge & Patterson, 2004). A key issue that affects family cohesion is treatment compliance and a complex relationship exists between meeting the health needs of a child with CF and meeting the overall needs of the family. Although attending to the needs of the family resulted in better long-term health outcomes, treatment needs must not be neglected in favor of normative family activities; thus, attentions must be divided and balance achieved (Berge & Patterson, 2004).

Parents of children with chronic illness are sensitive to the increased vulnerability of the children, thus overprotection may influence behavioral and emotional functioning (Hysing, Elgen, Gillberg, & Lundervold, 2009). Increased perception of vulnerability has been attributed to conscious and unconscious perceptions of fear regarding a child's health and/ or the possibility of premature death (Carpenter et al., 2008). As a result of this fear, parents of children with CF often engage in overprotective behaviors, characterized by behaviors that are overindulgent, overanxious, or controlling in nature and considered to be excessive given the child's age and developmental abilities (Carpenter et al., 2008). Anthony, Gil, and Schanberg (2003) found that increased parental perception of a child's vulnerability was related to increased social anxiety in children with chronic illness. Furthermore, perception of vulnerability was not strongly related to physicians' ratings of actual disease severity. Studies have found that CF families have more emotional over-involvement (enmeshment) with each other than families with healthy children, and that overprotection and maternal anxiety are associated with low self-esteem in the child. In conjunction with enmeshment and overprotection, parents tend to be more permissive and less likely to set limits with children with CF than their healthy siblings (Berge & Patterson, 2004), which can lead to externalizing behavior problems like temper tantrums and lack of impulse control. Both internalizing and externalizing behavior problems could adversely affect chronically ill students' school performance.

Psychosocial effects on siblings are also common in families of children with chronic illness. Siblings of disabled children are often expected to take on additional responsibilities related to the physical care and socialization of the disabled child in addition to receiving less personal attention from caregivers (Baxter, Cummins, & Lewi, 2000). Siblings of children with CF are at increased risk for both internalizing and externalizing problems, including depression, anxiety, aggression, jealousy, and defiance (Berge & Patterson, 2004).

Effects of Chronic Illness on School Performance and Experience

Children with chronic illness experience many physical and emotional side effects related to the condition and its treatment. Some very young children with CF experience mild delays in cognitive functioning, though most resolve by the age of five and older children are not statistically different from their health peers with regard to intellectual ability (Bradley-Klug, Grier, & Ax, 2006). Despite most children with CF having adequate cognitive resources, other factors can negatively impact their school performance and subjective experience. Chronic respiratory impairments in school-aged children can result in increased absence from school, restriction of physical activity, relatively poor social relationships which may result in subjective feelings of isolation, depression and mood disorders which may result in subjective feelings of hopelessness, and chronic and/or easy fatigue (Bray, Kehle, Theodore, & Peck, 2006). Children with CF experience recurrent pain associated with disease processes and medical treatments, fear of health decline and death, and embarrassment of being physically different from other children (Berge & Patterson, 2004). The psychoeducational implications of chronic illnesses are numerous and unaddressed could seriously impact the quality of a child's schooling.

The most obvious side effect of being diagnosed with a chronic health condition is absenteeism. Research shows that 58% of children with chronic illnesses routinely miss school and 10% miss more than one quarter of the school year (Thies, 1999). A survey conducted by Wildhagen and colleagues (1996) found that children with CF miss an average of 19.5 school days per year, compared to a healthy child who is absent an average of 3 days (Shaw & McCabe, 2007). These absences may be due to prolonged hospitalization or convalescence at home but more commonly are the cumulative effect of missing a few days at a time many times over the course of the year. The reasons for absences vary from minor illnesses like the flu to complications of the child's specific illness and related medical treatment or scheduled clinic visits. There are, however, several more complex factors that may also contribute to these higher rates of absenteeism such as the child's attitude toward school, the attitudes of significant adults, and the availability of school resources (Sexon & Madon-Swain, 1995). Depending on the severity of the illness and the prognosis for the child, the relative importance of education may change dramatically in the face of extensive treatment (Harris, 2009). Despite a weak correlation with physician-rated disease severity, increased parental perception of a child's vulnerability is strongly related to the increased school absences (Anthony et al., 2003), suggesting that parental adjustment is also a factor in the increased absence rates of these children. For these reasons, the impact of increased absenteeism varies widely from one individual to the next, but it is reasonable to assume that this could contribute significantly to academic and social difficulty.

Another common factor that school children with chronic illnesses must contend with is the treatment effects of medications and therapies prescribed to improve or maintain their health. Some treatment regimens are time consuming, taking 30 minutes or more to deliver medications or physical therapies and taking time away from other learning or social activities (Cystic Fibrosis Foundation, 2006). Other medications have neurochemical side effects such as decreased concentration, fatigue, depressed mood, or sleep and eating disturbances (Thies, 1999). These treatment effects may make it difficult for a child to participate fully in school.

Bronchodilators are one class of medications commonly used to treat symptoms of CF. Typically inhaled, these Beta-2 agonists help relax the muscles around the airways of the lungs. Some common side effects of bronchodilators in children include increased heart rate, dizziness, restlessness, irritability, and nervousness (Mayo Clinic, 2013). Corticosteroids are another class of drugs used as maintenance medications in CF patients to reduce swelling in the airways. Side effects include water retention and swelling in the limbs, increased ocular pressure (glaucoma), mood swings, and weight gain (Mayo Clinic, 2013). Patients taking Pulmozyme, an enzyme prescribed to thin mucus and help clear the airways may experience flu-like symptoms (fever, sore throat, nasal congestion), chest pain, voice changes, or eye irritation (NIH, 2013). Insulin, used to treat co-morbid diabetes and antacids, for indigestion and acid reflux, can cause increased thirst and stomach cramps (Mayo Clinic, 2013). Laxatives used to clear episodic intestinal blockage can lead to diarrhea, vomiting, dizziness and fainting (Mayo Clinic, 2013). Finally, the antibiotics typically used to treat acute respiratory infections, such as Ciprofloxacin and Tobramycin, have side effects including bronchospasm, nausea, stomach cramps, and dehydration (NIH, 2013). Any of these side effects or a combination of several could contribute to increased absences or decreased ability to fully attend to instruction in the educational environment.

While the physical aspects of illness and the treatment effects of medications may affect school performance, children with chronic illnesses are known to be at increased risk for behavioral and emotional problems as well (Hysing, Elgen, Gillberg, & Lundervold, 2009). Children who experience health problems tend to reach fewer milestones or are delayed in their achievement of these benchmarks of development. Additionally, they often struggle to get along with their peers because they no longer identify with typical children their own age and may become aggressive or withdrawn (NCI, 2013). These children may contend with social stigma or experience social and emotional difficulties as a result of not being able to fully participate in the day-to-day dynamics of the social environment due to restrictions from certain activities (Power, DuPaul, Shapiro, & Kazak, 2003). Sometimes social anxiety is related to body image concerns, particularly if an illness has caused visible physical changes (Harris, 2009). Children with CF are typically of short stature and thin build and may experience delayed onset of puberty and late development of secondary sex characteristics (Bradley-Klug et al., 2006), making them appear younger and less physically mature than their healthy peers. Patients may also have noticeable indications of the treatments they receive, such as intravenous (IV) lines for antibiotics or feeding tubes for supplemental nutrition. These physical differences may lead to teasing and internalizing problems like anxiety and depression. Another difficulty ill children often contend with is the contagion misconception, or other children’s fears of contracting infection due to misinformation or lack of knowledge about an illness, which may lead to shunning and exclusion (Bradley-Klug et al., 2006). Finally, children with chronic conditions may be faced with the “late effects” of an illness or treatment. Late effects refer to damage that is not immediately obvious and is only recognized when children grow into a deficit. These can include damage to organs, tissues, and body functions, which may affect growth and development, mood, feelings and actions, thinking, learning, and memory, social and psychological adjustment, and the future health of the child. For example, many adults with CF are infertile due to the physiological effects of the illness on the reproductive system.

In addition to physical limitations and social difficulties, children may experience emotional problems related to post-traumatic stress, including reliving news of the initial diagnosis or treatment through nightmares or flashbacks, perseverative thinking about state of health, impact of condition, life expectancy, etc., avoidance of places or people associated with illness, and emotional lability. In 1994, APA specified that learning of a life-threatening illness is a traumatic event and treatment of chronic illness and associated complications may constitute repetitive trauma (Santacroce, 2003). According to the DSM-V (2013), symptoms of Post-traumatic stress disorder (PTSD) may include: reliving trauma through nightmares or flashbacks, perseverative thinking, avoidance of places or people associated with trauma, and emotional lability, seeming overexcited, irritable, restless, or unfocused. Children with chronic illness may experience “pediatric medical traumatic stress” (PMTS), a broader and more inclusive cluster of post-traumatic symptoms including arousal, re-experiencing, and avoidance specifically linked to medical events such as diagnosis and treatment (Kazak et al., 2009). Given the potentially severe health exacerbations and subsequent treatments, children with CF may be affected by PMTS or PTSD, which could interfere with both school attendance and performance. Post-traumatic stress is implicated in many forms of arrested development including intense separation anxiety, a complicated result of psychosocial regression and enmeshed feelings of vulnerability for both children and parents (Sexon & Madon-Swain, 1995). Psychosocial regression refers to a child losing recently acquired developmental skills in the face of extreme stress or trauma, and may include toileting accidents, nightmares, temper tantrums, and irrational or intense fears which may develop or re-surface (National Center for PTSD, 2013). These children may cling to their caregiver, experience psychosomatic symptoms when separated such as headaches and stomachaches, or have difficulty regulating their emotions in an age-appropriate manner. Older children may have difficulty connecting with their peers and may feel left out or have trouble getting along with others (National Cancer Institute, 2013). These social and emotional challenges can lead to school refusal, described by Hersov (1972) as absences reflecting a persistent psychological inability to attend school which often starts as reluctance and progresses to total refusal despite persuasion and threat of punishment and may be accompanied by overt signs of anxiety and even panic. School refusal behavior is five times higher in chronically ill children than in the general population and the risk of phobia and dropout are high (Brook & Galili, 2001), likely due to intense anxiety associated with social situations and separation from caretakers.

Finally, there are academic implications of chronic illnesses. About 40% of children with chronic illnesses experience some type of school difficulty (Bradley-Klug, Grier, & Ax, 2006). Despite the fact that most of these children are of average intelligence, many perform significantly below expectations on tests of academic achievement in the absence of cognitive impairments (Sexon & Madon-Swain, 1995). Although there is some evidence that young children with CF experience mild cognitive delays, these typically resolve by age five and the intellectual functioning of older children with CF is not statistically different from their healthy peers (Bradley-Klug et al., 2006). The combination of absenteeism, treatment effects, and the emotional toll of illness can all contribute to decreased academic achievement (Thies, 1999).

When children miss instructional time, they are delayed in their acquisition of skills and because many curricula are sequential, children must make up missed work in order to fill gaps in the process being taught; thus, teachers cannot just forgo information that has been covered in their absence and students cannot simply jump back into general instruction. Many learning problems in children with chronic illnesses are simply attributable to missed opportunities to learn (Bradley-Klug et al., 2006) and accumulated work compounded by limited emotional and physical resources can greatly impact an ill child's academic performance.

Importance of Establishing Collaborative Partnerships

Taken together, the ramifications of diagnosis and treatment place an enormous burden on parents and children, but some of the responsibility for care can and should be shared with community providers such as medical professionals and educators. In order to comply with legal guidelines and address the varying effects of chronic illness on school performance and experience, the child suffering from a chronic illness will need the support and expertise of parents, teachers, and medical personnel. Establishing a partnership between these care providers of a child with chronic illness may be critical to the success of that child in the face of limitations posed by the illness. Open communication between parents, teachers, and the medical team, as well as the establishment and achievement of mutual goals for the student, can greatly influence educational outcomes. Parents, schools, and the medical team working together can limit tension and increase support for all parties in dealing with the effects of illness, in turn supporting more positive educational, medical, and quality of life outcomes for the child (NASP, 2012).

Home-school collaboration is "a reciprocal dynamic process that occurs among systems (e.g. families, communities, partnerships, etc.), schools/classrooms, and/or individuals who share in decision making toward common goals and solutions related to students" in which those involved "pool their resources to create a cooperative interdependent relationship" with the goal of improving student outcomes (Cowan, Swearer, & Sheridan, 2004, p. 201). Christenson (2003) offers some key characteristics of an effective parent-school partnership: parties must listen; value differences as strengths; share information and co-construct interventions; respect the skills and knowledge of others by asking for opinions; plan together and make decisions that address the needs of students, parents, and teachers; share decision making; share resources for working toward a goal; provide a common message regarding school work and behavior; demonstrate willingness to address conflict; refrain from finding fault; and share success. Particularly important among these prescriptions are the ideas that all partners must share information and resources. Making decisions without all of the available evidence or implementing interventions with insufficient support may contribute to less optimal health and educational outcomes for the child, particularly if application of treatments and interventions vary across settings.

With regard to chronic illness, this partnership can be critical for several reasons. First, parents and the medical team may need to educate school personnel about the child's condition and the care required. Second, parents may need to advocate for services and resources. Third, teachers may need to seek consultation with parents and the medical team to facilitate student progress (Power, 2006). When a child with a chronic illness enters or re-enters school, it is important to consider the wide-reaching effects of such a transition on the individual, the family, and professional personnel. A successful and collaborative transition back to the school setting can promote the self-esteem of a chronically ill child by empowering the child to teach others and speak positively about his or her condition or people with health problems in general. Re-entry planning can ease the anxiety of parents and teachers, increase communication between school and the family, and facilitate emergency action planning. Teachers may gain a clearer understanding of the child's condition and any treatment side effects. Finally, the child's classmates may be empowered to think of creative ways to support their classmate and teasing and bullying can be discouraged by providing classmates with factual information and allowing them to speak about their friend's situation (Children's Hospital & Medical Center, 2012). Counter to the medical home model and despite the widespread knowledge of these best practices, the literature suggests that coordination of care between service providers across settings is often facilitated by parents, who are forced into the unenviable position of liaison (Keonning, 1995).

Support Strategies for School Personnel. While students with chronic illnesses may miss more school than others, it is important that they be included to the maximum extent possible, whenever possible. One important aspect of accommodating these students is to coordinate with their families and the medical team to be sure that expectations are appropriate (Kaffenberger, 2006). This consultation should address a student's diagnosis, any physical limitations posed, potential side effects of medications, priorities for making up work if a great deal of school has been missed, and modifications to daily routines and assignments that might be necessary to combat fatigue and the overwhelming nature of catching up with academic work.

Chronic illness is individual to the child affected and educational planning must also be thus. School personnel can help students by revising priorities and compacting the curriculum to meet the essential needs of the child without inundating them with tedious and repetitive work (Fennell, Leitz, & Fantauzzi, 2009). Much of the information taught in school is over-learned for the purposes of fluency and automaticity, but it may be beneficial to the child to gain an understanding of the core concepts without such reiteration so that progress can continue at a quicker pace and make catching up a more realistic goal.

Another way that schools can support chronically ill students is by helping them develop effective coping strategies (McCabe & Scharf, 2007). The diagnostic and treatment process may have been a harrowing experience for these children and their families, and each crisis in the course of an illness can be life-altering; teachers and school personnel should be sensitive to the needs of these children for emotional and social support as well as academic remediation.

For children who suffer from more serious illnesses whose treatment and recovery necessitates more extensive absenteeism over long periods of time, options such as homebound tutoring, digital video copies of lessons and lectures, or extended school year programming should be considered (Wilson-Hyde, 2009). When children are preparing to return to the classroom, re-entry planning should be considered and should include consultation with the family and medical team (Power, 2006). For children who are able to attend school on-site, classroom accommodations can be made for those with chronic illnesses, such as frequent breaks from intense academic work, unrestricted access to the restroom, water fountain, and nurse's office, a quiet place to rest if fatigue is overwhelming, and lots of positive support and reinforcement from adults and peers.

Support Strategies for Parents. There are several reasons that families of children with chronic illness should be included in the evaluation process: families have the most powerful influence on a child's early development; the diagnosis of a disabling condition will affect the functioning of the entire family; and families can serve as invaluable partners for the planning and execution of treatments and interventions (Brassard, 2007). Parents are the gatekeepers of a great deal of information regarding their child's condition, they have great influence over the child's treatment and development, their lives revolve to an extent around the treatment and maintenance of their child's health, and they must be considered partners in educational planning.

Parents are vital to reintegration planning for a child with a chronic illness because they often serve as the conduit between school and medical personnel (Koenning, 1995). Parents decide what and how much information is provided to school personnel and their child's classmates. Parents also serve as advocates for their child; requesting services and resources that they feel will facilitate both the healing and learning processes (Power, 2006).

Support Strategies for the Medical Team. Medical personnel can support the reintegration process by providing clear and concise information to parents and schools. The healthcare team should retain a strong relationship with the family and child even after the child leaves hospital care or intensive treatment to ensure that families continue to communicate the health status of the child as well as addressing needs related to side-effects of treatment (Power, DuPaul, Shapiro, & Kazak, 2003). Additionally, the medical team can make themselves available to teachers for consultative services. Some clinics and hospitals have established programming that they are prepared to deliver to schools when students are returning from extensive absenteeism and/or serious illness. For example, The Valerie Fund Children's Centers for Cancer and Blood Disorders (The Valerie Fund, 2013) gives parents the option of having a child life specialist facilitate the re-entry process by visiting the child's classroom and helping teachers and classmates better understand the experience of serious chronic illness. Many healthcare providers can also provide literature and materials for distribution to classmates and their parents if the family wishes.

Medical teams can support families by educating them about the symptoms, disease course, treatment effects, and expected functional impact of a child’s illness. Condition-specific guidelines for participation in school and community activities should be developed and provided to families (Anthony et el., 2003).

Barriers to Establishing a Collaborative Relationship

Family Barriers. In order to function adequately in the face of a crisis such as the chronic illness of a child, families must possess sufficient levels of emotional and cognitive resources, financial stability, and social support (Brassard, 2007). Deficiencies in any of these areas can limit the coping skills of parents and make them less able partners in achieving positive educational outcomes for their children. Several barriers to optimal parental functioning have been recognized, including the extra workload of caring for a child with special needs, shame and lack of acceptance of a child with a disability, the demands of coordinating with service providers to meet the needs of a chronically ill child, lack of appropriate high-quality services or access to such, and having multiple children with disabilities or very young children in the home (Brassard, 2007). Some signs of maladaptive coping include overprotectiveness, lowered expectations, lack of discipline and boundaries, and capitulation to school refusal (Clay, 2004). These can lead to separation anxiety, when a child is too attached to a caregiver and leaving is traumatic, and psychosocial regression, when a child reverts to an immature state.

Some parents do not feel as though the school pays proper credence to their concerns, or have had an unpleasant past experience when working with school personnel for their child (Christenson, 2003). Following a health crisis, parents may be disconnected from issues related to school and lack the physical or mental energy to initiate or maintain communication with school personnel (Bradley-Klug, Grier & Ax, 2006). Other parents may lack the knowledge of their rights or information regarding available resources. Anthony, Gil, and Schanberg (2003) found that chronically ill children missed more school and were perceived as more vulnerable if their parents had fewer years of education. Less educated parents may not experience the same quality of interaction with their child's school and medical teams, often failing to ask questions or get clarification. Lack of information may lead to overprotective actions, such as keeping children home from school because it is too tiring or the exposure to germs would be too dangerous. Still others defer to the school as the expert in the educational arena out of fear or the misconception that school and home are separate arenas in which they have no influence (Lasky, 2000). One study found that 75% of parents with chronically ill children reported that their child needed health care in school provided by a skilled professional ranging from meal time supervision to medication delivery to monitoring for a critical emergency state; 56% of those parents did not feel that school personnel were sufficiently knowledgeable to care for their child and 11% were dissatisfied with the school's attempts to care for their child. These parents reported feeling marginalized and excluded, and several commented that their child's school was unwilling to help (Notares, 2002).

Another barrier to effective collaboration may occur when parents withhold vital information regarding their child's illness (Kaffenberger, 2006). Some parents do this out of a strong sense of privacy, believing that medical information falls into a separate realm of treatment apart from school functioning. Other parents feel that this information will unduly influence how others treat their child, and most families adjusting to or recovering from a health crisis wish for nothing more than the return of normalcy. Indeed, parents may equate school re-entry with a return to normality, not anticipating the social and academic difficulties that their child may face (Bradley-Klug, Grier & Ax, 2006).

School Barriers. The primary barrier for schools in providing appropriate services may be lack of recognition or understanding of a child's needs. Changes in a child's behavior or performance may seem temporary and educators might expect problems to resolve themselves as time passes following diagnosis or acute health crisis. Many teachers and parents anticipate that academic progress will resume where it left off, and performance will be commensurate with that demonstrated prior to the interference of chronic illness. There is often hesitation to make drastic changes in the educational program and instead a tendency to allow the child more time while things remain status quo. Consequently, children may not be recognized as having serious learning problems until they have become greatly exacerbated.

Another issue that can adversely affect a child's academic performance, though it may seem counterintuitive, is empathy. A teacher may significantly lower his or her expectations of a child or accept work of significantly diminished quality out a misguided sense of helping, when in reality the child adapts to the new expectations and cannot recover lost ground or falls farther behind (Irwin & Elam, 2011).

Another barrier that school personnel may face in partnering with families to ensure optimal educational outcomes is lack of understanding of a child's condition (Irwin & Elam, 2011), which can lead to misattribution of behaviors and motivations, poor modeling of appropriate reactions for a child's classmates, and outright discrimination against an ill child. Brook and Galili posit: "Discrimination towards chronic patients begins at school when teachers do not know enough or are ignorant to the medical condition and its sequellae" (p. 38, 2011). Kaffenberger (2006) adds that more than 70% of school counselors feel unprepared to provide the necessary consultative, counseling, and general support services that might be needed when a child with a chronic illness returns to school.

Finally, schools face structural barriers such as limited time and financial resources, or state mandated achievement standards. Many teachers do not feel that there is time in their day to incorporate consultative interactions with parents and even a child's medical team, or to implement individualized programming for a struggling student. Some schools feel they do not have the financial resources to provide the medical treatment necessary during school hours to maintain the physical health and safety of chronically ill students (Christenson, 2003). Still other schools are concerned with state-mandated achievement standards, and children with chronic illnesses who are not capable of achieving the level of academic proficiency demanded can put strain on the school's relationship with the family and child (Irwin & Elam, 2011).

Ultimately, these barriers must be overcome and decisions must be made in the best interest of the child and his or her educational experience. Children fighting chronic illnesses must still be viewed as capable learners and expectations must remain high:

"After all, many of these children come face to face with their own mortality, repeatedly choose to fight for their lives, and find ways to live with the various discomforts related to their illness. In response to their passion for survival, allowing the chronically ill equal access to well-established best practices in addition to crafting prescriptive guidelines seems the least educators can do in their role as caretakers of education" (Irwin & Elam, 2011, p. 70).

Medical Team Barriers. Medical teams face some of the same barriers as schools, in that families may not be forthcoming with information or communicative of their needs. Oftentimes, healthcare teams are relegated to the medical arena and have little or no influence once the child has returned to mainstream education, either because families fail to request their assistance or schools refuse to collaborate with them (Kaffenberger, 2006). Because healthcare teams often lack information about the services that schools are capable of providing, they may be seen as making sweeping and unreasonable demands and have unrealistic expectations of the level of care that teachers and school nurses are able to render.

A national study of pediatricians found that many had contact with school personnel only a few times each year, despite the majority of those doctors indicating that this would be beneficial for their patients (Grier & Bradley-Klug, 2011). The pediatricians participating in the study cited lack of time, lack of accessibility of school personnel, not being able to obtain reimbursement for collaboration, and not knowing who to contact at the school as barriers to consulting with educators and parents on problem solving teams.

Accommodating Students with Chronic Illnesses: The Law

Roughly one in six US school-aged children have a chronic illness, and though the majority of children with chronic illnesses are able to participate in the general education curriculum without modifications, more than 6% of children suffer an illness severe enough to interfere with normal schooling (American Academy of Pediatrics, Council on Children with Disabilities, 2005). During an acute health crisis, children may be treated in an inpatient hospital setting, but reforms in healthcare have shifted the majority of ongoing treatment to outpatient community settings, with schools being a primary venue for community-based service delivery (Bradley-Klug, Grier, & Ax, 2006). Although it is rare for an illness to interrupt schooling, about 40% of chronically ill students experience some school difficulty, and the appropriate steps must be taken to support the progress of these students. In the educational setting, school psychologists are considered healthcare providers to children with chronic illnesses who experience school difficulty and are expected to deliver and/or coordinate services to meet the educational, social, and medical needs of these children in accordance with international human rights guidelines and federal regulations.

The United Nations Convention on the Rights of the Child (United Nations Human Rights Office of the High Commissioner, 1989) put forth 54 articles related to rights that ought to be afforded to all children to allow them to live safely and with dignity. Article 18 states that governments must respect the responsibility of parents for providing appropriate guidance to their children. This article places a responsibility on governments to provide support services to parents and is in line with the principles of family-centered practice. Article 20 states that any child with a disability has the right to care and support so she/ he can live a life that is full and independent and articles 28 and 29 afford all children the right to a free primary education that should develop each child's personality, talents, and abilities to the fullest. These tenets are mirrored in United States federal legislation.

The Individuals with Disabilities in Education Act (IDEA, 2004) is federal legislation that applies to all primary and secondary educational institutions receiving public funds. Students can qualify for special education and individualized programming in a variety of categories that encompass many conditions that might interfere with learning. Children with chronic illness may qualify in multiple categories, but are often eligible in the category of "Other Health Impairment" (OHI). IDEA defines a person with OHI as having limited strength, vitality, or alertness, including heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (i) is due to chronic or acute health problems; and (ii) adversely affects a child's educational performance. If a child with a chronic illness meets these conditions, an Individualized Education Program (IEP) must be developed to ensure that his or her educational needs are met through the provision of supplementary services, aids, and accommodations designed to keep the child in school to the maximum extent possible (Lee & Janik, 2006).

Under IDEA, students with a disability are eligible for related services, defined as "supportive services as are required to assist a child with a disability to benefit from special education that include school health services and school nurse services." School health services and school nurse services are designed to enable a child with a disability to receive a free and appropriate public education (FAPE) as described in the child's IEP. A qualified school nurse provides school nursing services, but other qualified personnel may provide school health services. The National Association of School Nurses (NASN; 2013) issued a position statement regarding the role of the school nurse in individualized healthcare plans, stating that the nurse, in collaboration with the student, family, and healthcare providers, shall meet nursing regulatory requirements and professional standards by writing an Individualized Healthcare Plan (IHP) for students whose healthcare needs affect or have the potential to affect safe and optimal school attendance and academic performance. This plan serves as legal documentation of the appropriate standard of professional care, clarifies the priority of care and related procedures, and serves as the foundation for other educational and emergency plans. NASN asserts that it is the responsibility of the nurse to develop and oversee the implementation of these plans, however, that is not always the case in practice.

Children whose illnesses do not interfere with their schooling to the level of requiring specially designed instruction may be accommodated under Section 504 of the Rehabilitation Act of 1973. This legislation codifies the elimination of discrimination on the basis of disability in any program or activity that receives federal funding, including schools and mandates equal access and treatment for disabled persons. A child with a chronic illness is considered disabled if the condition substantially limits a major life activity (34 C.F.R. SS 104, 1973), including learning. The purpose of accommodation under Section 504 is to allow a child to participate in the same educational curriculum and activities as his or her non-disabled peers (Lee & Janik, 2006).

If it is determined that a child requires special education programming in order to make adequate educational progress, parents must be included as members of the educational team. IDEA (34 C.F.R. SS300.07, 2004) and Section 504 require that parents be included in the process of evaluation, planning, and service delivery (Cowan, Swearer, & Sheridan, 2004). Similar to findings from research regarding medical care, parents often describe their role as informant and observer on these teams, rather than full partners who share in the decision-making. Essential to the concept of a medical home is the provision for coordination of care among multiple providers, including educational and other community organizations (Health People 2020). Despite this prescription, literature suggests that coordination of medical and educational services for CSHCN is falling woefully short and parents are often required to assume the difficult role of liaison (Keonning, 1995).

Parent Satisfaction

Satisfaction refers to the extent to which people feel their needs are fulfilled to a satisfactory level and in a suitable fashion. As it relates to schools, parent satisfaction refers to a parent's perception of the extent to which their children's needs are being met in an agreeable manner. Few studies have explored the factors that lead to parental school satisfaction or the school and district characteristics associated with the construct. One of these studies, conducted by Friedman, Bobrowski, and Markow (2007), measured satisfaction by asking parents to grade their child's school using a ten point scale and indicate whether parents were proud of their child's school and would recommend the school to other parents. The researchers identified three factors, including school communication and involvement afforded to parents, the adequacy of school resources, and the effectiveness of school leadership, as accounting for 63% of the variance in satisfaction ratings. Furthermore, results of a study conducted by the National Association of School Psychologists (NASP) indicated that parents felt provision of information on how schools function and time for face-to-face interaction between parents and educators to share information about children, school requirements, and family needs were among the greatest areas of need with regard to strengthening home-school partnerships (Christenson et al., 1997). Given that communication and involvement were endorsed as contributing heavily to satisfaction, enacting the principles of family-centered practice could lead to increased parent satisfaction with their child's educational experience.

Aruda and colleagues (2011) surveyed parents of CSHCN between the ages of 3-22 to determine how parents perceived the adequacy of communication between medical and educational providers and what significant unmet healthcare needs they perceived for CSHCN in the school setting. Results of the study revealed that although most families ranked communication between settings as “good” or “adequate”, open-ended responses indicated that communication and the mechanisms required for successful coordination are still developing. Many parents perceived that their role was to act as an intermediary between the settings, though nearly one third felt uncomfortable in this role. Parents also indicated that lack of primary care support was a barrier to this critical communication. The majority of unmet needs were related to the availability of high quality services and the lack of palliative care, defined as “services addressing the medical, psychological, social, and spiritual needs of children and their families living with chronic illness, life-threatening episodes, or terminal conditions” (Aruda et al., 2011, p. 211). The aforementioned services, with the exception of meeting spiritual needs, fall within the responsibilities of a school to identify and mediate through the provision of educational supports.

Further support for increasing parent satisfaction was provided by Christenson and Sheridan (2001), who noted a bi-directional relationship between satisfaction and involvement. The researchers found that satisfaction shapes involvement and involvement influences satisfaction. Parents who are satisfied with a child's educational programming are more likely to be involved in the child's education both at school and at home. Likewise, involved parents are more likely to express satisfaction with the educational experiences being afforded to the child. Research emphasizing the critical nature of parent involvement in education has demonstrated an association between parent involvement and greater academic achievement at all grade levels, greater teacher perception of the child's social competence, lower grade-retention and high school dropout rates, and fewer years spent in special education (Fantuzzo, Perry, & Childs, 2006). Parent involvement is believed to influence a child's school performance through two main mechanisms, social capital and social control (Hill & Taylor, 2004).

Social capital refers to parents' skills and access to information related to school. Social capital allows parents to assist children with school-related activities. Parents with adequate social capital are likely to be familiar with school personnel, procedures, and curriculum (Hill & Taylor, 2004). Familiarity is important for parents of children with chronic illnesses because it increases the likelihood that parents are aware of school-related issues and that appropriate action is pursued to mediate school difficulty. Barriers to obtaining social capital for children with chronic illness might include demographic characteristics such as household income and educational attainment, caregiver quality of life, and the child's condition severity.

Social control refers to the communication of consistent expectations across settings (Hill & Taylor, 2004). Communicating similar messages about appropriate behavior and work quality across settings serves to clarify expectations and reduce confusion, thereby decreasing problem behaviors. Failure to establish these common standards between families and schools can undermine the authority and effectiveness of parents, teachers, and other adult caretakers and lead to a “poor fit” or dissonance across settings. Kohl and colleagues (2000) studied factors influencing parent involvement in their child’s education and noted that the quality of parent involvement was influenced by several factors, including the quality of the parent- teacher relationship, the value parents placed on education, and parent’s satisfaction with their child’s school. Satisfaction was characterized as parents’ endorsement of the school and was evaluated by determining whether parents felt their child’s school was a good place for their child, the staff was competent, and their child was being prepared for the future. When parents’ and teachers’ ratings of the above factors were consistent and positive, student outcomes were more favorable (Kohl et al., 2000). Furthermore, this research indicated that the quality of the parent- teacher relationship was even more influential on positive educational outcomes for children than the amount of parent involvement. Thus, increased satisfaction could lead to more consistent and reliable implementation of the educational plan across the home and school environments. Consistency of plan implementation and expectations across settings are highly correlated with positive academic, behavioral, and social outcomes for the all children. Barriers to social control for families managing a child with chronic illness might include lack of “fit” between families and school teams and limited resources for either party to devote to plan implementation (including time, money, social support, coping capacity, physical and mental health, etc.). It is critical to assess parent satisfaction to determine areas of strength and weakness, given the impact parent involvement has been shown to have on student success.

Theoretical Bases Influencing the Present Study

Systems Theory. Biologists Paul Weiss and Ludwig von Bertalanffy theorized that nature is ordered along a hierarchical continuum, with larger, more complex units superordinate to smaller, less complex units (von Bartalanffy, 1968). In application, this means that people are both individual systems unto themselves at the organismic level as well as members of the larger social hierarchy. Each level of a system has distinct properties and characteristics, with unique qualities and relationships but nothing exists in isolation, meaning that each system is a component of higher systems and every unit is both a whole and a part.

Family Systems Theory. Family systems theory is a theoretical perspective that views the family as a complex whole made of many semi-independent parts, and stress on any member or the collective family reduces the ability of the system to function cohesively, grow, and improve. Stressors may be internal, between the semi-independent parts of the system, or external, between the whole family system and another system with which they interact (Brassard, 2007). Research related to developmental disabilities has found support for a systems approach to assessment, acknowledging that the wellbeing and experiences of other family members can impact the outcomes of the child (Head & Abbeduto, 2007). From the systems framework, Kazak (1989) infers that chronic illness in a child is not contained within the individual, but affects all members of the family system who have to change to accommodate the child's illness and reach a new homeostasis.

Ecological Models. Bronfenbrenner's (1986) developmental ecological model accounts for the dynamics within a system as well as the interactions between systems. Using this framework, the child's system is placed at the center with connections to the systems of family, school, and community, and in the case of a child with chronic illness, the medical team. Each of the systems with which the child interacts influences development: the family system plays a key role in the development of attachments and self-efficacy, the school plays an important role in the development of self-regulation, social, and academic skills, and the medical team supports the development of accurate perceptions of personal health and the foundations of self-care (Power, 2006).

Bronfenbrenner (1986) further theorized that contact between individuals and their environment becomes a mutual transaction through which each alters the other, subsequently impacting interactions in an ongoing and continuous fashion. Thus, current behavior is influenced by current *and* past circumstances, meaning that past involvement with professionals may influence families' present and future interactions with these systems with potentially negative consequences for the child. Power et al. (2003) posit that it is imperative to link the healthcare, education, and family systems to resolve problems and promote competence for young children with chronic health conditions to ensure optimal health and education outcomes.

Biopsychoeducational Model. The principles of the biopsychoeducational model draw heavily from Engel's biopsychsocial model, which is grounded in systems theory. Within the biopsychosocial model, the systems involved are the patient and the members of the treatment community responsible for his or her care. According to Engel, "roles are based on linking the need of one party, the patient, with an expected set of responses (services) from another party, the physician" (Engel, 1980, p. 536). This is accomplished by the physician finding out how and what the patient has been feeling or experiencing, formulating hypotheses to explain the feelings or experiences and engaging the patient's participation in the testing of said hypotheses, and finally by eliciting the patient's cooperation in activities or treatments aimed at changing the feelings and alleviating the patient's distress (Engel, 1980). This model allows for the important inclusion of the person's behaviors and experiences in the treatment of the biological disease process, with the purpose of integrating this information into the formulation of a personal approach to treatment. Disciples of Engel recognize that arriving at the correct medical diagnosis is only part of the clinician's task and that the subjective experience of the patient must also be considered and in some cases will require its own treatment (Borrell-Carrio, Suchman & Epstein, 2004). This model serves to empower the patient and truly include him or her as a partner in the treatment process.

By extension, the Biopsychoeducational model promotes integration among all systems to support the child, and recognizes that improving the child's health or educational performance requires collaboration among all systems (Grier & Bradley-Klug, 2011). If each system operated separately, the needs of the child would not be addressed satisfactorily since some would be attended to redundantly while others remain unaddressed. The model integrates administrators, medical service providers, teachers, students, family members, and community members. The emphasis is on collaborative problem solving, and the stepwise process is the same identified in conjoint behavioral consultation (identify, analyze, intervene, evaluate). The biopsychoeducational model guides team members to develop hypotheses by examining ecological factors related to the child, family, educational setting, medical situation, etc. Analysis of assessment and other data collection procedures are used to test hypotheses, and interventions are developed and prioritized based on the information gathered (Grier & Bradley-Klug, 2011). This model is clearly relevant to the educational experience of children with chronic illnesses and their families and suggests not only that children and their parents should be included as collaborators in the re-entry or special education planning process but also that they should be recognized as the “expert” relative to family and personal issues, as in the Conjoint Behavioral Consultation (CBC) model (Sheridan and Kratochwill, 1992), which is widely accepted and utilized in schools. Developing relationships with families by discussing and weighing their experiences is important in building trust and cultivating open, honest communication between parties (Borrell-Carrio, Suchman & Epstein, 2004). Grier and Bradley-Klug posit that interventions will not be correctly selected or effectively implemented if the family is resistant to collaboration between the pediatric team and the school.

Study Rationale

Indeed, our current system of care for children with chronic illness is a “patchwork” of disconnected programs that don’t work together in the best interest of the child, whether this be due to inconsistently demonstrated need or lack of knowledge and resources on the part of families and school personnel. A model aimed at integrating educational and medical professionals with the chronically ill children and their families is critical to insuring optimal outcomes. Head and Abbeduto (2007) suggest that “translating a systems approach into practice requires incorporating ‘family-centered’ policies and practices into services throughout the diagnostic and treatment process” (p. 294). Improving collaboration by making it more family centered might lead children with chronic illness and their parents to a greater sense of satisfaction with their educational experience, and may in turn improve educational and lifelong health outcomes for this vulnerable population. This study aims to establish a baseline of parents’ overall satisfaction and perceptions of the strengths and weaknesses of the school attended by their child with CF, and bring to light potential areas for improvement.

Chapter III: Methods

The present study aims to gather information regarding factors that may influence a parent's satisfaction with educational services provided to their child with CF through analysis of parents' survey responses. Specific methodological procedures follow.

Participants and Setting

Participants include survey respondents who are the parent or legal guardian of a school-aged child (or children) with CF. For the purposes of this study, "school-aged" is defined as any child in kindergarten through twelfth grade who attends school outside the home (not homeschooled). Recruitment for this survey was via an email listserv maintained by the Western Pennsylvania Cystic Fibrosis Foundation and the setting for completion was on the respondent's computer or mobile device. Surveys were completed at the respondent's convenience.

Procedures

Sampling and Participant Recruitment Procedures. Nonprobability sampling was utilized as participants were recruited from a convenience sample of families voluntarily affiliated with local CFF chapters. Although this type of sampling can limit the generalizability of results, the CF foundation attempts to establish contact with all patients and their families through encounters at specialized CF medical care centers (CFF, 2012). Due to the necessity for routine specialized medical care, these care centers are frequented by most individuals with CF thus the likelihood of obtaining a representative sample of families who have a child with CF is high. One caveat of internet-based research is related to sampling bias. All possible participants may not have access to an internet connection and an email address; therefore, the ultimate participants may not be from a representative sample of the population of CF families.

In order to access this sample, the director of the Western Pennsylvania chapter of The Cystic Fibrosis Foundation was contacted and asked to assist in distribution of this survey. The director was provided with an informational email, including a description of the survey, procedure for providing informed consent, and a unique link to the survey, which was transmitted to members of the Foundation's listserv via email. Participants were asked to follow the link provided to access the survey, and submit responses upon completion. Survey responses were collected and data aggregated through Qualtrics, a web-based electronic survey distribution and data collection system.

Data Collection. A 36 question survey (Appendix A), consisting of dichotomous (yes/no), closed-ended, open-ended, and Likert-type questions were administered to all participants via an emailed web-link. This email included a direct link to the survey, with the indication that following the link implies their consent to participate anonymously and that they may opt out by discontinuing completion of the survey at any time. Each link was unique to the email recipient and was valid only for the initial completion of the survey. Qualtrics is an online electronic research tool that is password protected and de-identifies survey responses for the protection of human subjects. The online survey included step-by-step instructions for completion. Participants gained no direct benefit from completing the survey and were not be offered any compensation. Participants were informed that participation would contribute to the literature available for the support of school children with CF.

Research Design

The study utilized a survey design. This is a one-time parent survey with no experimental control group or experimentally manipulated independent variable (IV). Survey designs are useful for gathering descriptive data from a sample of respondents and using that information to attempt to make assertions about an entire population in order to help explain the relationship between one variable and another.

Measures

Criterion Variable. Overall parent satisfaction with educational service provision was be measured on a 1 to 10 scale by asking parents to indicate their degree of satisfaction with the totality of their child's educational experience.

Predictor Variables. Data regarding variables that are potentially predictive of satisfaction were collected based on the conceptual framework of Andersen's (2008) behavioral model, which proposes that the receipt of services is dependent on three groups of demographic factors: predisposition to use of services (including race/ ethnicity, child's age, and gender), level of need (illness severity; see below), and factors facilitating the use of services (including parent education level, household income, family structure, and geographic location). Gathering this information regarding access and utilization is a critical precursor to measuring satisfaction. Andersen further noted that consumer satisfaction following utilization of services or attempts to access them is predictive of future behavior, thus reemphasizing the importance of parent satisfaction with regard to the ultimate outcomes of a child's educational experience.

Demographics. The first eight survey questions characterize and describe the sample relative to the total CF patient population. Race/ Ethnicity was measured using 6 categories: Hispanic, American Indian Non-Hispanic, Asian Non-Hispanic, African American Non-Hispanic, White Non-Hispanic, and Other. Child age in the metric of "years old." Child gender was measured using two categories: Male and Female. Highest parent education level in household will be measured with 5 answer options: Less than High School/ No diploma, High School Diploma or GED, Associates Degree or Vocational/ Technical Certification, Bachelor's

Degree, Graduate Degree. Household income will be defined as the combined yearly income earned by all parents living with the child and will be measured with six levels: < $16,499, $16,500-$24,999, $25,000-$34,999, $35,000-$49,999, $50,000-$74,999, and > $75,000. Family structure will be defined as the family living environment of the child and will include six categories: Parents married and living together, parents living separately but co-parenting, single parent- widowed, single parent- divorced, single parent- never married, and other. Geographic location will be determined by population and will include four levels: Large city or metropolitan area (>200,000 people), small city (50,000-200,000 people), town (2,500-50,000 people), or rural area (<2,500 people).

Health insurance coverage was included in the health care related survey as a factor facilitating use of services, but was excluded from this survey, as public educational services are available to all students from birth to 21 years of age regardless of health insurance coverage. Instead, a question regarding school type (public or private) was included because accommodations are handled differently across these settings and could influence perception of partnership and satisfaction with service provision. School type information will be measured through two categories: Public and Private.

Illness Severity. Review of the literature has indicated that the severity of a child's condition is highly predictive of parental satisfaction with services. Kenney, Denboba, Strickland, and Newachek (2011) found that functional limitations were predictive of lower levels of satisfaction with care for parents and speculated that children with significant functional difficulties are more likely to test the boundaries a system and find its limits, whereas those who are never bothered by their conditions demand less from the system and are consequently less likely to find its faults. Illness severity was measured using the screening tool from the National

Survey of Children with Special Healthcare Needs (NS-CSHCN) conducted by the Maternal and Child Health Bureau and the National Center for Health Statistics (Appendix A). These survey items have been administered first in 2001, again in 2005-2006, and most recently in 2009-2010 to a nationally representative sample and the data collected has been analyzed for a number of peer-reviewed research publications (Aruda et al., 2011; Blackman et al., 2011; Bramlett et al., 2009; Houtrow et al., 2012; Montes, Halterman, & Magyar, 2009; Kagan, Strickland, & Newacheck, 2009). According to the design and operation manual of the 2009-2010 survey:

> The framework for the 2001 NS-CSHCN was initially discussed in August 1999. A panel consisting of selected state and federal Title V program directors, representatives from Family Voices and the Association of Maternal and Child Health Programs, health services researchers, and survey design experts identified the content domains of greatest epidemiological and policy importance. A subset of this panel then assembled questions to capture these domains. Upon approval by MCHB, these questions were pretested in 2000 and fielded in 2001 as NS-CSHCN.
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> Although the overall structure of the NS-CSHCN questionnaire remained static across the 2001, 2005–2006, and 2009–2010 administrations, questionnaire revisions did occur prior to each new iteration of the survey in order to improve data quality, accommodate new sample, and address research questions of interest. (Bramlett et al., 2014, p. 7)

Bramlett et al. (2008) found that the number of health consequences endorsed on the NS-CSHCN screening tool, consisting of five yes/no questions regarding the various needs associated with a child's condition, could be used to reliably indicate the severity of a child's illness and complexity of need. Three levels of severity were identified: (1) children who only require prescription medication (parents respond "yes" to Question 2 only), (2) children who require one or more services related to medical care, education, or mental health exclusively or in combination with prescription medication (parents respond "yes" to Questions 1, 4, and/or 5, in addition to Question 2, but respond "no" to Question 3), and (3) children who experience significant functional limitation as a result of their health condition (parents respond "yes" to

Question 3, and any others). Survey responses were coded to reflect these three previously established levels of illness severity.

Partnership. Next, data regarding specific aspects of the educational experience related to partnership was collected. Keen (2005) noted that relationships are most effective when they are perceived as partnerships, with key characteristics such as mutual respect, trust and honesty, mutually agreed upon goals, and shared planning and decision making. Summers et al. (2005) further surmised that satisfaction or attitude toward services included both child-focused factors such as the competence and commitment of the clinician, and treating the patient with dignity and respect, and family-focused factors such as communication and shared responsibility amongst parties in making and executing treatment decisions. Trust in the clinician was included in both the child- and family- focused factors.

Previous research has demonstrated the value of collaboration in increasing both positive outcomes for students and satisfaction of parents. Bailey (1987) recognized that the values and priorities of parents and professionals often differ, and this can interfere with effective treatment of children. He argued that the role of the parties is not to force one's values on one another, but to engage in collaborative goal setting to design mutually acceptable interventions. To do this, professionals must listen to families and communicate effectively. According to this research, family-centered practice has been shown to increase confidence in parenting skills, improve the emotional wellbeing of family members who feel supported, and enhance the family's functioning. When children make progress, stress is alleviated and confidence increases. It is hypothesized that successful integration of the school into the "medical home" by provision of comprehensive, well-coordinated, family-centered services that are perceived as the product of a mutually appreciated partnership can have a significantly positive impact on satisfaction.

Factors influencing partnership were measured using survey items adapted from the Family-Professional Partnership Scale, an empirically validated instrument developed to assess parent perception of "family-centered practice" and the quality of the parent- professional partnership for special education students (Summers et al., 2005). This scale is comprised of 18 items loading on two key factors. One factor, Child-Focused Relationships, includes 9 items focused on the activities, attitudes, and services of those caring for the child with a disability assessing the family's perception of educational professionals being reliable and competent to meet their child's needs, being respectful of the child's dignity, and being mindful of the child's best interests. The second factor, Family-Focused Relationships, includes 9 items related to respectful and supportive treatment of the family as a whole, assessing parent perception of communication and respect for the family's values. Chronbach's alpha for the18-item scale was .96, with an alpha of .94 for the child-focused subscale and .92 for the family-focused subscale (Summers et el., 2005). Survey responses were summed to obtain a "Child-Focused Relationships score" and a "Family-Focused Relationships score"."

Other Predictors of Satisfaction. Finally, questions related to other factors potentially predictive of satisfaction were measured with selected items adapted from the National Household Education Survey- Parent and Family Involvement in Education Questionnaire (PFI-NHES; 1996, 1999, 2003, and 2007) as conducted by the US Department of Education. This survey has been conducted repeatedly to gather data pertaining to family involvement in various aspects of schooling, as well as information regarding school choice, parent satisfaction with children's schools, and school-aged children with disabilities. As reported in the Data File User's Manual of the PFI-NHES, the questionnaire was designed by a private survey development agency, Westat (Hagedorn et al., 2008). In the design phase, a number of experts from academic and research institutions and government agencies were consulted to obtain their perspective on relevant survey topics. Additionally, a technical review panel was established to examine extant surveys, conduct a review of the existing literature, and develop research questions. The subsection coded PQ15 in the section of the questionnaire headed “Health and Disability” contains five survey items regarding satisfaction with services received, including parents’ assessment of communication, support, expertise, and commitment. These five items were adapted for use in the present study.

Statistical Analysis

Sample Size. A desirable sample size for obtaining a reliable regression equation is based on the recommended ratio of 15 subjects per predictor variable (Stevens, 2001). Thus, given 15 predictor variables, the desirable sample size would be 225 participants. Electronic survey response rates are typically around 33% (Nulty, 2008). Surveys were sent to all families affiliated with the regional chapter of the CFF, roughly 250, with expected return being around 80-100 participants. Due to the very restrictive parameters of inclusion in this special population, preliminary power analysis was not used to determine sample size.

Data Analysis. The first research questions was “*What relationships exist among Overall Satisfaction, Child Age, Likelihood of School Recommendation, Satisfaction Sum, Family Factors, Child Factors, and Illness Severity?”* Proposed analysis included calculation of Pearson correlation coefficients were computed to assess the relationships among overall satisfaction, child age, likelihood of school recommendation, satisfaction sum, family factors, child factors, and illness severity.

The second research question was, *"How satisfied are parents of children with CF with the educational services received by their child(ren)?"* Frequency statistics were calculated related to parents' responses to the satisfaction questions included in the survey.

The third research question was *"How can data collected regarding the following variables be used to accurately predict educational satisfaction for the parents of children with Cystic Fibrosis: illness severity, child-centered partnership factors, family-centered partnership factors, provision of information, suitable communication, suitable service provision, perceived ability to accommodate needs, perceived commitment to child, likelihood of recommending school to others with CF?"* The proposed analysis included multiple regression conducted using variables computed from survey responses as predictors and overall satisfaction as the dependent variable to determine which factors are significant predictors of overall satisfaction. A second analysis, using Logistic regression with dichotomous (Y/N) satisfaction as the dependent variable and the above listed categorical and continuous predictor variables, was also conducted. Binary Logistic Regression is used to find the best fitting model to describe the relationship between a dichotomous dependent variable (overall satisfaction, which will be collapsed from a 1-10 scale into dichotomous Y/N categories as follows: responses from 1-5 = No, and responses 6-10 = Yes) and a set of categorical and/or continuous independent predictor or explanatory variables (illness severity, family-focused relationship score, child-focused relationship score, satisfaction with communication, satisfaction with service provision, satisfaction with ability to accommodate, satisfaction with commitment to child, likelihood of recommending school to others, ethnicity, marital status, household income, caretaker education level, community type, and age of child). The "Forward LR" method will be utilized in this analysis, with variables being added to the model one at a time, using the likelihood ratio to determine variable selection.

Chapter IV: Results

The current study examined parental satisfaction trends related to services provided by schools to children with Cystic Fibrosis. The results section is organized in the following manner: an examination and description of the participant sample, data pre-analyses and tests of statistical assumptions, and the results of the main analyses.

Demographics

All participants were parents who have a child with Cystic Fibrosis between the ages of 5 and 18 enrolled in school (grades k-12). Although a total of 45 participants responded, after cleaning the main body of statistical data, the subsequent sample size is 35. The following demographics describe the participants and their children with Cystic Fibrosis. The most defining characteristics of the parent demographics are that they are married (94.1%), have an education of a bachelor's degree or higher (77.1%), and have a combined household income greater than $75,000 (71.4%). Child statistics are similar across gender; 51.4% of the subjects' children are male and 48.6% are female. 91.4% of the children represented in the sample are White non-Hispanic. The ethnicity of the remainder of the sample is as follows: 2.8% Native American, and 5.7% biracial (Caucasian and African American). 94.3% of the children attend public schools. 37.1% of participants live in cities, while 45.7% reside in towns and the remaining 17.1% live in rural areas. Furthermore, most parents indicate that their child is in the moderate range of illness severity (67%), requiring more medical care and/or therapeutic services than healthy peers but not functionally limited from participation in age-typical day-to-day activities. Demographics are displayed in Table 1.

Table 1
Demographics

Demographic Category		**Frequency (*n* = 35)**	**Percentage of Sample**
Race/ Ethnicity			
	White	32	91.4
	White and Af. Am.	2	5.7
	American Indian	1	2.8
Gender of Child			
	Male	18	51.4
	Female	17	48.6
Education of Parent			
	High School	5	14.3
	Associates Degree/ Vo. Tech. Certification	3	8.6
	Bachelor's Degree	14	40
	Graduate Degree	13	37.1
Household Income			
	$25,000-$34,999	1	2.8
	$35,000-$49,999	5	14.3
	$50,000-$74,999	4	11.4
	>%75,000	25	71.4
Parents' Marital Status			
	Cohabitating and getting married	2	5.7
	Married	33	94.3
Community Type			
	Large City	7	20
	Small City	6	17.1
	Town	16	45.7
	Rural Area	6	17.1
School Type			
	Public	33	94.3
	Private	2	5.7
State of Residence			
	Illinois	1	2.8
	Iowa	1	2.8
	Maryland	3	8.6
	New York	1	2.8
	Ohio	10	28.6
	Pennsylvania	18	51.4
	Texas	1	2.8

Data Screening, Pre-analyses and Tests of Statistical Assumptions

Prior to conducting the main analyses, the dataset was screened for missing data, outliers, and tested for statistical assumptions. Screening of the 45 total responses revealed that three respondents opened the survey, thus creating a record/ case, but either only completed the demographic questions (one case) or did not complete any questions at all (two cases). One additional respondent indicated that their child was 4 years old and in pre-kindergarten, thus outside of the inclusionary age range (5-21) and definition of "school aged" (grades K-12) established for the purposes of this study. Finally, six respondents indicated that their child was diagnosed with an Autism Spectrum Disorder and/or an Intellectual Disability. These 10 cases were eliminated, reducing the dataset to a total of 35 cases meeting all inclusionary criteria.

The data were examined for univariate outliers by calculating standardized values for each variable. All values were within three standard deviations of the mean (Mertler & Vannatta, 2005) and thus none were considered outliers. The data were also examined for multivariate outliers. The Mahalanobis distance across all 6 variables was less than the chi-squared critical value at $p=.001$ with $df=6$ of 22.458, indicating that there were no multivariate outliers (Mertler & Vannatta 2005). Finally, standardized values for residuals were then assessed. Of the 35 cases, one was identified with a residual z-score having an absolute value greater than 1.96, though this is considered acceptable (Field, 2013).

The assumption of normality was tested for the Overall Satisfaction, Likelihood of School Recommendation, Satisfaction Sum, Family Factors, Child Factors, and Illness Severity variables. Overall Satisfaction was normally distributed, with skewness of .47 (SE = .40) and kurtosis of -.31 (SE = .78). Likelihood of School Recommendation (skewness = .85; SE = .40; kurtosis = -.76; SE = .78), Child Factors (skewness = .73; SE = .40; kurtosis = .38; SE = .78), and Illness Severity (skewness = -.04; SE = .40; kurtosis = .40; SE = .78) were all normally distributed. Values for Satisfaction Sum (skewness = 1.53; SE = .40; kurtosis = 2.26; SE = .78) and Family Factors (skewness = 1.21; SE = .40; kurtosis = .74; SE = .78) violated the assumption of normality and required LOG10 transformations to correct for this (corrected values [respectively]: (skewness = .80; SE = .40; kurtosis = -.24; SE = .78 and skewness = .73; SE = .40; kurtosis = -.47; SE = .78).

Scatterplots with standardized residuals plotted against standardized predicted values were examined to evaluate for problems with linearity or homoscedasticity. No systematic relationship between error values and predicted values was identified, and assumptions for homoscedasticity and linearity were thus met.

Finally, multicollinearity was assessed through examination of VIF and tolerance statistics. VIF values were well below 10 and tolerance statistics were above .2; therefore, collinearity was not considered to be an issue (Field, 2013).

Descriptives

After evaluating the assumptions, preliminary analyses were run to examine the descriptive statistics for each variable; these are reported in Table 2.

Table 2
Descriptive Statistics

Variable	Mean	St. Dev.
Overall Satisfaction	2.46	1.31
Recommend	1.6	.775
Satisfaction Sum	6.23	2.73
-Communication*	1.69	.9
-Expertise*	1.51	.74
-Accommodation*	1.54	.82
-Commitment*	1.49	.78
Child Factors	15.97	5.04
Family Factors	14.71	5.10
Severity	1.91	.56

$n = 35$

*Responses to Communication, Expertise, Accommodation, and Commitment were summed to compute Satisfaction Sum

Main Analyses

Research Question 1: What relationships exist among Overall Satisfaction, Likelihood of School Recommendation, Satisfaction Sum, Family Factors, Child Factors, and Illness Severity?

Pearson correlation coefficients were computed to assess the relationships among overall satisfaction, likelihood of school recommendation, satisfaction sum, family factors, child factors, and illness severity. Significant correlations ($p < .01$) were identified between overall satisfaction and likelihood of school recommendation ($r = .561$), overall satisfaction and satisfaction sum ($r = .673$), overall satisfaction and child factors ($r = .592$), overall satisfaction and family factors ($r = .457$). Significant correlations were identified between likelihood of recommendation and satisfaction sum ($r = .798$), family factors ($r = .539$), and child factors ($r = .469$). Significant correlations were identified between Satisfaction sum and family factors ($r = .768$) as well as child factors ($r = .673$). Child factors and family factors were also significantly correlated ($r = .738$). Illness severity was not significantly correlated with any other key study variables. Results of the correlation analysis are presented in Table 3.

Table 3
Correlations Among Key Study Variables

	Illness Severity	Recommend	Satisfaction Sum	Child Factors	Family Factors
Overall Satisfaction	-.174	.561*	.673*	.592*	.457*
Illness Severity		-.261	-.175	-.125	-.305
Recommend			.798*	.539*	.469*
Satisfaction Sum				.768*	.673*
Child Factors					.738*
Family Factors					

*$p < .01$.

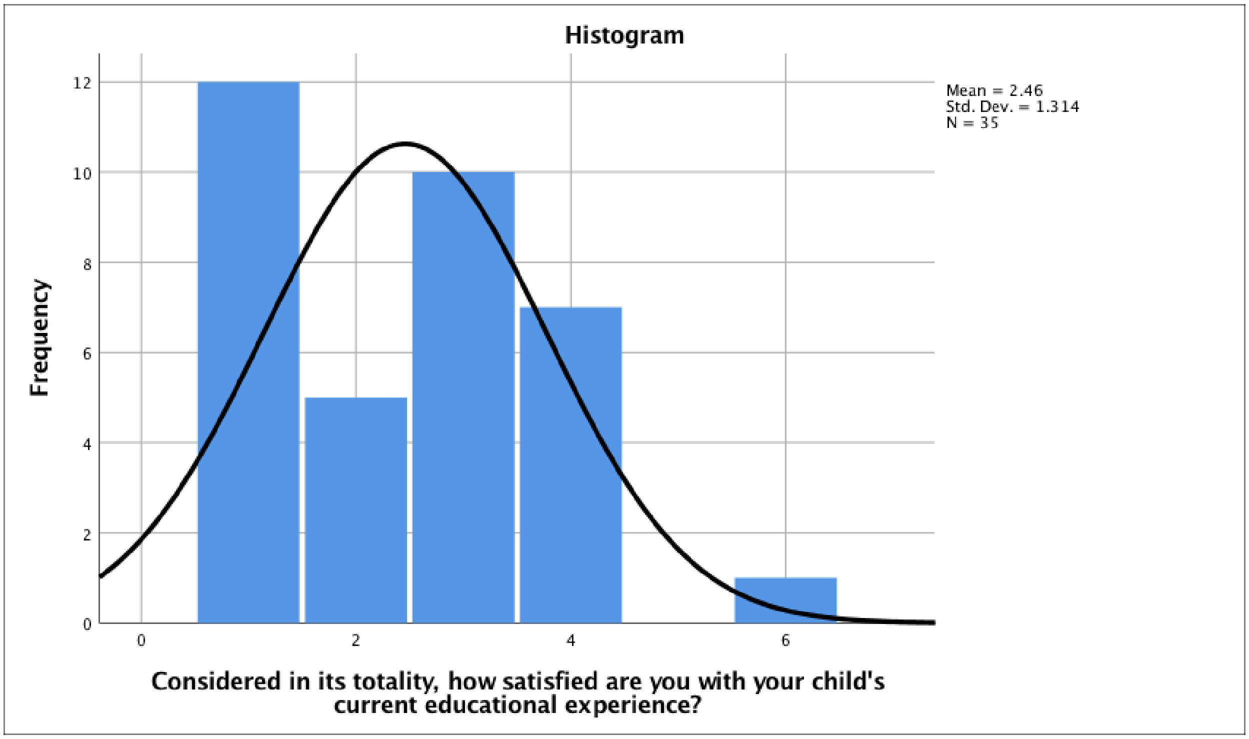
It should be noted that, due to scaling, lower scores indicated greater satisfaction, thus positive correlations indicate that as respondents rated components of satisfaction more poorly, they also rated overall satisfaction more poorly. The inverse was true of illness severity, which was negatively correlated with overall satisfaction and its component parts. Thus, as respondents reported more severe illness, they also reported less overall satisfaction and rated the component parts more poorly.

Research Question 2: Are parents satisfied with the educational experience provided to their child(ren) with CF?

It was hypothesized that the distribution of responses would be bimodal, with a portion of the satisfaction ratings falling very high while others fell very low. The proposed analysis called for inspection of frequency counts and descriptive statistics for the survey item pertaining to the variable “overall satisfaction” as well as to key elements of satisfaction identified from the research literature. Descriptive statistics indicate that the mean overall satisfaction rating reported was 2.46 (on a scale of 1 [very satisfied] to 10 [very dissatisfied]) with a standard deviation of 1.314. Of the respondents, 34.3% (12 of 35) rated their satisfaction as being “very high” or 1 of 10, and only 1 respondent (2.9%) rated their satisfaction as being “very mildly dissatisfied” or a rating of 6 of 10; graphic depiction of responses are represented in Figure 1. Although the histogram shows that a large number of the ratings indicate high satisfaction, it does not demonstrate that another significant portion are very unsatisfied, thus the hypothesis of a bi-modal distribution is rejected.

Figure 1

Frequency of Overall Satisfaction Ratings



Further inspection of descriptive statistics regarding the computed variable “Satisfaction Sum” (the summed total of ratings pertaining to four key elements of satisfaction: communication, quality of personnel, ability to accommodate, and commitment to help) indicated that 13 parents (37%) “strongly agree” with regard to school personnel fulfilling duties pertaining to all four key elements. Closer inspection of each individual element indicates that 91.4% (32 of 35) “strongly agree” or “somewhat agree” that they are satisfied with the school’s communication, 91.4% (32 of 35) “strongly agree” or “somewhat agree” that they are satisfied with the their child’s educational service providers (teachers, therapists, etc.), 85.7% (30 of 35) “strongly agree” or “somewhat agree” that they are satisfied with the school’s ability to accommodate their child’s needs, and 88.6% (31 of 35) “strongly agree” or “somewhat agree” that the school is committed to helping their child learn. Additionally, 20 respondents (57%)

“strongly agree” that they would recommend their child’s school to the family of another child with CF, while 9 (26%) “somewhat agree” and 6 (17%) “neither agree nor disagree”.

Research Question 3: How can data collected regarding the following variables be used to accurately predict educational satisfaction for the parents of children with Cystic Fibrosis: illness severity, child-centered partnership factors, family-centered partnership factors, provision of information, suitable communication, suitable service provision, perceived ability to accommodate needs, perceived commitment to child, likelihood of recommending school to others with CF?

It was hypothesized that the above listed variables would be significant contributing factors in the accurate prediction of educational satisfaction for parents of children with CF. The proposed analyses included multiple regression conducted using variables computed from survey responses as predictors and overall satisfaction as the dependent variable to determine which factors are significant predictors of overall satisfaction. A second analysis was proposed using Logistic regression with dichotomous (Y/N) satisfaction as the dependent variable and the above listed categorical and continuous predictor variables.

A multiple regression analysis was conducted to evaluate how well respondent ratings pertaining to the various elements of satisfaction identified in the research literature predicted overall parent satisfaction, as rated by survey respondents. Predictors were entered in a single block using the stepwise selection method to determine which were significant contributors to variability in overall satisfaction. Results of the initial analysis indicated that satisfaction sum and illness severity accounted for a significant amount of variability in overall satisfaction, $R^2 = .54$, $F(2, 32) = 18.77$, $p < .01$.

A second multiple regression analysis utilizing each of the four questions pertaining to an element of satisfaction as its own independent predictor variable (rather than computing a sum) in addition to the other predictor variables was conducted and results indicated that satisfaction with educational personnel, satisfaction with the school's commitment to help the child learn, and illness severity accounted for a significant amount of variability in overall satisfaction, $R^2 = .624$, $F(3, 31) = 17.18$, $p < .01$.

Logistic regression analysis was proposed to confirm the predictive validity of the various factors for accurately categorizing parents as "satisfied" or "dissatisfied" based on ratings regarding key elements of satisfaction as well as demographics thought to influence overall satisfaction; however, when "overall satisfaction" was recoded into a dichotomous (yes/no) variable, it was found that only one case fell into the "dissatisfied" category. Due to having severely unbalanced groups, statistical analysis was not deemed useful or necessary in this instance and the naïve model of classifying every case as "satisfied" or "yes" is considered the model of best fit.

Chapter V: Discussion

At present, there are more than 30,000 people living with Cystic Fibrosis in the United States and an additional 1,000 cases are annually diagnosed. The day-to-day impact of living with a chronic illness, such as CF, has the potential to significantly impact educational experiences. As a result, valuable information may be gained from better understanding the experiences of children with CF and those of their families relative to school which may also be generalizable to the larger illness and disability population.

Children with chronic physical illness perform below expectations in school despite average or possibly even better cognitive abilities (Clay, 2004; Power et al, 1999). Reasons for poor performance include missed instructional time, medication side effects, physical discomfort, and emotional and behavioral disturbance that occur at higher rates among the chronically ill than in the general population. A significant factor that contributes to overall perception of school experience is the notion of general school satisfaction. General school satisfaction includes concepts such as having one's needs met adequately, having just recourse when one's needs are not met, being a valued participant in the process of planning an educational program to meet identified needs, and the ease with which all of these aforementioned notions occur. Previous research has found that both the process and the product are important when considering consumer satisfaction.

Within the medical community, the concept of "family-centered practice" has become a standard tenet of high-quality care, with emphasis on inclusion of patients and their families as integral members of the treatment team and as "experts" relative to the psychosocial factors influencing the patient's current medical presentation and response to treatment (AAP, 2002). Similarly, within schools, students and parents are legally mandated to be included in the collaborative process of educational planning (IDEA, 2004). As it relates to schooling for chronically ill children, specific factors such as home-school communication, competence of professionals to manage the illness-related needs of children, and compassionate preservation of the dignity of the ill child have been identified as factors contributing to parent satisfaction.

Finally, individual factors are known to influence perception of overall experience and by extension satisfaction. As it relates to medical care, this includes level of need and access to high quality services, which may be influenced by geography or socioeconomic factors. Previous research has demonstrated that high level of need is associated with lower satisfaction, based on the hypothesis that increased needs test the limits of a system to accommodate them and tend to probe the "weak spots" (Kenney et al., 2011). Additionally, accessibility of services contributes to satisfaction due to its influence on subjective ratings of ease of use (Aruda et al., 2011). Those in remote geographic areas or with significant limitations posed by socioeconomic factors tend to report frustration and difficulty with obtaining appropriate services or resources, and are thus less satisfied with the process.

The present study aimed to explore the construct of satisfaction among parents of children with Cystic Fibrosis. Specifically, data were collected to determine the extent to which parents perceived their child's needs are being met at school, as well as determining correlates of satisfaction with school services.

The purpose of research question 1 was to explore the relationships between and among overall satisfaction, likelihood of school recommendation, satisfaction with professionalism, communication, competence, and commitment, perception of family-centered and child-centered care, child age, and illness severity. Results indicated, as expected, that a number of these constructs were highly related to the outcome variable "overall satisfaction"; however, they were also highly related to each other, suggesting that these are not truly independent elements of "overall satisfaction". Results also validated that the concept of "family centered practice" is highly related to "overall satisfaction" given that parents' positive perception of both child- and family- focused relationship factors were significantly correlated with overall satisfaction. The fundamental values of family-centered care include establishing the family as the focus of services, supporting and respecting the family as decision makers, and implementing interventions designed to improve the functioning of the family system (McBride et al., 1993). Parents completing this survey endorsed that school efforts are adequate or better in this regard. Similarly, key components of "overall satisfaction" endorsed by parents included the professionalism and quality of school personnel and their commitment to helping a child learn. This is further discussed below as it pertains to the biopsychoeducational model.

Research question 2 sought to characterize the distribution of responses regarding overall satisfaction. Survey responses were consistent with previous literature that found parents of children with chronic illness were generally satisfied with their child's school services. However, analysis did not reveal evidence of a dissatisfied minority. The finding that parent satisfaction is generally high is important in light of the research of Christenson and Sheridan (2001), who noted a bi-directional relationship between satisfaction and involvement, which consequently impacts student achievement (Fantuzzo, Perry, & Childs, 2006). When parents are satisfied, they are more likely to be involved in the educational process, and their children experience greater academic success.

Brook and Galili (2011) asserted "discrimination towards chronic patients begins at school when teachers do not know enough or are ignorant to the medical condition and its sequellae" (p. 38, 2011). Furthermore, Notares (2002) reported that 56% of parents did not feel that school personnel were sufficiently knowledgeable to care for their child and 11% of parents were dissatisfied with the school's attempts to care for their child. By contrast, the present study found that the majority of parents were confident that the school was capable of accommodating their child, that the quality of the school personnel met their expectations, and that they were satisfied on a whole with the educational experience provided to their child. This is important because a known reason for school absences in this population is related to a protective parenting style, due to limited confidence that schools can manage the child's health status (Anthony et al., 2003; Notares, 2002; Sexon & Madon-Swain, 1995). Results of the present study suggest that parents are confident that school personnel can adequately manage and maintain the health of their child with CF, making this factor less likely to contribute to absenteeism and lost instructional time. One possible explanation for this finding can be found in the supportive and proactive work of the CF medical community in conjunction with the CF Foundation. These professionals collectively offer resources to families and educators regarding school entry/ re-entry. Access to this information likely increases the confidence of parents to entrust the care of their children to others and increases the competence of educational service providers to meet the needs of these children.

The third research question aimed to understand the extent to which likelihood of school recommendation, satisfaction with professionalism, communication, competence, and commitment, perception of family-centered and child-centered care, child age, and illness severity predict parent satisfaction with school services. Results suggest that much of the information collected is extraneous, but that a few essential pieces of information are highly predictive and influential in the determination of whether or not a parent is satisfied with the overall educational experience of their child with CF. The factors that are most influential in predicting parent satisfaction include satisfaction with the expertise/ quality of school personnel and satisfaction with educators' commitment to helping a child learn. These factors closely parallel tenets of family-centered practice including competence and commitment of the clinician, and treatment of the patient and family with dignity and respect (Summers et al., 2005). Illness severity was also found to contribute significantly to the variability in overall satisfaction, which is in agreement with previous findings that greater severity leads to greater dissatisfaction (Kenney et al., 2011). This is likely a result of higher levels of need being more difficult to meet satisfactorily due to limitations of resources or expertise.

Application of Findings to the Biopsychoeducational Model

The Biopsychoeducational model promotes integration among all systems to support the child, and recognizes that improving the child's health or educational performance requires collaboration among all systems (Grier & Bradley-Klug, 2011). The model aims to integrate administrators, medical service providers, teachers, students, family members, and community members with an emphasis on collaborative problem solving. This model is clearly relevant to the educational experience of children with CF and their families and suggests not only that children and their parents should be included as collaborators in the re-entry or special education planning process but also that they should be recognized as the "expert" relative to family and personal issues. Developing relationships with families by discussing their experiences is important in building trust and cultivating open, honest communication between parties (Borrell-Carrio, Suchman & Epstein, 2004). The present study aimed to provide validation of the biopsychoeducationl model by demonstrating the inter-relationship of study variables associated with each individual system discussed below.

Biological implications. Previous research in the medical field suggests that satisfaction and illness severity have an inverse relationship, likely due to those with more severe illness having significantly greater needs and thus finding the "soft spots" or pushing the limits of a system to accommodate them (Kenney et al, 2011). Results of the present study did not find the relationship between satisfaction and illness severity to be significant, although they did confirm the inverse nature of this relationship. Despite the lack of a significant correlation, illness severity was found to contribute significantly to the variability in overall satisfaction ratings in a multiple regression analysis. One possible explanation for this is that the effects of illness severity on satisfaction are not as profound in the educational setting. Alternatively, the sensitivity of the survey instruments in conjunction with the very small number of parents who indicated that their child fell into the "severe" category, which includes functional disability, was likely not adequate to yield information regarding the specific issues faced or shortcomings of the system. Perhaps families of children with severe functional disability were less likely to respond to this survey request due to the high burden of care associated with such illness severity, and thus are underrepresented in the sample. Future research might use severity as a grouping variable for comparative analysis to further explore this concept.

Psychological implications. The American Academy of Pediatrics (AAP; 2002) define a "medical home" as a physician or team of healthcare workers known to the child and family and "family-centered care" as a partnership characterized by mutual responsibility and trust. These are also key components of satisfaction identified in the research literature. The present study sought to determine whether family-centered collaborative practices lead parents to a greater sense of satisfaction with their educational experience, which could have far-reaching implications for improved educational and lifelong health outcomes for this vulnerable population. Although these factors were not found to be significant contributors to overall satisfaction in the regression analysis, a significant positive relationship between parent- and child-focused factors and overall satisfaction was established. Additionally, participants endorsed generally positive perceptions of their child's educational service providers with regard to both family-focused and child-focused aspects of service provision, suggesting that schools are implementing tenets of family- and patient- (or student-) centered practice. Worth noting is that the single responded who indicated mild dissatisfaction also rated the parent-professional partnership as poor with regard to parent- and child- focused factors.

After a diagnosis of CF is assigned, parents are faced with integrating that diagnosis into a future not previously envisioned for the child and family. In order to function adequately in the face of a crisis such as the chronic illness of a child, families must possess sufficient levels of emotional and cognitive resources, financial stability, and social support (Brassard, 2007). Deficiencies in any of these areas can limit the coping skills of parents and make them less able partners. Furthermore, parents of children with chronic illnesses are more likely to experience major depression, generalized anxiety, panic disorders, post-traumatic stress, and marital discord (McCabe & Shaw, 2010). Survey responses of this study indicate that the majority of participants had adequate cognitive and financial resources, as evidenced by reports of attaining college education or beyond and securing a household income exceeding $75,000 annually. Additionally, biological parents of all children referenced in this study resided together. This finding reveals that this group of participants is not typical with regard to patterns of increased separation and divorce in families of children with chronic illness.

Not yet known - and beyond the scope of the present study - is specific information regarding the social-emotional functioning of parents of children with CF and its impact on educational satisfaction. This is critical because increases in parental psychological distress are linked to less optimal parent and family functioning, greater perception of disease severity and poor health-related quality of life, and poorer physical and social-emotional outcomes for children with CF (Carpenter, Mullins, Wolfe-Christensen, & Chaney, 2008). Future research could investigate parental distress and perceived quality of life to explore how pervasive their impact is on perception of satisfaction with school services, as well as with more objective measures of a child's school functioning.

Educational implications. Respondents generally indicated that schools are meeting the needs of their children with CF and making concerted efforts to build strong home-school partnerships, such as listening; valuing differences as strengths; sharing information and co-constructing interventions; respecting the skills and knowledge of others by asking for opinions; planning together and making decisions that address the needs of students, parents, and teachers; sharing decision making; sharing resources for working toward a goal; providing a common message regarding school work and behavior; demonstrating willingness to address conflict; refraining from finding fault; and sharing success (Christenson, 2003).The present study found two specific components to be influential with regard to overall parent satisfaction, including perception of the expertise/ quality of school personnel and commitment of those educators to helping their child learn. Interestingly, communication was not found to be an influential factor in overall satisfaction despite its frequent presence and endorsement in the research literature as critical to both the home-school partnership and family-centered practice. One possible explanation of this could be that the families of children with mild to moderate illness severity (the majority of this sample) do not demand a great deal of communication over and above what is typical for other school-aged children, thus parents find what is offered to be adequate.

Alternately, the influence of parent and patient education as well as the advocacy efforts of the CF community should be considered as contributing to the preparedness of families to navigate the school system, thus limiting or de-emphasizing the demand for communication. Education begins at diagnosis for families of children with CF, which for many comes in infancy, long prior to school entry. For this reason, most families have years to gain knowledge and seek mentorship in preparation for their children entering the school system. This is in contrast with some other chronic illnesses that may not be present from birth, causing a more drastic shift in caregiver and service provider mindset, from healthy to ill when diagnosis is delivered. Collectively, the benefits of experience with treatment and integration of the diagnosis into child and family mindset, as well as readily available support through educational efforts of the healthcare providers, and connection to the larger community of CF families provided by the Cystic Fibrosis Foundation, likely leads to increased knowledge and confidence regarding navigation of the school system and de-emphasizes the relative importance of communication with school personnel.

Integrated Model. Given the many significant correlations between key study variables, it is clear that these components do not exist separate of each other and that the systems are inherently intertwined. One possible application of this is related to illness uncertainty. Parents and children often experience uncertainty about the future, particularly for children with life-threatening illnesses or complications. Uncertainty has several dimensions including ambiguity about the illness state, overwhelming complexity or lack of information about the illness, its treatment, side effects, and management, establishing trusting relationships with healthcare providers, and the unpredictability of a child’s prognosis, quality of life, and ability to function (Stewart & Mishel, 2000). Uncertainty has been associated with high levels of emotional distress, reduced quality of life, and poor psychosocial adjustments as parents and children fear and prepare for the worst (McCabe & Shaw, 2010). This can interfere with parents' ability to engage as partners on a child's educational team (Santacruce, 2003). Following the premise that uncertainty increases with illness severity, it would follow that those who have children with more severe illness would also have lower satisfaction. This makes logical sense, considering the known impacts of uncertainty on mood and mental distress, which would be expected to apply to this population. As the disease process progresses, parents and children experience complex grief and higher incidence of anxiety and depression. When a person is in mental distress, they are less likely or able to recognize the positive aspects of a situation or utilize adaptive coping mechanisms. Therefore, due to their own distress, these parents may have a more negative perception of their child's school experience and may be less available to serve as integrated or productive members of the treatment team.

Given this, it seems that increasing support from educational providers, including recognition of need and referral for mental health services, for the parent and child would likely produce the best possible outcomes for the child. Parents, schools, and medical teams working together can limit tension and increase support for all parties in dealing with the effects of illness, in turn supporting more positive educational, medical, and quality of life outcomes for the child (NASP, 2012). Given that participants in the present study largely reported "moderate" illness severity, it is difficult to draw conclusions regarding the influence of uncertainty on their interactions with their child's school system and the impacts of this on satisfaction.

Limitations

The main limitations of this study involve the response rate and final sample size. Post-hoc power analysis conducted using G*Power version 3.1.9.3 (Buchner, Erdfelder, Faul, &

Lang, 1997) revealed that with a large effect size and 5 predictor variables, the calculated power of the regression analysis is .67, thus lower than ideal. Despite distributing surveys via several rounds of email blasts, response rate was low. This return rate limited data analysis significantly. Additionally, most of the received data did not display variability with regard to overall satisfaction, further limiting the generalizability of analyses to any broader population. Although survey responses indicating a very high proportion of satisfied parents represents a desirable outcome, it is atypical. There is clear evidence in the form of due process proceedings and educational case law to suggest that not all parents of children with disabilities are satisfied with their child's educational experience. This unexpected outcome may be partially explained by some of the demographic trends found in this sample, including higher-than-expected rates of intact families, above-average household income, and high educational attainment by parents. Additionally, the parents responding to this survey are all connected to the vital support provided by the CF Foundation, making them more likely to have access to resources such as information and advocacy.

Several factors may have contributed to low participation rates. First, a majority of the surveys were distributed around the winter holidays, a busy time for many families. Second, the targeted population has many time demands and possibly elevated stress due to the nature of their child's illness, which may have precluded them from completing the survey.

Recommendations for Future Research

Future research regarding this topic and population could benefit from knowledge gained while conducting the present study. Logistical suggestions include using a shorter survey instrument with fewer redundant/related questions, formulating a better distribution strategy or perhaps partnering with CF care centers and clinics to administer surveys in person during routine appointments to improve engagement.

Many family systems factors were beyond the scope of this research, and future research could investigate whether and how factors such as the presence of diagnosed mental illness of the parent(s), the effects of birth order of the child, the presence of other disability in the family, and the effects of parenting stress and/ or quality of life impact satisfaction. Additionally, the present study assumed parallels exist between medical and educational models with regard to patient-/ student- and family-centered care. It appears that each system is incorporating these principles on its own, but it was beyond the scope of the study to investigate the extent to which the systems utilize collaborative practice across more than two systems. Counter to the medical home model and despite the widespread knowledge of these best practices, the literature suggests that coordination of care between service providers across settings is often facilitated by parents, who are forced into the unenviable position of liaison between the two settings (Keonning, 1995). Future research could explore the extent to which this is occurring as well as piloting alternative consultative models that may be more effective for all partners and less stressful for parents.

Implications for Practice

In conjunction with previous research regarding chronic illness, the present study provides valuable information for practitioners in the field of school psychology, and more broadly, all educational professionals and related service providers working with children with Cystic Fibrosis. First and foremost, it appears that with regard to factors known to influence satisfaction, including communication and collaboration with families as well as compassionate and competent care for their children, schools may be meeting or exceeding the expectations of families of children with Cystic Fibrosis. If specific strategies leading to these successes can be identified, they may serve as a model for the larger disability and chronic illness community and lead to increased satisfaction of many parents and by extension more positive school experiences and outcomes for children.

Regarding illness severity, the present study suggests that a significant majority of children with CF attending school have moderately severe illness, requiring more than routine medical care though not including functional disability or limitation in their ability to participate at the level of their healthy peers under most circumstances. These children may require some accommodations regarding medication management in school, monitoring of symptoms during times of acute health crisis, or remediation of key instructional concepts due to absences, but overall are capable of engaging with the general education curriculum at the same level as their typically developing peers. This is an important distinction from the vast number of children interacting with our educational system that have functional disability, including developmental and learning problems or physical incapacity, who are not able to do so. As previously stated, the higher the level of need, the more likely a child is to test the boundaries of a system to adequately accommodate him or her, which in turn has a negative impact on satisfaction. For this reason, results of the present study are not considered generalizable to other populations with more diverse levels of illness and disability severity, including functional limitation.

With respect to communication between educators and families, respondents to this survey endorsed that schools are meeting or exceeding their expectations. This is important because previous research shows that home-school communication has a positive influence on student success. These results suggest that both the amount of communication and the content are satisfactory. As noted above, the majority of parents responding to this survey have children with moderate illness severity. Moderate illness severity does not impact the child's ability to function in the school environment. Considered together with the fact that CF is not inherently associated with any cognitive or learning deficits, the need for communication is likely no more than what is expected by most parents of typically developing children. If the demand for communication with parents is no higher than usual, it is logical to conclude that school personnel communicating in the way they do for parents of typical children would be meeting the needs of these parents as well. Of note, the parent indicating mild overall dissatisfaction also noted dissatisfaction with communication despite having a child with only moderate illness severity. One possible explanation for this occurrence is that this child's school fails to meet expectations regarding communication even for typically developing children. Additionally, the parents indicating that their child has severe illness, including functional disability, reported high (3 of 4) or moderately high (1 of 4) satisfaction with the schools' communication, suggesting that even when demands are high, these schools are meeting families' needs.

Similarly, parents responding to this survey reported a high level of satisfaction with the competence and compassion of their child's educators, and these are also known factors influencing student success. When educators display empathy and demonstrate respect for the dignity and rights of a child and family, a positive and collaborative relationship is more likely to develop. A compassionate educator integrates the academic needs of the child with the social-emotional needs of the child and family systems to deliver high-quality, individualized, and sensitive services. Likewise, a competent educator inspires confidence from parents, possibly leading to increased commitment of families and their children to attend and participate in school and school-related activities. Perceived competence is linked to better attendance, which in turn leads to greater benefits from exposure to instruction, opportunities for practice, and ultimately greater mastery of academic material as well as increased social and emotional competence due to opportunities for peer and adult engagement outside the home (Fantuzzo, Perry, & Childs, 2006). Perceived competence is also linked to greater information sharing. If families do not feel confident that there are professionals capable of addressing the needs of their child, they are less likely to share crucial information regarding illness and treatment. When parents do perceive competence, they are more inclined to work collaboratively and share information, leading to more consistency across home and school environments and thus better health and educational outcomes for their children. Although only a single case, the respondent who indicated mild overall dissatisfaction also noted dissatisfaction with the quality of service providers as well as poor perception of parent- professional partnership, with regard to both parent- and child-focused factors, suggesting that this family has had an unusually negative experience with their child's school and is the exception rather than the rule.

Conclusions

Approximately one in six children in the United States suffers from some form of chronic illness or disability, and many of these children have illnesses or conditions severe enough to impact their school performance and educational experiences. Cystic Fibrosis (CF) is one such chronic illness that can have significant impact on a child's health and quality of life. CF is an autosomal recessive genetic illness diagnosed in more than 15,000 children in the US, affecting digestive and respiratory fitness. CF poses an array of challenges to children, their families, and the school systems tasked with providing them an appropriate educational program. Some such challenges include adjusting to and accommodating the physical, behavioral, emotional, and social consequences and treatment effects associated with terminal or life-shortening illness. This may include absenteeism due to acute health crises, treatment side effects, and more complex psychosocial factors such as illness uncertainty, grief, and other mental distress. Given that school-aged children devote a significant proportion of their time and energy to education, it follows that CF-related factors may greatly impact their functioning in this arena, thus schools are challenged to identify and provide the appropriate supports and resources to help these children succeed.

The degree to which schools are able to accomplish this task is likely to factor heavily into parents' subjective ratings of satisfaction with their child's educational experience. Parent involvement and home-school collaboration are critical factors in assuring the success of all children, but especially those in need of specialized support. Previous research has identified satisfaction and involvement as having a bi-directional relationship, and parent involvement and educational outcomes as having a strong positive correlation, thus parent satisfaction and positive educational outcomes are assumed to share a similar relationship. Consumer satisfaction research has identified both high-quality products and services and ease of access or use as being important in overall ratings. Healthcare satisfaction research has identified illness severity or level of need and family- or -patient- centered care as contributing factors. Finally, educational satisfaction research has identified home-school communication, professional competence, resource availability, and educator compassion as significant contributing factors to overall satisfaction. The present study sought to integrate the information from these various fields to determine if there were a unique set of factors contributing to parent satisfaction with educational experience for children with CF.

The theoretical basis for this study is grounded in systems theory, and more specifically in the biopsychoeducational model, which recognizes the contributions of biological, psychological, and educational factors as well as the interplay of these in the school success of students. With this model in mind, survey instruments were selected to gather information about constructs related to each of these elements and study the relationships between and among them. Illness severity was identified as a key biological factor influencing overall satisfaction. Perceptions of family- and child- centered practice were identified as psychological factors influencing parent satisfaction. Finally, perception of the suitability of communication, competence, and commitment of school personnel were identified as educational factors contributing to satisfaction.

Results of the present study indicate that participants were generally satisfied with the services being provided to their child by their local school district and child's educators. Despite indication that some participants have severely ill children, only one indicated mild dissatisfaction. The importance of this is twofold: it suggests that parents are satisfied, which bodes well for child educational outcomes, according to the research literature, and it suggests that there may be some aspect of patient/ family education taking place within the CF community that prepares parents to advocate for their children more effectively thus than those with other illnesses, thus leading to increased satisfaction. If this can be more thoroughly investigated and modeled, other patient advocacy groups and treatment centers could perhaps replicate this success for other families of children with a variety of chronic health conditions.

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