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Identifying Health, Educational, and Social-Emotional Needs and Potential Intervention Strategies for Children with Cystic Fibrosis First Entering Elementary School

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Identifying Health, Educational, and Social Emotional Needs and Potential Intervention Strategies for Children with Cystic Fibrosis First Entering Elementary School

by

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Abstract

Cystic Fibrosis (CF) is one of the most common, life-threatening genetic disorders impacting children (Cystic Fibrosis Foundation, n.d.) and, although rare, has a broad impact on children's health, educational, and social-emotional functioning. Current interventions for children with CF lack comprehensiveness, do not occur in the school setting, and fail to employ systems collaboration. Further, interventions have taken a more reactive rather than proactive approach to meeting children's needs. This investigation addressed current gaps in the literature by identifying children's health, educational, and social-emotional needs and potential intervention strategies to be employed as children with CF first enter elementary school. The study utilized participatory action research methods (e.g., focus groups, individual interviews, advisory panel) to gain information from parents and caregivers of children with CF (*n* = 11), school personnel (*n* = 15), and CF health care professionals (*n* = 14) and to collaboratively identify intervention strategies perceived to be beneficial, acceptable, and feasible for implementation. Results indicated primary areas for intervention to include nutrition (e.g., malabsorption), health-related treatments (e.g., medications), educational difficulties (e.g., falling behind), disclosure, social support, and mental health (e.g., anxiety, depression). Comprehensive strategies (e.g., formalized plans, use of technology, multisystemic collaboration) to address primary concerns are discussed. It will be important for schools, families, and health care professionals to collaboratively plan to meet the comprehensive needs of children with CF in schools by increasing communication and education across systems.

Chapter I: Introduction

Cystic Fibrosis (CF) is one of the most common, life-threatening genetic disorders impacting the Caucasian population (Cystic Fibrosis Foundation, n.d.; O'Sullivan & Freedman, 2009). CF affects approximately 1 in 3,500 live births, with 30,000 people in the United States (55% children) diagnosed with CF and 1,000 new cases diagnosed each year. Advances in newborn screening, technology, and treatment have dramatically increased both diagnosis and life expectancy such that approximately 70% of children with CF are diagnosed by 2 years of age and individuals have a median survival age into the mid to late 30s (Cystic Fibrosis Foundation Patient Registry, 2012).

CF occurs as a result of a mutation in the CF transmembrane conductance regulator (CFTR), the gene that regulates the exchange of salt and water across cell membranes (Collins, 1992). This defect affects the exocrine glands of the lungs, digestive system, and reproductive organs and causes an accumulation of abnormally thick, sticky mucus, which leads to greater susceptibility to lung infections and inflammation and to obstruction of the pancreas (e.g., pancreatic insufficiency), prohibiting proper digestion and nutrient absorption (Cystic Fibrosis Foundation, n.d.). As a result, children with CF experience a progressive decline in lung functioning in addition to difficulties maintaining healthy weight and growth. Additional symptoms of CF include salty tasting skin, persistent cough (at times with phlegm), shortness of breath, and upset stomach (Cystic Fibrosis Foundation, n.d.).

CF Impact on Child Functioning

Although a relatively rare disorder, CF can have a broad impact on children's health, educational, and social-emotional functioning. The disorder is associated with a myriad of health difficulties, such as pain, inadequate nutrition, sleep difficulties, poor physical functioning, and lack of treatment adherence, that impact children's health-related quality of life (HRQOL), school attendance (Sermet-Gaudelus et al., 2009), and school and family activities (Sawyer et al., 2004). Children with CF are at increased risk for CF-related diabetes mellitus (CFRD; Cystic Fibrosis Foundation, n.d.), pancreatic insufficiency (McBride et al., 2010), and chronic or recurrent pain (e.g., abdominal pain; Britton & Saeed, 2008; Sermet-Gaudelus et al., 2009). They also experience difficulties related to malabsorption (e.g., 23% of children with CF fall below the 10th percentile for weight; Cystic Fibrosis Patient Registry Report, 2012), early motor delay (de Almeida Thomazinho, de Miranda Chaves, Passaro, & Meio, 2011), physical inactivity (Nixon, Orenstein, & Kelsey, 2001), and sleep disturbances (Meltzer & Beck, 2012).

There is a paucity of literature examining the impact of CF on educational functioning among school-age children. Available studies generally have found that children with CF perform in the average range of intellectual functioning (Grieve et al., 2011; Koscik et al., 2004; Stewart et al., 1995), below average to average in reading and math (Grieve et al., 2011; Thompson et al., 1992), and similar to same-age peers for self-efficacy and attitude toward school (Grieve et al., 2011). However, other findings indicate that children with CF average 23.6 days in school absences per year, and a significant association between higher absenteeism and lower GPA has been reported (Grieve et al., 2011). Additional studies examining the relationship between CF and school functioning are needed to truly understand the impact of CF on children’s educational experiences.

CF symptoms, treatment, and disease course certainly impact children’s social-emotional functioning. In fact, 60% of children with CF meet criteria for a psychological diagnosis (Berge & Patterson, 2004), including depression (Cruz, Marciel, Quittner, & Schechter, 2009; Thompson et al., 1998), anxiety (Thompson et al., 1998), and disruptive behavior disorders (Georgiopoulos & Hua, 2011). Socially, children with CF report difficulties related to telling peers about having CF (Ravert & Crowell, 2008), receiving negative reactions from peers (e.g., misconceptions, fear of contagion, overprotection, teasing; D'Auria, Christian, & Richardson, 1997), and missing out on social activities due to treatment demands (Christian & D'Auria, 2006). As a result, children may choose to keep their diagnosis a secret, engage in poor treatment adherence (e.g., not taking medications at school or in front of peers), and have difficulties developing and maintaining healthy friendships (Christian & D'Auria, 2006; D'Auria et al., 1997).

CF-Related Interventions

It is clear that because CF has a broad impact on children's health, educational, and social-emotional functioning, children with CF would benefit from interventions targeting these outcomes. A review of the literature revealed that interventions specific to CF have primarily focused on psychoeducation and self-management, treatment adherence, and improving coping skills and psychosocial support. Within these interventions, various treatment strategies have been utilized such as: (a) written materials (Bartholomew et al., 1997), group psychoeducation sessions (Cottrell, 1995; Goldbeck & Babka, 2001; Quittner, Modi, & Roux, 2004), and behavior strategies (Cox, 1994) to improve knowledge and disease management; (b) parent behavior management training (Bernard, Cohen, & Moffett, 2009; Janicke, Mitchell, Quittner, Piazza-Waggoner, & Stark, 2008; Powers et al., 2003, 2006; Stark, Mackner, Kessler, Opipari, & Quittner, 2002; Stark et al., 2003), child-focused behavior training (Ernst et al., 2010), family systems therapy (Quittner et al., 2004), home visiting (Bryon, Burton, Tostevin, & Madge, 2000), and text message reminders (Johnson, Culpepper, Scott, Gordon, & Harris, 2011) to improve treatment adherence; and (c) child-focused coping skills interventions (Christian & D'Auria, 2006; Davis, Quittner, Stack, & Yang, 2004), internet support groups (Johnson, Ravert,

& Everton, 2001), parent group counseling (Brown, Krieg, & Belluck, 1995), and multifamily support groups (Brodeur, 2005) to improve child, parent, and family coping and psychosocial functioning.

The current literature suggests that children’s health care and social-emotional needs are being met with promising interventions, typically in settings outside of school (Bartholomew et al., 1997; Christian & D’Auria, 2006; Cottrell, 1995; Janicke et al., 2008; Quittner et al., 2004); however, interventions that focus on meeting the unique needs of children with CF in schools are limited. Quittner and colleagues (2004) advocated for the importance of school consultation for children with CF; however, only one intervention included school personnel and the school context to improve child health functioning (Cox, 1994). In this case study, the school counselor implemented a behavior modification program to increase the health outcomes (e.g., increase number of coughs in the classroom) of an elementary-aged student with CF and encouraged disease acceptance through the provision of counseling and peer mentoring (Cox, 1994). Although this intervention included multiple components, outcomes were limited to behavioral data related to self-care (e.g., number of coughs), thus limiting the interpretation of a potentially comprehensive treatment approach. For children transitioning to elementary school, possible concerns related to disease management at school, absenteeism, interactions with peers, teacher psychoeducation, and need for accommodations in the classroom are likely to be encountered yet to date have not been addressed (DiGirolamo, Quittner, Ackerman, & Stevens 1997; Quittner et al., 2004). As a result, currently available research fails to account for the need for comprehensive interventions (e.g., interventions targeting health, education, *and* social-emotional functioning) and cross-systems collaboration to ensure the success of children with CF in school.

Theoretical Foundation

Developmental-ecological systems theory emphasizes the development of children within the context of systems, including family, school, and health care (Bronfenbrenner, 1979). Within this theoretical framework, consideration of the impact of relationships both within (e.g., parent-child relationship) and across systems (e.g., family-school relationship) is critical for understanding the dynamic influence of systems on child functioning and for intervening to promote positive child outcomes. The eco-triadic model of educational consultation (Shields & Heron, 1995) and conjoint behavioral consultation (Sheridan & Kratochwill, 2007; Sheridan et al., 2009) have also been successful models based in developmental ecological theory that have recognized the need to provide direct and indirect services to children with chronic health conditions using systems-level collaboration. These models value joint collaboration and decision-making among members of an interdisciplinary team (e.g., parents, school personnel, health care professionals) so that the unique needs of children across the home, school, and health care settings can be met successfully.

Similarly, the chronic care (CCM; Coleman, Austin, Brach, & Wagner, 2009) and medical home (American Academy of Pediatrics [AAP], 2005) models offer important theoretical frameworks for providing comprehensive, proactive care to individuals with chronic health conditions (Coleman et al., 2009). Specifically, the CCM emphasizes a team-based approach to providing planned care interactions, integrating evidence-based practices, supporting patient self-management, and developing community partnerships. Similarly, the medical home model emphasizes comprehensive, integrated care through ongoing health care partnerships and systems collaboration. Given the broad impact of CF on children’s health, educational, and social-emotional functioning, both theoretical models can be used to establish an intervention framework designed to link systems of care to meet the needs of children with CF within their ecological contexts, especially school. Further, the CCM and medical home models can be used to inform cross-systems family, school, and health care collaboration and to develop specific intervention components to meet children's comprehensive needs.

School Re-Entry Interventions

The school re-entry literature is a growing body of research that has focused on intervening to meet the needs of children in schools using a comprehensive and cross-systems approach. These interventions typically emphasize the importance of continued academic and social skills development in addition to school attendance in order to promote normalcy, psychosocial development, self-esteem, and peer relationships (Madan-Swain, Katz, & LaGory, 2004; Worchel-Prevatt et al., 1998). For example, school re-entry interventions have developed plans for making up missed work, delivered instruction through small groups or peer tutoring, adjusted the classroom environment and routines, and provided services under the Individuals with Disabilities Education Improvement Act (IDEIA) or section 504 of the Americans with Disabilities Act (Griffith & Doyle, 2009; Kaffenberger, 2006). Additionally, re-entry efforts have educated teachers and peers about the child's condition (Canter & Roberts, 2012; Nabors & Lehmkuhl, 2004; Prevatt, Heffer, & Lowe, 2000), which has helped to foster peer relationships and social interactions (Sexson & Madan-Swain, 1995) and change teacher and peer attitudes towards the re-entering child (Canter & Roberts, 2012; Prevatt et al., 2000). In order to achieve such re-entry goals, coordinators or teams (e.g., school team, health care team) are generally designated to manage a child's care and communicate across family, school, and health care systems (Harris, 2009; Madan-Swain et al., 2004; Power, DuPaul, Shapiro, & Kazak, 2003; Prevatt et al., 2000; Weil, Rodgers, & Rubovits, 2006; Worchel-Prevatt et al., 1998). Despite attempts to collaborate across systems, a general lack of communication often exists between home, school, and health care during the re-entry process, which results in a lack of coordinated efforts in receiving adequate medical knowledge, encouraging school attendance, and meeting the unique needs of children in school (Prevatt et al., 2000; Sexson & Madan-Swain, 1995). Further, few empirical studies have been conducted to support the efficacy of re-entry interventions due to methodological difficulties related to small sample size, challenges in collecting data from children who attend numerous schools across extensive geographic regions, and lack of quantitative measurements and control groups (Canter & Roberts, 2012; Madan-Swain et al. 2004; Prevatt et al., 2000).

Although few empirical studies are available, the school re-entry literature provides numerous models detailing broad components for children's school re-integration. Re-entry models (Madan-Swain et al., 2004; Weil et al., 2006; Worchel-Prevatt et al., 1998) typically utilize a three-phase process –establishing contact across systems, school re-entry (e.g., providing psychoeducation; developing individual accommodations) and follow-up (e.g., ongoing monitoring) – with components designed to address health care, family, and/or school-based needs. For example, models developed by Worchel-Prevatt and colleagues (1998) and Harris (2009) provide general guidelines for intervening at the child (e.g., individual counseling), family (e.g., connect to community resources), health care (e.g., educate school personnel on child's health condition), and school (e.g., provide accommodations) levels. The components of re-entry models are often disjointed; however, and do not achieve successful collaboration across all systems. In addition, models rarely provide practical tools or strategies for conceptualizing and intervening within and across each ecological context. These shortcomings point to the critical need to expand efforts for collaboration and provide services that are proactive, preventive, systematic, and strategic in addressing children's comprehensive needs in the educational setting.

Power and colleagues (2003) provided a paradigm for school re-entry that features comprehensive intervention and cross-systems collaboration. The proposed model includes a multisystemic framework for school (re)integration and is designed to: (a) strengthen the family; (b) prepare the family to work with the school; (c) prepare the school system to partner with the family; and (d) engage the family, school, and health care systems in a collaborative process. This is the only model within the literature to focus efforts on preparing systems to collaborate in addition to designing and implementing intervention supports. Moreover, this is the only model within the literature with the potential to parallel application to the integration of children with chronic health conditions into school as opposed to focusing solely on their re-integration. Although no studies to date have utilized this model to intervene at initial school entry, Power et al.'s model provides a proactive approach to meeting children's chronic health needs and enhancing child resiliency.

Gaps in the Literature

Although the school re-entry literature attempts to link systems of care to comprehensively meet the needs of children with chronic health conditions in schools, the current literature fails to document the use of re-entry or comprehensive school-based interventions for children with CF. Interventions that have been utilized with other chronic health conditions have lacked with regards to support for efficacy (Canter & Roberts, 2012), quantitative data methods and analysis (Canter & Roberts, 2012; Prevatt et al., 2000), theoretical basis (Prevatt et al., 2000), and development of intervention components using a participatory action model. Further, interventions have failed to apply comprehensive, multisystemic frameworks, such as those described in the school re-entry literature (Power et al., 2003), to facilitate children's initial school entry. Rather than waiting to intervene following a child's prolonged absence from school, efforts should be made to intervene early to meet the needs of children prior to the need for school re-entry services. Genetic conditions diagnosed during infancy and early childhood, such as CF, provide family, schools, and health care systems opportunities to anticipate the difficulties children may experience upon entry into school. As a result, this chronic health condition allows for proactive systems-level collaboration and consultation to alleviate and prevent health, educational, and social-emotional difficulties associated with CF as children first enter elementary school rather than waiting to intervene once problems arise or re-entry services are required. To date, however, no studies have focused on children with CF or any other chronic health condition at the time of school entry.

Purpose of Study

This investigation utilized information provided by key stakeholders to determine the health, educational, and social-emotional needs and/or difficulties of children with CF as they first enter elementary school and identified potential intervention strategies to address these needs and/or difficulties. This is the first study to the researcher's knowledge to discuss comprehensive needs and intervention strategies at the time of initial school entry and for the CF population. To date, no study in the re-entry or CF intervention literature has focused on meeting children's needs within the educational setting nor have prior studies focused on addressing health, educational, and psychosocial interventions through a collaborative model of care. This study addressed gaps in the current literature by utilizing a strong theoretical basis (e.g., developmental-ecological systems theory; CCM and medical home model) to inform intervention approaches and by employing participatory action research (PAR) methods to engage key stakeholders (e.g., parents, school personnel, CF health care providers) in the identification of children’s needs and associated intervention strategies in order to enhance relevance, feasibility, and acceptability (Nastasi et al., 2000; Power et al., 2005).

More specifically, this study aimed, first, to determine, according to parents of children with CF, school personnel, and CF health care providers, what are the health, educational, and social-emotional needs of children with CF as they first enter elementary school. Second, this research identified what intervention strategies stakeholders consider to be essential in addressing children’s health, educational, and social-emotional needs as they first enter elementary school. To date, there are no studies within the literature that have examined comprehensive treatment strategies for children with CF at initial school entry. Given research on the impact of CF on children’s general functioning (Berge & Patterson, 2004; Christian & D’Auria, 2006; Grieve et al., 2011; Quittner et al., 2004; Ravert & Crowell, 2008; Sawyer et al., 2004; Sermet-Gaudelus et al., 2009) and research on school re-entry for children with chronic health conditions (Canter & Roberts, 2012; Griffith & Doyle, 2009; Harris, 2009; Kaffenberger, 2006; Madan-Swain et al., 2004; Nabors & Lehmkuhl, 2004; Power et al., 2003; Prevatt et al., 2000; Worchel-Prevatt et al., 1998), it was hypothesized that: (a) health care needs and associated strategies would include establishing the need for medications (e.g., enzymes, inhalers) at school, assisting schools with adherence, and providing accommodations for pain, nutrition, and physical symptoms; (b) educational needs and associated strategies would include educating teachers, peers, and school personnel about CF, planning for and supporting school re-entry following hospitalizations or prolonged absences, and providing educational accommodations (e.g., 504 Plan); and (c) social-emotional needs and associated strategies would include teaching coping skills, implementing targeted mental health interventions as needed, and fostering social interactions and healthy friendships.

This study also aimed to utilize an advisory panel to hone the information gained from stakeholder focus groups and individual interviews in order to identify those needs that would be relevant for children first entering elementary school as well as those intervention strategies that would be beneficial, acceptable, and feasible for implementation. Based on previous research that PAR is associated with increases in intervention relevance, feasibility, and acceptability (Nastasi et al., 2000; Power et al., 2005), the purpose of the advisory panel was to confirm health, educational, and social-emotional needs as being relevant for children with CF, confirm intervention strategies as being beneficial for children with CF first entering elementary school, and problem-solve issues related to intervention acceptability and feasibility.

Chapter II: Literature Review

Cystic Fibrosis (CF) is one of the most common, life-threatening genetic disorders impacting the Caucasian population (Cystic Fibrosis Foundation, n.d.; O'Sullivan & Freedman, 2009), affecting approximately 30,000 people in the United States, 55% of whom are children. Each year, 1,000 new cases are diagnosed, 70% of which are children diagnosed prior to 2 years of age (Cystic Fibrosis Foundation Patient Registry, 2012). Although advances in treatment and technology have dramatically increased life expectancy (e.g., median survival age in the mid 30s; Cystic Fibrosis Foundation Patient Registry, 2012), CF-related symptoms, prognosis, and treatment have serious implications for the health, educational, and social-emotional well being of children.

Impact of Cystic Fibrosis

Health. Cystic fibrosis is associated with a myriad of health difficulties related to disease comorbidities, nutrition, treatment burden, sleep, and physical functioning that impact children's health related quality of life (HRQOL; Palermo, Harrison, & Koh, 2006), school attendance (Sermet-Gaudelus et al., 2009), and school and family activities (Sawyer et al., 2004). For example, children with CF are at increased risk for CF-related diabetes mellitus (CFRD; Costa et al., 2005) and pancreatic insufficiency (McBride et al., 2010), the most common comorbidities, and as many as 55% of children with CF experience chronic pain (e.g., abdominal pain; Britton & Saeed, 2008). Children with CF also experience difficulties related to malabsorption (Stallings et al., 2008), which results in 23% of children falling at or below the 10th percentile for weight by age and sex and requires dietary changes (e.g., high-energy, vitamin-supplemented) and frequent monitoring to promote growth (Cystic Fibrosis Patient Registry Report, 2012). In addition, children with CF must engage in intense daily disease management, which typically includes 20 minutes of chest physiotherapy at least twice per day, inhaled and oral medications, adherence to dietary recommendations, and enzymes at meals and snack times to facilitate digestion. Treatments are often time consuming and intrude on children's daily routines and activities (Foster et al., 2001), which results in high rates of treatment non-adherence (Modi et al., 2010; Modi & Quittner, 2006; Zindani, Streetman, Streetman, & Nasir, 2006). Studies have shown that children with CF spend approximately 74.6 minutes (± 57 min) on treatment-related tasks each day (Ziaian et al., 2006) and have adherence rates below 50%, the consequences of which can be quite serious (Modi et al., 2010; Modi, Quittner, & Roux, 2004).

Children with CF are also at risk for sleep and physical difficulties that impact daytime functioning. For example, approximately 40% of children with CF experience sleep disturbances, such as coughing during sleep, desaturations, sleep-disordered breathing, and night awakenings (Loughlin, 2001; Meltzer & Beck, 2012; Naqvi et al., 2008). Difficulties with sleep often lead to decreased sleep quantity and efficiency and greater symptoms of excessive daytime sleepiness (Meltzer & Beck, 2010), which can impact children's energy level throughout the day. Physically, children with CF are at risk for early motor delay (de Almeida Thomazinho et al., 2011) and physical inactivity (Nixon et al., 2001). Despite the importance of physical activity for children with CF (e.g., to increase energy, skeletal and respiratory muscle strength, endurance, bone mass), exacerbations of CF symptoms, such as coughing and breathlessness, during physical exertion often prevent participation in physical activities, such as peer sports (McBride et al., 2010; Moola, Faulkner, & Schneiderman, 2012).

Education. There is a paucity of literature examining the educational impact of CF on school-age children. In fact, only three studies specific to CF have been conducted, with educational information limited to cognitive functioning, academic achievement, and school absenteeism. There is consensus within the current research that CF does not impact children's cognitive abilities. Children with CF have demonstrated average intellectual functioning (e.g., mean IQ ranged from 102 to 107) in comparison to normative samples (Grieve et al., 2011; Koscik et al., 2004; Stewart et al., 1995), and any deviations in IQ have been associated with indicators of malnutrition and adverse family factors (e.g., single parent status, low socioeconomic status, less years of parent education; Koscik et al., 2004), much like would be found with other populations. Academically, there is less consistency within the research. Children with CF have been reported to score both within the average (e.g., average scores on standardized reading and math assessments; "B" GPA; Grieve et al., 2011) and below average (e.g., 1 year delay in reading and math; Thompson et al., 1992) ranges with regards to academic performance in reading and math. The lack of consistent findings for academic impact points to the need for continued research in this area to determine the degree to which children with CF experience achievement difficulties. Lastly, children's school absenteeism may be a significant factor in educational functioning. Children with CF average 23.6 days in absences from school each year, often due to health care appointments, hospitalizations, illnesses, and home-based antibiotic treatments (Grieve et al., 2011; Quittner et al., 2004). Increased school absences have been significantly associated with a lower GPA (Grieve et al., 2011), most likely as a function of decreased access to instruction and greater amounts of missed work. As a result, children's educational functioning is likely affected by a variety of disease-related factors; however, few empirical studies to date have explored this area of impact.

Social-Emotional Functioning. An estimated 60% of children with CF meet criteria for a psychological diagnosis (Berge & Patterson, 2004); however, the current literature is still in disagreement with regards to children's specific risk for psychological distress. Depression in children with CF has been reported both as being consistent with normative samples (Bregnballe

& Shiotz, 2007) and beyond normative standards (Quittner et al., 2008). For example, Bregnballe and Shiotz (2007) found no differences in levels of depression for children with CF compared to healthy peers, yet Cruz and colleagues (2009) reported rates of depression to be as high as 33% in a sample of children with CF. A recent study by Kastakou and colleagues (2014) examined psychosocial functioning in Greek youth with cystic fibrosis and found them to exhibit significantly higher levels of withdrawal/depression, thought problems, and poor peer relationships compared to healthy peers. There are clearer results for children's risk for anxiety. Children with CF, especially elementary-aged children, report higher rates of anxiety compared to normative samples (Bregnballe & Shiotz, 2007), with 35% of children with CF meeting criteria for an anxiety disorder (Thompson et al., 1998). Children with CF also report needle-related distress (93%; Ayers, Muller, Mahoney, & Seddon, 2011) and dissatisfaction with body image (Pinquart, 2013) as sources of anxiety, although perhaps not reaching clinically significant levels. Similar to internalizing symptoms, the current literature is also equivocal with respect to children's externalizing behaviors, with study findings ranging from no differences to increased difficulties. For example, Bregnballe and Shiotz (2007) reported no differences between children with CF and healthy peers for disruptive behaviors; however, other studies have reported 22.5%, 12.5%, and 9.6% of children with CF to be diagnosed with oppositional defiant disorder, conduct disorder, and attention deficit/hyperactivity disorder, respectively (Georgiopoulos & Hua, 2011; Thompson et al., 1998).

Socially, children with CF are impacted by a variety of factors that influence opportunities to interact with peers and develop friendships. For example, as mentioned previously, treatment demands may interrupt children's play and conflict with social activities, resulting in fewer opportunities for positive peer interactions (Christian & D'Auria, 2006).

Children with CF may also experience difficulties related to telling peers about having CF and receiving negative reactions from peers (e.g., misconceptions, fear of contagion, overprotection, teasing) once their diagnosis has been disclosed (Christian & D'Auria, 2006; D'Auria et al., 1997; Ravert & Crowell, 2008). At times, these difficulties result in children with CF choosing to keep their diagnosis a secret, which has been associated with poorer treatment adherence (e.g., not taking medications at school or in front of peers; Christian & D'Auria, 2006) and increased difficulties developing and maintaining healthy friendships (D'Auria et al., 1997). Friendships, however, can serve as an important protective factor for children with CF, buffering strained relationships with parents and improving quality of life, self-concept, and emotional and behavioral difficulties (Herzer, Umfress, Aljadeff, Ghai, & Zakowski, 2009). Unfortunately, recent guidelines for CF health centers have resulted in strict segregation policies for patients with CF during clinic visits and strong recommendations for children with CF to refrain from interacting with each other to minimize potential spread of treatment-resistant bacteria (Waine, Whitehouse, & Honeybourne, 2007). Although the health benefits of these recommendations are certainly supported, these guidelines have impacted children's opportunities for the development of friendships with peers who share similar experiences and have resulted in social costs, such as decreased social support, perceptions of alienation, and missing friends with CF (Russo, Donnelly, & Reid, 2006).

Interventions for CF

Although CF is relatively rare, it is clear that this disorder has a broad impact on children's health, educational, and social-emotional functioning. Thus, it is important to understand the extent to which outcomes in these areas have been addressed within the extant literature. An examination of interventions targeting children with CF revealed three intervention themes: psychoeducation and self-management, treatment adherence, and improving coping and psychosocial outcomes.

Psychoeducation and Self-Management. Interventions designed to increase knowledge and improve self-efficacy and self-management behaviors often include components of psychoeducation and behavior training. For example, the CF Family Education Program (Bartholomew et al., 1997) provides self-paced, developmentally appropriate written materials to educate participants on respiratory functioning, nutrition and malabsorption, communication, and coping issues. This intervention has been associated with significant increases in knowledge and self-management of disease. Other psychoeducation and self-management interventions have provided CF education in group formats, focusing on recognizing early warning signs of illness exacerbations and teaching self-management and problem-solving techniques (Cottrell, 1995; Goldbeck & Babka, 2001; Quittner et al., 2000). Lastly, behavioral management techniques, such as positive reinforcement and self-monitoring, have been utilized to improve the self-care of children with CF within the classroom (Cox, 1994).

Adherence. Interventions targeting treatment adherence have primarily used behavioral strategies, such as parent behavior management training and token economies, to improve outcomes related to exercise, nutrition, airway clearance therapy, and medications. For example, Bernard and colleagues (2009) evaluated the impact of implementing a token economy on increasing and maintaining exercise adherence for three children with CF and found positive long-term effects. Other studies have utilized group parent management training to increase children's caloric intake at mealtime by emphasizing behavioral strategies such as differential attention, contingent privileges, punishment (e.g., time out, loss of privileges), positive reinforcement, limit-setting, and provision of direct instructions (Janicke et al., 2008; Powers et al., 2003, 2006; Stark et al., 2002, 2003). Direct behavior training with children with CF has also been shown to increase treatment adherence by using strategies such as goal contracting, monitoring, and positive reinforcement (Ernst et al., 2010). Other successful adherence interventions have targeted the family system as a whole through family systems therapy to improve communication and problem solving (Quittner et al., 2000) and home-visiting (Bryon et al., 2000). Lastly, one study utilized technology to provide treatment reminders to child and adolescent participants in order to increase adherence to physician prescribed treatment regimens (Johnson et al., 2011).

Coping. Coping interventions for CF have targeted children, parents, and the family system in order to improve psychosocial outcomes. Several child-oriented interventions, such as Building CF Life Skills (Christian & D'Auria, 2006) and Fitting CF Into Your Life Everyday from the Starbright CD-ROM program (Davis et al., 2004), provide disease-specific psychoeducation and teach coping skills to children in order to improve their ability to problem solve and generate effective coping strategies during difficult situations (e.g., peer teasing). Other child- and adolescent-focused interventions have included written self-disclosure (e.g., writing about emotionally distressing situations; Taylor, Wallander, Anderson, Beasley, & Brown, 2003) and internet support programs (Johnson et al., 2001) that provide youth opportunities to disclose their diagnosis, express their psychosocial needs, and connect with other individuals to gain support.

Coping interventions targeting parents and families recognize the need for parents to also receive support in coping with their child's illness. Interventions, such as the parent support group developed by Brown and colleagues (1995), provide group counseling for parents of children with CF such that parents can discuss the value of supportive networking, patient care and disease management, grief reactions, the impact of CF on family functioning, and the role of health care within the family context. Other family-based interventions address coping through the provision of multifamily support groups, such as the Living Well program (Brodeur, 2005). Similar to parent-only support groups, the Living Well program facilitates discussions of family dynamics, grieving and coping, and psychosocial stressors and has been shown to increase family cohesion and perceptions of social support and reduce family conflict and negative mental health outcomes.

Across the literature, it is apparent that the health and social-emotional needs of children with CF are being met through promising interventions that provide psychoeducation, behavior management, coping skills, and support. Despite improved outcomes in these areas, there remains limited focus on children's educational needs, and interventions targeting the comprehensive needs of children with CF in schools are lacking. Unfortunately, despite recognition of the need to collaborate with schools (Quittner et al., 2004), only one CF-related intervention (Cox, 1994) focused on improving child outcomes within the educational context was available. In this case study, the school counselor implemented a behavior modification program to increase the health outcomes (e.g., increase number of coughs in the classroom) of an elementary-aged student with CF and encouraged disease acceptance through the provision of counseling and peer mentoring (Cox, 1994). Although this intervention included multiple components, outcomes were limited to behavioral data related to self-care (e.g., number of coughs); thus, limiting the interpretation of a potentially comprehensive treatment approach.

Other interventions examined within the literature, such as those utilizing psychoeducation and coping strategies, involve discussion of situations that include the school or school activities, such as telling peers about CF and peer teasing; however, there are no interventions currently available to broadly improve children's school functioning. For children transitioning to elementary school, concerns related to disease management at school, absenteeism, interactions with peers, teacher psychoeducation, and need for accommodations in the classroom are likely to be encountered yet are currently not addressed (DiGirolamo et al., 1997; Quittner et al., 2004). Thus, the current research fails to account for the need for comprehensive interventions (e.g., interventions targeting health, education, and social-emotional functioning) that can greatly improve child functioning in the setting in which they spend a majority of their time – school. Currently, interventions tend to focus on implementation of one treatment component (e.g., psychoeducation only, behavior management only) and lack successful integration of multiple treatment mechanisms into comprehensive intervention programs. Further, CF-specific interventions lack effective collaboration across family, school, and health care systems, an intervention component that Grier and Bradley-Klug (2011) and Sheridan and colleagues (2009) have advocated can improve child outcomes and increase opportunities for school success.

School Re-entry Interventions

The school re-entry literature is a growing body of research that has focused on intervening to meet the needs of children in schools using a comprehensive and cross-systems approach. School re-entry interventions for children with a range of chronic health conditions aim to "[ensure] continuing academic and social skills development by appropriately modifying the school environment and [assisting] parents [in being] effective advocates for their children" (Madan-Swain et al., 2004, p. 645). School re-entry interventions also emphasize the importance of school attendance to promote normalcy, psychosocial development, self-esteem, and peer relationships (Worchel-Prevatt et al., 1998), thus further establishing the importance for providing interventions to meet the comprehensive needs of children in school. Children requiring school re-entry services often fear returning to school due to the potential for teasing, social isolation, peer rejection, and misconceptions about their medical condition (Boonen & Petry, 2011; Griffith & Doyle, 2009; Sexson & Madan-Swain, 1995). In addition, children re-entering school often display psychosocial difficulties, such as anxiety, depression, hopelessness, separation difficulties, and school refusal (Madan-Swain et al., 2004; Prevatt et al., 2000; Sexson & Madan-Swain, 1995; Worchel-Prevatt et al., 1998). Further, parents are often concerned that their child will experience medical complications and teasing at school (Prevatt et al., 2000), which may result in a preference for homebound instruction or increase risk for school absenteeism (Sexson & Madan-Swain, 1995). Providing comprehensive support to children during the school re-entry process has been helpful in alleviating many of the aforementioned difficulties and has been associated with several important long-term benefits (Kliebenstein & Broome, 2002; Prevatt et al., 2000), such as improved child self-concept and behavioral functioning (Katz, Varni, Rubenstein, Blew, & Hubert, 1992) and enhanced peer support and interpersonal relationships (Kliebenstein & Broom, 2002).

A positive attitude from school personnel is one of the most important predictors of children's successful school re-entry (Parkin, Maas, & Rodger, 1996); however, lack of awareness of a child's illness and concern for how to meet the child's needs within the classroom are often barriers that impact school personnel's perceptions of children and school re-entry interventions (Sexson & Madan-Swain, 1995). In fact, many teachers express reluctance in meeting the needs of children in school due to a lack of knowledge of the child's medical condition, appropriate expectations for work completion and discipline, and how to handle peers' reactions (Prevatt et al., 2000). Although school re-entry interventions attempt to establish collaboration across systems, a general lack of communication typically exists between home, school, and health care during the re-entry process, which results in a lack of coordinated efforts in receiving adequate medical knowledge, encouraging school attendance, and meeting the unique needs of children in school (Prevatt et al., 2000; Sexson & Madan-Swain, 1995).

Parents and teachers often desire more hospital-school communication, more ongoing education, and more frequent medical updates (Kliebenstein & Broome, 2004); however, to date, health care professionals and schools provide few of these services during re-entry (Moore, Kaffenberger, Goldberg, Oh, & Hudspeth, 2009). Unfortunately, barriers such as limited time and reimbursement, lack of knowledge of other professionals' roles and responsibilities, and perceptions of schools as unsupportive of children with medical needs (Bradley-Klug, Sundman, Nadeau, Cunningham, & Ogg, 2010; Poursanidou, Garner, & Watson, 2005) often facilitate a lack of consistent communication and collaboration across settings. This lack of communication and cooperation points to the critical need to expand efforts for collaboration and provide services that are proactive, preventive, systematic, and strategic in addressing children's comprehensive needs in the educational setting.

The eco-triadic model of educational consultation (Shields & Heron, 1995) and conjoint behavioral consultation (Sheridan & Kratochwill, 2007; Sheridan et al., 2009) have been successful models based in developmental ecological theory (Bronfenbrenner, 1979) that have recognized the need to provide direct and indirect services to children with chronic health conditions using systems-level collaboration. These models value joint collaboration and decision-making among members of an interdisciplinary team (e.g., parents, school personnel, health care professionals) so that the unique needs of children across the home, school, and health care settings can be met successfully.

School re-entry interventions typically are designed to improve attendance and academic achievement for children with chronic health conditions through the implementation of targeted interventions and provision of new accommodations in the classroom (Griffith & Doyle, 2009). For example, school re-entry teams can plan to support a child who may be experiencing academic delays yet spending more time out of class due to treatment needs, resting, and tutoring by developing plans for making up missed work, providing small group instruction, designing opportunities for peer tutoring and study groups, adjusting the classroom environment and routines, and providing services under the Individuals with Disabilities Education Improvement Act (IDEIA) or section 504 of the Americans with Disabilities Act (Griffith & Doyle, 2009; Kaffenberger, 2006). Schools, parents, and health care professionals can also collaborate to develop decision rules that indicate when a child should be permitted to stay home and when school attendance is mandatory (Madan-Swain et al., 2004).

Re-entry efforts also focus on children's social-emotional functioning as a primary target for intervention. Efforts to increase knowledge of the child's health condition, foster peer relationships, and change teacher and peer attitudes are often implemented in order to prevent social-emotional difficulties upon a child's return to school (Canter & Roberts, 2012; Prevatt et al., 2000; Sexson & Madan-Swain, 1995). For example, re-entry interventions often include components such as arranging for ongoing social contact during absences using cards, letters, or technology (Griffith & Doyle, 2009); individual counseling (Kaffenberger, 2006); education of teachers, school personnel, and peers through psychoeducation workshops (Canter & Roberts, 2012; Nabors & Lehmkuhl, 2004; Prevatt et al., 2000); and connecting families to community resources and support networks (Griffith & Doyle, 2009; Madan-Swain et al., 2004; Sexson & Madan-Swain, 1995). These types of interventions have been successful in increasing school personnel’s knowledge and comfort level in working with students with chronic health conditions in their classroom and increasing peer knowledge and social interactions (Canter & Roberts, 2012; Prevatt et al., 2000); however, little more is known about children’s social-emotional functioning beyond these outcomes. In fact, few empirical studies have been conducted to support the efficacy of re-entry interventions as a result of methodological difficulties related to small sample size, challenges in collecting data from children who attend numerous schools across extensive geographic regions, lack of quantitative measurement, and failure to utilize a control group (Canter & Roberts, 2012; Madan-Swain et al. 2004; Prevatt et al., 2000).

Although few empirical studies are available, the school re-entry literature provides numerous models detailing broad components for children’s school re-integration. Re-entry models (Madan-Swain et al., 2004; Weil et al., 2006; Worchel-Prevatt et al., 1998) typically utilize a three-phase process –establishing contact across systems, school re-entry (e.g., providing psychoeducation, developing individual accommodations, anticipating psychosocial and adjustment difficulties) and follow-up (e.g., ongoing monitoring of absences, health status, and academic and social-emotional functioning) – with specific components designed to addressing health care-, family-, and school-based needs. For example, models developed by Worchel-Prevatt and colleagues (1998) and Harris (2009) provide guidelines for intervening at the child, family, health care, and school levels to address a child’s comprehensive needs. The child is typically provided with direct services, such as individual counseling, in order to address social-emotional difficulties related to disease awareness, experiences, and acceptance, body image, learned helplessness, and peer acceptance (Harris, 2009). Families are often consulted to provide detailed information on child and family functioning, the quality of family relationships, the family's adjustment to the child's chronic health condition, and the child's needs and goals during school re-entry (Harris, 2009; Worchel-Prevatt et al., 1998). Families may also be provided with information on educational law and community support resources (Worchel-Prevatt et al., 1998). The child's health care team provides expertise regarding the child's illness-related symptoms and treatment and is a beneficial resource for communicating relevant medical information to the school, collaborating with the school nurse on school-based treatment needs (e.g., medications, therapies, rest, treatment adherence), communicating anticipated absences, and providing psychoeducation workshops to teachers and peers (Harris, 2009; Worchel-Prevatt et al., 1998). Lastly, the child's school team is a vehicle for providing appropriate school-based services given their expertise on educational law, accommodations, and interventions to address children's academic, behavioral, and social-emotional functioning (Harris, 2009; Worchel-Prevatt et al., 1998). Unfortunately, the components of these models are often disjointed and do not achieve successful collaboration across all systems. In addition, models rarely provide practical tools or strategies for conceptualizing and intervening within and across each ecological context.

Power and colleagues (2003) provide a paradigm for school re-entry that features a comprehensive intervention program within the context of cross-systems collaboration. The proposed model includes a multisystemic framework for school (re)integration designed to (a) strengthen the family (e.g., strengthen parent-child and child-sibling relationships; support parent partnership; facilitate collaboration with health care system); (b) prepare the family to work with the school (e.g., educate family on school ecology and educational rights; provide framework for school consultation); (c) prepare the school system to partner with the family (e.g., educate school about child's needs and effective strategies for meeting those needs; assist school in understanding family's perspective; provide framework for family collaboration); and (d) engage the family, school, and health care systems in a collaborative process (e.g., strengthen family-school relationship; develop and strengthen school-health care relationship; guide systems through conjoint behavioral consultation). This is the only model within the literature to focus efforts on preparing systems to collaborate in addition to designing and implementing intervention supports. Moreover, this is the only model within the literature to suggest parallel application to the initial integration of children with chronic health conditions into school as opposed to focusing solely on their re-integration. Although no studies to date have utilized this model to intervene at initial school entry, Power et al.'s model provides a proactive approach to meeting children's chronic health needs and enhances opportunities for child resiliency.

Although the school re-entry literature attempts to link systems of care in order to comprehensively meet the needs of children with chronic health conditions in schools, the current literature is limited by a lack of support for the efficacy of school re-entry interventions (Canter & Roberts, 2012), overreliance on descriptive models (Canter & Roberts, 2012; Prevatt et al., 2000), insufficient theoretical basis (Prevatt et al., 2000), and failure to develop intervention components within a participatory action research model. More importantly, the current literature fails to document the use of re-entry or comprehensive school-based interventions for children with CF. Given the broad impact of CF on children's health, educational, and social-emotional functioning, it is important to utilize models of school re-entry, such as Worchel-Prevatt et al.'s (1998) and Harris' (2009) models for reintegration, to address this gap. Moreover, interventions have failed to apply comprehensive, multisystemic frameworks, such as those described in the school re-entry literature (Power et al., 2003), to children's initial school entry. Rather than waiting to intervene following a child's prolonged absence from school, efforts should be made to intervene early to meet the needs of children with chronic health conditions prior to the need for school re-entry services. Due to advances in screening and technology, genetic conditions, such as CF, are often diagnosed during infancy and early childhood, providing family, schools, and health care systems advanced knowledge and experience with CF-related difficulties and opportunities to anticipate the health, educational, and social-emotional difficulties children may experience upon entry into school. As a result, this chronic health condition allows for proactive systems-level collaboration and consultation to alleviate and prevent health, educational, and social-emotional difficulties associated with CF as children first enter elementary school rather than waiting to intervene once problems arise or re-entry services are required. To date, however, no studies have designed or evaluated interventions for children with CF or any other chronic health condition at the time of initial school entry.

Purpose of Study

This investigation was designed to utilize information provided by key stakeholders to determine the health, educational, and social-emotional needs of children with CF and to identify potential intervention strategies to address those needs as children first enter elementary school. This was the first study to the researcher's knowledge to discuss comprehensive intervention strategies for children with special health care needs at the time of initial school entry and with a specific focus on children with CF.

To date, there are no available studies in the current school re-entry or CF intervention literature that have focused on the needs of children with CF in the educational setting or that have targeted children's comprehensive needs, such as their health, educational, and social-emotional functioning, through collaborative models of care, such as those grounded in theory.

As a result, this study addressed gaps in the current literature by employing a strong theoretical foundation within intervention development. Using Developmental-Ecological Systems Theory and the CCM and medical home models, this study linked family, school, and health care systems to discuss comprehensive needs and intervention strategies for children with CF as they first enter elementary school. The intervention strategies developed were guided by principles of the Developmental-Ecological System Theory to account for child functioning in the context of the family, health care, and educational setting, thus linking systems of care to meet the complex needs of children with CF. Additionally, the CCM and Medical Home models were used to employ a team-based approach to identify specific needs for this population in order to plan for enhanced care interactions. In addition, intervention strategies were based on principles of the CCM and Medical Home Models, which endorse the provision of comprehensive and proactive care through systems collaboration.

This study also utilized PAR methods to engage key stakeholders (e.g., parents, school personnel, CF health care providers). PAR is an iterative process that involves participants as partners in the collaborative development of interventions to address identified needs and has been shown to enhance intervention relevance, feasibility, and acceptability (Nastasi et al., 2000; Power et al., 2005). To date, however, there are no available studies within the school re-entry or CF intervention literature in which PAR methods have been utilized to inform intervention development. This investigation utilized PAR in the identification of both comprehensive needs and essential intervention strategies for children with CF first entering elementary school.

Chapter III: Method

Participants and Recruitment

Phase 1: Focus Groups and Individual Interviews. Three groups of key stakeholders (i.e., parents and caregivers of children with CF, school personnel, CF health care professionals) were recruited by the primary investigator to participate in single-category (e.g., parents/caregivers only) focus groups or individual interviews. Eleven parents (*n* = 8) and caregivers (*n* = 3) of children with CF between the ages of 1.5 to 17 years were recruited from a local accredited CF Care Center and CF State Parent Chapter in eastern Pennsylvania using letters of invitation and electronic invitation. Three focus groups and three individual interviews were conducted, with more than one parent or caregiver per child permitted to participate in focus group discussions.

Fifteen school personnel were recruited from three local urban school districts in eastern Pennsylvania via letters of invitation and electronic invitation. Eligible school personnel participants involved individuals who would likely comprise a child's school team, including teachers (*n* = 3), school psychologists (*n* = 3), school counselors (*n* = 3), special education coordinators (*n* = 3), school nurses (*n* = 2), and school social workers (*n* = 1). Three focus groups and five individual interviews were conducted. Eligibility for participation did not require experience working with children with CF or other chronic health conditions; however, all recruited participants reported previous experience with at least one chronic health population.

Fourteen CF health care professionals were recruited via letters of invitation and personal invitation. CF health care professionals included physicians (*n* = 3), nurse practitioners (*n* = 1), registered nurses (*n* = 3), dietitians (*n* = 1), respiratory therapists (*n* = 1), social workers (*n* = 1), medical assistants (*n* = 2), and care coordinators (*n* = 2) who provide services to pediatric CF patients at a local accredited CF Care Center in eastern Pennsylvania. Three focus groups were conducted; each focus group included at least one physician and one registered nurse. See Appendix A for letters of invitation for all participants and Table 1 for participant demographic information.

Phase 2: Advisory Panel. Participants from each stakeholder group who completed Phase 1 were invited to participate in an advisory panel to refine qualitative data and translate thematic data into a quantitative measure. The advisory panel consisted of one working group of parents, school personnel, and CF health care professionals. Efforts to equalize representation from each stakeholder group were made, such that 2 parents, 2 school personnel, and 2 health care professionals participated. Refer to Table 3 for additional demographic information regarding Phase 2 participants. All Phase 1 participants were invited to participate in the advisory panel via written invitation at the time of their focus group or individual interview. Stakeholder participants who indicated that they would be interested in participating in the advisory panel were randomly selected using a random number generator assigned by the participant's identification number. Randomly selected participants were then personally invited (e.g., telephone, e-mail) to the advisory panel by the primary investigator. Participants continued to be randomly selected until two members from each stakeholder group agreed and were available to participate in the advisory panel. Due to lack of availability or inability to re-establish contact with participants, multiple iterations of recruitment for the advisory panel occurred. Specifically, the first and fourth parent participants, the first and second health care providers, and the third and fourth school participants were recruited.

The primary investigator also served as a pediatric behavioral health consultant to the advisory panel in order to promote empirically supported decisions as well as consider context-specific implementation strengths and barriers. The primary investigator had a background in pediatric school psychology with specialized knowledge and experience in collaborative consultation, evidence-based practice, prevention programming, and cystic fibrosis. The primary investigator operated from a mixed methods design perspective; that is, qualitative thematic results were maximized to inform future quantitative research. Thus, several quantitative methodological decisions (e.g., randomized selection of advisory panel participants, survey development) were utilized during Phase 2 to enhance future research endeavors. As a participant on the advisory panel, the primary investigator enacted decision rules to appropriately scale relevant needs and strategies as well as provided participants with pertinent information regarding theoretical and empirical support for identified intervention strategies. The primary investigator also influenced discussions amongst the advisory panel by posing specific questions regarding benefit, acceptability, and feasibility within a contextual framework. To the extent possible, the primary investigator served as a consultant rather than a true participant, offering an etic perspective while allowing stakeholders to interpret information and influence results based on their emic experience.

Measures

Demographic Questionnaire. Each participant completed a demographic questionnaire requesting information regarding their age, gender, and race (Caucasian, African American, Hispanic, Asian, Multiracial, or Other). See Appendix B for the complete measure.

Parent participants were asked additional questions related to their marital status, number of children living in the household, number of children with CF, and number of children with other pediatric chronic health conditions. Parents were also asked to respond to demographic questions related to their child with CF (e.g., age, gender, race, age at diagnosis, current year in school, has 504 plan or IEP). Finally, parents rated, on a 5-point Likert scale (very dissatisfied to very satisfied), their satisfaction with family-school communication regarding their child’s CF, family-health care communication regarding their child’s school functioning, and family-school-health care communication regarding meeting their child’s needs at school.

School personnel were asked additional questions related to their job title, number of years of school experience, experience working with children with CF in the school setting, and experience working with children with other chronic health conditions. School personnel also rated, on a 5-point Likert scale (never to almost always), the extent to which they were likely to engage in family-school communication regarding children’s chronic health conditions, school-health care communication regarding children’s chronic health conditions, and family-school-health care meetings regarding children’s school functioning.

CF health care professionals were asked additional questions related to their job title, number of years of experience, and number of years experience working with children with CF. CF health care professionals also rated, on a 5-point Likert scale (never to almost always), the extent to which they were likely to engage in health care-family communication regarding a child’s school functioning and family-school-health care communication regarding a child’s CF and school functioning.

Survey. Following the completion of Phase 1 of this research project, the advisory panel refined thematic data to include only those identified health, educational, and social-emotional needs and intervention strategies that were perceived to be relevant and beneficial for children with CF as well as enhanced intervention strategies to address issues related to implementation acceptability and feasibility. Based on the refined information, the advisory panel developed a survey to be utilized to inform future research and will likely be used to obtain quantitative data confirming needs as relevant and evaluating perceived benefit, acceptability, and feasibility of intervention strategies. The survey was developed such that participants would first be presented with category-specific (e.g., health, educational, social-emotional) needs and provided the opportunity to agree or disagree with the relevance of the need as well as offer additional open-ended input (e.g., additional needs, information on why selected needs were not relevant). Participants would then be presented with a list of intervention strategies for health, educational, social-emotional, and comprehensive needs and/or difficulties, respectively and use a 6-point Likert scale (strongly disagree to strongly agree) to rate each identified strategy for perceived benefit, acceptability, and feasibility in addressing children's needs at the time of initial school entry.

Procedures

Phase 1. Phase 1 was designed to clarify the health, educational, and social-emotional needs of children with CF as they first enter elementary school and brainstorm helpful strategies that may address those areas of need. Phase 1 included multiple rounds of single-category mini-focus groups and individual interviews, moderated and conducted by the primary investigator. In addition to the primary investigator, a trained data collector was present during focus group sessions to take notes during the discussion and monitor participant engagement. Data collectors were school psychology graduate students recruited from the College of Education at Lehigh University and were trained using didactic instruction, modeling, and role-play in the purpose of the research project, focus group facilitation, participant engagement, and analysis of qualitative data. Training was conducted during a 2-hour session. Data collectors were provided with instructional materials, including research articles, handouts on group facilitation strategies, and preliminary instructions for thematic analysis.

The integration of individual and focus group interviews has been shown to enrich conceptualization and interpretation of data as well as enhance the trustworthiness of the findings (Lambert & Loiselle, 2008). Single-category mini-focus groups (Krueger, 1994) consisted of members of a specific stakeholder group (e.g., parents only) with smaller sample sizing (e.g., three to six participants). Mini-focus groups have been endorsed for group discussion with individuals with specialized knowledge and/or experiences (Krueger, 1994) and, thus, were well matched as a data collection methodology for the recruited samples. Eight out of nine focus groups contained at least 3 participants, as recommended by Krueger (1994). Due to attrition, only one focus group did not meet the minimal participation threshold, comprised of only two participants. Due to the depth of information gained during this focus group, the primary investigator elected to retain the data for analysis.

All interviews (focus group and individual) were held at either the local CF Center or a convenient location (e.g., school) for stakeholders at a time that was convenient for all participants, such as pre-established meeting times. Primarily, focus group interviews were conducted first and individual interviews were used to supplement and enhance the depth of information and achieve saturation of themes (e.g., when new points of discussion are no longer heard; Krueger & Casey, 2009). Saturation of themes allowed the investigator to be confident that all important points had been discussed by participants and that any additional comments would fail to produce new, salient themes. It was recommended that approximately two to five focus group sessions per stakeholder group be conducted to reach saturation (Krueger & Casey, 2009). Three focus groups were conducted per stakeholder group. Subsequent individual interviews were conducted, as needed, until saturation of themes was met. All participants were compensated for their time and involvement in the research project with a monetary gift card.

During both single-category focus groups and individual interviews, parents, school personnel, and CF health care providers first identified health, educational, and social-emotional needs and difficulties of children with CF. Participants then discussed potential strategies to address children's comprehensive needs during initial school entry. Focus group interviews lasted approximately 90 minutes, while individual interviews ranged from 30 to 60 minutes. All interviews were semi-structured using the following procedural guidelines: (a) introduction to the purpose of the study and conduction of consent procedures; (b) completion of a demographic questionnaire; (c) provision of a brief overview of CF and the impact of CF on health, educational, and social-emotional functioning; (d) participant introductions (focus groups only); (e) facilitation of discussion; and (f) concluding statements and gift card distribution. A facilitation guide providing an overview of session content is available in Appendix C. In general, participants discussed (a) the health, educational, and social-emotional needs and difficulties of children with CF and (b) strategies to be employed at initial school entry to address or prevent health, educational, and social-emotional difficulties. Group facilitation and interview strategies, such as paraphrasing, reflective statements, open-ended questions and follow-up probes, validation of similarities and differences across participants, eye contact and nonverbal body language, and participation monitoring were employed to ensure participant engagement and discussion of all key topic areas. Following each session, the primary investigator and data collector debriefed to discuss overall impressions and relevant observations of the session.

All focus group and individual interviews were audio recorded; audio recordings were initiated following participant introductions so as to omit identifying participant information. Following the conclusion of each focus group session, the primary investigator transcribed the audio recording verbatim using NVivo 10 software (2012). NVivo 10 allowed for audio-recorded data to be imported into the software, time stamped, and manually transcribed to text. A trained data collector verified a randomly selected 20% of all transcriptions with the original audio recording to ensure accurate transcription. Each transcript was then read and coded by the primary investigator and an additional independent coder. The independent data coder was a school psychology graduate student recruited from the College of Education at Lehigh University with previous training and experience in conducting qualitative analysis and NVivo software. The primary investigator trained the data coder using didactic and written instruction in the purpose of the research project, inductive thematic analysis, and the specific analysis procedures for this study during a 2-hour training session. Instructional materials, reference articles, and a preliminary codebook were provided to the data coder. The primary and secondary coders conducted inductive analysis for each transcript prior to the next interview in order to determine whether saturation of themes had been reached. Once coders identified saturation of themes (e.g., no new themes occurred in the new transcription compared to the previous transcription(s)), interviews were discontinued for that stakeholder group.

Following the analysis of each transcript, 50% of focus group participants were randomly selected within each stakeholder group using a random number generator to conduct member checks. All individual interview participants completed member checks. Participants were mailed or electronically provided (depending on participant preference) a summary of the results and asked to verify if the results were an accurate reflection of the interview discussion. Participants provided a yes/no response with regards to each theme. If participants responded "no," they provided the necessary revisions and comments and returned the document to the primary investigator in the same manner in which it was initially received. The primary investigator utilized revisions and comments from member checks to amend Phase 1 results as needed as well as discuss concerns related to acceptability and feasibility during Phase 2 advisory panel discussions.

Phase 2. During Phase 2, the primary investigator consulted with an advisory panel to determine the saliency of information gained during Phase 1; elaborate on potential intervention strategies to address the health, educational, and social-emotional needs of children with CF as they first enter elementary school; and problem-solve concerns related to implementation acceptability and feasibility. The advisory panel also served to synthesize and translate the qualitative data into a quantitative measure (i.e., survey) to be used for future research. Phase 2 included a comprehensive examination of the thematic data by an advisory panel. The advisory panel collectively agreed-upon relevant needs and strategies, recursively expanded upon the ideas elicited from the Phase 1 focus groups, and provided feedback on acceptability and feasibility of strategies. During survey development, the advisory panel responded to multiple drafts of the survey to inform content and presentation of information. The advisory panel convened at a time and location convenient for all participants for a day-long workshop to allow for complete examination of thematic data. To compensate participants for their time and involvement in the advisory panel, refreshments were provided and all participants received a monetary gift card. Please refer to Appendix D for an outline of procedures utilized during the advisory panel workshop.

First, the advisory panel enacted a decision rule regarding which needs and difficulties identified during Phase 1 remained relevant and salient. The advisory panel suggested that needs and difficulties be retained according to their identification by a majority of stakeholder groups. Criteria for automatic inclusion included identification by all three stakeholder groups or, if identified by two of the stakeholder groups, the need or difficulty was endorsed by at least 50%

of the combined groups within those two categories. Needs identified by fewer than 50% of the combined groups in the two stakeholder category or those identified by only one stakeholder group were reviewed by the advisory panel to determine relevance for inclusion in a more synthesized representation of children's needs. In order to determine qualification of the reviewed items for inclusion, the panel held an open discussion on the identified need or difficulty followed by a majority vote. If the majority of panel members agreed the need and/or difficulty was relevant, it was retained. All needs and/or difficulties determined to be relevant for inclusion were then drafted into survey format, and the advisory panel provided feedback. Feedback was elicited for survey instructions, format, length, content, item wording and descriptions, and response anchors. Advisory panel feedback was incorporated into survey edits and re-issued for feedback until all members agreed upon the draft.

Second, the advisory panel expanded upon specific health, educational, and social-emotional intervention strategies. The panel utilized the aforementioned decision rule to review each emerging theme from Phase 1; that is strategies suggested by fewer than 50% of interviews in two of the stakeholder groups and all strategies identified within only one stakeholder group were reviewed. The advisory panel utilized their professional expertise and experience, reviewed the relevant literature, and applied theory to make informed decisions. This included describing, expanding, and/or condensing intervention strategies; considering the related benefit, acceptability, and feasibility of implementation of strategies; and discussing coordination of care among the family, school, and health care systems. Majority rule guided retention of intervention strategies. The synthesized representation of intervention strategies was then drafted into survey format and feedback elicited from advisory panel members following the aforementioned feedback and response procedures.

Third, the advisory panel identified strategies addressing children's needs comprehensively; that is strategies that promote or alleviate children's health, educational, *and* social-emotional needs and/or difficulties. A comprehensive strategies category was developed to include in the synthesized representation of potential intervention strategies for children with CF first entering elementary school. Survey items for comprehensive strategies were drafted from this representation and aforementioned survey feedback and response procedures followed. The panel then discussed any additional strategies that were not previously identified but that may address children's needs and/or difficulties, either at the health, educational, social-emotional, or comprehensive level. No additional strategies were identified. Finally, a complete survey, including consent, demographic questions, instructions, needs and/or difficulties, and strategies, was drafted using Qualtrics online survey software. Advisory panel participants completed a final review of the survey and provided overall feedback as well as specific feedback on length and directions.

Data Analysis

A qualitative research methods design was utilized. First, information collected using single-category focus groups and individual interviews were analyzed using inductive thematic analysis and verified through member checks. Next, these results were reviewed and expanded upon by an advisory panel. A survey was also developed for utilization in future research. It would be beneficial for future research to utilize both qualitative and quantitative methodology to determine triangulation and expand the breadth and depth of inquiry (Campbell, Gregory, Patterson, & Bybee, 2012).

Qualitative data were entered and stored using NVivo 10 software. Quantitative data (e.g., demographic information) were entered and stored using SPSS Statistics version 21. Both software programs are secure solutions to entering and storing research data. Both databases were password-protected and stored on a laptop in a secure location. Data checks at multiple levels were conducted for a randomly selected 20% of all data to ensure accuracy.

Phase 1. Inductive thematic data analysis, based in grounded theory (Baum, MacDougall, and Smith, 2006; Hatch, 2002; Thomas, 2006), was used for analysis of focus group and individual interview content. The primary investigator and one trained data collector independently read through the interview transcripts, line-by-line, and established a primitive coding system for themes that "[captured] something important about the data in relation to the research question and [represented] some level of patterned response or meaning within the data set" (Braun & Clarke, 2006, p. 10). The NVivo 10 software allowed coders to select specific text examples and create specific "nodes" or themes to be compared visually. Steps for inductive thematic analysis were guided by Hatch's (2002, p. 162) recommendations:

> (1) Read the data and identify frames of analysis; (2) Create [nodes] based on semantic relationships discovered in the frames; (3) Identify salient [nodes], assign them a code, and put others aside; (4) Reread data, refining salient [nodes] and keeping a record of where relationships are found in the data; (5) Decide if [nodes] are supported by the data and search data for examples that do not fit or run counterpart to the relationships in [relevant] domain[s]; (6) Complete an analysis within [nodes]; (7) Search for themes across [nodes]; (8) Create a master outline expressing relationships within and among [nodes]; and (9) Select examples that support the elements of [domains].

Key themes were categorized broadly according to (a) health, (b) educational, and (c) social-emotional needs and/or difficulties and (a) health, (b) educational, (c) social-emotional, and (d) comprehensive strategies at the time of initial school entry.

Following independent qualitative analysis, coders convened to compare coding, systematically discern emerging patterns, resolve discrepancies, and establish a final coding system. See Appendix E for codebooks and decision rules. Coders then independently reviewed and qualitatively analyzed the transcripts again using the final coding system. Intercoder reliability was calculated using Cohen’s kappa ($\kappa = \frac{(\text{Observed Agreement} - \text{Chance Agreement})}{1 - \text{Chance Agreement}}$; Cohen, 1960; Hruschka et al., 2004) in NVivo 10. Thematic results from each round of focus groups were systematically compared to results from the previous round to verify findings and determine saturation of themes, as previously described. Finally, results of the demographic questionnaire were analyzed using descriptive statistics (continuous data summarized and described using means, ranges, and standard deviations; categorical data presented by frequencies and percentages).

Chapter IV: Results

Demographics

Parents/Caregivers. Eleven parents or significant caregivers were interviewed. All parents and caregivers were married and cared for at least one child with CF (*M* = 1.27 children with CF, *SD* = 0.47). Demographic information is available for parents and caregivers in Table 1 and for children with CF in Table 2. Overall, 55% of parents and caregivers were somewhat or very satisfied with health care providers' communicating with them about school. Twenty-seven percent of parents and caregivers reported to be somewhat to very satisfied with communication between school and the family about the child's health condition as well as somewhat to very satisfied with family-school-health care collaborations. It is important to note that 46% and 36%, of responses regarding communication and collaboration, respectively, were missing. This likely reflects the young child age of the interviewed samples; thus, for children not yet in school, this question was often not applicable.

School. Fifteen school professionals were interviewed. Experience working as a school professional ranged from 5 years to 29 years (*M* = 13.97, *SD* = 6.78). All school participants had some experience working with children with chronic health conditions ($M_{health\ conditions}$ = 5.18, *SD* = 1.72), most commonly asthma, diabetes, seizure disorders, and pediatric heart conditions. Thirty-three percent of school professionals, often school nurses and school psychologists, had experience working with children with cystic fibrosis. When asked how likely they were to engage in communication with a family about a child's chronic health condition, 53% of school professionals reported often or almost always. However, only 26% of school professionals often or almost always communicated with health care providers about a child's health condition and school functioning. Thirty-nine percent of school professionals often or almost always participated in a meeting or collaboration that included the family, school, and health care provider.

Health care. Fourteen CF health care providers were interviewed. Professional experience ranged from 1.5 years to 38 years (*M* = 18.14, *SD* = 13.30), with predominant experience specializing in children with cystic fibrosis. Although 57% of CF health care providers reported often or almost always communicating with families about how the child was doing in school, only 14% of health care providers often or almost always communicated with schools about the child's health condition or participated in a family-school-health care meeting or collaboration. Forty-three percent of health care providers sometimes communicated with schools and 21% sometimes participated in family-school-health care collaborations.

Phase 1

Parents and caregivers, school personnel, and health care professionals provided detailed information on the health, educational, and social-emotional needs and/or difficulties of children with CF. Stakeholders also identified potential intervention strategies to address the aforementioned needs. Thematic results of Phase 1 focus groups and individual interviews regarding health, educational, and social-emotional needs and strategies are available in Tables 3 and 4, respectively. An interrater reliability analysis using the Kappa statistic was performed to determine consistency between raters for each thematic code per stakeholder group. The mean interrater reliability for raters was found to be Kappa = 0.92 [0.77-1.00] for school professional interviews, Kappa = 0.83 [0.60-1.00] for CF health care provider interviews, and Kappa = .74 [0.46-1.00] for parent and caregiver interviews. Kappa values ranging from 0.61 to 0.81 indicate substantial agreement and values above 0.81 suggest almost perfect agreement between coders (Landis & Koch, 1977).

Themes for Health Needs and/or Difficulties. Participants identified nine relevant themes for health needs and/or difficulties for children with CF at school. See Table 4 for a complete list of themes related to health needs and/or difficulties. Emerging themes from all three stakeholder groups (parents/caregivers, school personnel, CF health care professionals) included access to the school nurse (e.g., treatments, illness), nutritional supplements (e.g., extra snacks and/or calories), health care letters for school records, and greater risk for infection to be relevant needs and difficulties for children with CF at school. Specifically, participants reported that children with CF need access to the school nurse for medications, provision of medical treatment by a certified health care provider, and symptom monitoring. Participants noted that children often prefer for this process to be discreet; thus, having a health room pass or building health room visits into the child's typical routine may be beneficial. Participants also recognized the need for health care letters documenting the child's chronic health condition and associated needs and medications to be on file in the child's educational records. Written documentation was noted to both provide guidance for health care protocols at school as well as facilitate access to educational accommodations, such as 504 Plans or excused school absences for health care appointments and hospitalizations.

One health care participant advised that children with CF "have trouble maintaining an ideal weight because they burn so many calories." Within the context of nutritional difficulties, stakeholders identified opportunities for additional snacks, supplements (e.g., Ensure shake), and/or calories (e.g., higher calorie meal options) during the school day to be relevant health care needs. Stakeholders were particularly concerned; however, that schools' healthy eating initiatives are often contraindicated for children with CF, and, thus, access to higher calorie foods at school may be challenging. One health care participant shared the following concern:

> …the school parameters nowadays is the push of watching what you are eating…

> coming down from the top government. But with these children…there needs to be that consideration that they cannot follow that diet plan of low fat or low-sugar. We are actually promoting high-fat and high-sugar foods so that they can gain calories. Some of our children need three to four thousand calories a day to keep their weight up.

Additionally, participants were concerned for children's risk for infection, especially colds and respiratory illnesses, at school. Participants identified (a) children with CF to be at "higher risk compared to the general population for acquiring infections and more severe, prolonged illness" and (b) school to be a high-risk environment for cross-contamination. Moreover, participants recognized that children first entering school are at even greater risk for infection: "For any child that is starting school for the first time, there is a bigger risk of them getting [sick] because they have not been exposed to [infection and classrooms full of kids] before. And for kids [with CF], those first couple of years they can get a lot of viruses for the first time."

Additional themes discussed by health care providers and school professionals included more frequent access to the restroom and ability to complete treatments (e.g., medications, enzymes, nebulizer, inhaler, airway clearance) at school based on their individual needs. These two stakeholder groups also reported difficulties with treatment adherence to be a primary health concern. Specifically, participants reported that children often did not follow through with treatments due to feeling different or singled out, treatment burden (e.g., "They need specific treatments every couple of hours, and if they're trying to escape that reality while in school, there's going to be a lot of kick back"), and early school start times (e.g., not enough time in the morning to complete long treatments). Participants also noted increased difficulties with treatment adherence in early school age children: "as soon as [children with CF] get to school and realize not everybody does [treatments] and [they're] sort of the only one is when we in the

[CF health care] office start to see a little push back." Finally, feeling ill due to their disease was reported to be a difficulty by health care providers only and school personnel identified needing a specialized health care assistant at school as a potential health need.

Themes for Health Strategies. Eleven strategies to address the health needs and/or difficulties of children with CF at school emerged as relevant themes and are available for review in Table 5. All three stakeholder groups identified infection control to be an important prevention strategy for children with CF at school. This included frequent hand washing and hand sanitizing, minimizing contact between children with CF and classmates that appear sick, and following infection control guidelines disseminated by the Cystic Fibrosis Foundation (e.g., all children with CF must maintain a distance of at least 6 feet from each other in order to minimize cross-contamination). School professionals indicated the need for additional information from health care providers on effective infection control, and health care professionals reported the desire to provide schools with better educational materials on how to prevent infection.

Additional themes for health strategies emerged within only two of three stakeholder groups. Health care providers and parents advocated for increasing access to fluids (e.g., water bottle, water pass), health care providers and school professionals proposed unlimited, discreet access to the bathroom or use of the health room bathroom. Health care providers and school professionals also identified adult monitoring of treatments (e.g., nutritional supplements, enzymes, medications) as a potential strategy to address treatment adherence difficulties. Specifically, participants recommended teachers or lunch aides monitoring children's caloric and/or supplement intake during lunch, children going to the nurse to take their supplement, health room staff tracking adherence to medications, teachers sending children to the health room at prescribed times for treatments, and behavioral contracting with children to provide rewards for adherence. Health care professionals and school personnel also proposed extra time to each lunch to ensure satisfaction of caloric goals and modifications to meal plans (e.g., higher calorie options) as potential nutritional accommodations at school.

School personnel proposed having everything needed for treatments available at school (e.g., “When you have all the necessary tools and medications at the school…you’re able to remedy [health needs] during the school day and then [send the child] back to class”), utilizing extra personnel in the health room (e.g., additional nurses, school-based health centers, telehealth), and using siblings to assist with treatments as potentially beneficial intervention strategies at school. School personnel also recommended monitoring the child’s symptoms in the classroom to likely be important. Specifically, school participants discussed using formal and informal data to monitor a child’s behavior and symptomology to rule out avoidance or escape behaviors, monitoring physical activity levels for signs that the child may need to take a break or engage in an alternate activity, and monitoring health symptoms in the classroom to determine when the child should be sent to the health room. Health care professionals advocated for accommodations for medications and treatments at school, such as older children being able to carry inhalers and enzymes. Finally, some parents and caregivers indicated utilizing a specialized health care assistant, such as a home-health nurse or individual with advanced knowledge of CF, to administer treatments at school to be a potentially important health-related strategy. Other parents and caregivers disagreed, indicating that a specialized health care assistant may stigmatize their child and was likely an unnecessary level of support.

Themes for Educational Needs and/or Difficulties. Participants identified three themes related to educational needs and/or difficulties (see Table 4). Within all three stakeholder groups, frequent school absences and falling behind on schoolwork emerged as salient educational difficulties for children with CF. School absences included brief, intermittent, and prolonged absences from school due to appointments with health care providers, hospitalizations or home-based treatments, and CF-related illnesses and complications. Parents felt particularly strongly that “at some point, [school personnel] need to know that the absenteeism rate is high” and that children should not be penalized for their number of absences. Concern for falling behind in school was not only related to absences (e.g., missing classwork and homework, missing instruction) but also treatment-related demands. Health care providers noted that for children with CF, “treatments may be very time consuming” (e.g., three to four treatments per day) and there might not be “consideration for what homework needs to be done and how it is going to get done.” All participants were particularly concerned for increased absenteeism impacting educational performance throughout matriculation. Some school personnel related concerns that missing early literacy and numeracy instruction during early elementary school increases risk for unique recurring skill deficits (e.g., “fractions from elementary school….applying those fractions later on in pre-algebra…you might need to go back and teach those skills that they missed in third grade”). Participants also identified “getting the education when they’re out of school” as problematic. One participant shared that “When they’re admitted to the hospital, they miss out on their schoolwork [and] homework. There is no structured program as of right now [where children can] consistently [and] proactively [receive instruction for] their schoolwork [and] homework” if they do not qualify for homebound instruction. Even with homebound services, school professionals noted concerns that instruction is minimal and is not enough to keep the child “caught up.” Additionally, health care professionals indicated school transitions to likely be more challenging for children with CF. Specifically, health care professionals identified initial school entry, transition to middle school, and entering college to be the most difficult transition milestones for children with CF.

Themes for Educational Strategies. Seventeen potential themes emerged related to educational strategies (see Table 5). Educational accommodations, receiving additional instruction in school, home- or hospital-based instruction during absences, and use of technology were identified as relevant intervention strategies to improve and/or prevent children's educational difficulties. School professionals were particularly insightful in providing recommendations for educational strategies to improve children's school success. Specifically, it was recommended that instruction and practice be modified to the child's instructional pace and emphasize skill mastery:

> There has to be a completely different system that does not [include the child with CF] staying in for recess or [doing] twice the amount of reading during reading class. There has to be something more manageable and it's not even considered missing work but working through the instructional material at their pace.

Additional accommodations included providing more flexible or creative assignments for secondary students (e.g., independent reading, projects), providing additional time to complete homework or tests, and providing brief instructional breaks. Additional instructional assistance in the educational environment, such as one-on-one instruction following absences, re-teaching foundational skills, monitoring academic progress, and providing targeted academic skills interventions, was also highlighted.

Home- or hospital-based instruction through homebound services or in-home tutoring was noted as an imperfect (e.g., lack of requirements to provide education when in the hospital) but useful strategy in ensuring that children maintain at least minimal core instructional skills during absences. Participants also discussed the possibility of attending cyberschool during absences as a way to reduce barriers to accessing homebound and maintain access to the curriculum; however, concerns that children are not permitted to attend intermittently were noted. Several other feasible, cost-effective, and easily-accessible technological strategies were recommended. First, participants suggested the use of video streaming (live or recorded) for educational instruction (e.g., "My daughter's teacher posts some of the lessons, especially some of the more difficult ones online or on their website…it's not live so they can't interact with it, but a pre-recorded lesson might be helpful;" "They can Skype their classroom [from the hospital]. That way the student would be able to ask questions during the lesson."). Second, providing educational materials and practice electronically through web-based learning sites (e.g., Kahn Academy) or iPads/tablets was recommended. Finally, participants noted the utility of educational apps to teach foundational skills (e.g., early literacy, early numeracy), particularly for students who are first entering elementary school.

Additional themes related to educational strategies emerged within only two of the three stakeholder groups. Health care providers and school professionals supported access to educational materials (e.g., textbooks, worksheets, manipulatives, missing assignments) at home and discussed the importance of balancing expectations for children with CF in school (i.e., flexibility yet maintenance of academic standards, behavioral expectations, and school attendance). For example, school participants shared opinions that "there is a fine line between being flexible in your planning and reducing your expectations" and "you have to be wise in how to [balance expectations] because you don't want to minimize [a child's] medical needs." Health care providers and parents discussed getting schoolwork ahead of time (e.g., electronically, sent in child's backpack, parent pick-up) for predictable absences and increasing the number of allowed school absences. School professionals and parents proposed rearranging school schedules based on health and treatment needs and multitasking to complete schoolwork during treatments at home. School professionals and parents also indicated planning for school transitions to be of importance. Specifically, participants suggested using parents as experts to help plan for a child's needs when they first enter elementary school, at the start of each new school year, and during transitions to higher educational levels. Participants also reported facilitating a school visit to locate the health room prior to he start of the school year to be potentially beneficial for the child. Additionally, school professionals proposed educating relevant school staff at the child's subsequent educational level about their specific needs.

Finally, school personnel identified several additional strategies for addressing children's educational needs and/or difficulties. Broadly, school participants recommended flexibility in providing individual accommodations and planning educational lessons. One participant shared, "If we know what the situation is, we'll pretty much do anything we can do to just pull resources and try to meet their needs." School participants also suggested formal plans for school re-entry following prolonged absences, allowing children to complete treatments in the classroom to maintain them in the academic environment, and reinforcing children with frequent, positive praise for academic effort to be pertinent educational strategies. Additionally, administrative support providing time and resources to received CF education, create individualized plans to address children's specific needs, and collaborate and consult with relevant professionals was emphasized.

Themes for Social-Emotional Needs and/or Difficulties. Thirteen prominent themes emerged regarding children's social-emotional needs and/or difficulties (see Table 4). All stakeholder groups recognized adjustment to chronic disease, internalizing symptoms, need for normalcy, missing out on social opportunities and activities, isolation from peers with CF, decisions about disclosure, misunderstandings from others in school, and bullying or teasing as relevant needs and/or difficulties for school-age children with CF. Regarding adjustment to CF, participants noted emotional concerns related to questioning, sadness, frustration, and/or denial about having CF, acceptance of CF, adjusting to a shortened lifespan, and feeling uncertain about the future. Closely related, specific concerns for anxiety, depression, and/or withdrawal were prominent throughout discussions. For example, several participants noted increased risk for anxiety and depression in children with CF:

> *Parent participant*: "I think [children with CF] do run the risk for depression because I think kids get very sad about it at times, especially when they start comparing themselves to other kids and what their abilities are versus other kids' abilities."
>
> *School participant*: "Anxiety…kids worrying about things, especially for the younger ones - 'Is it time to go to the nurse? What time do I have lunch? Am I going to be allowed to bring water into class?' - It's a lot of uncertainty."
>
> *Health care participant*: "You know these kids are at high risk for depression [and] anxiety. There's a lot of research studies out there that the show the comorbidity of depression and chronic illness, especially CF with the isolation [from other peers with CF], treatment [burden], differences in siblings, and not necessarily knowing how to relate to peers when they get old enough because their peers aren't going through what they are going through."

Participants, most often parents and caregivers, frequently concluded discussions of adjustment and internalizing symptoms by noting the importance of maintaining "normalcy" for the child. Participants referred to this as children needing to engage in typical, developmentally appropriate behaviors, activities, and relationships, including attending school and following rules and expectations. Participants from all stakeholder groups often made comments similar to the following statements made by a health care professional and parent, respectively:

> *Health care professional:* "Kids with cystic fibrosis want to feel normal. They want to feel like everybody else in the classroom."
>
> *Parent*: "These children want to be normal. I want my child to be normal. I want her to be in the classroom as a normal child."

One insightful participant shared that maintaining normalcy for a child means also refraining from utilizing his or her health condition as a descriptive label (e.g., Johnny with CF).

Despite the need for normalcy, many participants noted that children with CF often miss social and/or extra-curricular opportunities due to school absences (e.g., attending health care appointments), treatments (e.g., embarrassment to complete compression vest treatments at sleepovers), illness, and/or disease-related limitations or restrictions (e.g., current lung functioning). Participants were particularly concerned about the impact of missed social opportunities for initiating and maintaining friendships. In addition to missed social opportunities with healthy peers, participants noted that children with CF might be isolated from peers with their disease due to infection control guidelines. As a result, participants shared concerns that children with CF are not able to rely on individuals who share their disease for in-person social support. For example, a health care professional stated that, "[children with] cystic fibrosis can't support each other like we'd like them to because of the infection control [guidelines]. Knowing you're not alone makes an enormous difference to a kid, and not many of our [patients] know another child with cystic fibrosis." School professionals also recognized this barrier – "If you talk about a support group, who better to go to than someone who is going to get what you're going through. That’s a big downfall for kids with cystic fibrosis because they can’t be together.”

Discussion on social-emotional needs and/or difficulties also yielded considerations for difficulties with disclosure. Specifically, participants noted child-reported concerns for embarrassment, feeling different or singled out, or experiencing teasing or differential treatment. Parents and caregivers often reported, “Certain kids know [and] certain kids don’t know [about their child’s CF] but [their child doesn’t] really like anybody to know.” Most participants reported decisions about disclosure to be personal and on a case-by-case basis with considerations for safety, severity, confidentiality, and the child’s and family’s preferences for disclosure taken into account. All participants reported that children with CF often worry or report that children and adults in school often misunderstand CF. Fears of contagion were the most commonly reported misunderstanding about CF.

> *School participant*: “The first thing they think of no matter what is ‘is it contagious?’ Students just automatically start to isolate themselves as a form of protection.”
>
> *Health care participant:* “These children have a chronic cough and the natural inclination when someone is coughing is to move away from them, and their classmates need to understand that their cough isn’t necessarily contagious.”

Participants also reported that others often misunderstand CF-related treatments (e.g., enzymes as non-pharmaceutical drugs) and disease complications (e.g., making up stories as to why the child is in the hospital) and lack an awareness about what the child is going through, which may lead to social difficulties (e.g., gaining and maintaining friends). Many participants recognized that children with CF face adversity from peers in the educational setting and reported social-emotional concerns for bullying or teasing as a product of the child’s CF symptoms (e.g., coughing), frequent absences, and/or treatments and peers’ misunderstandings about the disease.

Parents and caregivers, especially, reported concerns for bullying or teasing and indicated a greater concern for bullying as their child matriculated (e.g., “I don’t know that it’s so much bullying in Kindergarten as it would be in middle school.”)

Within two of the three stakeholder groups, children feeling different or singled out and needing to be accepted by others emerged as additional themes for social-emotional needs and/or difficulties. Specifically, parents and caregivers and health care professionals reported that children with CF often feel different from their healthy peers and singled out by their disease “because just that small difference makes them feel like they don’t belong.” Participants noted reasons such as coughing, treatments, physical appearance, and school absences to contribute to embarrassment and worries about being treated differently due to having CF, especially in sports-related activities. The need to feel accepted was discussed not only in the context of the child’s peers but also by relevant adult figures. For example, one parent shared a recent sports-related experience in which her son attributed reduced playing time to having CF: “[My child] plays tournament baseball, and he’s a very good little baseball player. He played tournament last year, and his coach sat him a lot. He was very upset, and he finally said to me, ‘Do you think it’s because I have CF that he sat me?’”

For school personnel, themes for low self-esteem and school phobia emerged. Specifically, two participants suggested that children with CF might experience lowered self-esteem if individuals lower expectations for them or take “pity” on them (e.g., “When people pity them and lower that expectation, I think it does have a negative effect on their self-esteem”). School personnel were also concerned that children with CF who experience chronic absenteeism due to their disease may develop fears or worries about going to school and avoid attending. Finally, health care professionals reported that children with CF experience exacerbated daily difficulties - “think how much their life really stinks on a daily basis and how much they go through…the simple things aren’t so simple to them.” Participants also highlighted that unlike other acute illness, difficulties for children with CF do not dissipate because “[CF] is never done. It often gets worse as they get older.”

Themes for Social-Emotional Strategies. Three themes related to social-emotional intervention strategies emerged: having a social support system, peer education about CF, and access to mental health services. See Table 5 for additional details. Participants referred to social and/or emotional support from family, friends, school adults, health care adults, and coaches to be particularly important for children with CF. Strategies to achieve peer support included encouraging involvement in school and extra-curricular group activities, facilitating typical friendships, educating peers on CF to gain understanding, having a peer buddy at school to help with school re-entry (e.g., peer tutoring, social broker, providing them with missed work), and continuing communication with the child’s class during absences (e.g., cards, Skype, FaceTime). Participants also noted that having at least one friend who understood CF would be beneficial (e.g., “It only takes one friend…someone who’s going to accept him as he is.”). Participants reported technology to be key in increasing social support, especially for children with CF to connect amongst each other. For example, a school participant shared the following: “I think technology could be used. If you’re talking about a support group and a way for students with CF to connect with each other, you can certainly use whatever technological resources there are. They can Skype with each other, as an example. If [children with CF] can’t be with each other physically, you remove that barrier.” Using FaceTime or Skype to maintain social interactions with classmates during absences was also highlighted. For example, a school participant shared the following idea regarding a current student with a chronic health condition:

> We are planning for a child to be in the hospital…and one of the things we came up with is FaceTime. There'll be 15 minutes of the day where he will FaceTime with the class. And it doesn't seem like much but that's huge to that continuity…so the kids don't forget about him and he doesn't forget that he's part of that class.

Additional support strategies included access to the school counselor or health room as a "safe place" during the school day, lunch groups with the school counselor and other children with chronic health conditions, regular informal check ins between the child and a school adult, open parent-child communication, and utilizing the CF Care Team as a resource for questions and/or assistance.

Peer education was a predominant point of conversation during all focus groups and individual interviews. Participants reported peer education to be beneficial to enhance understanding about the disease, prevent misperceptions and bullying or teasing, assist with disclosure, foster peer acceptance, and aid in infection prevention and control. Participants shared preferences for peer education to be delivered by either the CF Care Team or the school nurse as a presentation on basic disease information, demonstration of treatments (e.g., compression vest, nebulizer), lesson on proper hand-washing, and opportunity for peers to ask questions. Health care participants shared about a program they currently conduct through their care center:

> One of the nurses and the social worker go to the school and set [a peer education presentation] up with the school nurse. The child with CF will usually bring the nebulizer and the [compression] vest and come to the class. And usually the parents will come. And either it's the whole grade or just that student's class, and we'll talk about what CF is - that it causes sticky mucus, digestive problems, [and] respiratory problems. We talk

> about them doing their treatments. They put on their vest and show [their classmates] what they have to do. They put on the nebulizer. And then we [teach] proper hand-washing to get that infection control piece out there.

Participants, especially parents, noted the importance of involving the child and family in the peer education process; however, all participants advised that child and family preferences regarding disclosure and respect for child confidentiality be of primary importance. School participants were particularly sensitive to health privacy (e.g., “I think communication with the parents is key up front to find out what can we say [and] what can’t we say. And then, if it’s appropriate, educating the other kids about [CF].”) as well as collaborating with health care professionals to ensure accurate information.

Access to mental health services was another particularly salient theme proposed by participants. Discussions centered on mental health services to assist with adjustment to chronic disease, teach self-help and problem-solving skills, provide social skills training, address difficulties with treatment adherence, and discuss day-to-day life difficulties. Additionally, participants noted the importance of initiating services at a young age. Stakeholders proposed access to mental health services to be most beneficial at school and at the CF Care Center. School-based mental health services included both formal and informal weekly check ins with the school counselor or psychologist, lunch with the guidance counselor, an “all access pass” to the school counselor or psychologist, and school-wide prevention programming for mental health (e.g., social-emotional learning). Participants raised concerns, however, related to school resources (e.g., part-time counselors, counselor to student ratio) and recommended greater need for mental health professionals who were trained in providing services to children with chronic health conditions. Participants, especially health care professionals, indicated integrated mental health services at the CF Care Center would be extremely beneficial for children with CF and their families. For example, one health care physician shared, “the biggest thing that [they are] missing [at the CF Care Center]” is mental health services because to “have a psychologist who knows [the] family from the get-go makes a huge difference.” Currently, health care professionals reported that they utilize the CF Care Center to connect families with external mental health resources; however, services within the community are often lacking or require long wait lists and/or barriers to care result in poor patient follow-through with appointments.

Additional themes related to social-emotional strategies emerged within two of the three stakeholder groups and included non-restriction of children’s activity and bullying prevention and intervention programming. Specifically, health care providers urged that school and community members not limit a child’s activities based on medical reasons unless otherwise instructed by a health care professional (e.g., “We want kids to be active. Part of good CF care is physical exercise), and school personnel encouraged children’s participation in activities in to promote social and emotional health (e.g., “finding ways to not limit their activities because of all [their medical] appointments”). Parents and school participants recommended school-wide bullying intervention and prevention programming to assist with potential concerns for bullying at school. Specially, participants reported that students should be encouraged to report bullying, school counselors should meet with victims of bullying, and parents educated on the school’s bullying intervention and prevention efforts and procedures. School personnel also suggested leadership involvement, such as classroom and organizational leadership roles, to be potentially beneficial in promoting child self-esteem and self-efficacy.

Themes for Comprehensive Strategies. In total, 12 themes emerged as strategies that would likely address the comprehensive health, educational, *and* social-emotional needs and/or difficulties of children with CF (see Table 5). Five themes emerged within all three stakeholder groups: family-school-health care collaboration, school staff education, having and monitoring an IEP or 504 Plan, individualizing approaches to care, and educating the child with CF about their disease. Family-school-health care collaboration (i.e., coordination of care, communication, and education across the child's primary settings) was a predominant topic in all focus groups and individual interviews. Health care providers discussed the importance of a multi-disciplinary (e.g., teachers, counselors, coaches, parents, child, health care) team approach to caring for a child with CF and emphasized key aspects, such as relationship-building and reciprocal communication. Specifically, health care providers noted family-school communication about absences and hospitalizations, reciprocal health care-school communication about a child's medical needs and school functioning, and providing CF education, information, and resources to families and schools as important components of collaboration. Health care professionals also highlighted communication with schools to determine feasibility of strategies to be of high importance.

School professionals discussed collaboration more distinctively, with less focus on systematically collaborating across all three domains. Specifically, school professionals described positive experiences with school-health care collaborations but requested an increase in both verbal and written communication. School professionals vocalized diverse preferences for communication. For example, school nurses requested written orders, school counselors preferred written material for ease of information input in 504 Plans, and school psychologists indicated verbal communication (e.g., questions and answers) to be most helpful. Overall, school professionals reported receiving information on a child's short-term and long-term medical needs at school, monitoring and communicating with health care professionals about school absences, including the health care agency in school planning, shared medical records, and health care professionals providing CF education to schools as primary components of school-health care collaboration. With regards to family-school collaboration, school professionals identified the following strategies: regular communication about the child’s diagnosis, needs, absences, academic performance, and medical status at school; families educating classmates about CF; building relationships with families; and providing families with specific resources, worksheets, and academic skills practice to prevent academic decline.

Parents and caregivers emphasized frequent communication between families and schools as an important component of family-school-health care collaboration. Specifically, parents and caregivers recommended providing schools with CF education and communicating about absences and homework as well as school providing updates about their child’s medical status in school and educating parents on available educational accommodations as important components for collaboration. Additionally, parents and caregivers reported health care professionals communicating with their child’s school regarding medical needs (e.g., providing education to staff and peers, informing schools of medication changes, exchanging documentation) and having a liaison to assist with advocacy and educational accommodations to ease parental burden.

Having and monitoring an IEP or 504 Plan emerged as a beneficial strategy within all stakeholder groups. The majority of school and health care professionals were knowledgeable of educational accommodations for children with CF; however, parents were often less familiar with available resources for their children and expressed interest in learning more about IEPs and 504 Plans during focus group discussions. In general, participants reported documenting the child’s specific needs, difficulties, goals, and accommodations as early as possible to be beneficial. For example, a school counselor shared proactive efforts on the part of her school to ensure a child with a chronic health condition received the appropriate services upon initial school entry: “When she came into Kindergarten, we wanted to get her 504 Plan started a couple of days before school actually started so that when she walked into Kindergarten, this plan was already in place.” Parents of children with current 504 Plans often expressed concerns that 504 Plans were not as carefully monitored compared to IEPs (e.g., “Even though he has a 504 Plan, it seems like nobody reads it.”). Thus, monitoring the IEP or 504 Plan to ensure implementation of supports by notating pertinent information on the child’s educational file (e.g., “I think there should be some kind of red flag when they see a student’s name [to] know they have a 504 Plan in place) was recommended. Participants also advocated that there is not a “one-size fits all” approach to caring for children with CF; thus, children with CF require individualized strategies based on their unique needs. One health care professional suggested the following: "I think that it would be nice to have all those resources available to kick into action if we need them, but I don’t think there’s a one-size fits all program for people. I just think we need resources available but sort of on an a la carte basis.”

Participants also discussed the importance of educating the child with CF about their disease in order to increase self-advocacy skills, both medically (e.g., what they need, what they do not need, limitations) and social-emotionally (e.g., correct misperceptions, access mental health resources). Knowledge of CF was also identified as a means of fostering independence in self-care, improving treatment adherence, and accepting their condition (e.g., *Parent participant*: “He’s learning at an early age that this is normal for him. This is his norm.”). Participants identified one-on-one conversations, providing children with honest answers to their questions, directing children to the CF Foundation website, and utilizing age appropriate reading material as methods for delivery of disease education.

Additional themes that emerged within only two of the three groups included designation of a liaison for family-school-health care collaboration and supporting parents. Health care and school professionals emphasized having a specific point person to coordinate multi-systems collaboration across the family, school, and health care systems as beneficial for meeting the health, educational, and social-emotional needs of children with CF. Suggested liaison activities included, but were not limited to, care management and coordination, facilitation of communication, advocacy, and resource provision. Participants noted the potential benefit of having a liaison within each of the child's relevant systems that can continuously follow the child throughout their development but indicated the primary importance to be determining "who's going to work with the child to interface between the school and the hospital." Health care professionals and school personnel also emphasized the importance of providing emotional support to parents, educating parents on CF, alerting parents to available resources, and teaching parents how to advocate. Participants noted that families often do not know they can ask for help or that resources exist for their child; thus, offering support as early as possible and continuing to provide support as their child develops was a particularly salient point of conversation. Participants also suggested building relationships with families, assisting with navigation of the health and educational systems, and advocating for access to school and community resources to be important components for providing support to parents.

Themes supported by only school personnel included having specified procedures for who, what, where, when, and how collaboration and accommodations occur (e.g., designation of liaison, notifying substitutes of child's needs, 504 Plans, emergency plans, plans for school absences) and specific, detailed, written documentation of a child's condition, accommodations (e.g., 504 Plan), academic difficulties (e.g., skills and curriculum missed), and progress. School participants also suggested educating parents on the school environment (e.g., school routine), resources (e.g., nebulizers in health room), and supports (e.g., 504 Plan) to be a potentially beneficial comprehensive strategy. Specifically, school personnel shared that "The parent is not an expert on our educational environment. So while we expect a lot of the information to come from the parents, we also have to give them enough information to let us know how to help them." Health care professionals identified checking in with families about school during health care visits and having a formal plan at the beginning of the school year to be relevant strategies for children with CF. Health care professionals noted responsibility for discussing school functioning with families, especially prior to major school transitions such as initial school entry. Health care professionals also advocated for developing a formal oral or written plan at initial school entry and each subsequent school year that addressed CF education, child needs and accommodations, and specific action plans. Participants emphasized the importance of proactive planning - "You need to have a plan in place; otherwise, it's inevitable [that] you're going to be behind."

General Themes. Throughout focus group discussions and individual interviews, 15 general themes emerged as salient considerations for the care of children with CF. All stakeholders identified barriers to care as an important theme. Specifically, participants reported lack of school and mental health resources, need for documentation (e.g., health care letters for school), lack of information sharing within and across systems, lack of education during school absences, lack of supports, insurance, and treatment demands for children with CF as primary examples of typical barriers to care. Participants from all three stakeholder groups also emphasized the importance of early intervention and prevention (e.g., "sometimes we are more reactive than proactive"). For example, school participants discussed "opening up the lines of communication…when they first start school" and that the "process [for educational accommodations] should start long before the child puts their foot in the door." One health care provider discussed the importance of "preventative maintenance" by preparing school personnel (e.g., teachers, school nurse, staff), the child, and his/her peers to anticipate specific needs and difficulties. Finally participants identified parental protective responses (e.g., keeping children home from school more often than medically necessary; not exposing children to group activities) as a general experience for children with CF and their families, often in response to fears for infection.

Five general themes were represented by two of the three stakeholder groups: respecting child and family values and autonomy, parental worry, stress on the family system, treatment burden, and reliability of the school environment. Participants noted the importance of respecting the beliefs, values, opinions, and choices of both the child with CF and their family system. For example, "what we may think may be useful, they don't want." A health care participant noted that in their personal experience, "there are families who take an approach of left's wait-and-see how it goes and if I need help, I'll pull you in and…families who take the preventative maintenance [approach and] do it all up front [to] avoid problems." Participants also reported that parents often experience a great deal of fear, anxiety, worry, and/or anticipation about their child's disease, needs, and difficulties and the impact of CF on their child's school functioning. One health care participant shared, "I think from a parent's point of view, they would be quite anxious…putting [their child] in school. That's a big anxiety-provoking experience because they have this advice to minimize the infection exposure and now you're putting a child with cystic fibrosis into school where those things are quite common." Similarly, participants noted that families of children with CF endure greater physical and emotional stress compared to families of children without chronic health conditions; for example, stress related to coping with having a child with a chronic health condition, high frequency and high intensity treatments, frequent health care appointments, and worries about infection. These stressors reportedly impact the entire family system, including parents, the child with CF, siblings, and even extended family members. A common theme for children with CF and their families was also treatment burden. Children with CF experience both physical and temporal burden related to completing multiple treatments daily. An additional theme identified by participants included school as a reliable and consistent place for children with CF to receive treatments and needed care. Participants noted that children with CF, like all children, spend the majority of their day in the educational setting; thus, school is an ideal setting to receive medical treatments and mental health services, as needed.

School personnel identified two additional themes. First, school participants alluded to the balance of respecting child privacy and health confidentiality (e.g., HIPPA, FERPA) with the need to disclose their diagnosis to those individuals who need to know in school in order to provide them with the best care (e.g., school nurse, teacher, gym teacher). In general, school personnel deferred to family's preferences as best practices for determining that balance. Second, school participants emphasized the value of attending to cultural beliefs when working with culturally and linguistically diverse children and families. For example, a school counselor shared considerations for disclosure when working with a culturally and linguistically diverse family - "I'm not sure if [disclosure] is something in their culture that is approved of. In their culture, is it okay for everybody to know what is going on in their family?"

Parents and caregivers identified five additional general themes. Parents and caregivers shared a range of diverse experiences regarding severity level of CF. As a result, parents and caregivers often reported that they would like for others to be aware that CF impacts each child differently with regard to severity level and that differences in severity level are often linked to unique outcomes and unique needs. Similarly, parents and caregivers noted the importance of raising awareness for CF within the school and larger community through diverse means, such as benefit walks, fundraisers, education, and television commercials. Several parents and caregivers reported concerns for the impact of environmental conditions at school on the child's health and/or general functioning. For example, participants indicated perfumes, air fresheners, air ducts, carpets, and heating and cooling systems as potential concerns for placing their child at increased risk for poor school functioning. Parents and caregivers also reported uncertainty about the school's ability to meet the needs of their child with CF or previous negative experiences with school, which have shaped perceptions about the school environment and potential school experience for their child. Specifically, lack of school staff knowledge, difficulties with medications and/or treatments in the health room, and lack of follow through with accommodations were common themes related to school uncertainty or distrust. Finally, parents and caregivers reported a general lack of uncertainty due to a lack of experience. For example, several parents and caregivers had children who were not yet school-age. As a result, these participants often reported uncertainty about what it might be like for the child with CF in school or uncertainty about the types of supports a child with CF might need once in the educational environment.

Phase 2

Needs and/or Difficulties. During Phase 2, an advisory panel collaborated to determine which needs and/or difficulties identified during Phase 1 were relevant and salient for children with CF. Using the aforementioned decision rules, the advisory panel automatically included four health (i.e., access to nurse, greater risk for infection, nutritional supplements, health care letters for school), two educational (i.e., school absences, falling behind in school), and eight social-emotional (i.e., decisions about disclosure, need for normalcy, adjustment to CF, bullying or teasing, isolation from peers with CF, misunderstandings from others in school, missing out on social activities, internalizing symptoms) needs and/or difficulties. During the first iteration, advisory panel participants reviewed needs and/or difficulties that were identified in fewer than 50% of interviews when the need and/or difficulty was endorsed by only two stakeholder groups and all needs and/or difficulties identified by only one stakeholder group.

Within health needs and/or difficulties, advisory panel participants voted to retain feeling ill by a vote of five to one (83%). Five out of six advisory panel participants (83%) voted to remove the need for specialized health care assistance due to beliefs that this would single the child out, result in insurance barriers, and are typically only available on a district-by-district basis. The advisory panel retained transitioning to different school levels as a relevant educational difficulty by a vote of five out of six (83%). All advisory panel participants (100%) decided to keep the social-emotional difficulty that day-to-day problems are exacerbated by CF, and all participants (100%) voted to exclude low self-esteem and school phobia. Participants vocalized preference for removal of the latter two social-emotional difficulties due to perceptions that these difficulties were not specific to children with CF but more general to children with chronic health difficulties. See Table 6 for a complete list of retained health, educational, and social-emotional needs and/or difficulties.

Relevant needs and/or difficulties were drafted into survey format and feedback elicited from the advisory panel. Participants advised using a yes/no response format for needs and/or difficulties rather than a checkbox system. Participants also shared that it would be beneficial to distinguish needs from difficulties within the health, educational, and social-emotional categories for ease of responding. Reported strengths included use of examples to describe each need and/or difficulty and use of bolded and underlined text in survey directions. Participants' feedback were incorporated into survey edits and re-submitted for review by participants; all participants approved the draft.

Strategies. Infection control, access to fluids, and adult monitoring of treatment adherence were automatically retained for inclusion as pertinent health strategies per the advisory panel's decision rule. The advisory panel reviewed eight additional health strategies. See Table 7 for a complete list of retained health care strategies. The advisory panel voted to include access to the bathroom (100%), nutritional accommodations (100%), teachers monitoring symptoms in the classroom (100%), accommodations for treatments and/or medications (100%), and families providing everything needed for treatments at school (83%). All participants (100%) voted to omit having a specialized health care assistant for children with CF at school due to the decision to omit this as a relevant need and for similar concerns about stigmatization. All advisory panel participants (100%) also voted to exclude additional personnel in the health room and utilizing siblings to assist with treatments. Additional health room personnel was determined to likely be beneficial for children with CF, as well as other school children, but not likely feasible due to school resources. Participants were concerned about using siblings to assist with treatment at school, vocalizing concerns that siblings should not be burdened with such responsibility and should not miss valuable academic class time. The advisory panel reviewed the final agreed-upon eight health-related strategies to determine potential benefit, acceptability, and feasibility. Participants determined that Phase 1 participants adequately described all intervention strategies and the strategies would be beneficial, acceptable, and feasible to implement in schools.

Health strategies were drafted into survey format and feedback elicited from advisory panel members. Advisory panel participants indicated strengths to include utilizing specific examples to describe strategies. Suggestions for edits included reducing the length of example descriptions, shortening survey directions, and repeating strategy sections for benefit, acceptability, and feasibility ratings separately rather than rating each of the aforementioned immediately following the survey item. Participants also suggested alternate, more accessible word choices for benefit (i.e., helpful), acceptability (i.e., reasonable), and feasibility (i.e., realistic). Recommended changes were incorporated into survey edits. All advisory panel participants reviewed and approved the draft.

The following educational strategies were automatically retained based on Phase 1 results and the advisory panel decision rule: home- or hospital-based instruction, accommodations for instruction or missed work, using technology to keep up with missed work, extra help in school, access to educational materials at home, and getting schoolwork ahead of time. Eleven additional educational strategies were reviewed. All advisory panel participants (100%) voted to include administrative support for teachers, schools providing flexibility, and planning for school transitions. Five of the six advisory panel members (83%) determined re-arranging the child’s school schedule and planning for school re-entry to be relevant educational strategies. Additionally, five of the six members (83%) approved balancing expectations. Increasing the number of allowed absences was also retained by a majority vote of four to two (67%). All participants (100%) voted to omit reinforcing academic effort as an educational strategy, noting that all teachers should already be providing positive attention to children for academic skills as a part of best practices in teaching. All participants (100%) also excluded monitoring attendance and completing treatments in the classroom. Participants discussed that monitoring attendance placed a great deal of burden on the school and would likely not be feasible to implement. Participants also discussed that monitoring of attendance would likely only be needed on a case-by-case basis and participants wanted parents to remain accountable for sending their child to school and communicating about absences. Completing treatments in the classroom was omitted due to concerns for singling the child out in front of their classmates, making teachers and classmates uncomfortable, and potentially increasing the risk for infection. Five of the six advisory panel members (83%) voted to exclude multitasking during treatments at home. Participants noted it might be possible to use the nebulizer while completing homework but quite impossible to use the compression vest, which is the most time consuming treatment, while completing written assignments.

The advisory panel reviewed the final agreed-upon seven educational strategies to determine potential benefit, acceptability, and feasibility. Advisory panel members added an additional qualifying statement to increasing the number of allowed absences. Specifically, participants noted that increased absences should only be allowed with documentation by a health care provider to ensure that children are remaining in the educational environment except when medically necessary. Participants advised that it is important for medical professionals to make this determination rather than leaving it to the parent’s discretion. Participants also revised the description for planning for school re-entry. Rather than having a formalized plan, participants lobbied for a more feasible, informal plan, such as a checklist or a phone consultation. Participants also noted that during school re-entry planning, team members should first determine if anything had changed for the child, proceed with planning if yes, and discontinue planning if no. Based on the school re-entry literature, the primary investigator provided consultation regarding the impact of extended absence from school regardless of health or educational changes. Participants determined that an informal plan should be established but could include simple strategies, such as reviewing the schedule with the child or having a peer buddy, if no health or educational changes were apparent for the child. Participants also reviewed balancing expectations, which was determined to be important yet more beneficial if condensed within another category. The advisory panel voted to incorporate balancing expectations within school staff education, a comprehensive strategy. All other strategies were determined to be adequately described and potentially beneficial, acceptable, and feasible for implementation.

Educational strategies were drafted into survey format and feedback elicited from advisory panel members. Advisory panel participants suggested using bulleted descriptions rather than paragraph descriptions and including briefer descriptions. Recommended changes were incorporated into survey edits and approved by the advisory panel. See Table 7 for a complete list of retained educational strategies.

Support systems for the child with CF, peer education, and access to mental health services were identified by all stakeholder groups as potentially beneficial social-emotional strategies and, thus, automatically retained. The advisory panel reviewed three additional strategies. Only non-restriction of activities was voted by advisory panel members (100%) to be included. All six participants voted to remove bullying prevention and intervention programs and five of the six participants (83%) recommended leadership roles for exclusion. Both strategies were noted to be not specific to CF but generalizable to all children. Additionally, participants vocalized that both strategies should already be occurring within schools as a part of best practices. Advisory panel members reviewed the final four social-emotional strategies and determined needed revisions. Based on information reported in Phase 1, social support consisted of support from children with CF, peers, and adults (e.g., school adults, parents, CF care team). Advisory panel members recommended that social support be divided into three separate domains, one for social support from children with CF, one for social support from peers, and on for social support from adults. Access to mental health services was also noted to be a large category with distinctive components of services at school and services at the CF Care Center. Participants suggested that this category be revised as two such separate strategies. All other strategies were determined to be adequately described and potentially beneficial, acceptable, and feasible. The primary investigator drafted the retained social-emotional strategies into survey formation. Advisory panel members approved the draft with no recommendations for revisions. See Table 7 for a complete list of retained social-emotional strategies.

Finally, the advisory panel reviewed comprehensive strategies; that is strategies that likely met the health, educational, and social-emotional needs of children with CF. Seven strategies were automatically included based on the decision rule: family-school-health care collaboration, school staff education, educating the child with CF about their disease, individualizing plans, having and monitoring an IEP or 504 Plan, having a designated liaison for systems-level collaborations, and parent support. Five additional strategies were reviewed (e.g., having specific procedures, discussing school at health care visits, having a formal plan in place at initial school entry, documentation, and school professionals educating parents on the school environment) and elected for inclusion by all advisory panel participants. Participants voted to combine school professionals educating parents on the school environment as a key component of the formalized plan at initial school entry. The advisory panel determined that all retained comprehensive strategies were adequately described and potentially beneficial, acceptable, and feasible for implementation. Comprehensive strategies were drafted. Participants recommended minimal changes, such as wording alterations, and approved the draft. See Table 7 for a complete list of retained comprehensive strategies.

Survey Draft. During the last iteration, the primary investigator drafted a complete survey using Qualtrics online survey software. Advisory panel members reviewed survey consent, demographic questions, instructions, and content and provided feedback. Advisory panel participants approved of the survey's readability, incorporation of brief examples within item content, response anchors, instructions, and general format. Participants recommended providing a brief description or synonyms for reasonable and realistic to increase readability and accessibility. Participants also suggested using bolded and underlined text in the consent section to emphasize the length of the survey as well as incentive for completion (e.g., donation to CF Foundation). Feedback was incorporated and the final version of the survey approved by advisory panel participants. Please use the following link to access the final survey: https://lehigh.co1.qualtrics.com/SE/?SID=SV_0TmyRkhPgbAoMQZ.

Chapter V: Discussion

This investigation utilized information provided by key stakeholders to determine the health, educational, and social-emotional needs and/or difficulties of children with CF as they first enter elementary school as well as potential intervention strategies to address such needs and/or difficulties. As hypothesized, parents and caregivers, school professionals, and CF-related health care providers confirmed several health care needs previously identified in the literature as relevant for children with CF. Specifically, stakeholders confirmed nutritional difficulties, such as malabsorption and need for supplemental calories, similar to those identified in the Cystic Fibrosis Patient Registry Report (2012) to be important areas of consideration for children with CF in the educational setting. Parents and health care providers added that addressing the nutritional needs of children with CF, however, may prove to be difficult due to recent healthy eating initiatives implemented within schools. Children with CF are required to eat higher calorie foods and are often encouraged to eat high fat, high sugar options; thus, families and health care providers are concerned that schools' healthy eating initiatives may not offer the needed caloric intake for children with CF. Children with CF may require more creative school meal planning to satisfy nutritional recommendations. Allowing children additional time to eat school lunch as well as modifying school meal plan options were recommended as important strategies to address children's nutritional needs. Providing such accommodations, however, raises concerns for both feasibility and acceptability. Providing alternate meal options would require logistical and political maneuvering and may not be feasible for implementation in single schools, which then places the burden for nutritional accommodations on families.

Stakeholders confirmed the need for children with CF to complete multiple treatments throughout the day (Foster et al., 2001) and difficulties related to treatment adherence, an area thoroughly discussed by Modi and colleagues (2010). Stakeholders reported that treatment burden for children with CF and their families is particularly high due to frequent, time-consuming treatments. Treatment burden coupled with children's perceptions of being "singled out" at school for completing treatments and early school start times (e.g., not enough time to complete treatments in the morning) were often reported to be primary predictors for poor treatment adherence. This information heeds importance for the educational planning of students with CF. Educators will need to consider implications for treatment burden (e.g., less time to complete homework/make-up assignments, missing instructional time) as well as how to balance academic expectations with flexible accommodations when planning to meet the needs of children with CF in their classrooms. Stakeholders also suggested that school adults may serve as important monitors for children's treatment adherence. For example, teachers can provide reminders to children when it is time to complete treatments and school nurses can collect data on treatments completed at school. Additionally, school adults, especially school psychologists, are often well trained to use or support others in their use of behavioral principles (e.g., positive reinforcement and contingency management; Bernard et al., 2009; Ernst et al., 2010) to improve student behavior and could utilize empirically-supported interventions to improve treatment adherence at school (Quittner et al., 2004).

Stakeholders also identified additional health needs and difficulties that were not hypothesized, such as increased risk for infection, need to access the restroom, and importance of health care documentation (e.g., diagnosis, treatment plan). Although increased risk for infection has been documented in the health care literature, infection risk, as well as the other aforementioned health care needs, has not been previously identified within the psychological or educational literature with regards to accommodating children with CF in the educational setting. Given the Cystic Fibrosis Foundation's guidelines (Saiman et al., 2014) to minimize infection risk, schools' knowledge and adherence to inflection prevention and control standards (e.g., hand hygiene and respiratory hygiene practices) is of utmost importance in keeping children with CF safe and healthy at school, and stakeholders prioritized infection control as an essential health intervention.

Although the educational needs of children with chronic health conditions has been well documented (Kaffenberger, 2006; Power et al., 2003; Shiu, 2001), a paucity of literature exists for the specific educational needs of children with CF. As hypothesized and discussed in previous literature (Grieve et al., 2001; Quittner et al., 2004), parents, school professionals, and health care providers confirmed frequent absenteeism and falling behind in school to be educational difficulties for children with CF. Potential absences were predicted to occur for health care appointments, hospitalizations, illnesses, and home-based treatments and ranged from brief and intermittent to prolonged, two-week hospital stays. Stakeholders emphasized that children with CF should not be penalized for frequent absences. Stakeholders also expressed concern that due to absences and treatment demands (e.g., less time to complete homework, treatments during the school day), children with CF are at significant risk for academic difficulties. School professionals stressed that frequent absences during the initial school years may prove problematic if children begin to fall behind in foundational literacy and numeracy skills, as this can impact future academic proficiencies (e.g., reading, complex math).

Given this knowledge, it will be important for school teams to be proactive in planning for children's school absences in order to ensure that children with CF are receiving the same educational opportunities as their healthy peers. Unfortunately, school professionals noted that securing homebound instructional programming for children with CF is often difficult due to their frequent and brief absences versus prolonged hospital stays (e.g., absence length often not long enough to qualify for homebound services). As a result, the burden of providing education and ensuring children remain on target with academic skills is largely placed on parents. Previous findings report that many teachers lack knowledge and confidence in meeting the needs of children with chronic health conditions in the classroom (Nabors et al., 2008); however, a majority of accommodations identified by stakeholders are likely already being informally implemented by many teachers or easily implemented once formally acknowledged and prescribed. Parents, school professionals, and health care providers agreed that teachers providing missed assignments (e.g., classwork, homework) to families during absences is important; however, a formal plan for when and how assignments will be provided and considerations for prioritizing assignments (e.g., skill mastery) and allotting flexible deadlines were identified as being most beneficial.

Stakeholders also identified opportunities for individualized instruction following absences as ideal; although they recognized that this may not always be feasible for teachers to implement. Thus, stakeholders explored opportunities outside of homebound services for children with CF to receive education during absences from school. Stakeholders suggested use of live video-streaming or pre-recorded instructional lessons, web-based learning sites (e.g., Khan Academy), and educational apps to support children's learning. Advances in today's technology offer creative, cost-effective solutions in the provision of educational services to children with chronic health conditions and are likely underutilized as feasible solutions to absenteeism and academic support. In fact, Svensson and colleagues (2014) recently described the advantages of using technology-based services (i.e., Skype) as a communication tool for young children with chronic health concerns. This modality can easily be translated to helping individuals with CF communicate with teachers and participate in classroom lessons during absences in order to prevent both current and future academic struggles.

Regarding children's social-emotional health, stakeholders confirmed the hypothesis that mental health difficulties, such as anxiety and depression (Berge & Patterson, 2004), were salient factors impacting children's social and emotional functioning. It is important to note that parents and caregivers were less likely to identify this as a specific social-emotional difficulty compared to school professionals and health care providers. This difference across stakeholder groups may be due to school and health care professionals' recognition of risk factors and/or experience with children who qualify for mental health diagnoses. Additionally, the young age of parent participants' children may have resulted in a lack of relevance or knowledge of mental health concerns. The risk for mental health difficulties has been well documented in the literature both for children with chronic health conditions (Hysing, Elgen, Gillberg, Lie, & Lundervold, 2007; Roberts & Steele, 2009) as well as for children with CF (Berge & Patterson, 2004; Kastakou et al., 2014); however, many children with chronic health conditions are reported to have unmet mental health care needs (Ganz & Tendulkar, 2006). Providing early psychoeducation (e.g., warning signs, treatments) to parents of children with CF may be beneficial in preventing significant social and emotional impairment by increasing rates of access to care; however, it is also imperative that health care professionals help screen for children with mental health needs and assist parents in coordinating services to facilitate the receipt of necessary psychological services.

The results of this study demonstrated consistent requests from stakeholders for expanded mental health services, especially within the CF health care setting. Integrating pediatric psychologists into CF health care services would greatly reduce access barriers to care for those children needing to seek mental health services as well as improve coordination of care (e.g., collaboration with physicians, school consultation) and clinical outcomes (e.g., treatment adherence, mental health prevention) for all children with CF. Additionally, implementation of programs such as Building Life Skills (Christian & D'Auria, 2006) or Fitting CF Into Your Life Everday (Davis et al., 2004), which have already been demonstrated to be effective for children with CF and their families, could improve social-emotional outcomes for all children with CF. School-based programs have also demonstrated promise for improving access to treatment for mental health care needs (e.g., AAP, 2004; Nabors, Leff, & Mettrick, 2001) and could also reduce barriers to care by offering affordable, on-site services to children on a regular or as-needed basis. Schools are uniquely equipped not only as a reliable resource for health care treatment (e.g., adherence to medications and therapies) but also for delivery of mental health treatment. Stakeholders expressed concerns that additional training on pediatric health conditions for school mental health practitioners, however, may be warranted. Pediatric school psychologists are uniquely trained in prevention, intervention, and consultation in both the educational and pediatric health settings as well as equipped to link family, school, and health care systems for children with chronic health conditions; thus, pediatric school psychologists would be valuable members of a child's comprehensive team and would offer unique insights and experience to providing services for children with CF in schools.

Additional social-emotional areas of needs were identified during this study. Stakeholders confirmed previous reports in the literature that children with CF experience social difficulties, such as poor peer relationships and inconsistent opportunities to engage in social interactions (Christian & D'Auria, 2006) as well as difficulties with disclosure (Christian & D'Auria, 2006; Ravert & Crowell, 2008). Interviews with parents, school professionals, and CF health care providers emphasized that children with CF often feel left out, singled out, or different due to their physical symptoms (e.g., coughing), need for treatments, and/or frequent school and social activity absences. Stakeholders also shared that children with CF often fear disclosing their diagnosis of CF to others due to sensitivities towards misunderstandings about the disease or concerns for teasing and/or bullying. Finally, recurrent themes for feeling isolated from other children with CF (e.g., inability to gain in person social support due to infection control guidelines) were noted. As a result, support from peers, adults, *and* other children with CF should be encouraged to the greatest extent possible in order to promote social-emotional health. Further, Barker, Driscoll, Modi, Light, and Quittner (2012) showed that support from family and friends was perceived by adolescents with CF to contribute to improved disease management as well as emotional and relational coping. Targeted interventions designed to provide psychoeducation to teachers and classmates may prove helpful to children with CF in disclosing their diagnosis to classmates and dispel misconceptions about the disease. Additionally, gaining social support from peers by having a classroom or peer buddy, educating classmates on CF, and continuing communications with classmates during absences may negate social difficulties and aid in establishing a pattern of healthy social opportunities and relationships. School adults also have regular opportunities to ensure the child feels safe and supported at school. For example, teachers, school counselors, or school nurses can check-in informally with the child as needed and/or ensure the child of “safe spaces” at school where the child can share his or her concerns or apprehensions. It is important to again note that technology (e.g., FaceTime, Skype, social media, web-based support groups) can also be a valuable tool for establishing social support, especially amongst children with CF who have restricted access with one another. It is imperative, however, that at least several, if not all, of the aforementioned social-emotional strategies be implemented early in the child’s educational career to promote social opportunities and prevent difficulties related to gaining and maintaining friendships and to feelings of isolation and poor social support.

Implications

Previous literature has not accounted for comprehensive intervention strategies to meet the health, educational, and social-emotional needs of children within the educational setting. This study is the first to the investigator's knowledge to gain relevant stakeholders' perspectives and opinions that underscore the importance of offering a continuum of comprehensive strategies. Stakeholders identified having a comprehensive plan (e.g., 504 Plan, IEP) to address children's needs in school as an opportunity to document and integrate individual strategies as well as designate roles and responsibilities for school staff and provide effective monitoring for implementation. The school re-entry literature base has attempted to establish comprehensive models for meeting the needs of children with chronic health conditions as they re-integrate into school (see Power et al., 2003); however, these models have failed to provide practical tools and strategies for intervening within and across a child's multiple ecological systems (e.g., home, school, health care). The information gleaned from this study provides additional insight into relevant and practical strategies for implementation across multiple settings and can serve to inform children's initial school entry. Additionally, the outcomes of this study provide for anticipatory guidance by alerting key team members to potential long-term or future difficulties, thus permitting the implementation of strategies early (e.g., at initial school entry) to prevent poor outcomes. Future research and practice should use the identified needs and strategies as well as previous school re-entry models (Harris, 2009; Worchel-Prevatt et al., 1998) to guide development of a specific, comprehensive model for preventing difficulties and facilitating coordination of care for children with CF at school. It will be important for such a model to be utilized as a prevention or early intervention approach to caring for children with CF (e.g., comprehensive plan implemented on child's first day of school) as well as an opportunity to establish collaboration across children's health, educational, and family systems. Future research should also utilize previously identified models, such as the conjoint behavioral consultation model (Sheridan & Kratochwill, 2007; Sheridan et al., 2009) and Power and colleagues' (2003) multi-systemic framework, to ensure utilization of systems-level collaborations, joint decision-making, and interdisciplinary care.

Although family-school-health care collaboration (Grief & Bradley-Klug, 2011; Sheridan et al., 2009) is not a novel concept and previous scholars have acknowledged and encouraged multisystemic collaboration as a means for establishing a continuum of care for children with chronic health conditions (Prevatt et al., 2000; Sexson & Madan-Swain, 1995), multisystemic collaboration has largely been neglected within the CF care literature. Nevertheless, all stakeholder groups in this study expressed a desire for *increased* education, *increased* collaboration, and *increased* communication. The results of this study add additional data to support the enactment of models of collaboration in order to better service children with CF and their families. Grier and Bradley-Klug (2011) as well as Sheridan and her colleagues (2009) have determinedly advocated for the implementation of multisystemic efforts in more recent years, yet lack of evidence for effective implementation in research or practice has continued to persist. This is likely due to many of the feasibility barriers previously mentioned in the chronic health care literature, such as limited time and resources, lack of knowledge of the functioning of other ecological systems, and/or absence of understanding about the condition, associated needs, and beneficial strategies (Bradley-Klug et al., 2010; Sexson & Madan-Swain, 1995). This study identified a plethora of comprehensive needs and strategies that are specific to children with CF and can serve as a relevant resource for families, schools, and health care professionals in order to promote collaboration and coordination of care in order to ensure comprehensive treatment for the child. Although this investigation centered specifically on children with CF, it is important to consider that many of the needs and strategies identified in this study may also apply to other chronic health conditions. For example, it is likely that children with conditions such as asthma, diabetes, and other chronic medical concerns need treatments at school, suffer from high rates of absenteeism and academic difficulties, and deliberate whether or not to disclose their condition to others. Similarly, it is also likely that they would benefit from several of the interventions identified in this study. Unfortunately, the use of a PAR model to garner information from key stakeholders within different chronic illness categories has been underutilized. Future research should focus on obtaining similar information from other chronic health populations to determine the applicability of an overarching model of chronic health needs and intervention strategies. Additionally, it is important for PAR to be recognized as an essential tool in garnering breadth and depth of information in a clinical capacity. Practitioners can utilize PAR as a clinical methodology within their particular context or population to obtain and address key experiences, values, and perspectives of groups or individuals.

Limitations

Although data were enhanced by recruitment of multiple, diverse stakeholders and enriched by using the PAR model, several limitations for this study exist. First, focus groups were comprised of a small number of participants. Typical focus groups are often comprised of 8 to 12 participants; however, this study utilized small *n* focus groups comprised of only three to five members. As a result, breadth and depth of information may have been limited by restricted sample size as fewer participants offer fewer viewpoints and experiences. Larger focus groups may have gleaned additional information. Similarly, the advisory panel was comprised of a limited number of participants, which may also have constrained the PAR process. Restriction of the advisory panel to a small working group, however, served to ensure forward progress in revising thematic results and developing a quantitative measure by selecting representatives rather than utilizing all participants to obtain cross-systems consensus.

The perceptions of children's needs and recommendations for intervention strategies were limited to a small sample of participants in northeastern Pennsylvania. It is possible that inclusion of participants from diverse regions may have expanded data. CF health care providers recruited for this study also had previous experience working with pediatric school psychology trainees in a partnership that offered integrated behavioral health care services for children with CF in the CF health care setting. As a result, health care providers had previously received training on educational resources (e.g., 504 Plan, IEP) and participated in consultation regarding patients' social-emotional and educational needs. Health care providers' increased knowledge and experience is believed to have strengthened the results of this study by enriching conversations about children's comprehensive needs and treatment; however, breadth and depth of information gained from this stakeholder group may have been artificially enhanced and/or biased due to prior knowledge and experience.

This study was also limited by the composition of the parent participant sample. Although rigorous recruitment efforts targeted parents of school-age children with CF, few school-age parents participated in this research study. One hypothesis for the aforementioned recruitment difficulties may be related to the identified needs addressed in this study. According to relevant stakeholders, families of children with CF experience health care demands, treatment demands, and educational demands on a regular basis. Such demands in addition to other family, extra-curricular, and work-related obligations may have left little time to participate in voluntary research, despite efforts to reduce the burden of participation. Another hypothesis may be that due to the aforementioned partnership with a local training program for pediatric school psychology students, a large majority of school age children targeted for recruitment had previously received behavioral health and educational consultative services to address their specific health, educational, and social-emotional needs. As a result, families may no longer have been experiencing difficulties and thus could not identify information to contribute or did not perceive the focus of research to be pertinent or applicable.

This study may have been unintentionally biased by the participation of the primary investigator as moderator during Phase 1 as well as behavioral health consultant to the advisory panel during Phase 2. The primary investigator possessed a strong knowledge of the current literature base and may have inadvertently influenced focus group discussions by posing specific inquiries that may not have naturally transpired within the interview process. Additionally, the primary investigator's focus on empirically-based strategies and contextual influences may have influenced advisory panel participants' decisions and detracted from the emic lens through which Phase 1 thematic results were interpreted. Multiple efforts, however, were established to reduce bias, such as the presence of a second data collector during interviews, debriefing following focus group sessions, and reliance on intercoder reliability. Additionally, to the extent possible, the primary investigator provided consultation in a limited but informative manner to reduce the likelihood of potential influence of results based on an inadvertent power differential between participants and researcher. Participants may also have been inadvertently influenced by brief psychoeducation on CF and associated difficulties prior to holding Phase 1 interviews. Standardization of information was utilized to offset the potential impact on interview discussions and thus thematic results. It was the primary investigator's intent to provide background information to orient participants, especially school professionals, to CF as well as provide initial points of discussion. Given the semi-structured approach to Phase 1 interviews as well as the breadth of thematic outcomes resulting from Phase 1, the provision of brief background information was not believed to significantly impact results, though it should be noted as a potential influencing factor. Finally, this study was restricted by logistical barriers that prevented the researcher from conducting a mixed methods study. It was the intent of the researcher to enhance qualitative findings with quantitative results from the survey developed by the advisory panel. It will be important for future research endeavors to utilize triangulation methods to validate stakeholders' perceptions and quantitatively investigate the relevance, beneficence, acceptability, and feasibility of the data gleaned from this study.

Future Research

This study is the first to the researcher's knowledge to identify relevant health, educational, and social-emotional needs and difficulties and associated strategies for children with CF. The information gained from this study increased knowledge within the relevant literature and serves as a preliminary guide for intervening to provide comprehensive care for children with CF in the educational setting. Given the knowledge of CF prior to entering school, implementation of proactive strategies, such as those identified through this study, at the time of initial school entry will likely alleviate and/or prevent health, educational, and social-emotional impairments. Additionally, the needs and strategies identified in this study can serve as both an educational and advocacy resource for parents and health care professionals. It will be important for future research and practice to use the information gleaned from this study to develop and evaluate the efficacy of a comprehensive model for school entry for children with CF as well as establish multisystemic collaboration.

As this study established an initial knowledge base with regards to children's needs and potential strategies to address such needs, future researchers should utilize quantitative methodology to support the results and enhance both reliability and validity of the current data. As part of the advisory panel methodology, a quantitative survey comprised of the qualitative concepts from this study was created. Future researchers should consider using the developed survey to establish triangulation (e.g., validation through confirming or disconfirming results) and complement the findings generated by qualitative methodology (Campbell et al., 2012). In addition, future research should expand the sample of participants to include a larger, more representative sample. Finally, research endeavors should also aim to develop a comprehensive intervention model for initial school entry and pilot the model with a small number of participants to determine initial feasibility and health, educational, and social-emotional outcomes.

Conclusions

Parents and caregivers of children with CF, school professionals, and CF health care providers determined multiple health, educational, and social-emotional needs and/or difficulties to be relevant for children with CF as they first enter elementary school. The use of qualitative methods added new knowledge to the paucity of literature on children with CF in schools. Additionally, qualitative methods strengthened findings by utilizing relevant experts and firsthand experiences to establish novel guidance for researchers and practitioners. It will be important for schools, families, and health care professionals to collaboratively plan to meet the comprehensive needs of children with CF in schools, which will require increased communication and education across systems. Interdisciplinary teams should carefully consider implementing strategies to address nutritional difficulties (e.g., malabsorption, school meal plan), provide health care treatments at school, remediate educational difficulties due to multiple school absences, assist with disclosure, and prevent or alleviate mental health difficulties (e.g., anxiety, depression).

Table 1

Phase 1 Participant Demographics

	Parents/Caregivers	Health Care Providers	School Professionals
N	11	14	15
M_{age} *(SD)*	41.55 *(13.16)*	42.27 *(13.89)*	45.60 *(11.80)*
$\text{Gender}_{\text{female}}$	8 (73%)	11 (79%)	15 (100%)
Ethnicity			
Caucasian	10 (91%)	12 (86%)	14 (93%)
Hispanic	1 (9%)	1 (7%)	1 (7%)
Asian	-	1 (7%)	-
African-American	-	-	-
Multiracial	-	-	-
Other	-	-	-
$M_{\text{No. yrs. in profession}}$ *(SD)*	-	18.14 *(13.3)*	13.97 *(6.78)*
School Profession			
Teacher	-	-	3 (20%)
School Counselor	-	-	3 (20%)
School Psychologist	-	-	3 (20%)
School Nurse	-	-	2 (13%)
Other	-	-	4 (27%)
Health Care Profession			
Physician	-	3 (21%)	-
Nurse Practitioner	-	1 (7%)	-
Registered Nurse	-	3 (21%)	-
Medical Assistant	-	2 (14%)	-
Dietician	-	1 (7%)	-
Social Worker	-	1 (7%)	-
Respiratory Therapist	-	1 (7%)	-
Care Coordinator	-	2 (14%)	-

Table 2

Demographics Characteristics of Children with CF from Parent/Caregiver Stakeholder Group

$M_{\text{Child Age}}$	4.68 [1.5–17]
$M_{\text{Age at Diagnosis}}$	2.15 [birth–14]
Child's Gender$_{\text{female}}$	6 (55%)
Child's Ethnicity	9 (82%)
Caucasian	-
Hispanic	-
Asian	-
African-American	2 (18%)
Multiracial	-
Other	
Educational level	
Early childhood	5 (45%)
Preschool	4 (36%)
School age	2 (18%)
Has IEP	1 (9%)
Has 504 Plan	1 (9%)

Table 3

Phase 2 Participant Demographics

	Stakeholder Group	Age	Gender	Ethnicity	Age of Child	Profession	Yrs. of Experience
Participant 1	Parent	27	Male	Caucasian	3	--	--
Participant 2	Parent	40	Female	Caucasian	11	--	--
Participant 3	School Professional	34	Female	Caucasian	--	School Counselor	6
Participant 4	School Professional	56	Female	Caucasian	--	Teacher	27
Participant 5	CF Health Care Provider	27	Female	Caucasian	--	Social Worker	6
Participant 6	CF Health Care Provider	54	Female	Caucasian	--	Respiratory Therapist	35
Participant 7	Primary Investigator	26	Female	Caucasian	--	Pediatric Behavioral Health Specialist	5

Table 4

Health, Educational, and Social-Emotional Needs and/or Difficulties

Need/Difficulty	Stakeholders	Percent Endorsed	Examples
Health			
Access to school nurse	All	15/17 (88%)	• Access to medications • Provision of medical care by trained, knowledgeable health care professional • Monitoring of health status • For rest, when not feeling well, or for emergencies • To eat lunch or access snacks
Greater risk for infection	All	10/17 (58%)	• More likely to catch illnesses • More likely to be sicker and sick longer compared to non-CF peers
Nutritional supplements	All	9/17 (53%)	• Snacks throughout the school day • Access to extra calories, such as double portions and fattier, high caloric options • Supplements for meals, such as Ensure or supplement shakes
Health care letters for school	All	6/17 (35%)	• To provide medical services at school • To document the chronic health condition, excuse school absences, and access accommodations in the educational setting • To consent to exchange information across educational and health care settings
Treatments at school	Health Care, Parents	8/9 (89%)	• Enzymes before meals and snacks • Medications • Respiratory treatments (e.g., nebulizer, inhaler) • Airway clearance (e.g., coughing; percussions)

Treatment non-adherence	Health Care, Parents	7/9 (78%)	• Child not wanting friends to know or because s/he does not want to feel different or singled out • Treatment burden (e.g., multiple treatments, multiple times a day, treatments take extended duration) • Early school start times do not allow for full treatments to be done in the morning
Access to bathroom	Health Care, Parents	6/9 (67%)	• Need to use the bathroom more frequently or more quickly due to digestive difficulties
Feeling ill	Health Care	2/3 (67%)	• Feeling ill on a regular basis • Can impact motivation and school functioning
Specialized health care assistant	School	3/8 (38%)	• To administer medications and treatments • Individual with increased knowledge of CF
Educational			
School absences	All	17/17 (100%)	• Frequent appointments with multiple specialty health care providers • Hospitalizations • Home-based treatments • Illnesses • Infection prevention
Falling behind in school	All	16/17 (94%)	• Missing or not completing classwork or homework due to school absences or treatment-related demands
School transitions	Health Care	2/3 (67%)	• Major transition milestones that may be difficult for children with CF • Initial school entry, transition to middle school, and entering college
Social-Emotional			
Decisions about disclosure	All	14/17 (82%)	• Range of decisions (e.g., no one knows, some friends know, everyone knows) • Often based on CF severity • Family concern that disclosing will lead to child being treated

			differently • Concerns for embarrassment, not wanting to be singled out
Need for normalcy	All	14/17 (82%)	• Need to engage in typical, developmentally appropriate behaviors, activities, and relationships • Normalizing treatments as part of daily routine • Not labeling the child
Adjustment to disease	All	9/17 (53%)	• Adjusting to shortened lifespan • Denial or acceptance of having CF • Sadness and frustration about having disease • Questioning why they have CF • Uncertainty about the future
Bullying or teasing	All	9/13 (53%)	• Due to: CF symptoms (e.g., coughing), frequent absences, peers' misunderstandings about the disease
Isolation from peers with CF	All	8/17 (47%)	• Unable to seek in-person social support from others who understand what they are going through
Misunderstandings from others in school	All	8/17 (47%)	• Fear of contagion • Not understanding the disease process or treatments • Lack of awareness of what child is experiencing • Leads to difficulties gaining and maintaining social relationships
Missing out on social opportunities or activities	All	7/17 (41%)	• Due to: absences, health care appointments, treatments, health limitations • Impacts social relationships, ability to participate in extra-curricular activities, or participation in social activities (e.g., sleepovers)
Internalizing symptoms	All	6/17 (35%)	• Anxiety • Depression • Withdrawal

Feeling different or singled out	Health Care, Parents	7/9 (78%)	• Worry that others will treat them differently once they know they have CF • Feeling different or embarrassed about having CF, CF-related symptoms (e.g., coughing, digestive difficulties), or treatments • Feeling singled out because receiving accommodations
Acceptance	School, Parents	6/14 (43%)	• Feeling accepted by peers (e.g., having friends that they can relate to) • Feeling accepted by adults
Typical difficulties exacerbated	Health Care	2/3 (67%)	• Typical daily activities, difficulties, or worries are often magnified for children with CF • School professionals need to consider that daily difficulties are magnified • Difficulties do not dissipate after a period of time, as with many acute illnesses
Lowered self-esteem	School	2/8 (25%)	• Due to lowered expectations or others "pitying" them
School phobia	School	2/8 (25%)	• Fears or worries of going to school after extended absences • Avoiding school due to worries about academics or social difficulties

Table 5

Health, Educational, Social-Emotional, and Comprehensive Strategies

Strategy	Stakeholder	Percent Endorsed	Examples
Health			
Infection control	All	10/17 (59%)	• Hand sanitizer • Frequent hand washing • Educating classmates on germs, hand washing, and how to keep one's self healthy • Minimizing contact with sick classmates (e.g., moving desk; minimizing group work; staying home from school) • Regular classroom cleaning • Following infection control guidelines for contact with others with CF at school
Access to fluids	Health Care, Parents	5/9 (56%)	• Fluids at desk (e.g., water bottle) • Unlimited access to water
Adult monitoring of treatment adherence	Health Care, Parents	5/9 (56%)	• School staff monitoring caloric and/or supplement intake during lunch • Drinking supplement in health room under school nurse's supervision • School nurse monitoring and keeping data on adherence to treatments • Behavioral contracts to reward treatment adherence
Access to bathroom	Health Care, School	5/11 (45%)	• Ability to leave classroom for bathroom without permission • Use of health room bathroom for privacy
Nutritional accommodations	Health Care, School	4/11 (36%)	• Extra time to eat lunch in ensure calorie goals • Modifications to school lunch (e.g., double portions, whole milk, fattier options)
Specialized health care assistant	Parents	3/6 (50%)	• Administers treatments

			• More knowledgeable about CF
Extra personnel in health room	School	3/8 (38%)	• Additional staff in the health room (e.g., second nurse, nurse aide) • School-based health clinics • Telehealth
Having everything needed for treatments at school	School	3/8 (38%)	• Family providing all of the child’s needed treatments to the school so that the child has access to them during the day if needed • School nurse getting physician’s orders/consent to treat the child at school
Utilizing siblings	School	2/8 (25%)	• Siblings assisting child with CF-related treatments at school to help them feel more comfortable (especially for younger siblings first entering elementary school)
Educational			
Instruction at home or in the hospital	All	12/17 (71%)	• Homebound instruction – teacher provides instruction in child’s home or at hospital for specified number of hours per week during prolonged absences • In-home tutoring for missed academic skills • Cyberschool – emphasis on attending intermittently • Homeschooling
Accommodations for instruction or missed work	All	11/17 (65%)	• Modifying or reducing quantity of missed work • Focusing on mastery • Matching child’s instructional pace • Modifying curriculum to meet child’s individual academic needs • Additional time to take tests and complete homework • Providing brief breaks during instruction
Using technology to keep up with missed work	All	8/17 (47%)	• Live video streaming of instructional lessons (e.g., Skype, videoconferencing) • Pre-recorded instructional lessons

			• Specific skills instruction via web-based learning (e.g., Khan Academy, YouTube, Study Island) • Schoolwork provided electronically using laptops or tablets • App-based learning for foundational academic skills
Extra help in school	All	6/17 (35%)	• One-on-one teacher instruction • Re-teaching foundational skills that may have been missed in previous grades due to school absences • Monitoring academic progress and providing academic interventions as needed
Access to educational materials at home	Health Care, School	6/11 (55%)	• Extra set of books at home • Posting homework and classwork online through a school portal • Providing manipulatives and instructional aides for practice at home • Providing access to technology, as needed (e.g., tablets) • Teacher sending home a folder of missed work
Getting schoolwork ahead of time	Health Care, Parents	5/9 (56%)	• Teacher sends work home with child or provides it electronically prior to known absences (e.g., scheduled appointments or hospitalizations) • Parent picks up work from school
Increasing number of allowed absences	Health Care, Parents	4/9 (44%)	• School not penalizing child for absences due to doctor's appointments and hospitalizations • Increasing the number of allowed absences for when the child does not feel well • CF physician providing documentation that child will likely be absent from school often
Rearranging school schedule	School, Parents	6/14 (43%)	• Adjusting hours child attends school based on their health or treatment needs • Re-arranging core subjects (e.g., English, math) to be available during times child is in school

Balancing expectations	Health Care, School	4/11 (36%)	• Flexibly maintaining standards for academics, behavior, and attendance
Planning for school transitions	School, Parents	4/14 (29%)	• Utilizing the parent to plan for child’s educational transitions • School professionals educating colleagues at next educational level about the child’s specific needs • Planning for accommodations at next educational level • Facilitating school visit prior to start of school year (e.g., to locate health room)
Multitasking during treatments at home	School, Parents	3/14 (21%)	• Completing treatments and homework at the same time
Schools providing flexibility	School	6/8 (75%)	• Providing individualized accommodations • Providing treatments during more convenient or inconspicuous times of the day
Planning for school re-entry	School	3/8 (38%)	• Formal plan prior to child’s return to school • Documents transition plan and accommodations • Emphasis on planning ahead • Using the child to assist with planning
Reinforcing academic effort	School	2/8 (25%)	• Balancing the type and amount of attention given to a child’s health condition with the type and amount of attention given to their academic effort • Providing frequent, positive praise for academic effort
Monitoring attendance	School	1/8 (13%)	• School team keeps track of number of days a child has missed school • Teacher communicates with school nurse to let him/her know that the child is absent • School nurse calls home to check-in and educate parents on resources available at school
Teacher support	School	1/8 (13%)	• Administrative provision of time and resources for CF

			education, planning, and consultation • Setting timers or reminders to prompt teacher to send child to health room or provide an accommodation
Treatments in the classroom	School	1/8 (13%)	• Completing treatments in the classroom to maintain them in the instructional environment
<u>Social-Emotional</u>			
Support system for child with CF	All	17/17 (100%)	• Using social media to connect with other children with CF • School lunch groups with children with other chronic health conditions • Continuing social interactions with peers during school absences (e.g., Skype, letters) • Having at least one friend • Peer buddies to help with school re-entry (e.g., peer tutoring, social broker) • Extra-curricular involvement • Check ins with school adults • Questions answered by CF Care Team • Open parent-child communication
Peer education	All	16/17 (94%)	• Presentation of general disease information, demonstration of treatments, hand-washing tutorial, opportunity for questions • Create understanding and acceptance, assist with disclosure, aid in infection control • Emphasizing CF is not contagious • Classroom-based and/or school-wide awareness initiatives (e.g., handouts, presentations)
Access to mental health services	All	13/17 (76%)	• For: adjustment to disease, problem-solving skills, social skills, treatment adherence • Weekly check-ins with school counselor or psychologist • Individual counseling sessions • All access pass to school counselor or psychologist • School-wide prevention programming • Integrated mental health services at CF Care Center

			• Available community referral resources
Non-restriction of activity	Health Care, School	3/11 (27%)	• Not limiting participation in activities (e.g., gym, sports, field trips) unless otherwise instructed by health care professionals • Encouraging participation in activities, especially physical exercise
Bullying prevention and intervention	School, Parents	3/14 (21%)	• School-wide bullying prevention initiatives • Educating students to report bullying • School counselor checking in with child and family following occurrence of bullying • Warnings and disciplinary action for bullying • Educating parents about school's intervention and prevention efforts and procedures
Leadership roles	School	2/8 (25%)	• Ensuring that the child gets the opportunity to be in leadership role • Finding leadership positions in classroom and school-wide (e.g., designating with special role) • Encouraging leadership involvement in extra-curricular activities • Linking leadership role to child's interests
Comprehensive			
Family-school-health care collaboration	All	17/17 (100%)	• Using a multidisciplinary team approach to caring for children with CF (e.g., parents, child, health care professionals, school personnel, coaches) • Communicating and coordinating care across systems • Having a designated liaison to facilitate collaboration • Team problem-solving
School staff education	All	17/17 (100%)	• Educating relevant school staff members on CF and child's individual needs • Include general information on CF, treatments, severity, infection control, and available resources • Emphasize symptoms to monitor in the classroom

			• In-service presentations, educational materials, documentation, verbal education from health care team, • Have brief, specific, easily accessible reference materials for teachers • Educating early and continuously
Educating child with CF about their disease	All	14/17 (82%)	• Access to health room • Treatments • Limitations • Common misperceptions • Fosters independence in disease management and treatment adherence • Promotes self-advocacy and disease acceptance
Individualizing plans	All	14/17 (82%)	• Recognizing every child is unique and may require a more individualized approach • Individualizing plans based on the child’s specific health, educational, and social-emotional needs
Having and monitoring an IEP or 504 Plan	All	13/17 (76%)	• Having a legal document and plan to address child’s comprehensive needs at school • Documenting specific needs, difficulties, goals, and accommodations • Monitoring plan to ensure implementation
Designated liaison for family-school-health care collaboration	Health Care, School	9/11 (82%)	• Care coordination across multiple systems • Communication and information sharing • Support for resources and advocacy • Relationship-building with families • Designated liaison may be helpful within each system
Parent support	Health Care, School	7/11 (64%)	• Educating parents about resources for their child and family at school, health care center, and/or community • Educating parents about CF • Having school professionals check in with families • Having designated liaisons to assist with advocacy, resource

			access, and systems collaboration • Parent support groups • Teaching parents advocacy skills
Having specified procedures	School	7/8 (88%)	• Designating a liaison • School treatment plan • Notification of substitutes about child's needs and accommodations • Educational accommodations (e.g., IEP, 504 Plan) • Plan for school absences
Checking in about school at health care visits	Health Care	2/3 (67%)	• Health care provider discussing school functioning during CF health care visits • Attending to school functioning at major school transitions (e.g., entering school, transitioning to middle school)
Formal plan at beginning of school year	Health Care	2/3 (67%)	• Multidisciplinary meeting to develop formal plan • Provision of written materials, such as a checklist of items to plan for, binder of resources, educational materials • Preparation should happen as early as possible so that there is a plan in place prior to school entry • Plan should be revisited yearly
Documentation	School	5/8 (63%)	• Documentation of health condition, skill deficits, missed curriculum, and specific needs and supports
Educating parents on school environment	School	3/8 (38%)	• Describing school environment to family so they know what resources and supports are available • Collaborative planning of child's school day prior to school entry (e.g., planning class by class)

Table 6

Needs and/or Difficulties Retained by Advisory Panel

Health	Educational	Social-Emotional
• Access to nurse	• School absences	• Decisions about disclosure
• Greater risk for infection	• Falling behind in school	• Need for normalcy
• Nutritional supplements	• School transitions	• Adjustment to disease
• Health care letters for school		• Bullying or teasing
• Treatments at school		• Isolation from peers with CF
• Treatment non-adherence		• Misunderstandings from others in school
• Access to restroom		• Missing out on social opportunities or activities
• Feeling ill		• Internalizing symptoms
		• Feeling different or singled out
		• Acceptance
		• Typical difficulties exacerbated

Table 7

Strategies Retained by Advisory Panel

Health	Educational	Social-Emotional	Comprehensive
• Infection control • Access to fluids • Adult monitoring of treatment adherence • Access to bathroom • Nutritional accommodations • Monitoring health symptoms in classroom • Accommodations for treatments • Family providing everything needed for treatments at school	• Home- or hospital-based instruction • Accommodations for instruction or missed work • Using technology to keep up with missed work • Extra help in school • Access to educational materials at home • Getting schoolwork ahead of time • Increasing allowed absences • Rearranging school schedule • Planning for transitions • Schools providing flexibility • Planning for school re-entry • Administrative support for teachers	• Support system for child with CF • Peer education • Access to mental health services • Non-restriction of activity	• Family-school-health care collaboration • Having a designated liaison for systems-level collaborations • School staff education • Educating child with CF about their disease • Individualizing plans • Having an IEP or 504 Plan • Supporting parents • Having specific procedures • Discussing school at health care visits • Documentation • Having a formal plan at initial school entry

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Appendix A: Sample Letter of Invitation

Invitation to Participate

Date

Title of Study: Identifying Health, Educational, and Social Emotional Needs and Potential
Intervention Strategies for Children with Cystic Fibrosis First
Entering Elementary School

Principal Investigator: Kristen Carson, MEd, School Psychology Program, Lehigh University

Faculty Supervisor: George DuPaul, PhD, School Psychology Program, Lehigh University

You are cordially invited to participate in a research study that is looking to identify the needs of children with Cystic Fibrosis (CF) as they first enter elementary school and to discuss intervention strategies to help address these needs. The following information outlines the intention of the research and the requirements of your involvement, should you choose to participate.

What is this study about?
Children with CF may experience difficulties at school, such as taking medications, being absent from school due to appointments or hospitalizations, needing to make up missed work, and helping friends and teachers understand CF. As children with CF first enter elementary school, parents, schools, and health care professionals can anticipate these difficulties and use strategies to help address these difficulties. However, this is currently not routine practice. This study will use information provided by parents of children with CF, school personnel, and CF health care professionals to identify children's health, educational, and social-emotional needs as they first enter elementary school. In addition, this study will seek information on ways to address those needs.

Why have I been asked to participate?
You have received an invitation to participate in this project as you are a parent of a child with CF; therefore, you are an expert in knowing what your child needs in order to be successful in school.

How will I benefit from this research?
There may not be direct benefits from participating in the study; however, your involvement in providing information and identifying intervention strategies will likely result in helping to meet the needs of future children with CF as they first enter elementary school.

What will I have to do if I agree to participate in the study?
If you agree to be in this study, we would ask you to do the following:

- To come to the Pediatric Pulmonary, Cystic Fibrosis, and Sleep Disorders Center at Lehigh Valley Hospital to meet with about 3 to 11 other parents of children with CF. The meeting will be hosted by researchers from Lehigh University and is expected to last approximately 90 minutes.

- At the meeting, the host will ask you to share your opinions, experiences, beliefs, and possible concerns about how to meet the health, educational, and social-emotional needs of children with CF as they first enter elementary school.
- You will also be asked to answer a short form gaining background information about you and your child.

Are there any risks in participating in this study?
The possible risks of participating in this study are small. They may include feeling uncomfortable or embarrassed with sharing your opinions and beliefs with other parents of children with CF or the meeting host.

What about confidentiality?
The records and information shared by you during this study will remain private. Only the researchers will have access to identifiable information about you and your child. The contents of the meeting will not be disclosed to anyone outside of the research project; that is information discussed will not be provided to your child's school or health care providers in a way that personally identifies you or your child.

Who do I contact if I need further information or have any concerns?
You are invited to contact the researchers of this study should you have any questions or concerns regarding participation in this study. Please contact them at Lehigh University at (610) 758-3256 (email: kmc309@lehigh.edu; gjd3@lehigh.edu).

If you have any pertinent questions about your rights as a research participant, please contact the Lehigh University Office of Research and Sponsored Programs (tel: (610) 758-3020; email: sus5@lehigh.edu).

If you would like to participate in the study, please contact Kristen Carson at kmc309@lehigh.edu.

Thank you,

Kristen Carson
Candidate for Doctor of Philosophy
School Psychology Program
kmc309@lehigh.edu

Lehigh University
College of Education
111 Research Drive
Bethlehem, PA 18015

Appendix B: Demographic Questionnaire

Demographic Questionnaire for Parents

Information About You:

Gender: ☐ Male ☐ Female

Age: __________

Race: ☐ Caucasian ☐ Hispanic ☐ Multiracial
☐ African American ☐ Asian ☐ Other

Marital Status: ☐ Single ☐ Divorced ☐ Other
☐ Married ☐ Widowed

Number of children living in the household: _______________

Number of children with CF: ______________

Number of children with other chronic health conditions (not including child with CF): ____________
Please list chronic health conditions: ____

Information About Your Child:

Gender: ☐ Male ☐ Female

Age: __________

Age at diagnosis: _____________

Current grade level: ____________

Race: ☐ Caucasian ☐ Hispanic ☐ Multiracial
☐ African American ☐ Asian ☐ Other

Does your child currently have an IEP? ☐ Yes ☐ No

Does your child currently have a 504 plan? ☐ Yes ☐ No

How satisfied are you with the communication between you and your child's school regarding your child's CF?

☐ Very dissatisfied ☐ Somewhat Dissatisfied ☐ Neutral ☐ Somewhat Satisfied ☐ Very Satisfied

How satisfied are you with the communication between you and your child's health care provider regarding your child's school functioning?

☐ Very dissatisfied ☐ Somewhat Dissatisfied ☐ Neutral ☐ Somewhat Satisfied ☐ Very Satisfied

How satisfied are you with the level of communication between you, your child's school, and your child's health care provider regarding meeting your child's needs at school?

☐ Very dissatisfied ☐ Somewhat Dissatisfied ☐ Neutral ☐ Somewhat Satisfied ☐ Very Satisfied

Demographic Questionnaire for School Personnel

<u>Information About You:</u>

Gender: ☐ Male ☐ Female

Age: _________

Race: ☐ Caucasian ☐ Hispanic ☐ Multiracial
☐ African American ☐ Asian ☐ Other

Current profession: ☐ Teacher ☐ School Psychologist
☐ School Counselor ☐ School Nurse

Number of years of experience working in the school setting: _______________

Have you had experience working with a student with CF? ☐ Yes ☐ No

Have you had experience working with students with other chronic health conditions? ☐ Yes ☐ No

If YES, please list conditions:
____

How likely are you to communicate with a family about a student's chronic health condition?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Almost always

How likely are you to communicate with a student's health care provider about a student's chronic health condition?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Almost always

How likely are you to participate in a family-school-health care meeting for a student with a chronic health condition?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Almost always

Demographic Questionnaire for Health Care Professionals

<u>Information About You:</u>

Gender: ☐ Male ☐ Female

Age: __________

Race:	☐ Caucasian	☐ Hispanic	☐ Multiracial
	☐ African American	☐ Asian	☐ Other

Current profession:	☐ Physician	☐ Registered Nurse	☐ Dietician
	☐ Nurse Practitioner	☐ Respiratory Therapist	☐ Social Worker

Number of years of experience in current profession: _________________

Number of years of experience working with children with CF: _______________

How likely are you to communicate with a family about a child’s school functioning?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Almost always

How likely are you to engage in communication with a child’s school about their CF?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Almost always

How likely are you to participate in a family-school-health care meeting for a patient with CF?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Almost always

Appendix C: Focus Group and Individual Interview Facilitation Guide, Phase 1

Welcome, introductions, brief description of the study (5 min)

1. Introductions – moderator, data collector (discuss their roles).

2. Thank you for agreeing to be a part of this discussion group. We appreciate your time and your willingness to share you experiences. The purpose of this group is to find out your ideas, opinions, and beliefs about what children with CF need when they first enter elementary school. Children with CF may experience difficulties at school over time, such as taking medications, being absent from school due to appointments or hospitalizations, needing to make up missed work, and helping friends and teachers understand CF. As children with CF first enter elementary school, parents, schools, and health care professionals can anticipate these difficulties and enact strategies to alleviate or prevent these difficulties from occurring; however, this is currently not routine practice. Today, we want you to provide us with information so that we can determine what strategies are needed to meet the health, educational, and social-emotional needs of children with CF as they first enter elementary school.

3. Group guidelines

    a. We want to hear from everyone today, and we want you all to do the talking. Please feel free to speak whenever you feel you have something to say. Everyone's opinions and experiences are important, and it is okay if people disagree with one another.

    b. Also, we have limited time today so we may have to stop or change the direction of our discussion to make sure that we are able to discuss all of our topics.

Consent (5 min)

1. The first form is a consent form that asks if you agree to participate in this research project. Before you leave today, we will provide you with a copy of the consent form so that you have one for your records. Right now, I will briefly go over the key points aloud but feel free to read the consent to yourself if you prefer.

2. Go over key points of consent: Procedures, risks, confidentiality (discuss audio recordings)

3. Are there any questions about the consent or the study? If you are still willing to participate, please sign and date on the line. One of the staff members will also sign and date this form.

Demographic Questionnaire (5 min)

1. The second form is a demographic questionnaire. This form asks several questions about your background. Please complete this form now. If a question makes you uncomfortable and you prefer not to answer, you may skip that question.

Brief overview of CF & impact of CF (10 min)

1. What is CF?

    a. CF is one of the most common, life-threatening genetic disorders impacting the Caucasian population, although it impacts every race. CF occurs in 1 out of every 3,500 live births in the US and approximately 30,000 people in the US are living with CF, a little over half of which are children. 1,000 new cases of CF are diagnosed every year, typically by the age of 2. With advances in technology and treatment, individuals with CF are now living into their mid to late 30s.

   b. CF is caused by a mutation in the gene that regulates the exchange of salt and water across cell membranes and affects the exocrine glands of the lungs, digestive system, and reproductive organs. The genetic defect causes an accumulation of abnormally thick, sticky mucus and leads to greater risk for lung infections and inflammation and pancreatic insufficiency (e.g., difficulties with digestion, malabsorption, underweight). Individuals with CF generally have salty tasting skin, persistent cough (at times with phlegm), shortness of breath, and upset stomach.

2. CF Impact

   a. Health: Children with CF are at increased risk for CF-related diabetes mellitus, pancreatic insufficiency, malabsorption (23% below 10th percentile for weight by age), chronic or recurrent pain (e.g., abdominal), early motor delay, physical inactivity, and sleep disturbances.

   b. Education: Children with CF have average cognitive abilities; however some children with CF experience academic difficulties in reading and math. Children with CF certainly experience difficulties related to high rates of school absenteeism, missing an average of 23-24 days each school year. This may lead to lower GPA and a great deal of missed work that students need to make up.

   c. Social-emotional: 60% of individuals with CF meet criteria for a psychological diagnosis, such as depression, anxiety, or disruptive behavior disorders. Children with CF often report social difficulties and worries, such as telling their peers they have CF, having peers react negatively to learning they have CF (e.g., misconceptions, fear of contagion, overprotection, teasing), and missing out on social activities due to treatment demands.

Participant Introductions (5 min)

1. Parents - name, how many children, do you have any children with CF who are currently in school (what grade)
2. School personnel – name, job title, school district, any experience working with children with CF
3. Health care professionals – name, job title, years of experience working with children with CF

General Discussion (55 min)

1. Needs/Difficulties (30 min)
    a. What are the health care needs of children with CF at school? (10 min)

       If PARENTS need prompting: In your personal experience, what has your child needed at school related to the care of their CF and/or associated health difficulties? What health difficulties has your child faced at school? Has your child ever needed anything specific to address their health needs at school? If so, what? What health care needs are unique to your child starting elementary school? What health needs should be addressed by family/school/health care?

       If SCHOOL/HEALTH CARE PERSONNEL need prompting: Given what you know or just learned about CF, what difficulties do you think children with CF may experience at school related to their health? What health needs should the school consider for a child with CF? What health care needs are unique to a child with CF just starting elementary school? What health needs should be addressed by family/school/health care?

b. What are the educational needs of children with CF at school? (10 min)

   <u>If PARENTS need prompting</u>: How has your child's education been impacted by CF? Grades? Attendance? Performance in reading and math? What difficulties has your child had in school? What difficulties do you anticipate that your child may have in school? What educational difficulties are unique to initial school entry? What educational need should be addressed by family/school/health care?

   <u>If SCHOOL/HEALTH CARE PERSONNEL need prompting</u>: How may a child's education be impacted by CF? Grades? Attendance? Performance in reading and math? What difficulties might a child with CF have in school? What educational difficulties are unique to initial school entry? What educational need should be addressed by family/school/health care?

c. What are the social-emotional needs of children with CF at school? (10 min)

   <u>If PARENTS need prompting</u>: How has your child's social life been impacted by CF? What social difficulties has your child experienced? What emotional difficulties has your child experienced? Does your child have difficulties telling others about their CF? What social difficulties are unique to initial school entry? What emotional difficulties are unique to initial school entry? What social needs should be addressed by family/school/health care? What emotional needs should be addressed by family/school/health care?

   <u>If SCHOOL/HEALTH CARE PERSONNEL need prompting</u>: What social difficulties might a child with CF encounter? What emotional difficulties might a

child with CF experience? What difficulties might a child face regarding telling others about their CF? What social difficulties might be unique at initial school entry? What emotional difficulties might be unique at initial school entry? What social needs should be addressed by family/school/health care? What emotional needs should be addressed by family/school/health care?

2. Strategies (25 min)

    a. What strategies can be employed at the time of initial school entry to address or prevent health needs at school?

       Prompts: Establishing need for medications (e.g., enzymes, inhalers) at school, assisting schools with adherence, and providing accommodations for pain, nutrition, and physical symptoms

    b. What strategies can be employed at the time of initial school entry to address or prevent educational needs?

       Prompts: Educating teachers, peers, and school personnel about CF, planning for and supporting school re-entry following hospitalizations or prolonged absences, and providing 504 accommodations

    c. What strategies can be employed a the time of initial school entry to address or prevent social-emotional needs?

       Prompts: Providing coping skills, implementing targeted mental health interventions as needed, and fostering social interactions and healthy friendships

Wrap-up and gift card distribution (5 min)

1. Summarize major themes of discussion

2. Does anyone have any additional comments or questions?

3. Thank you so much for your time today and for sharing your thoughts and experiences. As a thank you for coming today, we would like to give each of you a gift card. When we give you the gift card, please sign the receipt saying that you received it. Also, please make sure to take a copy of the consent form home with you for your records. Remember, if you have any questions, please feel free to contact me or the other contacts listed on your consent form.

Appendix D: Outline of Procedures for Advisory Panel, Phase 2

Welcome, introductions, brief description of the study

1. Thank you for agreeing to come back to be a part of this advisory panel. We appreciate your time and your willingness to share you experiences and help us to further expand upon the strategies discussed during the previous groups.

2. Introductions – moderator, panel members

3. The purpose of this group is to utilize the information gained during Phase 1 to elaborate on potential intervention strategies to address the health, educational, and social-emotional needs of children with CF as they first enter elementary school and to aid in the development of a national survey. We will do this by discussing both the needs and the strategies in multiple rounds. After each round, we will create a draft of the survey and ask you for your feedback on the presentation and content of information.

4. Group guidelines

    a. We want to hear from everyone today, and we want you all to do the talking. Please feel free to speak whenever you feel you have something to say. Everyone’s opinions and experiences are important, and it is okay if people disagree with one another.

Examining needs for inclusion in national survey

1. Collaborative determine decision rule regarding which needs identified by focus groups should be considered for inclusion in the survey

   a. Suggestion: Needs should be automatically included if identified by at least 2 stakeholder groups; Needs should be evaluated for relevance for inclusion by panel if only identified by 1 stakeholder group

2. Review needs by category per decision rule
3. Draft needs into survey item format
4. Elicit feedback from panel on first survey draft

Examining, expanding, and drafting strategies

1. Review each intervention strategy from Phase 1 results – using knowledge, expertise, experience, research, and theory
   a. First, review strategies endorsed by 2 more stakeholder groups. Second, review strategies endorsed by 1 stakeholder group.
   b. Describe, expand, condense intervention strategies.
   c. Discuss benefit, acceptability, feasibility of strategies (e.g., Will these strategies be beneficial for the child? Are these strategies acceptable for meeting the child's needs? Will these strategies be feasible to implement?)
   d. What are the potential concerns related to collaboration, coordination, and communication among family, school, and health care team regarding these strategies?
2. Draft needs into survey item format (per broad category, e.g., health, educational, social-emotional)

3. Elicit feedback from panel on second survey draft
4. Iteration 3: Identify comprehensive intervention strategies
5. Review all strategies included in survey for comprehensiveness; that is, which strategies address children's health, educational, *and* social-emotional needs
    a. Majority consensus from panel needed for inclusion in survey
6. Create a new category entitled "Comprehensive Strategies" and revise survey draft to reflect the inclusion of these strategies into this category
7. Elicit feedback from panel on third survey draft

Identify additional strategies that have not been included in survey

1. Are there any additional strategies that can be employed at the time of initial school entry to address or prevent children's needs at school? Specifically, strategies to address health needs? Strategies for educational needs? Strategies for social-emotional needs? Comprehensive strategies?
    a. Generate list of additional strategies
2. Vote on inclusion of any additional strategies (majority consensus needed)
3. Refine strategies
4. Determine appropriate category for strategy inclusion
5. Revise survey – add newly identified strategies to appropriate categories
6. Elicit feedback from panel on final version of survey

Wrap-up and gift card distribution

1. Summarize major results of advisory panel

2. Does anyone have any additional comments or questions?

3. Thank you so much for your time in participating on this advisory panel and for sharing your thoughts and experiences. As a thank you, we would like to give each of you a gift card. When we give you the gift card, please sign the receipt saying that you received it.

Appendix E: Codebooks

General Instructions

1. Code the first transcript independently using thematic analysis to determine a preliminary coding system.
2. Primary and secondary coders meet to determine final coding system by comparing codes and resolving discrepancies.
3. Re-code first transcript using final coding system. Intercoder reliability will be run to ensure at least 80% agreement.
4. Code second transcript using final coding system from first transcript (see codebook). Determine if there are any new codes that need to be added to coding system.
5. Primary and secondary coders meet to discuss new codes, resolve discrepancies, and agree on final coding system for second transcript.
6. Re-code second transcript using newly determined final coding system (see codebook).
7. For coding third (and subsequent) transcript(s), use final coding system from previous transcript. Determine if there are any new codes to be added (refer back to steps 5 and 6).

Coding Instructions

1. Read through the transcript and identify frames of analysis (e.g., themes to code).
2. Create themes (aka nodes in NVivo) that reflect a pattern of responses or relationship within the text.
    a. Given the semi-structured nature of the focus group interview and the research questions, structure themes into the following “umbrella” categories:
        - Health Needs/Difficulties
        - Health Strategies

    - Educational Needs/Difficulties
    - Educational Strategies
    - Social-Emotional Needs/Difficulties
    - Social-Emotional Strategies
    - Combined Strategies – Strategies that include health, educational, and social-emotional aspects
    - General Themes - Themes that do not fall under the aforementioned categories but reflect an important patterned response (e.g., difficulties accessing resources at school)

   b. Include specific themes under each of the broad categories.

      For example: '*Needs medication*' would be a theme under '*Health Needs/Difficulties*'

3. Assign text to specific codes.

   For example: *"My child needs to take several medications at school every day"* would be coded as *'Needs Medication.'*

   a. Text can be coded in multiple places.

      For example: *"My child has so many doctors appointments that she misses school a lot and then falls really far behind in her classes"* should be coded as (a) *'Multiple doctors appointments;'* (b) *'Frequent absences;'* and (c) *'Falling behind on schoolwork' or 'Poor academic outcomes'*

4. Continue reading and re-reading the transcript until confident everything related to the theme has been coded within that node.

5. Examine codes within and across nodes and determine whether or not codes need to be collapsed *(e.g., 'Needs medication' and 'Treatments at school' collapsed into 'Treatments at*

school') **and/or** <u>coded into new themes</u> *(e.g., disclosing to friends/classmates and disclosing to teachers were two salient themes in a theme you coded as 'Disclosure.' These two patterned responses may warrant two codes – one as 'Disclosure to Peers' and one as 'Disclosure to school adults' and recoded accordingly)*

Reminders

- Text can be coded in more than one node/theme
- It is acceptable to find new codes during the re-reading process. This is part of qualitative analysis. Add new nodes and then complete steps 3 through 5 above.
- Look for important relationships or patterned responses within the health, educational, and social-emotional domains to code.
- Also, look for broader general themes that persist across the data

Clarifications

1. Need versus Strategy

- Depends on the context of the participant's text
- Code as Need if participant phrases in such a way that it indicates that 'a child needs…' or it implies a need or difficulty (e.g., *'It is probably difficult for them to stay on top of their school work when they are absent so frequently'* should be coded as falling behind in school under educational needs)
- Code as Strategy if participant phrases in such a way that is action-oriented or indicates that something 'should' happen (e.g., 'They should have access to fluids on their desk.')

2. What does Educational mean?

- Educational refers to a child’s functioning in school related to any of the following: grades, absences, schoolwork, school performance, classroom participation
- When thinking about whether something is classified as an educational need or educational strategy do not code if it is just something done in the school setting. All needs and strategies are focused in the context of ‘at school.’ Rather think about coding educational needs and strategies as those addressing the aforementioned (e.g., grades, absences, schoolwork, school performance)

3. Only include content that is directly related to the theme. Please include at least the whole sentence. If there are several sentences or a paragraph that is related, please include this as well. Do not include broad context before or after if it is unrelated to the theme.
    - For example, if coding **‘Peer Education’** under Social-Emotional Strategies. The underlined section is the only context that SHOULD be included. Text not underlined should NOT be included:

      Participant 1: I think that you should definitely allow a child to go down to the health room and eat their lunch with the nurse because that way we will make sure they eat all their food.

      Participant 2: I agree.

      Participant 3: I also think that beyond that, children in the classroom need to be educated about CF so they know why the child might be disappearing for lunch every day. If they know it is because they need to do a treatment or eat enough food, then maybe they won’t gossip so much. It’s just an idea that I think might help them fit in better.

Health Care Interviews: Codebook 1a

Health Needs/Difficulties	**Description**
Greater risk of infection	More likely to get sick or pick up germs. Being sicker or sick longer compared to non-CF peers.
Nutritional supplements	Need for extra calories in the form of either a true supplement (e.g., Pediasure, shake), extra snack, or fatty/higher calorie foods.
Access to bathroom	Need to use the bathroom more frequently or have a bathroom at their disposal. Can include rationale for need (e.g., digestive issues).
Access to nurse	Need ability to go to health room (e.g., to use bathroom, to eat lunch, because not feeling well)
Treatment non-adherence	Intentionally choosing not to follow through with treatment (e.g., medication, enzyme, nutritional supplement, airway clearance). Refers to some form of 'push back' from the child about having to engage in treatment.
Treatments at school	Needs to engage in treatment (e.g., medication, enzyme, airway clearance, enzymes) at school. Can include treatments being done either in the health room or at a different location in school (e.g., cafeteria, classroom).
Extra time to eat lunch	Refers to needing extra time to consume needed calories in the cafeteria.
Health care letters for school	Refers to the school needing a letter from the health care provider (e.g., for treatments, permission to engage in specific activities)

Health Strategies	**Description**
Adult monitoring of treatment adherence	Refers to a school adult (or other adult) supervision or presence while a child is engaging in a treatment related activity, such as airway clearance, taking nutritional supplements, caloric intake, taking enzymes, taking medications, etc.
Access to health room bathroom	Access to a private bathroom. This is differentiated from the public school bathroom.
Educating child with CF about their disease	This includes any type of oral or written education provided to the child with CF so that they have a better understanding about their disease.
Infection control	Refers to any procedures or strategies put into place to reduce the risk of infection to the child with CF. This can include but is not limited to activities such as proper hand washing, adhering to proximity guidelines for children with CF amongst one another, or having Kleenexes and hand sanitizer available in the classroom.
Access to fluids	Refers to being able to have fluids easily accessible, such as having a water bottle at their desk or being able to visit the water fountain frequently.
Educational Needs/Difficulties	**Description**
School Absences	Refers to brief, intermittent, and/or prolonged absences from school. Includes absences due to appointments with health care providers, hospitalizations, home IV treatments, or illnesses.
Falling behind on schoolwork	Refers to the child missing or not completing classwork or homework due to either absences or treatment-related demands.

Typical educational opportunities	Refers to the concept of normalcy for the child's educational functioning (e.g., ability to participate in class, complete assignments, go on field trips, participate in extra-curriculars).

Educational Strategies	**Description**
Increasing number of allowed absences	Refers to increasing number of school absences that the school allows for the child due to knowledge that child will be absent more frequently than a non-CF peer
Modified assignments during absences	Refers to reducing or modifying classwork and homework assignments during a child's absence from school
Extra time to complete homework	Refers to providing flexibility (e.g., flexible due dates) for homework assignments due to treatment demands or school absences.
Communicating with teachers	Refers to oral or written communication with teachers. Parents or school nurse communicating with teachers about child's educational functioning (e.g., grades, absences, schoolwork, performance)
Brief home instruction	Refers to receiving educational assistance in the form of a tutor or teacher coming to the child's home.
Hospital-based instruction	Refers to receiving educational assistance while in the hospital. This can include homebound instruction if it is within the context of the child being hospitalized (e.g., for a tune-up). This could also include a tutor or educational program in place at the hospital.
Extra help in school	Refers to receiving educational assistance from the teacher or another school staff member while at school.
Getting school work ahead of time	Refers to either the parents getting classwork and homework assignments or teachers providing schoolwork before it is known that the child will be absent from school (either brief or prolonged absence)

Social-Emotional Needs/Difficulties	**Description**
Isolation from peers with CF	Refers to physical isolation from other individuals with CF (due to infection control guidelines) that results in feeling isolated, disconnected, or any negative emotion.
Feeling different or singled out	Refers to feeling different from healthy peers or peers who do not have CF. Also includes feeling singled out from peers because of their disease. Both of these may be due to reasons such as coughing, treatment needs, physical appearance, missing school, or any other activity or physical symptom that may not be relevant for healthy children.
Internalizing symptoms	Refers to having symptoms or difficulties related to anxiety, depression, or withdrawal (*Note: withdrawal is different from isolation (having to be physically isolated from others with CF) and feeling different (expressing feelings of difference or atypicality from peers). Withdrawal suggests the child is engaging in the act of isolating themselves and choosing not to be around other people or participate in activities once found enjoyable)*

Adjustment to disease	Refers to adjusting to having CF (e.g., coming to terms with having the disease, disease symptoms, lifespan, etc.) or dealing with developmentally appropriate levels of understanding the disease
Decisions about disclosure	Refers to any of the following: (a) the child considering disclosure of CF; (b) engaging in disclosure or non-disclosure type behaviors; or (c) differences in disclosure decisions (e.g., some children do, some children do not)
Need for normalcy	Refers to children needing to engage in typical, developmentally appropriate behaviors, activities, and relationships. May also include the need to normalize the experience of the disease itself.

Social-Emotional Strategies	**Description**
Support system	Refers to receiving social and/or emotional support (e.g., outlet for talking, friendships, advice) from family, friends, school adults, health care adults, coaches, etcetera. Can also include receiving support from others with CF through means of technology. This can also include encouraging social relationships and opportunities for social involvement.
Access to counseling in school	Refers to accessing the guidance counselor or receiving some type of counseling or therapy in the school setting
Assisting with disclosure	Refers to the act of discussing options for disclosure with child with CF or engaging in an activity or program (e.g., CF School Program) that aids the child in telling others about their CF
Peer Education	Refers to any oral or written education directed towards the peers of a child with CF in order to help them understand the disease and bridge the gap between the child with CF and their healthy peers
Providing external resources	Refers to providing or gaining access to external resources for social-emotional needs, such as assessment or therapy from an agency outside of the school

Combined Strategies	**Description**
Family-school-health care collaboration	Refers to engaging in collaboration across the family, school, or health care systems related to coordinating care, communicating, or educating others about CF or the child with CF. Can include family-school, family-health care, school-health care, or family-school-health care collaborations.
Formal plan at beginning of school year	Refers to having a formal oral or written plan at initial school entry or at the beginning of a subsequent school year. Plan can include written materials or be considered to be a meeting (where a plan is going to be developed).
504 Plan	Refers specifically to the words '504 Plan.' 504 Plan can be in the context of addressing a child's needs at school within health, educational, and/or social-emotional domains.
School staff education	Refers to educating adults at the child's school (e.g., counselors, teachers, school psychologists, administrators, etc.) about CF and the associated needs and/or difficulties. Education can be oral or written materials.

General Themes	**Description**
Stress on the family system	Refers to physical and social-emotional stress on parents, siblings, or family system as a whole due to having a child with CF in the family *(Note: can include burden related to treatments)*
Treatment burden	Refers specifically to the difficulties (physical or temporal) associated with CF-related treatments
Barriers to care	Refers to obstacles or reasons why it may be difficult to access care in any setting (e.g., home, school, health care center)
Importance of acting early	Refers to the need to intervene early. Could mean either early on when the need or difficulty is first discovered or early on in the child's life or early in the school year (e.g., beginning of school year or at initial school entry).
Need for case management	Refers to the need for some type of point person. Point person's activities may include but are not limited to: managing the child's care, facilitating communication across systems, or coordinating care.
Reliability of school environment	Refers to school as being a reliable place for a child to receive treatments or needed care. Could also refer to school as a place where the child spends the majority of their day/time.

Health Care Interviews: Codebook 1b

Note: Only new codes are listed. Previous codes from Codebook 1a were assumed.

Health Needs/Difficulties	**Description**
Feeling ill	Refers to the child with CF frequently feeling ill due to their disease. Acknowledges it almost as part of their daily disease experience.

Health Strategies	**Description**
Accommodations for medications or treatments	Recognition that schools have certain policies about treatments/medications and that children with CF may need accommodations to these policies, such as carrying their own medications.

Educational Needs/Difficulties	**Description**
School transitions	Refers to the difficulty of children transitioning into, throughout, and out of school. Includes all levels of education.

Educational Strategies	**Description**
Access to school materials at home	Refers to having a set of books or specific school-related materials kept at home so that the child does not have to carry them back-and-forth or has access to them when absent from school.

Social-Emotional Needs/Difficulties	**Description**
Misunderstanding from others in school	Questions, misconceptions, or misunderstandings about CF from individuals in the school setting

	(e.g., peers, teachers, school nurse, administrators)
Typical difficulties exacerbated	Typical daily activities, events, or difficulties are often magnified or worse for children with CF because they are also dealing with the reality and demands of their diagnosis.

Social-Emotional Strategies	**Description**
Mental health interventions at health center	Refers to providing mental health services by a mental health clinician co-located or integrated into the CF health care center.
Non-restriction of activities	Children should not be restricted from participating in school-based, extra-curricular, or community activities due to their CF unless otherwise instructed by health care professionals. Includes the notion that individuals should not assume that children with CF are unable to participate in activities.
School-wide mental health interventions	Refers to providing social-emotional interventions school-wide so that all children learn to be accepting of differences and so that the child with CF is not singled out.

Combined Strategies	**Description**
Parent Support	Providing emotional support to parents. Educating parents about the disease and about available resources. Also includes educating parents in how to be advocates for their child.
Checking in about school at health care visits	Health care providers check in about school or discuss school-related difficulties and/or needs with the child and family at their routine CF health care visits. Refers to the responsibility of discussing school to be that of the health care providers.

General Themes	**Description**
Demands placed on school system	Participant recognition of multiple demands placed on school system. System demands/stress may include but are not limited to lack of staffing, lack of resources, financial constraints, feeling overwhelmed by chronic health conditions, etcetera.
Fear/anticipation of child starting school	Refers to parent/family fear, anxiety, worry, or anticipation about their child starting school (or day care)
Need for individualized approach	Recognizes that there is not a one-size fits all approach to care for children with CF. Includes providing resources in an individualized way or an a la carte basis.
Importance of prevention	Stresses the importance of taking a preventive, pro-active approach to providing care for children with CF.
Respecting autonomy of child and family	Refers to respecting the beliefs, values, opinions, and choices of the child with CF and/or family system. Also includes respecting the independence of the child (e.g., taking medications independently).
Parental protective responses	Refers to parents allowing (or not allowing) a child to do something

Health Care Interviews: Codebook 1c

Note: Only new codes are listed. Previous codes from Codebook 1a and 1b were assumed. **No new codes identified. Saturation of themes met.**

School Interviews: Codebook 2a

Health Needs/Difficulties	**Description**
Infection control	Need to provide infection control strategies because children with chronic health conditions more likely to get sick or pick up germs.
Nutritional supplements	Need for extra calories in the form of either a true supplement (e.g., Pediasure, shake), extra snack, or fatty/higher calorie foods.
Access to nurse	Need ability to go to health room (e.g., to use bathroom, to eat lunch, because not feeling well)
Specialized health care assistant	Having a specialized staff person (other than the school nurse) who is responsible for administering treatments and attending to the health care needs of the child. For example, a personal care aid or a specialized health care assistant.

Health Strategies	**Description**
Access to bathroom	Providing access to a bathroom as often as needed.
Infection control	Refers to any procedures or strategies put into place to reduce the risk of infection to the child with the chronic health condition. This can include but is not limited to activities such as proper hand washing, adhering to proximity guidelines for children with CF amongst one another, or having Kleenexes and hand sanitizer available in the classroom.
Utilizing siblings	Including siblings in the care and support of the child at school. For example, allowing the sibling to assist the child with CF with their treatments under the supervision of a trained adult.
Modifications to meal plans	Enacting changes to the standard meal plan provided at school in order to meet nutritional needs, such as extra calories.
Monitoring physical activity levels	Adhering to physical activity levels (e.g., gym, recess) as prescribed by a medical provider, and monitoring physical activity levels for potential risks (e.g., knowing when the child should take a break).
Monitoring behavior vs. symptomology	Using formal and/or informal data to monitor a child's behavior and reactions within the educational environment. Data is used to determine antecedents, specific behavior, and consequences to discern whether the child is engaging in disruptive or avoidance behaviors (e.g., avoidance of classwork, learned helplessness, school refusal) or is experiencing symptoms or difficulties related to their disease.

Educational Needs/Difficulties	**Description**
School Absences	Refers to brief, intermittent, and/or prolonged absences from school. Includes absences due to appointments with health care providers, hospitalizations, home IV treatments, or illnesses.
Reduced educational expectations	Refers to school adults lowering expectations for a student's performance in the educational

	environment. This is viewed as an associated difficulty and a negative side effect of having a chronic health condition. Participants advocate for maintaining expectations.
Skill deficits due to missing school	Refers to the child demonstrating specific skill deficits or learning difficulties as a result of frequent absences. Skill deficits may result immediately or become apparent later in their educational career.

Educational Strategies	**Description**
Accommodations for instruction and missed work	Refers to reducing or modifying instruction, classwork, and homework assignments during a child's absence from school or once a child returns to school in order to catch them back up
Extra help in school	Refers to receiving educational assistance from the teacher or another school staff member while at school.
Using technology to keep up with missed school work	Refers to the use of technology (e.g., computers, tablets, Skype, apps, video taped lessons, internet-based instructional aides) to maintain academic skills while absent from school.
Balancing expectations	Refers to parents and school educators maintaining expectations for academic performance while balancing the need to make certain accommodations as a result of a child's chronic health condition
Having and monitoring an IEP or 504 Plan	Having legal documents (e.g., IEP or 504 Plan) that provide students with an individualized plan to address their needs at school and their access to the curriculum. This also includes monitoring the plan to ensure that the plan is being followed and goals are being met.
Planning for school re-entry	Having a formal plan to help a student re-integrate into the educational environment prior to the return of that child to the educational setting.
Schools providing flexibility	Providing flexibility within the educational environment with regards to the planning of educational lessons for children with chronic health conditions, expectations, absences, typical school rules. This may also include being flexible as an educator, such as shifting to roles outside of typical 'teacher' role (e.g., collecting data on symptomology vs. behavior, taking temperatures).
Teacher support	Teachers receiving support from administrators and other school personnel to help them plan, prepare, and educate themselves on specific students' needs.
Treatments in the classroom	Allowing students to undergo treatments (e.g., inhaler, nebulizer) in the classroom in order to maintain them in the instructional environment.
Planning for transitions within school	Engaging in planning specific to a child's transition into or throughout school. This can refer to any educational level (e.g., entering elementary school, transitioning to middle school). Approaches to planning may vary (e.g., utilizing the parent to observe and provide feedback of the educational environment; interdisciplinary team meetings, etc.)
Reinforcing academic effort	Providing positive praise and reinforcement to the academic effort of children with chronic health conditions.
Access to educational materials at home	Refers to having a set of books or specific school-related materials kept at home so that the child does not have to carry them back-and-forth or has access to them when absent from school.

Social-Emotional Needs/Difficulties	**Description**
Isolation from peers with CF	Refers to physical isolation from other individuals with CF (due to infection control guidelines) that results in feeling isolated, disconnected, or any negative emotion.
Bullying	Recognition that children with chronic health conditions may face adversity from peers in the educational setting. Peers may engage in repeated patterns of cruel behavior (e.g., verbal or physical) towards the child as a result of their differences due to having a chronic health condition.
Lowered self-esteem	Recognition that children with chronic health conditions may experience lowered self-esteem as a result of individuals lowering expectations for them and 'pitying them'
Adjustment to disease	Refers to adjusting to having a chronic health condition (e.g., coming to terms with having the disease, disease symptoms, lifespan, etc.) or dealing with developmentally appropriate levels of understanding the disease
Decisions about disclosure	Refers to any of the following: (a) the child considering disclosure of CF; (b) engaging in disclosure or non-disclosure type behaviors; or (c) differences in disclosure decisions (e.g., some children do, some children do not)
Need for normalcy	Refers to children needing to engage in typical, developmentally appropriate behaviors, activities, and relationships. May also include the need to normalize the experience of the disease itself.

Social-Emotional Strategies	**Description**
Support system (for child with chronic health condition)	Refers to receiving social and/or emotional support (e.g., outlet for talking, friendships, advice) from family, friends, school adults, health care adults, coaches, etcetera. Can also include receiving support from others with CF through means of technology. This can also include encouraging social relationships and opportunities for social involvement.
Peer Education	Refers to any oral or written education directed towards the peers of a child with CF in order to help them understand the disease and bridge the gap between the child with CF and their healthy peers
Social skills training	Providing coaching and training specific to helping children with chronic health conditions gain and maintain friendships.
Leadership roles	Placing the child with CF in leadership roles in order to enhance self-esteem and self-efficacy.
Reducing activity limitations	Children should not be restricted from participating in school-based, extra-curricular, or community activities due to their health condition unless otherwise instructed by health care professionals. Includes the notion that individuals should not assume that children with CF are unable to participate in activities.

Combined Strategies	**Description**
Parent Support	Providing emotional support to parents. Recognizing the need to build trust and support parents in barriers and in coping with having a child with a chronic health condition. This also includes educating parents about the disease and also in how to be advocates for their child.

Having specified procedures	Having specific procedures for who, what, where, when, how students with chronic health conditions will be accommodated at school or for how communication and collaboration with occur.
Documentation	Having specific, detailed, written documentation of a student's accommodations (e.g., IEP or 504 Plan), academic difficulties, and progress. For example, noting what skills were missed during an extended absence.
Educating parents on school environment	Refers to educating parents on the nature of the school environment (e.g., class structure, requirements of classes, transitions) so that parents are able to identify key areas where their child may need an accommodation.
School-health care communication	School professionals reaching out to health care professionals to communicate about a child with a chronic health condition
Family-school communication	Communicating openly and frequently with families with regards to the needs and progress of a child with a chronic health condition at school
School staff education	Educating all school professionals who will be in contact with the child on the common symptoms/characteristics of the condition and the needs of the child. Providing only the need-to-know information (e.g., signs to look for; what to do)
Designated liaison for family-school-health care collaboration	Having a specific point person to engage in collaboration across the family, school, and health care systems in order to meet the health, educational, and social-emotional needs of a child with a chronic health condition.
Individualizing plans	Ensuring that educational plans for children with chronic health conditions are individualized to that child's specific needs and goals.
General Themes	**Description**
Barriers to care	Refers to obstacles or reasons why it may be difficult to access care in any setting (e.g., home, school, health care center)
Importance of acting early	Refers to the need to intervene early. Could mean either early on when the need or difficulty is first discovered or early on in the child's life or early in the school year (e.g., beginning of school year or at initial school entry).
Parental worry	Refers to parent/family fear, anxiety, worry, or anticipation about their child starting or being in school, their child's disease, or their child's needs and difficulties.
Balancing privacy with disclosure	Recognizing that information about chronic health conditions is covered by confidentiality laws (e.g., HIPPA, FERPA). Recognition of need for balance in families giving up some of that privacy in order to better educate the school in how to meet the child's needs.
School staff comfort level	Indicators of the level of school staff comfort in providing accommodations for children with chronic health conditions and comfort in planning for children with chronic health conditions in school.
Respecting family values	Refers to respecting the beliefs, values, opinions, and choices of the child with the chronic health condition and/or family system.
Parental protective responses	Refers to parents allowing (or not allowing) a child to do something

School Interviews: Codebook 2b

Note: Only new codes are listed. Previous codes from Codebook 2a were assumed.

Health Strategies	**Description**
Extra personnel in health room	Having additional assistance available to provide medical care to children with chronic health conditions at school. This includes additional nurses, nursing assistants, or nurse practitioners. This also includes provision of community health or school-based health services.
Having everything needed for treatments at school	Ensuring that the school has all medications and treatments for the child available at school in order to ensure that the child's medical needs can be met.

Social-Emotional Needs/Difficulties	**Description**
School phobia	The child exhibits fear or worry about going to school or stays home from school to avoid having to attend. Participants associate this with having a chronic health condition, with the health condition is often being used as an excuse for not wanting to attend school.
Decisions about disclosure	Refers to any of the following: (a) the child considering disclosure their health condition; (b) engaging in disclosure or non-disclosure type behaviors; (c) differences in disclosure decisions (e.g., some children do, some children do not); or (d) family considerations in disclosing

Combined Strategies	**Description**
Team approach	Indicates that a team of individuals should be involved when planning and providing for a child with a chronic health condition. The team includes the parent(s) and may also include but not be limited to interdisciplinary professionals at school (e.g., teacher, administrator, school nurse) and health care center (e.g., physician, nurse, social worker).

General Themes	**Description**
Parental protective responses	Refers to parents allowing (or not allowing) a child to do something based on their health condition
Reliability of school environment	Refers to school as being a reliable place for a child to receive treatments or needed care. Could also refer to school as a place where the child spends the majority of their day/time.
Cultural perspective	Recognition of the impact of cultural diversity on working with students with chronic health conditions and their families. Note: This may be positive or negative.
Negative attitudes towards families	Expression of negative feelings about parents and/or families. Typically expressed as barriers to care. Represents a negative attitude when working with families and/or negative perception about families' actions, inactions, experiences, or beliefs.

School Interviews: Codebook 2c

Note: Only new codes are listed. Previous codes from Codebook 2a and 2b were assumed.

Health Strategies	**Description**
Educating child about disease	Any type of oral or written education provided to the child with the chronic health condition so that they have a better understanding about their disease. This also includes educating children in how to advocate for themselves and their disease-related needs or experiences.
Monitoring symptoms	Monitoring child's disease symptoms or child for changes in disposition for the purpose of knowing when to send the child to the health room or engage in strategies to address the child's health care needs.

Educational Strategies	**Description**
Monitoring attendance	Keeping track of the attendance of students with chronic health conditions in order to prevent excessive absences. Monitoring attendance includes keeping track of number of days missed and calling home to determine reason for absences if school has not been notified by parents.
Home Instruction	Receiving home-based instructional support. This can be through formalized programs such as homebound instruction (or temporary medical excusal), tutoring services, or alternative education services such as cyberschooling.

Social-Emotional Strategies	**Description**
Bullying prevention	Providing school-wide bullying prevention and intervention programs in order to create a positive school environment that promotes acceptance but also teaches children what to do during instances of bullying.

School Interviews: Codebook 2d

Note: Only new codes are listed. Previous codes from Codebooks 2a through 2c were assumed.

Health Needs/Difficulties	**Description**
Health care letter	Refers to the school needing a letter from the health care provider that documents consent/permission to exchange health-related information (between the school and health care provider) and information about medical diagnosis and treatment.

Social-Emotional Needs/Difficulties	**Description**
Misunderstanding from others in school	Questions, misconceptions, or misunderstandings about child's health condition from individuals in the school setting (e.g., peers, teachers, school nurse, administrators). For example, fear of contagion.

School Interviews: Codebook 2e

Note: Only new codes are listed. Previous codes from Codebooks 2a through 2d were assumed.

Social-Emotional Needs/Difficulties	**Description**
Missing out on social opportunities or activities	Refers to the child having to miss out on social or extra-curricular activities due to school absences, not feeling well, or disease-related limitations/restrictions.
Internalizing symptoms	Refers to having symptoms or difficulties related to anxiety, depression, or withdrawal. Can include tearfulness/crying.

Social-Emotional Strategies	**Description**
Access to mental health services	Refers to accessing the guidance counselor or receiving some type of counseling, therapy, or mental health intervention in the school or health care setting.

General Themes	**Description**
School's need to attend to chronic health	Acknowledgement that schools often do not give priority to attending to the health of students; that schools often perceive academics and behavior to be the only areas in which they should concern themselves with or intervene on. Acknowledgement that schools need to attend to students with chronic health conditions.

School Interviews: Codebook 2f

Note: Only new codes are listed. Previous codes from Codebooks 2a through 2e were assumed.

Educational Strategies	**Description**
Rearranging school schedule	Re-arranging school schedule to meet their health care needs. The goal is for the student to maintain access to core subjects but have flexibility to come in late, go home early, or access treatments at a specific time.

School Interviews: Codebook 2g

Note: Only new codes are listed. Previous codes from Codebooks 2a through 2f were assumed. **No new codes identified. Saturation of themes met.**

Parent/Caregiver Interviews: Codebook 3a

Health Needs/Difficulties	**Description**
Greater risk of infection	More likely to get sick or pick up germs. Being sicker or sick longer compared to non-CF peers.
Access to bathroom	Need to use the bathroom more frequently or have a bathroom at their disposal. Can include rationale for need (e.g., digestive issues).
Treatment non-adherence	Intentionally choosing not to follow through with treatment (e.g., medication, enzyme, nutritional supplement, airway clearance). Refers to some form of 'push back' from the child about having to engage in treatment.

Treatments at school	Needs to engage in treatment (e.g., medication, enzyme, airway clearance, enzymes) at school. Can include treatments being done either in the health room or at a different location in school (e.g., cafeteria, classroom).
Health care letters for school	Refers to the school needing a letter from the health care provider (e.g., for treatments, permission to engage in specific activities)

Health Strategies	**Description**
Adult monitoring of treatment adherence	Refers to a school adult (or other adult) supervision or presence while a child is engaging in a treatment related activity, such as airway clearance, taking nutritional supplements, caloric intake, taking enzymes, taking medications, etc.
Access to fluids	Refers to being able to have fluids easily accessible, such as having a water bottle at their desk or being able to visit the water fountain frequently.
Specialized health care assistant	Having a specialized staff person (other than the school nurse) who is responsible for administering treatments and attending to the health care needs of the child at school. For example, a personal care aid or a specialized health care assistant or a home health nurse.

Educational Needs/Difficulties	**Description**
School Absences	Refers to brief, intermittent, and/or prolonged absences from school. Includes absences due to appointments with health care providers, hospitalizations, home IV treatments, or illnesses.
Falling behind on schoolwork	Refers to the child missing or not completing classwork or homework due to either absences or treatment-related demands.

Educational Strategies	**Description**
Increasing number of allowed absences	Refers to increasing number of school absences that the school allows for the child due to knowledge that child will be absent more frequently than a non-CF peer
Modified assignments during absences	Refers to reducing or modifying classwork and homework assignments during a child's absence from school
Extra help in school	Refers to receiving educational assistance from the teacher or another school staff member while at school.
Using technology to keep up with missed school work	Refers to the use of technology (e.g., computers, tablets, Skype, apps, video taped lessons, internet-based instructional aides) to maintain academic skills while absent from school.
Planning for school transitions	Engaging in planning specific to a child's transition to different educational levels (e.g., elementary to middle, middle to high school).
Considering alternatives to public school	Parent consideration for alternative forms of education other than public school. For example, homeschooling or private school.

Social-Emotional Needs/Difficulties	**Description**
Isolation from peers with CF	Refers to physical isolation from other individuals with CF (due to infection control guidelines) that results in feeling isolated, disconnected, or any negative emotion.
Teasing/Bullying	Recognition that children with chronic health conditions may face adversity from peers in the educational setting. Peers may engage in repeated patterns of cruel behavior (e.g., verbal or physical) towards the child as a result of their differences due to having a chronic health condition.
Missing out on activities	Refers to the child having to miss out on social or extra-curricular activities due to not feeling well
Feeling different or singled out	Refers to feeling different from healthy peers or peers who do not have CF. Also includes feeling singled out from peers because of their disease. Both of these may be due to reasons such as coughing, treatment needs, physical appearance, missing school, or any other activity or physical symptom that may not be relevant for healthy children.
Decisions about disclosure	Refers to any of the following: (a) the child considering disclosure of CF; (b) engaging in disclosure or non-disclosure type behaviors; or (c) differences in disclosure decisions (e.g., some children do, some children do not)
Acceptance	Refers to the need of the child to be or feel accepted by his/her peers and the adults in his/her life despite their chronic health condition
Need for normalcy	Refers to children needing to engage in typical, developmentally appropriate behaviors, activities, and relationships. May also include the need to normalize the experience of the disease itself.

Social-Emotional Strategies	**Description**
Teaching tolerance	Refers to providing specific teaching/instruction to peers on tolerance and acceptance of individuals who are different from them, specifically for those with chronic health care conditions.
Access to mental health services	Refers to accessing the guidance counselor or receiving some type of counseling or therapy in the school or health care setting
Teaching child to advocate for themselves	Refers to teaching the child to advocate for their needs (e.g., health or social-emotional needs). This may include teaching the child to talk to the parent when problems or needs arise at school or teaching the child to seek out another individual at school and tell them their needs.
Using technology for social support	Providing social support and friends with peers, especially peers who also have CF, through the use of technology and social media. For example, online support groups and websites, Skype, FaceTime. Technology as an outlet for peers to relate to one another, discuss their experiences, and build friendships. Technology is used to overcome the barrier of infection control guidelines for children with CF.
Peer Education	Refers to any oral or written education directed towards the peers of a child with CF in order to help them understand the disease and bridge the gap between the child with CF and their healthy peers

Combined Strategies	**Description**
Educating child with CF about their disease	This includes any type of oral or written education provided to the child with CF so that they have a better understanding about their disease.
Parent involvement and advocacy	Parent involvement in the school or the community in the capacity of parents serving as advocates for their children or educating others about CF or their child with CF.
Family-school-health care collaboration	Refers to engaging in collaboration across the family, school, or health care systems related to coordinating care, communicating, or educating others about CF or the child with CF. Can include family-school, family-health care, school-health care, or family-school-health care collaborations.
Individualizing plans	Ensuring that health and educational plans for children with CF are individualized to that child's specific needs and goals.
School staff education	Refers to educating adults at the child's school (e.g., counselors, teachers, school psychologists, administrators, etc.) about CF and the associated needs and/or difficulties. Education can be oral or written materials.

General Themes	**Description**
Treatment burden	Refers specifically to the difficulties (physical or temporal) associated with CF-related treatments
Barriers to care	Refers to obstacles or reasons why it may be difficult to access care in any setting (e.g., home, school, health care center)
Importance of acting early	Refers to the need to intervene early. Could mean either early on when the need or difficulty is first discovered or early on in the child's life or early in the school year (e.g., beginning of school year or at initial school entry).
Parental distrust of school/negative school experiences	Parent distrust of the school's ability to meet the needs of the child with CF or negative school experiences which have shaped parent perceptions about the school environment and staff and what they might expect their child with CF to experience (or not experience) in school.
Raising awareness	Raising awareness of cystic fibrosis within the school and larger community (e.g., benefit walks, fundraisers, TV commercials, education, etc.)
Environmental conditions of school	Concern for environmental conditions in the school such as perfume, air fresheners, air ducts, carpets, heating/cooling, etc. that may impact the health and/or functioning of the child with CF
Parental protective responses	Refers to parents allowing (or not allowing) a child to do something based on their health condition

Parent/Caregiver Interviews: Codebook 3b

Note: Only new codes are listed. Previous codes from Codebook 3a were assumed.

Health Needs/Difficulties	**Description**
Nutritional supplements	Need for extra calories in the form of either a true supplement (e.g., Pediasure, shake), extra snack, or fatty/higher calorie foods.
Access to nurse	Need ability to go to health room (e.g., to use bathroom, to eat lunch, because not feeling well)

Health Strategies	**Description**
Infection control	Refers to any procedures or strategies put into place to reduce the risk of infection to the child with the chronic health condition. This can include but is not limited to activities such as proper hand washing, adhering to proximity guidelines for children with CF amongst one another, or having Kleenexes and hand sanitizer available in the classroom.

Educational Strategies	**Description**
Early education	Engaging in early education school-readiness skills in the home in order to prepare the child to enter school with basic alphabetic and numeric skills.
Multitasking during treatments	Multitasking while completing treatments, such as wearing the vest and completing homework assignments, in order to reduce treatment burden as well as homework burden.
Rearranging school schedule	Re-arranging school schedule so that student maintains access to core subjects but has more time to conduct treatments in the morning before coming to school.
Getting school work ahead of time	Refers to either the parents getting classwork and homework assignments or teachers providing schoolwork before it is known that the child will be absent from school (either brief or prolonged absence)

Social-Emotional Needs/Difficulties	**Description**
Internalizing symptoms	Refers to having symptoms or difficulties related to anxiety, depression, or withdrawal (*Note: withdrawal is different from isolation (having to be physically isolated from others with CF) and feeling different (expressing feelings of difference or atypicality from peers). Withdrawal suggests the child is engaging in the act of isolating themselves and choosing not to be around other people or participate in activities once found enjoyable)*

Social-Emotional Strategies	**Description**
Support system (for child with CF)	Refers to receiving social and/or emotional support (e.g., outlet for talking, friendships, advice) from family, friends, school adults, health care adults, coaches, etcetera. Can also include receiving support from others with CF through means of technology. This can also include encouraging social relationships and opportunities for social involvement.

Combined Strategies	**Description**
504 Plan	Refers specifically to the words '504 Plan.' 504 Plan can be in the context of addressing a child's needs at school within health, educational, and/or social-emotional domains.

General Themes	**Description**

Uncertainty because of lack of experience	Parent expression of uncertainty (e.g., I don't know; I'm not sure) because of lack of experience on the topic. For example, having a lack of experience with school so expressing uncertainty of what it might be like for the child with CF in school.

Parent/Caregiver Interviews: Codebook 3c

Note: Only new codes are listed. Previous codes from Codebooks 3a and 3b were assumed.

General Themes	**Description**
Family coping with disease	Parent expression of emotional reactions to child being diagnosed or having CF. Recognition that the family experiences a coping process much like the child with CF.
Differences in CF severity	Recognition that a range of severity with regards to symptoms and needs are present for CF. Differences in severity may also link to different outcomes (e.g., needs and strategies) and different experiences.

Parent/Caregiver Interviews: Codebook 3d

Note: Only new codes are listed. Previous codes from Codebooks 3a through 3c were assumed.

Educational Strategies	**Description**
Homebound instruction	Receiving instruction provided by the school at home during prolonged or extended absences from school.

Parent/Caregiver Interviews: Codebook 3d

Note: Only new codes are listed. Previous codes from Codebooks 3a through 3c were assumed. **No new codes identified. Saturation of themes met.**

Kristen M. Carson

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Education

Ph.D. **Lehigh University** August 2015
Doctoral Candidate, School Psychology
Program APA-accredited (full), NASP Approved (full)
Specialization: Pediatric School Psychology
Dissertation: Identifying Health, Educational, and Social-Emotional Needs and Potential Intervention Strategies for Children with Cystic Fibrosis First Entering Elementary School
(Major Professor: George J. DuPaul, Ph.D.)
Clinical Internship: Nebraska Internship Consortium in Professional Psychology, Munroe-Meyer Institute, Behavioral Pediatrics and Integrated Care 2014-2015

M.Ed. **Lehigh University** May 2011
Human Development
Specialization: School Psychology

B.S. **University of South Carolina** May 2009
Psychology; Minor, Spanish
Summa Cum Laude

Clinical Experience

Children's Physicians Dundee; Village Pointe Pediatrics July 2014 - June 2015
Munroe-Meyer Institute, University of Nebraska Medical Center
Omaha, NE
Supervisors: Jennifer Burt, Ph.D.; Rachel Valleley, Ph.D.

Responsibilities: Provided behavioral and cognitive-behavioral therapy to children ages 2 to 19 and their families. Common targets for treatment included anxiety, depression, non-compliance, academic difficulties, disruptive behavior, obsessions and compulsions, pain, toileting, sleep disturbance, improved parent-child interactions, aggression, and social skills. Conducted evaluations to determine diagnoses impacting child's current level of functioning. Evaluations were conduced for ADHD, anxiety, depression, and autism spectrum disorder. Collaborated with physicians, nurses, and social worker for treatment plan and care coordination. Consulted with families attending medical appointments to provide brief interventions or anticipated guidance for common childhood emotional and behavioral difficulties (e.g., time in, timeout, sleep). Assisted families in school consultation and communication regarding child behavioral or academic needs and accommodations.

Pediatric Pulmonary, Cystic Fibrosis, and Sleep Disorders Center Sept 2012 - July 2013

Pediatric Specialty Center, Lehigh Valley Hospital

Allentown, PA

Supervisor: Patricia Manz, Ph.D.

Responsibilities: Member of interdisciplinary team. Consulted with patients with cystic fibrosis, asthma, sleep disorders, muscular dystrophy, and other pulmonary needs on academic, behavioral, social, emotional, and health-related concerns. Assisted families in navigating individualized education plans (IEPs) and 504 service plans. Increased hospital-school communication about medication, health, and treatment needs. Assisted families with behavior difficulties at home and school through parent management training, behavioral sleep recommendations, and conjoint consultation. Implemented and evaluated treatment adherence interventions. Provided individual cognitive-behavioral therapy. Facilitated school re-entry. Educated health care professionals on impact of chronic health conditions on children's education, behavior, and mental health.

Hiram W. Dodd Elementary School and Francis D. Raub Middle School Sept 2012 - June 2013

Allentown School District

Allentown, PA

Supervisors: Cynthia Ilgenfritz, Ed.S.; Ilsa Loetzbeier, Ed.S., LPC

Responsibilities: Conducted comprehensive multidisciplinary psychoeducational evaluations to determine special education eligibility for elementary and secondary students. Evaluated children with pediatric health conditions, psychiatric conditions, and cognitive, developmental, and learning disabilities. Consulted with teachers and parents to develop and implement classroom- and home-based interventions to improve students' behavior and academic performance. Provided group counseling services to secondary students. Conducted evaluations to determine Section 504 eligibility and Chapter 16 giftedness eligibility. Implemented academic and behavioral interventions for children at risk for emotional and behavioral disorders and academic difficulties. Consulted with teachers, administrators, and school counselors on student crisis situations. Participated in multidisciplinary team meetings to discuss special education service provision and review individual student progress.

The Sleep Center Sept 2011 - July 2012

The Children's Hospital of Philadelphia

Philadelphia, PA

Supervisor: Melisa Moore, Ph.D.

Responsibilities: Member of interdisciplinary team. Conducted developmental and medical history interviews. Assessed medical and behavioral sleep patterns of infants/toddlers, preschoolers, school-aged children, and adolescents. Consulted with team to determine diagnosis and to design medical and behavioral interventions. Described recommendations to family under supervision of attending psychologist and collaborated to develop individualized intervention plan. Provided follow-up consultation with families as needed via telephone, electronic communication, and/or outpatient visits. Follow-up consultation included goal setting, goal monitoring, intervention training, problem-solving, and discussion of implementation strategies. Summarized assessment results in written report. Interpreted and summarized results of actigraphy in written report.

Partnering to Achieve School Success (PASS) Feb 2012 - July 2012

Center for Management of ADHD
Children's Hospital of Philadelphia
Philadelphia, PA

Supervisor: Jennifer Mautone, Ph.D.

Responsibilities: Provided consultation and family therapy services to children with ADHD and their families through a multi-systemic collaborative care intervention program. Collaborated with families to design, implement, and monitor home- and school-based interventions to improve children's behavior and academic performance. Facilitated communication between families, primary care providers, and teachers to promote more positive parent-child and family-school-pediatrician relationships. Implemented culturally sensitive considerations for working with underserved populations. Participated in medication consultations and monitored medication side effects in partnership with families, schools, and primary care physicians. Co-facilitated multi-family training groups providing psychoeducation and behavioral treatment strategies for parents of school-age children with ADHD. Conducted diagnostic evaluations for children exhibiting symptoms of ADHD.

Primos Elementary School and Stonehurst Elementary School Sept 2012 - June 2012

Upper Darby School District
Upper Darby, PA

Supervisor: Catherine McCoubrey, Ed.S.

Responsibilities: Conducted comprehensive multidisciplinary psychoeducational evaluations. Evaluated children with pediatric health conditions, such as asthma, epilepsy, and sickle cell disease. Engaged in parent-teacher consultations. Implemented classroom- and home-based behavioral and academic interventions. Provided individual counseling services to children. Conducted kindergarten transition assessments. Participated in multidisciplinary meetings to discuss special education service provision, review student progress in Response to Instruction and Intervention (RtII), and identify students at risk for emotional, behavioral, and/or academic difficulties.

Families Taking Control (FTC) Sept 2011 - Jan 2012

The Sickle Cell Center
The Children's Hospital of Philadelphia
Philadelphia, PA

Supervisors: Lamia Barakat, Ph.D.; Chavis Patterson, Ph.D.

Responsibilities: Member of team of pediatric psychologists (neonatology, oncology and hematology) and clinical research staff. Co-facilitated manual-based multi-family intervention workshops to educate parents and school-aged children in using a problem-solving model for challenges related to sickle cell disease management, school functioning, and psychosocial functioning. Conducted follow-up consultation with families to discuss barriers to problem-solving implementation and develop additional family goals. Served as school services expert and consulted with hospital team on school reentry materials. Developed a program of materials to be provided to families and school staff following workshops that included information on accessing educational resources, sickle cell disease education and accommodations, and community supports. Conducted home- and clinic-based assessments of behavior, academic, and family functioning for school-aged children. Integrated medical history and assessment results into written report. Implemented culturally sensitive considerations for working with underserved populations.

Provision of Supervision

Provided competency-based supervision to third year pediatric school psychology doctoral student entering their first year of practicum. Supervision was provided in face-to-face meetings one hour per week for 10 months. Sept 2013 - June 2014

Research Experience

Dissertation Research Jan 2013 - Present

Department of Education and Human Services, School Psychology Program, Lehigh University, Bethlehem, PA

Title: Identifying Health, Educational, and Social-Emotional Needs and Potential Intervention Strategies for Children with Cystic Fibrosis First Entering Elementary School

Faculty Chair: George J. DuPaul, Ph.D.

Committee: Lee Kern, Ph.D., Patricia Manz, Ph.D., Thomas Power, Ph.D.

Utilizing participatory action research methods (e.g., focus groups, advisory panel) to gain information from parents of children with cystic fibrosis (CF), school personnel, and CF health care professionals to identify health, educational, and social-emotional needs and potential intervention strategies for children with CF at the time of initial school entry. Confirming perception of health, educational, and social-emotional needs as relevant to children with CF as they first enter elementary school and assessing the degree of benefit, acceptability, and feasibility of the proposed strategies through a national survey of parents of children with CF, school personnel, and CF health care professionals.

Predictors of Mental Health Treatment for Children with Special Health Care Needs Jan 2013 - May 2013

Department of Education and Human Services, School Psychology Program, Lehigh University, Bethlehem, PA

Research Supervisor: Stacy Martin, Ph.D.

Examined effects of systems-level predictors (e.g., individual, family, health care, community, and policy) on the receipt of mental health care for 8,135 children with chronic health conditions from the 2009/10 National Survey of Children with Special Health Care Needs. Responsibilities, shared with a co-investigator, included development of research question, recoding variables, data analysis, presentation of findings, manuscript writing, and submitting for publication.

Contribution of Care Coordination and Health Condition Type to Severity of Special Health Care Needs March 2012 - June 2012

Department of Education and Human Services, School Psychology Program, Lehigh University, Bethlehem, PA

Research Supervisors: George J. DuPaul, Ph.D., Edward Shapiro, Ph.D.

Examined predictors (i.e., receipt of care coordination; medical versus emotional, behavioral, and/or developmental condition) of symptom severity ratings as reported by parents of children with special health care needs using the 2005/2006 National Survey of Children with Special Health Care Needs. Replicated analyses using the 2009/2010 National Survey of Children with Special health Care Needs database upon its release. Responsibilities, shared with two co-investigators, included development of research question, recoding variables, data analysis, presentation of findings, and manuscript writing.

Doctoral Qualifying Project Jan 2010 - March 2012

Department of Education and Human Services, School Psychology Program, Lehigh University, Bethlehem, PA

Title: Effects of Epilepsy Severity and Gender on Positive Peer Interactions In Childhood

Research Supervisor: Robin Hojnoski, Ph.D.

Investigated the effects of severity of disorder and gender on positive peer interactions for elementary aged students with epilepsy, hypothesizing that children with more severe epilepsy and females would experience more problematic peer interactions when compared to boys and girls with mild or moderate epilepsy. Positive peer interactions were assessed using a parent-reported measure of social competence for 176 children with epilepsy, ages 6 to 11, who participated in the 2007 National Survey for Children's Health. Responsibilities included development of research question, recoding variables, data analyses, presentation of findings, manuscript writing, and submitting for publication.

Relative Efficacy of Vyvanse for ADHD Medical Protocol (Project REVAMP) Jan 2010 - May 2011

Department of Education and Human Services, School Psychology Program, Lehigh University, Bethlehem, PA

Primary Investigators: George J. DuPaul, Ph.D., Lisa Weyandt, Ph.D.

Medication trial examining the effects of Vyvanse® (an FDA approved prodrug stimulant) on the academic, behavioral, and social functioning of college students with ADHD. Responsibilities included conducting weekly medication monitoring sessions with participants, interobserver agreement observations, data collection and entry, preliminary data analyses, and manuscript writing.

Medical Home Care for Children with Special Health Care Needs Sept 2009 - May 2011

Department of Education and Human Services, School Psychology
Program, Lehigh University, Bethlehem, PA
Primary Investigator: George J. DuPaul, Ph.D.

Examined medical home services, family burden, and time spent coordinating health care for children with special health care needs. Analyzed data for children ages 3 to 17 from the 2005/2006 National Survey of Children with Special Health Care Needs according to five groups: ADHD, mental health disorder, chronic illness, cognitive/developmental disorder, and healthy children. Responsibilities included development of research question, recoding variables, and manuscript writing.

After School Study Skills Program Sept 2009 - May 2011

Department of Education and Human Services, School Psychology
Program, Lehigh University, Bethlehem, PA
Primary Investigators: George J. DuPaul, Ph.D., George White, Ph.D.

Examined the effects of an after-school study skills program for middle school students with and without ADHD. Responsibilities included screening for participants, conducting intake interviews, scheduling project meetings, collaborating with school faculty and administrators, conducting fidelity observations, data collection and entry, and data analyses.

Publications/Presentations

Publications

Mautone, J. A., **Carson, K. M.**, Power, T. J. (2014). Best practices for linking families and schools to manage children with attention problems. In A. Thomas & J. Grimes (Eds.), *Best practices in school psychology* (6th ed.). Bethesda, MD: National Association of School Psychologists.

Weyandt, L. L., DuPaul, G. J., Verdi, G., Rossi, J. S., Swentosky, A., Vilardo, B. A.…**Carson, K. M.** (2013). The performance of college students with ADHD: Neuropsychological, academic, and psychosocial functioning. *Journal of Psychopathology and Behavioral Assessment, 35,* 412-435. doi: 10.1007/s1086-013-9351-8

DuPaul, G. J., **Carson, K. M.,** & Fu, Q. (2013) Medical home care for children with special health care needs: Access to services and family burden. *Children's Health Care, 42,* 27-44.

DuPaul, G. J., **Carson, K. M.**, Gormley, M. J., Vile Junod, R., & Flammer-Rivera, L. (2012). Attention deficit hyperactivity disorder: School-based cognitive behavioral interventions. In R. B. Mennuti, R. W. Christner, & A. Freeman (Eds.), *Cognitive-behavioral interventions in educational settings: A handbook for practice* (2nd ed., pp. 405-440). New York, NY: Routledge.

DuPaul, G. J., Weyandt, L. L., Rossi, J. S., Vilardo, B. A., O'Dell, S. M., **Carson, K. M.**,…Swentosky, A. (2012). Double-blind, placebo-controlled, crossover study of the efficacy and safety of lisdexamfetamine dimesylate in college students with ADHD. *Journal of Attention Disorders, 16,* 202-220.

DuPaul, G. J., **Carson, K. M.**, Fu, Q. (2011). Promoting comprehensive treatment for children with ADHD through medical home services. *The ADHD Report, 19(6),* 1-3.

Presentations at Professional Conferences

Valleley, R. J., O'Dell, S. M., Lancaster, B., Rennie, B., **Carson, K. M.,** Bruni, T.,…Sevecke, J. (2015). Clinical and economic aspects of integrated primary practices. Symposium presented at the Society of Pediatric Psychology Annual Conference, San Deigo, CA.

Carson, K. M., Krehbiel, C., & Hermetet-Lindsay, K. (2013). Perceptions of symptom severity: Contribution of care coordination and diagnosis. Poster presented at the National Association of School Psychologists Annual Convention, Seattle, WA.

Carson, K. M. & Hojnoski, R. (2012). Peer interactions in childhood epilepsy: Exploring condition severity and gender. Poster presented at the National Association of School Psychologists Annual Annual Convention, Philadelphia, PA.

Pressimone, V., Krehbiel, C., Hostutler, C., Hermetet-Lindsay, K., Gray, L., **Carson, K.**,…DuPaul, G. (2012). Pediatric school psychology: Advancing the training of doctoral level school psychologists. Poster presented at the Pennsylvania Psychologists Association Conference, Harrisburg, PA.

DuPaul, G. J., **Carson, K. M.**, & Fu, Q. (2011). Medical home care for children with ADHD: Access to services and family burden. Poster presented at the American Psychological Association Annual Convention, Washington D.C.

DuPaul, G.J., Weyandt, L. L., Vilardo, B. A., O'Dell, S. A., **Carson, K. M.**, Swentosky, A.…Rossi, J. S. (2011). Effects of lisdexamfetamine dimesylate on functioning of college students with ADHD. Symposium presented at the American Psychological Association Convention, Washington D. C.

Teaching Experience

Guest Lecturer, K-12 Classroom Environment and Management April 2013

Department of Education and Human Services, Special Education Program, Lehigh University, Bethlehem, PA November 2013

Course Instructor: Brenna Wood, Ph.D.

Guest lectured on internalizing disorders in children and adolescents in schools. Provided direct instruction to pre-service elementary and secondary teachers regarding types and general characteristics of internalizing disorders, identification and referral procedures, and intervention strategies for the classroom. Facilitated discussions based on case examples and course readings.

Professional Activities

Publicity Chair, Student Association of School Psychologists Aug 2010 - May 2012

Department of Education and Human Services, School Psychology
Program, Lehigh University, Bethlehem, PA

Served on the executive board of the Lehigh University chapter of the Student Association of School Psychologists (SASP) as the publicity chair. Responsibilities included assisting with planning and promoting of SASP sponsored events to Lehigh University graduate and undergraduate students and community partners.

Representative, Graduate Student Council Aug 2010 - May 2011

Department of Education and Human Services, School Psychology
Program, Lehigh University, Bethlehem, PA

Served as School Psychology Program representative to the College of Education Graduate Student Council. Responsibilities included communicating graduate student needs and concerns and planning graduate student support opportunities (e.g., programming, services, and social connections).

School Psychology Program Representative Aug 2010 - May 2011

Department of Education and Human Services, School Psychology
Program, Lehigh University, Bethlehem, PA

Served as the Doctoral School Psychology student representative to the School Psychology Program. Responsibilities included acting as a liaison between students and faculty, assisting with planning and facilitation of program candidate interviews for incoming students, serving as a student representative on candidate interview committee, and attending monthly school psychology program meetings.

Secretary, Student Association of School Psychologists Jan 2010 - May 2012

Department of Education and Human Services, School Psychology
Program, Lehigh University, Bethlehem, PA

Served on the executive board of the Lehigh University chapter of Student Association of School Psychologists (SASP) as the secretary. Responsibilities included administrative duties, such as recording meeting minutes, facilitating communication amongst SASP members, and conducting executive board nominations and voting procedures for the following academic year.

Honors and Awards

Lehigh University

Leadership Training Grant in Pediatric School Psychology Sept 2011 - Sept 2015

Funded by U.S. Department of Education, Office of Special Education,
Division of Personnel Preparation
Full tuition and stipend support

Graduate Assistantship Sept 2009 - May 2011

Full tuition and stipend support

Affiliations/Memberships

Student Affiliate, American Psychological Association, Division 16, 54 Aug 2009 - Present

Graduate Student Affiliate, National Association of School Psychologists Aug 2009 - Present