AN EXPLORATION OF PARENT PERCEPTIONS OF SCHOOL ADVOCACY EXPECTATIONS FOR CHRONICALLY ILL CHILDREN

A Record of Study

by

Kimberly Diane Martin

Submitted to the Office of Graduate and Professional Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF EDUCATION

Chair of Committee,	Sara Raven
Co-Chair of Committee,	Julie Singleton
Committee Members,	Melissa Fogarty
	Sharon Matthews
Head of Department,	Michael De Miranda

May 2020

Major Subject: Curriculum and Instruction

ABSTRACT

This record of study applies a qualitative research design to explain the phenomenon of parent advocacy in school systems for parents whose children suffer from a specific illness known as chronic recurrent multifocal osteomyelitis. This study seeks to explain frustrations experienced by parents during their work as the key communicators between the educational and medical communities on behalf of their children. Semistructured interviews were conducted and analyzed using in vivo coding to create five case studies in which parents described in their own words how they function as action researchers. The results of this analysis explain how the study participants have overcome obstacles in their advocacy. These case studies show how parents have created partnerships within their children's school settings and social media platforms to leverage the best possible academic, emotional, and social outcomes for their children. Using this knowledge from successful parent advocates, I created a communication guide and video that can be used by other parents within the diagnosed community to replicate some of the strategies identified as successful by the study participants. I shared the communication guide and video on the disease-specific social media channel and website for future use by parents.

DEDICATION

This record of study is dedicated to my children, Brennan McKay Martin and Patrick Scott Martin. Brennan is the true definition of a CRMO warrior; he reminds me every day that we are braver and stronger than we know. Patrick has a profound gift for learning, and he is undoubtedly my favorite teacher and first adventure. I further dedicate this work to my husband, Scott Martin. I cannot remember one single idea or dream of mine that he has not supported in the last 25 years. His supportive spirit has often been extended to include the children in my schools. By his giving nature, I am uncommonly blessed. Finally, to all the parents out there advocating for your children—thank you! You inspire me to be a better advocate, educator, and mother. I am beyond grateful for those of you who gave of your time to help me complete this study.

ACKNOWLEDGMENTS

I would like to thank my committee chair, Dr. Sara Raven, co-chair, Dr. Julie Singleton, and committee members, Dr. Melissa Fogarty and Dr. Sharon Matthews, for their support and guidance through this journey. I wholeheartedly appreciate the inspiration, time, and advice I received from this amazing group of educators.

I would also like to thank Dr. Viruru and Ambyr Rios, who work diligently to ensure that distance does not exist in this distance-learning program. Your hearts are indeed teachers' hearts, and I was supported by both of your caring natures throughout my time in the program.

To my Yellow Jacket family—I could not have completed this journey without the power of the hive! I am better for working and learning from you all. You understand what it means to be a team and support one another through the highs and lows in life. I am proud to be a homegrown product of the community we all serve. Without your support, I would not have been able to complete the rigorous process required by this program.

I have been lucky to work with a fantastic array of talented mentors in my home district. I am grateful to each and every one of them. In particular, many years ago, a gifted principal took a chance on a novice teacher. I was grown into the educator and leader I am today by Kenneth Wallace. I am so thankful for his guidance throughout my career. I was strong enough to finish this program in spite of life happening because he believed in my ability to do anything!

Finally, I cannot express enough gratitude to my family. My parents, Debra and Raymond Morlock, taught me the value of education and hard work. Those are the two lessons that have served me best in life. My children and my husband continue to surround me with love,

laughter, and reasons to be inspired. Thank you for your sacrifices and love. I am a better woman because of you all.

TABLE OF CONTENTS

Page

Page

LIST OF TABLES

CHAPTER I

INTRODUCTION: CONTEXT AND PURPOSE OF THE ACTION

The Context

Global and National Context

Children with complicated medical issues are attending schools in more significant numbers. Accurate global statistics related to medical conditions are difficult to obtain, partly because of changing definitions of these conditions, as well as variances in how medical conditions are tracked around the world. Hundreds of chronic physical ailments affect school-age children in the United States (Clay, 2004). Nearly 15 million children under the age of 18 suffer from chronic illnesses (Compas, Jaser, Dunn, & Rodriguez, 2012). Chronic diseases limit a student’s ability to participate fully in the educational experience. However, medical advancements have increased the number of chronically ill students in mainstream schools (A'Bear, 2014; Baird & Ashcroft, 1984). Recent literature has confirmed that one in four children attending school is living with a chronic illness (Boles, 2017; Kish, Newcombe, & Haslam, 2018). Improvements in medical technology worldwide, allowing more children who are chronically ill to attend school, coupled with an increase in children with chronic illnesses, create complicated issues that school systems must mitigate to instruct students who are sick.

The statistics of chronically ill students in the State of Texas are no easier to describe accurately. Currently, Chapter 38 of the Texas Education Code provides for the health of students in Texas schools. A search of the word “chronic” in this code produces only five results (State of Texas, 2019). Chapter 38 of the Texas Education Code requires the creation and tracking of individual health plans only for students who suffer from anaphylaxis and asthma, despite the mandate that the Texas Education Agency should include information on how to treat and manage the impact of chronic illnesses in schools (State of Texas, 2019). Furthermore, the Texas Department of Health and Human Services recently posted a Texas School Health Survey aimed at collecting data on the size and training of school health staff, the number of students with chronic health conditions, and the number of clinic visits in schools (Texas Department of Health and Human Services, 2019). The lack of current statistics available in Texas indicates a need to collect more accurate data on students who are chronically ill in the state. National statistics produced over the last 20 years remain consistent and indicate the high likelihood that schools of all sizes are educating students with illnesses. This study focuses on a bone disorder known as chronic recurrent multifocal osteomyelitis (CRMO) / chronic nonbacterial osteomyelitis (CNO), which is just one of the 200+ chronic conditions referenced as possible by Clay (2004) and Thies (1999). At this moment, the reality that roughly one-third of school children in the United States suffer from debilitating illnesses creates a situation whereby "students with chronic health conditions are at the intersection of health and education systems" (Thies, 1999, p. 382). Increasingly, school systems are finding it necessary to implement unique strategies to meet the needs of students with chronic health conditions.

Situational Context

This study addresses a specific rare disease that presents unique challenges to describing the situational context. The study focuses explicitly on a chronic illness known as CRMO or CNO. Both terms are used interchangeably to describe an autoinflammatory bone disorder. The majority of patients are young children who are treated by a variety of specialists, particularly pediatric rheumatologists. CRMO results in bone destruction and severe pain to those who are afflicted with the disease, largely because of prolonged excessive inflammation (Oliver, Lee, Halpern-Felsher, Murray, Schwartz, Zhao, 2018). CRMO can take a significantly long time to diagnose. The median onset age at which patients notice symptoms is 8 years old, while the median diagnosis age is 10 years old (Oliver et al., 2018). This two-year gap between onset and diagnosis creates a unique time of struggle for parent advocates. They have little information about what is wrong with their child and elevated stress due to the lack of diagnosis. Oliver et al. (2018) reported a significant number of their survey respondents strongly agreeing that they had been unable to perform their daily tasks (including their academic assignments) because of pain (41%), physical limitations (36%), and fatigue (28%) related to CNO.

CRMO is a rare disease. This rarity, in addition to geographic location and length of time between disease onset and diagnosis, can leave both parents and patients feeling isolated. Limited information available to educators about rare conditions increases the difficulty of developing effective strategies to ensure that all children are significantly engaged in their education. Several CRMO parents and patients have unified via a private social media group, a Facebook page on which family members and caregivers can exchange information (https://www.facebook.com/groups/CRMOawareness/?ref=bookmarks). Additionally, parents and doctors have created a workgroup that developed a CRMO awareness website. This website includes resources that can be utilized by all stakeholders. The workgroup meets at an annual conference of pediatric rheumatologists known as the Childhood Arthritis and Rheumatology Research Alliance (CARRA). The situational context of this study is unique in that the context exists in these online methods of parent support. The artifacts developed in the study were added to the educational resources section of the CRMO awareness website established by the workgroup (http://crmoawareness.org/504-2/) so that all parents, schools, medical professionals, and patients can have open access to the document.

The Problem

Parents of children who suffer from chronic illnesses have expressed frustration with their role as the key communicator between the educational and medical communities they navigate. This frustration is rooted in the fact that these parents rarely have training in either the medical or educational field. Parents are often expected to explain the complicated medical diagnosis of their child to the stakeholders at school, such as their child's administrator, school nurse, counselor, and teachers (Cunningham & Wodrich, 2006). Additionally, parents are often asked to be the go-between to carry necessary forms and documents to and from the doctor for appropriate signatures and recommendations so that the school can provide resources that match their child's needs. Parents are often unaware of the programs, strategies, resources, and funding available to students with special needs through their schools. Parents are also unaware of the process used by schools to identify whether a child even has needs that are different from their healthy peers (Maslow, Haydon, McRee, & Halpern, 2012). The communication burden placed on parents of chronically ill students to connect the medical and educational communities often occurs in times of family turmoil due to diagnosis, increasing the stress on already overburdened parents. Likewise, doctors who are unaware of many of the social, emotional, and academic resources available in schools are often asked to determine the fitness of a child to attend school. Doctors are also invited to provide recommendations for how the school can meet the needs of ill children with little practical knowledge of the strategies that can be employed by teachers and school nurses (Cunningham & Wodrich, 2006). Parents who are asked to act as caregivers and key communicators will continue to struggle to connect their school and medical communities until they are provided the support needed to bridge the gap between these communities.

In turn, school systems struggle to develop a variety of strategies that can be used to help parents feel successful in navigating their child’s educational needs (Boles, 2017). While most often there is not a lack of desire to help children in schools, there is a lack of understanding of disease-specific requirements faced by children (Irwin & Elam, 2011). This lack of understanding impedes the ability of professional educators to customize the educational day for children who are chronically ill. Students with chronic illnesses face several obstacles that must be overcome to allow for full participation in school. Full school participation includes academic learning, involvement in extracurricular activities of the student’s choice, and social and emotional well-being. Schools, not unlike parents, need assistance in developing plans to act in the best interest of struggling ill students to ensure that they are allowed full participation in their educational settings.

Relevant History of the Problem

Prior to 1970, students whose chronic illnesses resulted in few or minor limitations due to the symptoms created by their illnesses were enrolled in school with their nonill peers. There were no expectations of accommodations on the part of schools for these students. Students who were chronically ill with moderate to severe symptoms were often excluded from school because of the belief that education would serve little benefit before the onset of death (Walker & Jacobs, 1984). As compulsory attendance laws were created and enforced, health-impaired children began to make their way into segregated classrooms, often special education classrooms with decreased academic rigor. Segregated classes for medically fragile students grew substantially in the 1940s, largely because of the desire to contain the polio epidemic (Walker & Jacobs, 1984). As inclusion and mainstreaming became a model in the 1970s, medically fragile students moved into traditional classrooms. Social services such as school nurses, as well as medical advancements that improved quality of life, helped to ensure that students suffering from chronic illnesses were exposed to higher academic rigor and were allowed to participate with their peers (Baird, Ashcroft, & Dy, 1984; Walker & Jacobs, 1984). By the mid-1980s, researchers began to question how special education law applied to students who are chronically ill. In 2020, most chronically ill students do not qualify for special education protections, but they do qualify for Section 504–related services that help meet the unique needs of individual learners (Clay, 2004). Today, most students with chronic illnesses are mainstreamed in general education classrooms with their peers, and teachers are expected to provide accommodations for the unique needs of students who are suffering from illness's.

Significance of the Problem

There are complex communication networks that connect parents, students, educators, and doctors in effectively educating children who are chronically ill. Issues such as lack of communication among the child, parents, school, and medical community contribute to untrained parents acting as the liaison between the school and the medical community. Parents serving as key communicators with little guidance may have a damaging effect on the community relationships formed by families with their local schools. While acting as key communicators, parents often also experience coping struggles. Chronic sorrow is a coping model defined as a process of parent adaption to disease management in an effort to avoid disease acceptance (Melnyk, Feinstein, Moldenhouer, & Small, 2001). Another coping model, the time-bound model, refers to the stages of disease acceptance (impact, denial, grief, attention, and closure) that parents must work through before they can begin to advocate for their child (Melnyk et al., 2001). These coping struggles limit the ability of parents to act as advocates for their children. Finally, rarely does a formal process exist for the medical community to communicate with school officials to create meaningful plans for students who suffer from chronic illnesses. The identified coping struggles and the lack of a formal process of communication delay the institutional responses needed to aid sick children in the school setting.

Chronic illnesses often lead to increased absences. Factors contributing to absences include the illness itself, feelings of an inability to “catch up” academically, and a lack of participation in school activities and events, which could increase feelings of school connectedness for students (Boles, 2017). Gan, Lum, Wakefield, Donnan, Marshall, Burns, Jaffe, Leach, Lemberg, and Fardell (2018) explained that social and emotional implications exist for students with chronic illnesses. These social and emotional concerns, including potentially socially awkward elements of disease management such as infusions, wheelchairs, and wearing masks, are often ignored by all stakeholders (Gan et al., 2018). Students who are chronically ill struggle to find the coping skills necessary to manage factors such as depression and anxiety, which often exist in conjunction with physical illness. Additionally, peer groups often lack disease and medical equipment knowledge, which leads to a feeling of isolation for chronically ill students (Gan et al., 2018). Isolation, disease maintenance, and social and emotional factors continue to contribute to chronic absenteeism in students who are chronically ill, often resulting in significant educational gaps.

Finally, educators bear an enormous burden of care for students for long periods each day. Educators are untrained to deal with the medical realities of chronic illnesses. Teachers may fear pushing medically fragile students academically (Cunningham & Wodrich, 2006). Teachers are often uneducated about the particular disease a student may be diagnosed with and may feel ill-equipped to handle medical situations that may occur in class. Even medical personnel such as school nurses may feel unprepared for students who are chronically ill (Basch, 2011; Boles, 2017). There is a need to create tools to help parents, students, and educators decrease the impact of chronic illness on the ill student's educational journey.

In a recent study addressing the social implications of CRMO on children, several doctors and parents worked together to determine the most critical problems currently faced by families of chronically ill children. The study specifically addressed the need to provide families with tools to help them solve a variety of disease management topics. The study stated that parents need help handling "socioeconomic stressors and mental health matters and to establish school accommodations, such as a 504 plan . . . that addresses needed accommodations for children with chronic disease to help prevent them from falling behind academically" (Oliver et al., 2018). Oliver et al. (2018) addressed the role of parents as critical team members in their child's health condition by identifying areas in which parents need disease management assistance. The study was a collaboration between parents and the medical community but lacked representation from educators.

Research Questions

The following questions guided this study:

1. What obstacles have parents encountered in their role as an advocate for their child between the child's medical and educational needs? Do parents feel that they have overcome these obstacles to ensure academic support for their child? If so, how?
2. What are parents' perceptions of their advocacy role? What factors contribute to parents' feelings about their advocacy role?
3. What type of guide can be developed to help parents navigate their advocacy role between the school and medical communities for their ill child?

The discussion surrounding these questions aided in the development of a guide that can be utilized by a variety of stakeholders to increase communication to improve educational outcomes for children who are chronically ill. Practical tools previously used by parent advocates also were cataloged to develop a toolkit for future parent advocates and schools with CRMO/CNO-diagnosed children. The goal of this research study was to create collaborative tools to provide support for parents advocating for their children through the creation of materials designed to help parents in advocating for their children in both educational and medical meetings to facilitate a collaborative approach to the academic and medical care of children with chronic illnesses.

Personal Context

Researcher Roles and Personal Histories

I am the mother of a child with a chronic illness. Additionally, I am a high school principal and a parent participant in the CRMO Facebook group. My experience as a parent of a child who is chronically ill, coupled with my experience as an educator, provides me the unique opportunity to develop a multilayer understanding of the burdens placed on many parents by the unintended expectation that parents serve as the key communicator between the school and medical communities. I have served as an educator for the entirety of my career, close to two decades. I have been a social studies teacher, assistant principal, dean of instruction, associate principal for curriculum and instruction, and principal in a high school setting. I have supervised parent inclusion programs such as campus-planning committees, parent-teacher-student organizations, and campus booster clubs. Additionally, I have a wide array of previous and current supervisory duties related to school nurses and 504 and special education programs, which often directly impact children who are chronically ill.

Journey to the Problem

In February 2017, my then-nine-year-old son was diagnosed with CRMO. Like many families, we experienced times of extreme stress in the year before Brennan's diagnosis. We would learn later that CRMO is a "disease of exclusion," meaning that, quite literally, almost every other possible diagnosis would be tested for and ruled out. Tests as simple as an X-ray to diagnose a broken bone or as extreme as a surgical bone biopsy were required in the year before receiving an official diagnosis. During this time, we struggled as a family to help our son maintain his usual level of academic achievement. As an educator, I was very concerned that my son was "falling behind," as his health was rapidly declining. In the months leading up to his diagnosis, Brennan required a variety of modifications and accommodations to his physical and academic school programming. I found that asking the school system to treat my child differently during this time was met with resistance, primarily because of the lack of diagnosis. Despite my professional experience, when my role expanded to include being the parent of a student with a chronic illness, I had few resources to gain the help we needed as a family. During our son's health crisis, I had to rely on the strength of my friendships with district employees to respond quickly to the medical requests being made of the school by Brennan's doctor. It was beyond the scope of my abilities in the midst of a personal crisis to find and complete forms required by the school to allow for homebound education. As I navigated the process of asking the district to provide my child with 504 protections and homebound services, I found myself completely overwhelmed. I was also angry at the school, despite its willingness to help us, when I received attendance letters warning of the dangers of truancy. Although I was a very experienced member of the educational community, I was unable to navigate the nuances of the system alone.

As my role moved from the parent of a child who is chronically ill to the “teacher” in our parent support group, many parents of sick children turned to me to vent about struggles they had faced with their children’s schools or for advice on how to write 504 plans. Because I had lived their situations, I wanted to provide resources to anyone who reached out to me. In May 2017, I was invited to the CARRA conference to participate in a parent workgroup with doctors specializing in CRMO. During this meeting, doctors and parents discussed school efficacy in helping children who are chronically ill; at that point I began to believe that the lack of communication and knowledge of available resources was what led to the negative perceptions I heard during visits to the hospital and at the conference. As a result of those meetings, this workgroup created a CRMO awareness website including educational resources. After fielding many parent phone calls, attending a national rheumatology conference as a parent participant, designing the CRMO foundation webpage information on 504 resources, and participating in several 504 meetings for parents within the support group, I determined the necessity for more information to help address similar problems discussed by many parents. I found the need for a communication tool to be developed to help parents navigate their role as an advocate for their child to improve communication among all stakeholders so that positive student outcomes can occur.

Significant Stakeholders

There are a variety of significant stakeholders involved in this study. Children who suffer from CRMO, as well as their families, are the most significant stakeholders engaged in the context of this problem. Children who are chronically ill face many hurdles related to their health issues. These children face social, emotional, physical, and academic challenges for prolonged periods (Boles, 2017; Compas et al., 2012; Lum et al., 2017). These challenges need to be mitigated as much as possible to improve quality of life for this subset of students. Parents are the stakeholders who carry the most substantial burden in the context of this study. In their role as medical caregivers, parents are concerned for the health of their child while being overwhelmed by an educational bureaucracy that they do not understand (Martire & Helgeson, 2017; Oliver et al., 2018). Parents who are asked to serve as the primary communicator between their child’s doctors and their child’s educational community deserve a well-developed communication tool that can be used to establish clear communication goals that will benefit their child.

Additionally, teachers are directly impacted by the research involved in this study. School district employees who are faced with the challenge of maintaining academic rigor for students facing chronic illnesses need tools to accomplish this task. Teachers are not expected to be trained in the management of daily health for their students, yet if they do not provide additional resources to students who are chronically ill, the students will not be able to reach their full potential (Bonaiuto, 2007; Maslow et al., 2012). Given more information, teachers can become essential partners in the health of their students who are chronically ill. Additionally, teachers have the power to positively impact the social and emotional well-being of students with chronic illnesses in their classrooms by helping to manage classroom dynamics (Bonaiuto, 2007). Teachers play a crucial role in the emotional and academic well-being of their students.

Finally, extended school district personnel such as school nurses and administrators provide extensive leadership in the coordination of services and connection of families to the school. The more information that nurses and administrators have, the more likely they are to be able to create positive outcomes for the sick students within their school settings. School nurses are often the frontline defense against catastrophic health incidents for students who are chronically ill in schools. The nurses' access to information and the ability to act in a medically appropriate way could be lifesaving for students (Bonaiuto, 2007). School administrators who become knowledgeable about the unique needs of their students are in a position to commit resources and find creative solutions to problems. Once true partnerships exist among all stakeholders, advocacy can begin for children with chronic illnesses.

Important Terms

Chronic illness. A chronic illness is one that persists over a prolonged period of time, often defined as three months or more. Additionally, a chronic illness limits a person's daily activities and requires medication, a special diet, or assistive programs to manage the illness (Thies, 1999).

Chronic nonbacterial osteomyelitis (CNO). CNO is the broader term used to describe an autoinflammatory bone disorder that typically presents as an insidious onset of bone pain with or without localized swelling, warmth, and tenderness. CNO can be in one bone or can be multifocal. Common bones involved include the pelvic bone, vertebrae, and clavicle, but any bone can be involved. Symptoms may include persistent inflammation, bone destruction, severe continuing pain, growth disturbances, functional limitation, and pathological fractures (Oliver et al., 2018).

Chronic recurrent multifocal osteomyelitis (CRMO). CRMO is interchangeable with CNO as defined above, except that the word "multifocal" in the term implies that a variety of bones are involved in multiple locations; thus, CRMO is used for patients with more than one area of disease activity (Oliver et al., 2018).

Key communicator. In this study, key communicator describes the role taken by a chronically ill child's caretaker in leading communication or bridging communication gaps among all stakeholders, specifically the child, school system, and medical community.

Section 504 plan. A Section 504 plan is a formal written plan to address the academic needs of a child with a variety of physical or mental impairments. The plan is often appropriate for use with chronically ill children (Clay, 2004).

Closing Thoughts on Chapter I

A communication or navigation guide that helps caretakers bridge the communication gaps found among the school, home, and medical communities is necessary to ensure that parents are comfortable in their advocacy role. Additionally, a toolkit of previously identified effective strategies aimed at improving educational outcomes for children who are chronically ill was made available on a public website to ensure that all stakeholders have more access to critical information. Caretakers armed with information on school-provided resources, as well as technologies and therapies recommended by the medical community, can vastly improve outcomes for students who live with chronic conditions. This study sought to identify struggles encountered by parents in their role as an advocate for their child, as well as understand why parents feel these obstacles exist. Additionally, the study took identified best practices that caretakers had previously utilized to connect their children with chronic illnesses to academic supports in schools. These best practices and obstacles informed the construction of a communication tool for parents with chronically ill children.

Though there is acknowledgment in the literature that chronic illnesses create obstacles in the academic arena for students, there is little information available to parents or educators on how to overcome those obstacles. By focusing on artifacts aimed to increase communication through the study of parent barriers and best practices, this study hopes to fuel discussions and further research on how the academic and medical communities can work together for the overall well-being of the children in their care. As a researcher with a unique perspective, a stakeholder in two of the three identified communities (home, school, medicine), I explored the obstacles faced and successes had by families in their advocacy role. I want to enable these parents—who are often facing one of the most challenging times in their life—to have easy access to information that could aid them in their parent advocacy role.

CHAPTER II

REVIEW OF SUPPORTING SCHOLARSHIP

Chapter II presents prior literature related to the impact of chronic illness on a variety of stakeholders in the educational setting. A brief overview of what defines a chronic illness is followed by a historical review of how chronic illnesses have previously been addressed in schools. This historical background is vital to understanding the medical and legislative advancements that have been developed over time, which have led to an increased need to focus on children who are chronically ill. The action research and autoethnographic frameworks guiding this study are examined, as is the critical disability theory (CDT). Next, the chapter examines prior literature on the student voice concerning the social and emotional limitations of children with chronic illnesses. The section on student voice is followed by a review of literature related to chronic illnesses and the connection to absenteeism. The impact shown in previous literature of chronic illnesses on parents of children who are sick and the parent role of serving as a case manager is discussed, followed by a review of educator beliefs in their ability to educate students who are chronically ill in their classrooms. The chapter's conclusion reviews the gaps identified in previous literature and stresses the continued need for further study to address how to increase communication for all stakeholders to improve the plight of children who are chronically ill in our schools.

Overview and Historical Background

Chronic illness differs from acute illness in a variety of ways. An acute illness in childhood is one that can be easily diagnosed and treated in a short amount of time, such as a cold or the flu. Opposite of an acute illness, a chronic health condition is one that has

> a biological basis that . . . is expected to last for at least 3-12 months, and is accompanied by one or more of the following consequences: 1) limitations in routine day-to-day functioning; 2) reliance on compensatory modalities such as medications, special diets, and assistive devices; and 3) a need for services beyond routine medical care. (Theis, 1999, p. 393)

Compas, Jaser, Dunn, and Rodriguez (2012) offered additional insight into the chronic illness definition by including that children who suffer from chronic illnesses often also suffer from episodes of acute illness. A chronic disease limits a student’s ability to participate fully in the educational experience. However, medical advancements have increased the number of students with chronic illnesses in mainstream schools (A'Bear, 2014; Baird & Ashcroft, 1984). Globally, children with complicated medical issues are attending schools in higher numbers. There are more than 200 chronic physical conditions that affect school-age children. The most common chronic illness, asthma, impacts 10 million American youth under the age of 18 (Basch, 2011). According to the National Health Interview Survey, which includes only 25 of the estimated 200 possible physical conditions, 6.5% of school children in the United States have a chronic disease. Additionally, 31% of children under the age of 18 will at some time in their life be considered to have a chronic health condition (Clay, 2004; Thies, 1999). More recent literature has suggested that 1 in 4 children receives a diagnosis of chronic illness in their lifetime, meaning that 10% to 30% of children are living with a chronic condition (Boles, 2017; Kish et al., 2018). Prevalent chronic conditions found in schools today include asthma, eczema, diabetes, epilepsy, congenital heart disease, and cancer (Mukherjee, Lightfoot, & Sloper, 2000). Rarer chronic conditions include arthritis, Crohn’s disease, sickle cell anemia, spina bifida, and cystic fibrosis (Clay, 2004; Thies, 1999). It is difficult to pinpoint the exact number of chronically ill students in the public school system today. Even studies identified in this review include significant variations in the number of students who are chronically ill in schools. However, the numbers suggest “that most medium to large secondary schools would include affected pupils” (Mukherjee et al., 2000, p. 60). These numbers create a situation whereby “students with chronic health conditions are at the intersection of health and education systems” (Thies, 1999, p. 382). School systems must find a way to include the increasing number of students who are chronically ill in all aspects of the educational experience. To move forward, we must review how these children have previously functioned in the school setting.

Historically, students with chronic health conditions did not attend schools. Over time, compulsory attendance laws, as well as legislation aimed at increasing inclusivity in education, increased the number of students with chronic illnesses attending schools (Baird & Ashcroft, 1984). Previously, children with chronic illnesses were often excluded from school or sent to specialized schools (Baird et al., 1984). Students with mild symptoms of chronic disease enrolled in schools, and those who suffered more severe conditions were rarely educated in the public system (Baird & Ashcroft, 1984; Terzi, 2008; Walker & Jacobs, 1984). “The primitive state of medical treatments” allowed students “little functional time between onset and death” (Walker & Jacobs, 1984, p. 30). Between 1880 and 1940, health-impaired children entered segregated special education classrooms as tuberculosis and polio epidemics created the need for disease containment, which resulted in segregated programs for medically fragile students that continued for nearly half a century (Walker & Jacobs, 1984). In the mid-20th century, as public health institutions became increasingly popular in large cities, the introduction of school nurses grew in popularity. School nurses were seen as a resource to reduce absenteeism and to teach effective disease-control methods (Walker & Jacobs, 1984). By 1970, an increasing number of chronically ill children were moving out of segregated classrooms and entering mainstream educational settings. Prior research has suggested this increase as being the result of improved medical advancement and increased exposure to academic content for chronically ill students (Baird & Ashcroft, 1984; Walker & Jacobs, 1984). Legislation adopted in 1975, Public Law 94-142, guaranteed students with disabilities access to public education under the 14th Amendment to the United States Constitution. Public Law 94-142, reauthorized in 1997 as the Individuals with Disabilities in Education Act (IDEA), is still the most applicable piece of legislation for students who are chronically ill (Clay, 2004; Thies, 1999). While Public Law 94-142, IDEA, and the Americans with Disabilities Act (ADA) increased the numbers of students with chronic illnesses in mainstream classrooms, the quality of instruction received by these students was questionable.

While IDEA and ADA legislation opened avenues to inclusion for special education students, the same inclusivity was not apparent for those with chronic illnesses. Although the 1970s brought to light many necessary reforms needed for disabled children, “unmet educational needs of chronically ill children were not addressed . . . as thoroughly as were those of other handicapped children” (Walker & Jacobs, 1984, p. 35). In the mid-1980s, researchers began to question the applicability of special education laws to children who were chronically ill. In a review of policy needs, Baird and Ashcroft (1984) questioned the protection of chronically ill children under Public Law 94-142. The authors determined that 2 of the 11 categories in which students could be labeled “handicapped” apply to several chronic illnesses. The categories of “orthopedically impaired” and “other health impaired” were found to be broad categories that could be used by some students with chronic illnesses to qualify for protections defined in Public Law 94-142. However, multiple studies at the time determined that often children who were chronically ill were in need of related services such as counseling, home or hospital instruction, and physical or medical services, but they were often not in need of specialized instruction (Baird & Ashcroft, 1984; Baird et al., 1984; Walker & Jacobs, 1984). Therefore, students who were chronically ill at that time often did not qualify for special education services or protection. Baird and Ashcroft (1984) pointed out that “there can be no related services without special education” (p. 93). Though Baird and Ashcroft (1984) were the first to question how special education legislation is related to chronic illness, other researchers later identified related services as necessary for ill students. Walker and Jacobs (1984) suggested that students with chronic illnesses could benefit significantly from related services such as support therapies, physical modifications, counseling services, and school health services. The litmus test established by Public Law 94-142, as well as several state laws built on the federal law, includes the “adverse effect test,” meaning that the illness has to be severe enough to prevent a student from achieving success in the regular education setting (Thies, 1999; Walker & Jacobs, 1984). Therefore, although students who are chronically ill often need related services, they rarely qualify to receive those services through special education legislation.

Studies continued to explore how to ensure that students who are chronically ill can be provided with legislative protections. Literature in both the 1980s and 1990s identified the adverse effect test as a litmus for identifying a child’s needs. The adverse effect test states that a child must fail or have poor academic performance before interventions are suggested. Kathleen Theis (1999) stated, “Academic performance must be compromised before a child is deemed in need of educational services” (p. 393). Therefore, students who are minimally successful but not necessarily failing could be missed. Students with chronic conditions should not be required to fall behind academically to receive support. Unfortunately, children who are chronically ill rarely fit into the established guidelines for special education programs and are often unserved despite their need for related services such as psychological services and counseling (Clay, 2004). A federal mandate should be developed to provide protections for children who are chronically ill or to ensure that the necessary related services can be provided to them (Thies, 1999). In the healthcare world,

> children with special health care needs' are often entitled to the protection of legislation that allows for special school programming while students who have a "chronic health condition" are often a population not entitled to special services in the educational setting. (1999)

This distinction is critical to understanding the historical support provided to students who are chronically ill in public schools in the United States. If special education legislation does not always apply to a growing population of children with chronic illnesses in public schools, how can educators ensure that these children's needs are met?

More recent literature has sought to explore how to provide students with chronic health conditions the services they need but do not qualify for under special education law. Several researchers have suggested that 504 plans may help meet the needs of students who are chronically ill (Clay, 2004; Moses, Gilchrest, & Schwab, 2005). In a review of Section 504 of the Rehabilitation Act of 1973 and its application to students with chronic illnesses, researchers have pointed out that for a student to qualify for a 504 plan, the local school district must have well-developed policy guidelines (Moses et al., 2005). Although Section 504 is not new legislation, its usage is gaining in popularity, largely because of those with chronic medical conditions who otherwise do not qualify for special education under the provisions of IDEA (Clay, 2004; Moses et al., 2005). Clay (2004) pointed out that despite Section 504 being a federal mandate, "many children fail to receive appropriate educational accommodations due to a shortage of resources in schools” (p. 52). As many students who are chronically ill do not qualify for protection and services within special education law, the 55-year-old provisions held in Section 504 are currently gaining popularity as a way to meet the related service needs of children who are chronically ill in schools.

Alignment with Action Research Traditions

Action Research and Autoethnography Frameworks

The action research and autoethnographic frameworks complement one another well when studying phenomena in schools. According to Anderson, Herr, and Nihlen (2007), action research is neither new nor trendy. Action research has a variety of definitions in the literature, but at the core of all of the definitions is the study of the practitioner’s interaction to social reality (Anderson, Herr & Nihlen; 2007, p. 1.) When action research is applied to education, it provides an “insider” view of a previously hidden educational phenomenon. Action research began with teachers who utilized their classrooms as laboratories. In this way, teachers were using their own experiences and reflections to drive practice. Early action research developed into multiple case studies utilizing educator common sense more often than scientific inquiry.

Autoethnography has been defined as “a qualitative method that utilizes ethnographic methods to bring cultural interpretation to the autobiographical data of researchers with the intent of understanding self and connection to others” (Chang, 2016, p. 56). This definition provides an excellent understanding of how autoethnography can aid action research. Replacing the word “researcher” with “teacher” in the definition of autoethnography rewrites it to mean that autoethnography is a method that gives teachers an understanding of themselves and their connection to others in their classrooms and schools.

> Autoethnography benefits greatly from the thought that self is an extension of a community rather than it is an independent, self-sufficient being, because the possibility of cultural self-analysis rests on the understanding that self is part of a cultural community. (Chang, 2016, p. 26)

Educators as action researchers are valuable in understanding the phenomena that occur in schools. When combining these two frameworks, educators as researchers become a voice for a broader cultural community.

Action research and autoethnography have similar advantages and disadvantages. Kurt Lewin was the first to develop a theory of action research that made it respectable within the social sciences. He believed "that knowledge should be created to solve real-life situations" (Anderson, Herr, & Nihlen, 2007). Likewise, Chang (2016) suggested that the individual is the starting point of all culture. Thus, individual educators can use the reflective methodologies found in the autoethnographic framework to conduct action research in their schools. The advantages of this insider action research includes a "tacit knowledge of a setting," as well as a way to make the voices closest to a situation or phenomenon in education matter (Anderson, Herr & Nihlen, 2007, p. 3). Thus, another advantage of action research is observed in cycles of plan-act-observe-reflect. An additional advantage of this type of action research is that it leads to more agency and empowerment for teachers (Anderson, Herr & Nihlen; 2007). Likewise, autoethnographic methodology produces empowerment for researchers. However, Chang provided a critique of autoethnography that illustrates the existing "tug-of-war" between its advantages and disadvantages. He suggested two positions—objectivity and subjectivity—in social science that create this tug-of-war. Chang (2016) identified objectivity as the position that "promotes the 'scientific,' systematic approach to data collection, analysis and interpretation that can be validated by more than researchers themselves" and suggested that subjectivity "allows researchers to insert their personal and subjective interpretation into the research process" (p. 45). This tug-of-war can serve as both a strength and weakness of autoethnography; it is up to the researcher to ensure that integrity is maintained in the study, allowing for autoethnography to be a powerful method. Additionally, action research has several disadvantages, such as a lack of subjectivity, that researchers must embrace and acknowledge (Anderson, Herr, and Nihlen; 2007). To avoid bias that may occur as a result of the lack of subjectivity, researchers have suggested the idea of a "critical friend" to help ensure that the researcher does not bring practitioner bias into the field (Anderson, Herr, and Nihlen; 2007; p. 130). The strength of both the action research and autoethnographic methods relies on the proximity of the researcher to the study; thus, researchers must work to ensure that biases are acknowledged and minimized to produce the most impactful study. This study sought to use both my experience as mother of a child who is chronically ill and my position as an administrator in a public school to engage in autoethnographic action research to benefit students with chronic illnesses in the future.

Conceptual Framework

Several conceptual frameworks were considered for use in this study. Students who are chronically ill may suffer from physical impairments that limit their daily ability to function as their nonill peers do. Thus, at first glance, a framework based on CDT appeared to be a good fit for this study. At a disability conference held at Lancaster University in the United Kingdom, CDT was described as a theory that

> adopts a version of the social model based on the principles that (1) disability is a social construct, not the inevitable consequence of impairment, (2) disability is best characterised as a complex interrelationship between impairment, individual response to

> impairment, and the social environment, and (3) the social disadvantage experienced by disabled people is caused by the physical, institutional and attitudinal (together, the "social") environment which fails to meet the needs of people who do not match the social expectation of "normalcy." (Hosking, September 2, 2008)

Hosking's definition of CDT accounts for a variety of factors that are important to this study. His definition addresses the relationship between ill students and their social environment at school. Additionally, the theory considers the failure of the environment, the school system in this case, in meeting the needs of ill students who may not be seen as matching the social expectation of normal. The failure of the CDT framework is the perception that the impairment, CRMO/CNO in this case, is not the cause of the failure to appear normal. Current law related to disability education in the United States mandates that specific requirements be met in order to receive special education services for disabled students. The perception of disability as a social construct makes theoretical sense; however, it does not fit into the current realities of disability education practice.

A second theory, Bandura's social learning theory, was considered in conjunction with social justice ideology as a conceptual framework for this study. The social learning theory suggests that if people view modeled behaviors that are aligned with their core values, they are more likely to adopt the modeled behavior for themselves (Bandura, 1977). Connecting Bandura's theory with modern social justice practices could produce essential changes in behavior in public school settings. Social justice ideology suggests that all students, regardless of their differences, should be afforded agency in their educations (Marshall & Oliva, 2010). Social justice leaders have suggested that the focus of increasing student agency is essential "to build truly integrated, socially just schools and districts, not just for students with disabilities but for all students" (Marshall & Olivia, 2010, p. 190). While Bandura's theory suggests that the behavior of nonill peers and teachers could be modified to positively impact the social and emotional well-being of students who are chronically ill, neither Bandura's theory nor social justice ideology addresses the medical realities faced by CRMO/CNO students.

CDT, social justice ideology, and the social learning theory do not work as independent conceptual frameworks for this study. However, they all have valuable components relevant to this study. An interesting, though not well-established, framework known as the capability perspective on disability provides a combination of all of the previously discussed frameworks. In her book, Terzi (2008) asked some vital questions about disabilities while establishing her capability framework. She wanted to know the relevancy of the causes of a disability from a theory-of-justice standpoint. She asserted that regardless of the cause of a disability, a person who is disabled faces a power imbalance that needs to be rectified. Terzi also asked how the power imbalances can be equalized to provide relief to the disabled. "The concept of disability is articulated in terms of differences to be positively recognized, rather than stigmatized" (Terzi, 2008, p. 97). Terzi went on to argue that if the perspective can be switched from a position of disability (what a person cannot do) to a position of capability (what a person can do), there will be more social justice and equity in special education. Finally, Terzi's capability theory connects her theoretical position to the practical application necessary to achieve her theory.

> Although difficult to conceptualize, educational equality has a crucial role to play at two interconnected levels: the level of ideal theory, concerned with the norms and values, and the level of policy, where those norms and values can be enacted. (Terzi, 2008, p. 180)

The positive approach to capability and the practical application of Terzi's theory make the capability perspective the most applicable conceptual framework for this study in seeking to create tools to equalize the capability of students diagnosed with CRMO/CNO.

Most Significant Research and Practice Studies

Student Voice

To determine how schools can meet the needs of children who are chronically ill, the first thing to examine is what the literature says about how those students are doing in their schools. Students with chronic illnesses often suffer social and emotional stressors in addition to their physical limitations. These stressors can be related to the amount of time spent in the medical community rather than the school community. Robert Massie (1984) identified that ill children spend their lives learning to wait. They are always in waiting rooms for various appointments, as well as waiting for the next treatment to decrease symptoms and increase healing. This waiting also applies to their commute between being students and patients. As patients, waiting is a prized skill that young children who are chronically ill often use during their education. In the school system, waiting is a less prized attribute than it is in the medical community. Unhealthy children are constantly negotiating which skillset to use in which setting (Massie, 1984). This negotiation between skillsets may be responsible for social delays. Also, periods of absenteeism due to the commute from the medical community to the school can cause students anxiety as a result of the inability to catch up with their peers (Sexson & Madan-Swain, 1995). This sense of falling behind, coupled with a lack of academic success, can lead to school-phobic attitudes. School phobia is a stressor that is seen in several ways; most commonly noted is the refusal to attend school because of fear and separation anxiety (Shiu, 2001). Additionally, adolescence is a time of wanting to "fit in" among peer groups. "Simply being different by virtue of needing to take medication, having even minor or transitory restrictions of physical education and sports, or needing to follow dietary regimes can cause major differences" (Walker & Jacobs, 1984, p.45). The cumulative effects of negotiating between the social norms in the medical and educational realms, isolation from peers, and the desire of adolescents to be like their peers create increased stressors for students with chronic conditions in school.

Self-image is a factor in the social and emotional development of all students. Students who are chronically ill show signs of having a weaker self-image than their healthy peers. In fact, in a meta-analysis of self-esteem indicators, children who are chronically ill, especially sick females, showed signs of having more fragile self-esteem than their nonill peers (Pinquart, 2013). Even students who are keeping up with coursework can suffer from a more inferior self-image than their healthy peers (Erkolahti & Ilonen, 2005). Students are often overwhelmed by the day-to-day tasks of keeping up academically. The emotional and academic tolls of "doing school," combined with medication side effects that can include decreased ability to focus, impact on short-term memory, chemical stimulants, weight gain, and extreme fatigue, lead to student feelings of failure (Thies, 1999). These feelings of failure can result in a lower self-image in students with chronic conditions that negatively impacts their academic performance.

Additional factors that influence self-image and negatively impact student success were found by a 2014 study using focus group interviews designed to identify factors to support students who are chronically ill. The study identified fatigue as one of the most limiting factors to academic success for students who are chronically ill. The students interviewed collectively expressed having often been pulled from classes to catch up on previously taught material, thereby missing the new material covered when they were healthy enough to attend school (A'Bear). Nearly half (45%) of students with chronic health conditions have reported feelings of falling behind their peers, while 35% of students qualifying as other health impaired have reported failing grades (Thies, 1999). “Falling behind academically leads to catching up, and catching up takes time away from keeping up” (Thies, 1999, p. 395). Another study comparing the perceived competence in scholastic aptitude and temperament of children with a variety of chronic illnesses versus their nonill counterparts produced several interesting conclusions. The authors determined competency scores on a variety of measures to be lower for the ill group than the healthy group. The finding that a long-term physical illness contributes to the competency felt by a child in school is compounded by the fact that disease is seen as a contributing factor for lowered educator expectations of ill students (Irwin & Elam, 2011; Perrin, Ramsey, & Sandler, 1987). Irwin and Elam (2011) suggested that educators have the ability to increase ill children’s competency and their quality of life. The described element of competency connects to self-image because it explains that not only is self-perception decreased for a chronically ill student, but others’ perceptions of the sick student are lower as well. Competency could be related to academic, social, and emotional feelings of inadequacy, which directly supports several pieces of literature showing that students who are chronically ill often feel left out and unable to compete with their healthy peers. The social and emotional well-being of students with chronic health conditions impacts their self-image as well as the perceptions of those around them.

Other researchers have found groups of students with chronic illnesses who were thriving despite their illnesses. Ferguson and Walker (2014) found a group of adolescents who were chronically ill whom they labeled as “resilient.” These adolescents were experiencing social and emotional successes in dealing with their chronic illnesses and had the following three things in common: higher rates of optimism about their circumstances than their peers, clear goals for their futures, and deep connections to their schools (Ferguson & Walker, 2014). Also, Maslow, Haydon, McRee, and Halpern (2012) found that students with chronic health conditions possessing what they called “connectedness” show higher academic attainment throughout their adolescence. Connectedness for Maslow, Haydon, McRee, and Halpern (2012) is made up of several factors, including an influential mentor, quality parent relationships, religious attendance, and school connectedness. The authors were able to determine that school connectedness is related to college graduation rates for chronically ill adolescents (Maslow et al., 2012). Several authors determined isolation to be one of the most challenging social factors faced by students with chronic illnesses (A'Bear, 2014; Boles, 2017; Gan et al., 2018). Therefore, it is essential to find ways to integrate students who are chronically ill into the social structures at school to create the feelings of connectedness described as necessary in the literature. Several studies have shown that students with increased access to technological devices describe feeling more connected to their peers and the school community (A'Bear, 2014; Boonen & Petry, 2012). The goal of school systems should be to replicate these previous practices that have allowed students with chronic illnesses to thrive.

It is essential to reflect on the emotional well-being of students who are chronically ill. In an autoethnographic reflection, Robert Massie, who served as a chaplain in a children’s hospital and suffered from hemophilia throughout his life, described what chronic illness feels like to children. He reminded readers that the word “chronic” is paramount to understanding chronic illnesses. In addition to the constant repetitive nature of these illnesses, he wanted readers to understand that children do not suffer in isolation. Instead, entire families and school systems are engulfed in trying to understand the children who are living with chronic illnesses. Massie (1984) stated, “Each parent and child I worked with in the hospital was strikingly different, yet the looks of anguish, uncertainty, and relief were often the same” (p. 17). School plays a critical role in a child’s development—academically, socially, and emotionally. Children with chronic health conditions often have different academic, social, and emotional needs than their healthy peers. “Education acts as a prime agent in socializing the child,” which is especially true for sick children (Baird & Ashcroft, 1984, p. 91). Finding ways to allow for full social, emotional, and academic participation for children who are chronically ill is critical to their success in school and their emergence as productive adults.

These studies provide evidence for a need to create tools that can be used by parents, medical professionals, and schools to create a better home and school connection for families of students who are chronically ill. Understanding the voice of the student with a chronic condition ensures that ill students receive all the necessary resources and accommodations. This helps a subpopulation of students who are often overlooked to stay connected in their academic content, as well as to ensure social and emotional support despite the ability of these students to attend school physically.

Chronic Illness and Absenteeism

Chronic illness and chronic absenteeism are often found together in the literature related to chronic conditions in childhood. Absenteeism related to chronic health conditions negatively impacts a child’s academic performance; however, specialized educational settings are challenging to obtain for children who are chronically ill (Thies, 1999). If a student with a chronic health condition is a minority or is living in poverty, the impact of absenteeism on academic performance is magnified (Minier et al., 2018). A study conducted in Australia identified problems faced by students who have chronic illnesses in school and suggested recommendations to overcome the identified barriers (Shiu, 2001). Additional studies have acknowledged that children with chronic conditions are attending schools at an increased rate

(Bonaiuto, 2007; Kaffenberger, 2006; Leroy, Wallin, & Lee, 2017). The problems associated with more students who are chronically ill attending school include increased absenteeism and attaining full incorporation of these children socially and emotionally in school (Shiu, 2001). Although homebound education services and hospitalization schools are options to reduce the impact of missed instructional time for students with a chronic illness, the rules surrounding those services makes usage very difficult (Baird et al., 1984). Most states require a child to be absent for four weeks before beginning educational services outside of school. Most states require a minimum of four hours of instructional time to account for missing five days of instruction (Baird et al., 1984). These requirements existed 35 years ago, and little has changed in requirements today. In the proposed attendance accounting handbook located on the Texas Education Agency's website for the 2019–2020 school year, one hour of homebound education is equivalent to one full day of attendance at school. Students must be absent for a minimum of four weeks to be provided homebound instruction, and four hours of homebound instruction per week is equivalent to a full week of school attendance (Texas Education Agency, 2019). The process to begin homebound or hospitalized schooling requires complicated paperwork and meetings in which parents are asked to serve as the key communicator or go-between from the school to the medical community (Baird et al., 1984). While services vary from state to state in the United States, most require formal individualized educational plans (IEPs) through IDEA or individualized accommodation plans through Section 504 (Clay, 2004). Burdens such as paperwork, certified professionals, funding, and locations can create a situation in which homebound or hospitalized education is delayed or wholly denied for chronically ill children (Baird et al., 1984; Shiu, 2001). Many chronic illnesses result in increased absenteeism from school with delayed or denied specialized educational settings. Even though the cause of absence is a chronic illness, the absenteeism hurts the academic performance of students.

An illness has negative implications on school functioning even when the child who is ill makes it to school regularly. In addition to absences, schools must remember that even a student who is present is often on strong medications that can have disorienting effects, thereby impacting the student's ability to entirely focus and perform to their full potential (Walker & Jacobs, 1984). Chronic illnesses often create decreased stamina and concentration in children, making intermittent absences necessary to regain strength (Walker & Jacobs, 1984). As discussed, many states require students to be absent anywhere from two to four weeks before interventions such as homebound or hospitalized education can begin. Statutes ensuring that students are out of school for long periods before intervention begins, decreased student stamina, and medication disorientation all lead to increased anxiety for students, parents, and educators alike (Terzi, 2008; Walker & Jacobs, 1984). These factors combine to ensure that students who are ill have significant gaps in learning before interventions are attempted.

Not all of the literature has agreed that illness is the primary factor in increased absences. Unlike much of the other literature in this review, an Australian study looked at absenteeism as a root cause of the social maladjustment that can occur in children who are chronically ill at school (Shiu, 2001). The survey answers in Shiu's (2001) study identified that many chronically ill students became school-phobic. Participants reported often being left outside of the social circles developed by students, thereby making attendance in school socially awkward after prolonged periods of illness. The Australian study found it imperative that school counselors, teachers, and families work together to support positive attendance for children because "the school may represent the only place where the chronically ill student can be viewed as a child and student rather than a patient” (Shiu, 2001, p. 241). The burdens of bureaucracy, as well as social maladjustment identified in the literature, may create hardships for families that result in increased absences and delays for measures that would increase instructional time for ill children.

Although evidence from a variety of studies has suggested that chronic illness increases absenteeism, there are conflicting reports on the effect of those absences throughout the history of the provided literature. In a study by Fowler, Johnson, and Atkinson (1985), pediatricians were asked to identify chronically ill patients and then rate students with chronic conditions on a scale from 1 to 4 related to their health and mobility. The chronically ill group averaged 16 days per school year absent, while their healthy peers were absent an average of 7 days. However, when looking at the achievement test scores of the students who were chronically ill compared to their absence rates, no significant association was found between the number of days absent and lower achievement. Socioeconomic factors, as well as race, were seen as better predictors of achievement scores than attendance (Fowler, Johnson, & Atkinson, 1985). The Fowler, Johnson, and Atkinson (1985) study is the only research found in the literature suggesting that the increased absences created by chronic conditions does not adversely affect the students with increased absences. However, these findings could be attributed to the success rates of different populations on standardized exams rather than absences and illness. Many other authors have included the negative implications of chronic absenteeism that chronically ill students struggle to overcome (Basch, 2011; Bonaiuto, 2007; Leroy et al., 2017; Maslow et al., 2012). In their meta-analysis, Lum et al. (2017) suggested that most literature related to chronically ill children has reported decreased attendance for those children. This decreased attendance results in compounded problems such as poorer interpersonal school experiences including relationships with peers, participation in events, and reported bullying (Lum et al., 2017). Though chronic absenteeism is a common theme, there are few solutions found in the literature to overcome the burdens created by increased absences for a student who is chronically ill.

Parent Burdens and the Role of Case Manager

Often, the entire family of a student who is chronically ill is impacted by illness in a variety of ways. Massie (1984) asserted that chronic illness impacts the entire family and extended support systems of a child with a chronic condition. Parent stressors can include financial, emotional, and psychological burdens that can spread to the siblings and extended members of the family. How a family responds to these stressors can often predict how a child will live with or overcome the illness (Massie, 1984). Melnyk, Feinstein, Moldenhouer, and Small (2001) are pediatric nurses who agreed that family stressors play an essential role in the health of a child with a chronic illness. They studied potential triggers and stressors for parents of chronically ill patients. In their study of 42 mothers of low-birthweight babies and their infants, the nurses found that one of the most stressful times for the parent of an ill child is school entry or school change. “When the child enters the school system, parent’s give up control of their child’s health care management during the day to teachers and other professionals” (Melnyk, et al., 2001, p.549). This time-bound stress model asserted that parent stressors are highest at times of disease diagnosis, developmental milestone, and school entry or change (Melnyk et al., 2001). The nurses who authored this study found that educating parents before, during, or even after stressful moments in disease development leads to increased parent coping abilities. Additionally, their infants also achieved higher developmental scores at their three- and six-month check-ups (Melnyk et al., 2001). The ideas provided in this study of instructional courses and decision-making strategies for parents could be applied to the educational setting to lower parent stress during school entry or school change.

Families of children with chronic conditions have reported a variety of stressors in the literature. Parents of ill children, particularly those in the United States, often learn that they must battle insurance companies for quality care for their children because chronic illnesses are often determined as preexisting conditions, and disease treatment involves a combination of expensive experimental medications (Massie, 1984). Additionally, parents often feel that they are battling the school system. A small qualitative study conducted by Hewitt-Taylor (2009) on parent perceptions of mainstream education in the United Kingdom found a theme of parent feelings of inadequacy at handling the coordination of medical and school teams. Parents are often asked to serve in the role of liaison between medicine and school systems though they have expertise in neither field. Hewitt-Taylor (2009) performed semistructured interviews with 14 parents of children who are chronically ill aged 18 months to 18 years. The interviews identified obstacles that parents described to mainstream education for their children with chronic illnesses. Parents often juggle appointments and meetings in the medical field and educational setting in which they are asked to act as the key communicator between both fields. Mainstream education requires coordination with a variety of services that parents reported as lacking in their school settings (Hewitt-Taylor, 2009). Parents reported feeling that they could not serve as the coordinator of services between the medical and school communities including doctor appointments, interventions, leisure time, and academic work (Hewitt-Taylor, 2009). Parents reported encountering a variety of obstacles including school staffing, funding, attitudes, and training as barriers to mainstreaming a child who is chronically ill in the education process even though the law requires that their child be included in a general education classroom (Hewitt-

Taylor, 2009). Parents are often the primary advocate in a variety of settings for their child who is chronically ill (Melnyk et al., 2001). This advocacy can be seen by the parents as battling for their child, which places them on the defensive in a way similar to how they deal with insurance companies. The parent stressors created by this advocacy with insurance companies and within the school system are well documented in the literature related to children who are chronically ill.

Parent perceptions of their child's abilities are fundamental as parents act in the role of advocate for their child. Some studies have suggested that parent perceptions may not align with those of their child or the educators who aid their child. In opposition to several other studies, Mukerjee, Lightfoot, and Sloper (2000) urged the school system to utilize caution when relying on parent perceptions alone for information related to students with chronic diagnoses. If parents are the sole information-givers between the school and the medical community, this cautious attitude could be incredibly valuable. "Parents are not a reliable source of information on their child's perspective . . . we do not know what assistance pupils themselves would like to help them overcome the difficulties they encounter" (Mukherjee et al., 2000, p. 60). This perspective challenges researchers to include students in the development of support plans and academic needs. Mukherjee et al. (2000) suggested that perhaps the child's perception of their own needs is the most critical perspective to be considered as school systems struggle to meet the needs of students who are chronically ill. Much of the literature has shown that although parents want to advocate for their child, they often feel unable to navigate the expertise needed to bridge the gap between home, the medical community, and school (Maslow et al., 2012; Perrin et al., 1987; Sexson & Madan-Swain, 1995). However, a gap exists in the literature to prepare parents for acting in the role of advocate for their child with a chronic illness. Because research has shown that parents are often expected to be the key communicator of their child's condition, tools must be developed to help close the preparation and perception gaps described by the literature.

Educator Beliefs in Their Ability to Educate the Chronically Ill

Teachers are charged with many roles and responsibilities in their daily jobs. The literature provides strategies currently employed by school systems to increase educator efficacy in the field of medically fragile students; however, those strategies lack implementation because of a lack of educator confidence. Shiu (2001) attempted to identify ways that educators are overcoming barriers faced by children who are chronically ill when attending school. Natural inclusion or mainstreaming was heavily identified as a positive strategy utilized by schools for students who are chronically ill (Shiu, 2001). Interestingly, mainstreaming is the most heavily identified strategy, yet it is also required by law in many parts of the world and has been for nearly 50 years (Baird et al., 1984). The primary reason identified by Shiu that educators feel ill-equipped to handle chronic illness is a lack of experience doing so. "Due to the relatively low incidence rates," it would be rare that an educator has previously been charged with dealing with a particular illness; therefore, teachers are "faced with unfamiliar problems which few of their colleagues have faced or understand" (Shiu, 2001, p. 241). In Shiu's geographically small survey, a large number of illnesses (49) was identified. The variety of illnesses described in this particular location supports the educator view that they lack experience in handling illness-specific concerns in addition to the varied requirements of an educator's job. The rareness of a disease ensures that teachers lack confidence in handling complicated medical issues that they would rarely see repeated in their careers.

In addition to their academic tasks, schools must develop and disseminate crisis response plans that all staff members are well-versed in using in the event of an illness-related emergency

(Walker & Jacobs, 1984). However, crisis intervention plans are only useful if the teachers using them have a moderate level of competence in utilizing the plan. Shiu's (2001) study, which took place in New South Wales, found that teachers feel ill-equipped to handle medical emergencies. The geographic location is vital to this study because schools in the New South Wales system do not include healthcare professionals such as school nurses. However, an American study also found that teachers in the United States lack the confidence to have children who are chronically ill in their classrooms despite the prevalence of school nurses in the United States (Nabors, Little, Akin-Little, & Iobst, 2008). How can educator competency be increased so that teachers are comfortable hosting medically fragile students in their classrooms?

Teachers need tools to gain competence in dealing with medical plans to support the growing number of students with chronic illnesses being seen in schools. Recommendations for overcoming the identified barriers in the school system include documentation and adherence to a specific medical plan, academic support, communication among home, school, and medical professionals, access to resources, coordination of services among home, school, and medical staff, emotional support, peer support, professional development, and physical access (Shiu, 2001). As previously discussed, the coordination of services between the school and the medical community is a difficult roadblock. In the absence of direct communication with medical professionals, educators are often asked to rely solely on parents for information related to the illness. Neither educators nor parents are equipped to train one another on how to handle the daily management of disease or medical emergencies (Cunningham & Wodrich, 2006; Hewitt-Taylor, 2009). Tools must be developed for teachers to increase communication so that their competency in applying the recommendations provided in the literature can help overcome barriers for children who are chronically ill in their classrooms.

American educators, despite the inclusion of school nurses, often lack confidence in dealing with students who are chronically ill. Many teachers are familiar with diseases such as asthma and report healthy confidence levels in dealing with the academic, social, and emotional needs of students in their care with common diseases (Leroy et al., 2017; Nabors et al., 2008). However, teacher confidence in their ability to meet the academic and social needs of a student decreases dramatically with a rarer diagnosis (Nabors et al., 2008). With estimates of school-age children who are diagnosed with chronic medical conditions varying between 10% and 20% of school populations in the United States, it is evident that increased training is needed for educators in the United States related to chronic medical conditions (Nabors et al., 2008). Nabors et al. (2008) suggested that school psychologists and school nurses serve as consultants to create the detailed health plans necessary for student success that would incorporate academic and social context for children with chronic conditions. Leroy, Wallin, and Lee (2017) pointed out that the majority of literature related to chronic medical management by school nurses is aimed at asthma. They suggested that additional studies need to be completed that place the school nurse in a position of case manager for other illnesses to determine if the school nurse can positively impact student health (Leroy et al., 2017). To increase the confidence of educators in dealing with chronic illnesses on their campuses, the licensed specialist in school psychology (LSSP) and school nurse could provide individual training needed for teachers who often serve as frontline responders to medical issues for children who are chronically ill attending schools.

As previously stated, educators must follow a well-developed medical plan that they often feel incompetent implementing. A study specific to diabetes education for teachers showed that 92% of educators expressed wanting more information on how to correctly accommodate for students with the disease in their classrooms (Cunningham & Wodrich, 2006). After disease-specific training, teachers were shown to be almost twice as likely to develop interventions or accommodations benefiting diabetic students in their classrooms (Cunningham & Wodrich, 2006). Walker's and Jacob's (1984) view that medical professionals and educators must collaborate to create individualized health plans supports Cunningham's and Wodrich's (2006) study. Previously, healthcare professionals have been granted the higher status of expert in this medicine/school collaboration. However, "a physician's assessment of educational concomitants of the illness is probably less valid in this situation than that of a variety of school professionals who are well acquainted with educational programming" (Walker & Jacobs, 1984, p. 39). Walker and Jacobs (1984) are not alone. Over time, many researchers have asserted that school leaders must take on the leadership role in the necessary collaboration between the medical community and the school, but a resource still has not been developed that allows for the creation of a well-developed medical plan in the school system.

Lack of disease awareness, the ability to communicate with medical professionals, and misaligned goals are the most commonly identified concerns discussed by the literature concerning teacher competency with ill children. In Shiu's (2001) surveys, teachers and parents discussed a lack of awareness of specific illnesses and a systematic way to ensure that information is passed on as school change occurs. In a similar study, parent and educator perceptions related to the competency of children were shown to be more closely aligned in the healthy-student group than in the chronically ill–student group (Perrin et al., 1987). This misalignment means that parents and teachers believe that the same skill level exists for their nonill children, but struggle to align their beliefs about their ill children. The misalignment of educator and parent competency ratings related to ill children reveals the need for further study into how these two adult groups view the abilities of students who are chronically ill (Perrin et al., 1987). In yet another study where nurses, parents, and educators were asked to select the most critical quality-of-life factors for children with chronic diagnoses, parents and nurses agreed that physical health is the most essential factor, while educators selected planning for the future as the most important factor in an ill child's life (Meuleners, Binns, Lee, & Lower, 2002). The diverging beliefs of what is most important to a child suffering from a chronic illness are enlightening. It seems that parents and medical professionals are focused on the daily struggles of chronic illness, while teachers are planning the futures of their ill students. This misalignment of priorities may be responsible for what many studies have described as a lack of communication between the teachers and parents of children who are chronically ill.

The importance of educator and home connection is abundant in the literature. An American study conducted by Sexon and Madan-Swain (1995) compared chronic illness over time in North America. Although the authors did not offer a specific treatment or intervention, the paper reinforced that the increased number of students who are chronically ill in the school system creates a need for the medical community, the school system, and families to continually cooperate with one another to ensure that the educational and social development of chronically ill students remains focused. The study examined the perceptions of school employees related to a lack of understanding or fear of the disease, perceptions of fragileness that lead teachers to fear challenging students who are chronically ill, and an overall belief that school personnel are ill-equipped to handle students in a medical crisis (Sexson & Madan-Swain, 1995). In addition to educator fears, healthcare provider attitudes related to disease, infection, and injury can often delay school reentry, creating a prolonged disassociation from school for chronically ill children. Sexon and Madan-Swain (1995) and others have suggested that school psychologists can act as liaisons among all groups to focus on faster school reentry and increased social and emotional health for physically ill students (Clay, 2004; Sexson & Madan-Swain, 1995). This recommendation would allow the home, school, and medical communities to have common academic goals, as well as offer protection for the social and emotional needs of children with a chronic illness.

Teachers have the power to positively impact the well-being of their ill students. However, if they are not careful, they can negatively impact their chronically ill students unintentionally. A student's social or emotional well-being can be impacted when teachers who are uncomfortable when faced with medical scenarios increase restrictions on their chronically ill students to shield them from harm (Massie, 1984; Terzi, 2008; Walker & Jacobs, 1984). Massie's (1984) reflection on his childhood experiences with chronic illness included a vivid memory of returning to school after a hospitalization to be told that an assembly had been held during which students were threatened with Saturday detention if they dared to touch or play with him. This well-intended assembly designed to keep him safe resulted in feelings of fear and humiliation that lasted throughout his life (Massie, 1984). Academic performance can suffer when well-meaning teachers have lower academic expectations for students with illnesses (Nabors et al., 2008). However, educators have the unique opportunities to positively instruct peers on how to respond to students who may look, feel, or act differently because of a chronic illness, thereby improving school experiences for students with chronic conditions (Walker & Jacobs, 1984). Mukerjee et al. (2000) identified four areas in which students need support in order to prevent negative impacts while in school, as reported by parents and teachers. The four areas are managing their medical condition, overcoming absences, relating to peers, and managing school social life (Mukherjee et al., 2000). Additionally, the researchers identified that teachers who feel uninformed about chronic conditions worry about their ability to manage a health emergency, worry how much to push students who are chronically ill, both academically and physically, are concerned about peer reactions to chronically ill students, and lack the knowledge to appropriately discipline students who suffer from chronic conditions (Mukherjee et al., 2000). While most of the research on teacher perceptions of their ability to handle the challenges related to teaching students who are chronically ill is related to medical emergencies and the social and emotional health of the pupils, Mukherjee et al.’s (2000) study stands out for its inclusion of disciplinary issues related to children with chronic illnesses. The literature has shown that teachers and school leaders must act as liaisons between school and medical communities. Teachers have the power to implement powerful practices to increase the functionality of students at school, but they require disease-specific training and well-crafted health plans to be able to do so.

Gaps in the Literature

There are several noticeable gaps in the literature. An identified gap in the literature is the student’s/patient’s perspective about what they need to be successful in a variety of settings. An attempt to identify the student perspective was made in a study that occurred in three school districts in the United Kingdom, including both rural and urban school settings (Mukherjee et al., 2000). Mukherjee et al. (2000) investigated what is needed by students, teachers, and family members in terms of support to ensure academic engagement for students with physical disabilities and chronic illnesses. Despite their attempts to address the student perspective, Mukherjee, Lightfoot, and Sloper (2000) determined a lack of student voices or perceptions related to their illnesses in the literature. Mukherjee, Lightfoot, and Sloper (2000) were focused on including student perceptions about the support needed to allow them to be successful in school.

Interestingly, the authors found differences in educators and parent perceptions versus those of chronically ill students in several areas. An example of this perception gap is related to the school nurse. While parents and teachers reported often identifying the school nurse as someone students could turn to for counseling or disease-coping, the students themselves reported seeing the school nurse as having a precise medical role in their lives. Students in the study did not identify the nurse as someone from whom they would seek help to cope with the nonmedical conditions of their illness. Students reported perceiving the nurse as a member of the medical community, despite their location in the school (Mukherjee et al., 2000). A project by a large suburban school district that formalized the role of the school nurse as a medical case manager supports the student perception of the school nurse having a very distinct medical purpose in their lives at school (Bonaiuto, 2007). The reported goals of the Bonaiuto (2007) project were improved attendance, behavior, academic success, quality of life, and health compliance. While this project was not directly linked to chronic illness, it was an attempt to bridge the gap between the school and medical communities for increased communication without increasing parent stressors. These opposing studies on the role of the school nurse show that the chronically ill student's voice may be lacking in the literature.

While the lack of communication among school, home, and medical professionals has been described as a primary concern, an intervention to remedy the gaps of student perspectives and tools to increase communication continues to be scarce in the literature. Teachers have reported a lack of knowledge preventing them from providing the support needed by students (Hewitt-Taylor, 2009). There is a need for creating structured opportunities for healthcare providers to share information with educational representatives to improve students' academic experiences (Mukherjee et al., 2000). School nurses and school psychologists appear as critical points of contact between schools and medical centers who could increase effective communication among all stakeholders for children who are chronically ill (Kaffenberger, 2006). The literature provides limited information on how these people can serve as connections between the school and medical communities. Kaffenberger (2006) determined that school counselors know that focusing on social, emotional, and academic challenges plays a more significant role in helping to facilitate a relationship among all stakeholders, particularly in school reentry. Kaffenberger stated that while school counselors are well equipped to serve in a leadership role in the relationships that need to be established for children who are chronically ill, they “will not be prepared to assume this role without training and the support of supervisors and school administration” (2006, p. 226). There is a strong need in the literature to address how to develop the roles of these school personnel that allows a chronically ill student to have access to adults, such as the school counselor, school psychologists, or the school nurse, who will provide advocacy and communication on the student’s needs in the educational setting.

Closing Thoughts on Chapter II

School systems must acknowledge and respond to the increasing number of students with chronic health conditions on their campuses each day. Currently, too often, the medical community and schools work in isolation to meet the unique needs of ill students. Schools, parents, and medical communities must come together to create ways in which all stakeholders can accommodate students to meet the needs of those with chronic illnesses. The literature shows that communication between the identified student’s family, medical professional, and school is imperative for the ill student’s academic, social, and emotional success. Despite the need for effective communication identified in the literature, very few strategies have been developed to help stakeholders accomplish this task. Further research needs to be conducted on how chronically ill families have successfully bridged this communication gap in the past, and tools should be developed to increase effective communication in the future.

Literature has stated that school personnel require individualized training related to specific health concerns for their students, in addition to increased communication between the school system and the medical community. Parents, often acting as the self-reporters of chronic health conditions, are currently expected to be the experts in their child's medical diagnosis, as well as the special programming their child may need at school. School personnel such as LSSPs, counselors, and nurses are in the unique position to be utilized for training other educational professionals on the needs of children with chronic illnesses. A training plan should be developed to increase communication between the medical expert and school programming expert, as well as teachers, to help ensure that the academic, social, and emotional needs of students with chronic health conditions are being met.

CHAPTER III

SOLUTION AND METHOD

Proposed Solution

CRMO/CNO is rare; thus, parents and schools need access to a set of strategies and tools that they can use to improve academic outcomes for children who are chronically ill. Because of the rare nature of this autoimmune disease, as well as the geographic disbursement of students with CRMO/CNO, parents and school systems do not currently have access to strategies that have previously proven useful in aiding this group of students (Oliver et al., 2018). A storehouse of effective strategies available on the CRMO website to all stakeholders could improve school outcomes for ill students. Additionally, this listing of strategies would empower parents in their advocacy role to enhance communication with their schools. School systems could use these tools to develop quality individual health plans and 504 plans to aide in the success of students diagnosed with CRMO/CNO in their schools. The goal of this study was to catalog effective strategies that parents have previously used to effectively communicate between their children's schools and healthcare providers and to provide access to these tools in a public online forum. I also created a navigation guide to help parents of children with chronic conditions understand the educational accommodations available to their children in the public school setting.

This study used qualitative methods to identify the specific needs had in the school setting by children diagnosed with CRMO/CNO. A needs assessment and a bank of practical strategies that parents have used to create partnerships between their school and medical communities were put together based on semistructured interviews with parents. A bank of practical strategies and tools was added to the educational resources section of the CRMO website, ensuring that parents, doctors, and school personnel can access information to increase the academic, social, and emotional functioning of children diagnosed with CRMO/CNO. These resources were created in the tradition of the disability capability framework with an emphasis on also including components of action research that school settings can utilize. Access to information about how to help children with this rare disease is increased by cataloging the tools and practical strategies previously used by parents to successfully advocate for their children on a widely used platform such as the CRMO/CNO website. Information is now accessible to all stakeholders.

Study Context and Participants

Participants and Sample

The sample size of this study was set at between three and six participants. The group consisted of parents who have acted as advocates for their children diagnosed with CRMO/CNO, as well as one student with CRMO/CNO acting as a self-advocate. The study sought to include participants with experience advocating for their children at both the primary and secondary school levels. Participants were recruited from the CRMO Facebook group using this recruitment message:

> Greetings, Hi! I am Kimberly Martin a mom of a child with a chronic illness and a doctoral student at Texas A&M University. I am interested in what roadblocks and successes parents in this group have faced in getting their child’s school to understand their unique needs as a student with a chronic illness. If you would be interested in participating in a research study, please email me kdmartin2@tamu.edu for more information. The research study is being conducted in conjunction with Dr. Sara Raven the Principal Investigator and my faculty advisor at Texas A&M located at 400 Bizzell

> St, College Station, TX 77843. To participate, you must currently have one or more children with a chronic illness.

The recruitment script used on the CRMO Facebook page was approved by the Texas A&M University Internal Review Board, study number 088105. Willing participants engaged in phone interviews via Zoom. Interviews lasted from 30 to 90 minutes, and participants received a transcript of their conversation to check it for accuracy. After an initial screening to ensure that respondents met the study criteria, participants were selected for interviews to create cases.

Several qualitative methods were utilized in this study. The qualitative method of case study research was used. The case study method was selected in order to create an in-depth, detailed description of the obstacles that parents have faced in their advocacy role, as well as the successes they recall in helping their children. Robert Yin created a two-fold definition of case study research. He suggested that case study research investigates a contemporary phenomenon despite unclear boundaries between the case and the context in which the phenomenon is found (Yin, 2018). Thus, it is essential to select "cases" from which we can gain valuable knowledge. Purposeful sampling was used to identify participants to serve as cases for this study. Purposeful sampling is a qualitative sampling method defined as a core strategy of qualitative inquiry used to gather information-rich examples of a phenomenon of interest rather than empirical generalizations (Patton, 2015). The theoretical method of purposeful sampling was used to find participants for this study. As Patton (2015) explained, "qualitative inquiry typically focuses in depth on relatively small samples" (p. 52). Consequently, interview participants were required to have previously worked as a liaison between their child's medical team and school system so that information-rich examples could help explain the phenomenon of parent advocacy for CRMO/CNO children due to the relatively small sample size that this rare disease necessitates.

To gather as much information as possible, cases spanned the primary and secondary public school settings.

Proposed Research Paradigm

This research study asked questions about the essence of parent advocacy for a group of medically fragile students. According to Patton (2015), phenomenology is a qualitative research framework designed to answer questions aimed at the essence of a lived experience for a group of people. Furthermore, my situation as both an educator and parent of a child with CRMO allowed me to offer insight into my lived experience as a parent advocate. Therefore, the research paradigm guiding this work was phenomenology through case study and action research methodology, as well as autoethnography.

Case Study Research

I used semistructured interviews to qualitatively explore the lived experience of parents who feel that they have successfully navigated the role of liaison between their ill child's medical community and educational community to understand how they have navigated their advocacy role. These interviews, along with any records willing to be shared by participants, such as 504 documentation, generated individual cases to be studied (Patton, 2015). According to Robert Yin (2018), case studies are generally used "to investigate a contemporary phenomenon in depth and in its real world context" (p. 286). The semistructured interviews used in the case study design allowed for exploration of the phenomenon of interest, successful advocacy, using qualitative methods. Utilizing the interviews to create case studies describing how parents have advocated for their children allowed the researcher to study each individual, the primary unit of analysis, during a significant critical incident in their life to create a more accurate picture of the participant’s case (Patton, 2015). During the interviews, I sought to find out what the parents feel they had done well in their advocacy role that generated their feeling of success.

Action Research

Action research has a variety of definitions in the literature, but at the core of all of the definitions is the study of the practitioner’s interaction to social reality (Anderson, Herr & Nihlen; 2007, p. 1.) In this particular study, researcher and practitioner were synonymous. The researcher was an educational practitioner seeking to describe how parent advocates interact with the social realities found in their school systems and medical communities. According to Anderson, Herr, and Nihlen (2007), action research is neither new nor trendy. Action research began with teachers utilizing their classrooms as laboratories. Often, that research developed into multiple case studies utilizing educators’ common sense more often than scientific inquiry. Thus, case study research and action research have been partnered by educators to create a more precise qualitative picture of a specific phenomenon in educational research. Kurt Lewin was the first to develop a theory of action research that made it respectable within the social sciences. He believed “that knowledge should be created to solve real-life situations” (Anderson, Herr, & Nihlen; 20017). Action research should be in cycles of plan-act-observe-reflect. This type of action research leads to more agency and empowerment (Anderson, Herr & Nihlen; 2007). I believe that parents who have successfully navigated their role in their child’s academic and healthcare settings have used a form of action research to identify successful strategies that work for their child. The parents have utilized their child’s doctor offices and school as their laboratories to produce positive outcomes for their child. Parent advocacy as a form of action research needs further study.

When action research is applied to education, it provides an insider view of a previously hidden educational phenomenon. This insider view can be used to explain previously hidden parent roles as well. The advantages of this insider action research include a “tacit knowledge of a setting,” as well as a way to make the voices closest to a situation or phenomenon in education matter (Anderson, Herr & Nihlen, 2007, p. 3). Action research has several disadvantages, one being a lack of subjectivity that researchers must embrace and acknowledge (Anderson, Herr, and Nihlen; 2007). To avoid bias that may occur as a result of lack of subjectivity, the authors suggested the idea of a “critical friend” to help ensure that the researcher does not bring practitioner bias into the field (Anderson, Herr, and Nihlen; 2007; p. 130). The action research portion of this study’s design determined which strategies parents have used that can be replicated by school systems to help improve the academic and social functioning of students who are chronically ill in schools. Using an action research model allowed the problem of practice to be explored to inform the most effective potential strategies for parents and schools to apply to improve communication among all stakeholders. Action research has previously been tied to case study research, as well as ethnographic tasks. There is a need to remove theoretical knowledge from practical tools in action research. “To do this, we must make the familiar seem strange, a task enhanced by both ethnographic and action research” (Anderson et al., 2007, p. 96).

Autoethnography

Finally, autoethnography was used in this study. Autoethnography is defined as “a qualitative method that utilizes ethnographic methods to bring cultural interpretation to the autobiographical data of researchers with the intent of understanding self and connection to others” (Chang, 2016, p. 56). As the researcher, I recorded my observations and emotions after each interview, as well as reviewed the contents of journals kept following my son's diagnosis. Studying my notes allowed for autoethnographic data collection from my advocacy role as a parent. "Autoethnography benefits greatly from the thought that self is an extension of a community" (Chang, 2016, p. 26). As a member of the CRMO and educational communities, I utilized autoethnography methods to describe my potential bias as a parent, as well as my own lived experiences, to create an authentic understanding of my advocacy role. According to Heewon Chang (2018), the individual is the basis for understanding all cultural experiences; therefore, the strength of autoethnography is that it studies the most basic unit of culture. Autoethnography is not without weaknesses. Chang's (2018) critique illustrates the existing tug-of-war between two positions—objectivity and subjectivity—in social science:

> The objectivity position promotes the "scientific," systematic approach to data collection, analysis, and interpretation that can be validated by more than researchers themselves; on the other hand, the subjectivity position allows researchers to insert their personal and subjective interpretation into the research process. (p. 45)

Throughout this project, I engaged in the objectivity-subjectivity struggle identified by Chang. Using my role as both a parent and a principal, I used autoethnography to evaluate the data provided in the semistructured interviews as a way to ensure the replicability of identified strategies by other parents in multiple school settings.

As both a parent of a child who is chronically ill and a school administrator, I used autoethnographic methods to help determine which identified strategies could be used effectively by both parents and schools. The autoethnographic role used in this study placed me, as the researcher, in the "key instrument" role described by John Creswell (2014). As both a parent of a son with CRMO/CNO and a school principal, I used a methodology that allowed me to explicitly explain any experiences that may have added bias to the study (Creswell, 2014). By combining semistructured interviews to create detailed case studies, documenting parent attempts at advocacy with action research methodology, and using autoethnography to look at my own experiences, I developed in-depth insight into the struggles and successes experienced by parents while moving among the communities they face in ensuring the holistic education of their children. Creating resources to be posted to the disease-specific website and shared with both parents and school systems ensures the sharing of actionable strategies. With these strategies available, more parents can successfully navigate the communication gap to ensure the success of their ill children. Access to the strategies identified through this study also provides information to school systems that allows them to support their students with rare diseases such as CRMO/CNO.

Data Collection Method

Because of the rareness of CRMO/CNO-affected children and the geographical locations of participants, recruitment for participants occurred via social media—the CRMO Facebook page. Once recruitment was completed via social media for purposeful sampling, technological methods such as conferencing software and telecommunication methods were utilized to conduct the semistructured interviews. Therefore, the sampling site was virtual. Parents who defined their advocacy as successful were selected using purposeful sampling techniques. These participants were interviewed utilizing a semistructured interview guide. In Chapter 39 of *The SAGE Handbook of Qualitative Research*, Peter Dahler Larsen stated that “the interview has become one of the most common ways of producing knowledge” (Denzin & Lincoln, 2018, p. 577). During the semistructured qualitative interviews, each participant was screened to determine whether they identify as having had a successful outcome for their student due to their advocacy.

The interview questions were designed to elicit information about the lived experience (phenomenology) of this group of parents. Additionally, the interviews were intended to identify which strategies used by these parents they would describe as successful advocacy. According to Peter Dahler Larsen, the use of a semistructured interview has significant knowledge generation potential because it allows for flexibility to follow up with the interviewee about relevant information to create a deeper understanding of the phenomenon described (Denzin & Lincoln, 2018). Data collected during the qualitative one-on-one interviews were designed to gather information related to the central phenomenon of this practical educational problem. The problem of practice under consideration in this study was that parents of children who suffer from chronic illness have expressed frustration with their role as the key communicator between the educational and medical communities of their children. This study helps to determine if the frustration is rooted in the fact that the parents rarely have training in either field. This phenomenon was further examined through the use of an interview guide, which included the following questions:

1. What chronic diagnosis does your child have?
2. Please help me better understand what __________________________ is?
3. What has your role been in managing the illness?
4. How has school integration been since your child's diagnosis?
5. What/How did you do to help alert educators to signs or symptoms?
6. What has been the response of the school? What do you wish you knew before the diagnosis that would have helped you work with your child's school?
7. What is a typical school day like for your child?

8. What supports do they need?
9. Are they getting those supports regularly?
10. What have you found to help deal with communication issues between the school and the medical needs of your child?
11. What has been not-so-helpful or a challenge to you in setting up education supports or communication with your child's school?
12. What advice do you have for parents of newly diagnosed children in working with their child's school system?
13. What else would you like to share with me about managing the relationship with your child's school concerning their chronic illness?

The data were collected in the form of handwritten notes while using the semistructured interview guide. Using a semistructured interview guide provided an initial assessment of the practical problem through the participants' own words.

Data Analysis Strategy

Qualitative data analysis involves segmenting and pulling apart data to construct knowledge when the data are put back together (Creswell, 2014). Creswell discussed that qualitative data analysis is different from other methods because the researcher is engaged in cyclical analysis methods whereby they may be interviewing one participant while writing findings from a different participant, all while actively coding data from another interview. This juggling act means that the researcher must be deeply immersed in the data set to construct meaningful knowledge (Creswell, 2014). In order to ensure high-quality data analysis, thematic coding was used in this study. "Coding is the process of grouping evidence and labeling ideas" (Creswell & Plano Clark, 2011, p 14). Interviews were transcribed so that as I read through transcribed interviews, codes were applied to create themes. To ensure that participants' voices were honored, the in vivo coding method was used (Saldaña, 2016). Saldana asserted that in vivo coding is effective in ethnographic educational studies. Furthermore, it is a useful coding method that can be used by novice qualitative researchers to prioritize data (Saldaña, 2016). The constant comparative method was used as transcripts were read from each of the semistructured interview participants. Additionally, my thoughts were recorded and coded to identify the autoethnography methods utilized in this study. Data analysis was represented in a visual model of themes. I believe that the themes identify best practices for effective strategies that can be used by parents and schools when helping serve their chronically ill children.

Timeline

My proposed timeline for completing the study is outlined in Table 1.

Table 1

Timeline for the Record of Study

Month/Year	Contact/Activity	Collect	Analyze/Action	Product/Audience
Spring 2019	Acquire Institutional Review Board approval for record of study			
October 2019	Submit methods to the committee for approval			
November 2019	Post recruitment request to the CRMO Facebook page	List potential participants for the study	Complete initial contact to determine if participants meet study criteria	Contact the final list of potential participants to determine their availability to participate in the study
November to December 2019	Complete interviews for final participants	Transcribe interviews; complete personal journal after each interview for the autoethnographic component	Analyze notes to create themes; type notes and send to participants for member-checking	Code data from typed notes and journals; list practical strategies utilized by parents and my responses to each strategy for possible implementation
December 2019 to January 2020	Complete navigation guide and practical strategies guide for website publication	Share with participants for review; make edits as necessary	Share with participants for review	Complete navigation guide and practical strategies guide for CRMO website
January 2020	Write drafts of record-of-study chapters to share with chairs	Complete all synthesis of data for chapters	Share draft copies with chairs	Write drafts of record-of-study chapters to share with chairs
February 2020	Share all edits of drafts with chairs	Share final drafts with chairs	Share final drafts with chairs	Share final drafts with chairs

Reliability and Validity Concerns

As this study is qualitative and sought to create a thick description of strategies that participants have previously used to advance the academic, social, and emotional needs of their children who suffer from CRMO, the study should be judged using the tenets of "trustworthiness." Some authors have defined qualitative validity as the checks for accuracy of a study's findings completed by the researcher (Creswell, 2014). Qualitative validity is the process of ensuring the accuracy of qualitative findings (Creswell & Plano Clark, 2011). However, a more thorough definition of accuracy checks within qualitative inquiry is known as trustworthiness. Trustworthiness has been described by many as synonymous with rigorousness (Creswell, 2014; Denzin & Lincoln, 2018; Patton, 2015). Trustworthiness involves ensuring the credibility of both the researcher and the study, transferability of findings, and confirmability of the study (Patton, 2015). Credibility is related to internal validity, while transferability, also called authenticity, is the qualitative version of external validity, and confirmability is the ability to provide for the objectivity of a study (Creswell, 2014; Patton, 2015). Thus, the goal of this study was to be a study utilizing dependability and authenticity to ensure its rigor. Furthermore, trustworthiness was established through the effective use of triangulation and member-checking to capture multiple perspectives on useful intervention strategies. Triangulation of several interviews, as well as any documentation shared by families, ensured that multiple perspectives from various participants were included in the study (Creswell, 2014; Patton, 2015). Using member-checking to determine the accuracy of the themes and strategies developed allowed the participants to ensure the authenticity of the themes. By combining triangulation strategies and member-checking, I had the opportunity to correct errors and inaccuracies, as well as update the data provided. Additionally, as Patton (2015) said, "it is the ethical thing to do" (p. 669). By having the results reviewed by participants, I ensured that the participants in the study were provided the opportunity to relate and confirm the findings, thus increasing the trustworthiness of the study.

Finally, as an autoethnographic action researcher, I focused on reflexivity in the research process. Creswell (2014) defined reflectivity as the open and honest narrative the researcher brings to the table about how their background impacts a study. Though spelling the concept differently, Patton (2015) described reflexivity as the researcher being “reflective about his or her own voice and perspective” to create an authentic balance in their research (p. 603). This study, like most qualitative studies, did not seek to generalize findings. Instead, the goal of this study was to construct a deeper understanding of how parents of children with CRMO/CNO have successfully navigated their advocacy role. By examining successful advocacy while studying my own role through autoethnography, a storehouse of strategies was developed that parents can use to help them construct their advocacy role related to their situations in the future.

Closing Thoughts on Chapter III

This phenomenological study used a variety of qualitative methodologies (case study, action research, and autoethnography) to create detailed descriptions of successful parent advocacy for a population of students suffering from a rare chronic illness. The goal of this study was to create a storehouse of practical strategies that can be utilized by educators, medical professionals, and parents of children diagnosed with CRMO. Additionally, a navigation guide for communication was developed to help parents bridge the communication gap inherent in their advocacy role. While this study does not generalize findings, it does provide strategies that have previously proven effective for all stakeholders to employ in their attempts to enrich the lives of the children with chronic diagnoses with whom they work.

CHAPTER IV

ANALYSIS AND FINDINGS

Introducing the Analysis

The purpose of this research study was to answer the following questions:

1. What obstacles have parents encountered in their role as an advocate for their child between the child’s medical and educational needs? Do parents feel that they have overcome these obstacles to ensure academic support for their child? If so, how?
2. What are parents’ perceptions of their advocacy role? What factors contribute to parents’ feelings about their advocacy role?
3. What type of guide can be developed to help parents navigate their advocacy role between the school and medical communities for their ill child?

Presentation of Data

In this section, data are presented by individually numbered case studies with an overview summarizing each case. Case studies are included in the order they were completed. Participants are identified using pseudonyms to protect the identity of the participant and their children. In vivo coding was utilized in the compilation of each case study in order to tell each participant's story in their own words, thereby increasing the trustworthiness of this work. Additionally, summarization was used to create a narrative description of each case.

Case Study 1

Participant Laurie is a parent of a ten-year-old. Her daughter received a diagnosis of CRMO about one year ago. She attends a small private K-8 school in the suburbs of Houston, Texas. The interview occurred via Zoom on November 16, 2019. Laurie’s daughter has been “very lucky,” according to Laurie because her CRMO is not as bad as many of the other cases she has heard about. Right now, Laurie’s daughter controls her disease and symptoms through the use of oral and injectable medications.

Laurie describes few obstacles in working between her daughter’s doctors and school. She says, “It is such a small school, and they have been pretty good so far.” Her daughter is currently in the fourth grade. She describes working with teachers “one on one” to facilitate accommodations for her daughter. At this time, Laurie does not have a formalized plan to manage her daughter's educational needs. She currently manages her child’s needs through face to face interactions at events like meet the teacher or parent drop off. Laurie also relied on the school nurse during the initial diagnosis to help share information.

Laurie describes her role as the manager of her daughter’s medical diagnosis. Her advocacy is not limited to her daughter's education. She often shares information between her daughters’ medical specialist and pediatrician. Finally, she finds that educating herself and others is a primary concern in her advocacy. She used a European study she was given by her rheumatologist to learn about her child’s diagnosis. She also describes the CRMO Facebook group as a valuable resource for educating herself. Laurie talks candidly about how her friends tell her to get off the CRMO Facebook group because it makes her sad. She says she often responds no because it is a learning resource. “You have to have a place to learn all you can.” Laurie’s final piece of advice to newly diagnosed parents is to, “A: get that handout and B: Be part of that [Facebook] community.” These statements suggest that Laurie is educating herself so that she may educate those people who spend time with her daughter.

Case Study 2

Participant Olivia is the parent of a current 10th grader. Her daughter received a CRMO diagnosis at the age of 7. She now has two other diagnoses related to medication she has received for CRMO. This participant has experience working with traditional elementary, middle, and high school systems near Seattle, Washington. Additionally, Olivia works with the CRMO research foundation as a parent liaison. Olivia is also an administrator on the CRMO Facebook page. The interview occurred via Zoom on December 3, 2019.

Olivia describes her daughter's CRMO diagnosis as “ultra-rare” and continuously changing. She says that her daughter has a challenging case because she has had severe reactions to most medications used to treat CRMO. The medication reactions lead to secondary diseases such as junior idiopathic arthritis and psoriatic arthritis. There have been times when her child was wheel-chair bound and missed significant periods of school in her educational career.

Olivia describes that in early elementary, she worked one on one with teachers to help support her daughter. Olivia states that she relied on the 504 committee extensively in middle school when her daughter’s health declined. Olivia shares how her daughter emotionally begged to stay in school. Olivia talks about genuinely listening to her daughter's needs and then having a wonderful sit-down meeting with the middle school counselor. Olivia also stated that when her child entered high school, she needed the education she received from an elementary counselor who taught her the 504 processes, to teach the high school counselor how to help her daughter. “The high school counselor had no idea how to run a case like hers,” so Olivia used the education she was given by the previous counselors to teach the high school counselor how to manage her daughter’s case.

Olivia describes how her doctor works to give the best medical treatment to her daughter. However, as a clinician, he may not see the implications of her child's health on the non-medical aspects of her life. Olivia says that neither the doctors nor the school initiated support for her child. Olivia states that the fields may not be "connected enough to really know the needs" of her daughter. Olivia describes her advocacy role as one that bridges the gap in communication between these two fields.

Olivia has extensive knowledge of both her child's disease as well as how to function in the educational setting. Much of this knowledge has been acquired through her participation in what she describes as "grassroots" efforts to help other families. Olivia believes that if we could visually teach parents to implement 504 plans that educated educators about CRMO, the bridges that could be built between the parents, schools, and medical communities would be compelling for CRMO families.

Case Study 3

Participant Dana is a parent of a current 7th grader. Our interview occurred via Zoom on December 6, 2019. Dana's daughter was diagnosed last year at 11 years of age. Although Dana tells me her daughter is doing really well right now, she shared that her daughter's time in the hospital due to broken vertebrates was terrifying. She described moments in the hospital where she was "thinking [her daughter] was going to die because, at that point, she had crazy numbers that weren't going down." Dana's daughter is currently 12 years old.

Dana's daughter attends a K-12 school that her mother described as a "school of character" in North Carolina. Dana describes minimal obstacles to acting as a liaison between the school and the medical community. After the initial diagnosis and the struggles Dana faced in working with the school on her attendance, she described a much easier process in developing a plan to help her daughter integrate back into school. Dana also regularly sees teachers face to face to ensure that her daughter's needs are met. Dana never discussed a formal plan with the school or met with the school counselor, whom she described as "useless." When the 2019-2020 school year began, Dana shared her daughter's diagnosis with the teachers at the meet the teacher event before school started. Dana described her advocacy role in her daughter's education as "ultra, ultra involved in her school." As a mother, she sees volunteering as a way of being present at the school, "just in case anything should happen."

Finally, Dana values the CRMO Facebook page immensely. She described how connecting on this social media platform with other families who have children with this rare disease has benefited her family. The information exchange described has been essential for her learning. Dana believes other families must connect in this way, as well.

Case Study 4

I met participant Mary during an interview, which occurred via Zoom on December 6, 2019. Mary is a parent of two children with chronic health conditions. She has a 13-year-old son whose diagnosis is ulcerative colitis. He also has a diagnosis for Asperger syndrome, for which he had an existing Individualized Education Plan (IEP). Mary's daughter is nine and was diagnosed with CRMO in April 2019. Her daughter also already has an IEP in place for an emotional disturbance. Mary's son attends middle school. Her daughter is in an elementary school. Both children go to school in southern California.

Mary had a strong knowledge base of acting in an advocacy role for both of her children due to their learning differences. As both children developed chronic medical conditions, she was able to apply her knowledge in creating individualized educational plans to include accommodations for the children's medical issues. Mary described her advocacy in terms of being a key communicator for her children. Creating a partnership at her children's school is an advocacy technique that Mary feels aides in her success. After working in partnership with the school, Mary used a pamphlet from a CRMO resource to read to her daughter's class. With the teacher's guidance, she then hosted "a little Q & A, and we were like very matter of fact." Mary feels that talking in person when issues arise can often solve any problems quickly. She listens when the school makes recommendations and works to ensure they hear her when she is making them. In addition to her partnership approach to advocacy, Mary believes she needs to teach her children to be their own advocates. Mary said, "these are their chronic conditions, and they need to know" how to manage them.

When asked about what advice she would give to parents of newly diagnosed children with a chronic illness that might be included in a guide, Mary points out how different individual cases are. Her advice to help parents new to navigating their advocacy roles would be, "take a really good look at your kid and be very realistic about what they can and cannot do when they are well." Mary then advises parents to think about their children and determine "what they can and cannot do when they are not well." Mary described her role as a "powerful one." She says you "have to know what you want. No one else knows your kid or what it is you want" or need as well as you do as a parent.

Case Study 5

Participant Sara is an adult college student. She was diagnosed with CRMO in 2001 at the age of five. She also has been diagnosed with secondary diseases related to CRMO, such as psoriasis. Although she has had CRMO for the majority of her life, most of our discussion focused on her role as a self-advocate throughout her college career. She describes her experiences in working with her university disability service center for necessary accommodations at the interview that occurred via Zoom on December 15, 2019.

Sara described her emergence as a self-advocate late in high school. She said as she watched teachers losing faith in her, she decided to “be an advocate for [herself].” Sara stated that it was at this time she also felt she needed to start talking to doctors for herself as well. At the age of 19, she switched from a pediatric to an adult rheumatologist. Sara said she was recently told, “You are an adult. You need to figure out your health conditions and mitigate those while going to college.” In addition to the rigid structure she describes at the university level as well as her financial obligations, Sara said that socially people simply do not understand the burdens her disease places on her. She went on to say how traumatized she was by trusted adults who had no idea of her pain levels judging her so harshly. Sara perceives her current advocacy role as one of a communicator. She said the primary way she currently advocates for herself is by “communicating with your professor that you are a person with a disability even though you are not required to.” Sara believes communication is the key to her successful self-advocacy.

Sara, who has been living with CRMO since she was five years old, said that students with CRMO need to take into consideration times of transition when planning for how to manage their disease. Transition periods such as puberty or entering adulthood can change the disease for people, and you have to learn to cope differently than you have been. Finally, Sara shared how impactful going to school in pain is. She said, aside from the physical disease cycle, plans must consider how pain “affects processing and learning specifically.” She goes on to point out that when you are in severe pain, “your brain isn’t functioning at the same level.” In her experience, “even though [CRMO] is a physical issue with bones, it is affecting . . . how you intake and absorb information." Sara wants people to be very understanding with those diagnosed with CRMO because there is so much to this disease you can not see.

Findings of Research

This study is phenomenological. The study was designed to describe the phenomenon of the parent advocacy (and self-advocacy in the exception of case study 5) role in managing illness within the educational and medical settings. As a descriptive analysis, the results of these findings are exclusive to a particular illness, CRMO, across five different educational settings. Therefore, the context of this study is specific and cannot be generalized to a larger population. However, patterns emerged across the five case studies that provide insight into the research questions examined in this study.

Research Question 1

What obstacles have parents encountered in their role as an advocate for their child between the child's medical and educational needs? Do parents feel that they have overcome these obstacles to ensure academic support for their child? If so, how?

Obstacles. One common obstacle that emerged across all five case studies was that of the children's attendance at school. All five participants interviewed discussed the effects of high absenteeism on their advocacy roles when working with the school. Though this was a common concern among all participants' the responses to the concern varied considerably across all cases. Dana expressed anger and frustration at being asked to present written excuse notes from doctors while her child was hospitalized. Dana was waiting to learn if her daughter had cancer, and she says the "school had been sending me messages, like, your daughter has been out a week, now we need a note." Dana described her disbelief when she explained the situation, and the school said, "could you just ask one of the doctors to send a note?" Dana says she was also really bothered when the school said, “she would have to be out eight weeks before they would do anything as far as tutoring.” Sara expressed similar frustrations when telling a story about a $10,000 scholarship award being reduced to $5,000. She was told, “you are only getting $5,000 because other students have fewer tardies and absences than you,” despite what she described as a similar GPA and standardized test scores to other classmates who were awarded the full amount. Physical presence in school impacted more than grades and scholarship awards for several of the students.

Sara described the emotional toll she felt when teachers lost faith in her abilities as a student due to her poor school attendance. She says she had abysmal attendance due to the disease fatigue that accompanied CRMO. Sara said that despite her poor attendance she was an honor roll student but was forced into a “cycle of . . . having teachers . . . everyday lose faith in [her] to be a good student.” Other participants understood that absenteeism was affecting their daughters but chose to prioritize health concerns over academic ones. Laura says her school requested notes, but in a very thoughtful way, “they needed me to bring notes, but the front office was so sweet, and she was like if you have them great, but if not that is okay.” When describing the attendance laws in Washington Olivia says, “I think that there is a button that the office manager pressed that stopped us from getting those [attendance letters] anymore.” Olivia goes on to say, “I probably had the wrong attitude, but I was like, I don’t care. You kick us out of school. I’ll just homeschool her.” During her daughter’s 7th grade year, Olivia took on a lot of the instructional load at home. She said, “there are a lot of families that choose to homeschool because they don’t want to fight the fight.” Attendance issues were the only obstacle discussed across all five participants.

Another obstacle that four out of the five participants addressed as a concern was that their children or themselves appear healthy and are often judged for the outward appearance despite the internal suffering that is occurring. The fact that CRMO/CNO is not an illness one can visibly detect was seen over and over again in the data collection. The participants expressed this obstacle using different terms such as my daughter presents beautifully (Olivia), you are not that sick (Sara), it is in your bones (Laura), if it looks like she is in pain it is probably ten times worse than you can imagine (Dana) however they all feared people would not understand how ill CRMO patients genuinely are.

The idea of disease invisibility as an obstacle was most eloquently explained by Sara as she described what living with CRMO was like for her as a teenager. She described how people did not believe she was really sick because she did not look sick. Sara said, “and this isn’t just like peers,” she said these are people “I should be able to trust and confide in. You know none of my teachers are required to know my medical history.” She described a painful “huge communication issue where I look able-bodied most of the time” but was actually in deep cycles of painful disease flairs. Sara described memories of people judging her abilities based on an outward appearance rather than an understanding of her medical issues. During a particular moment, she said, “educational professionals looked me straight in the eye and are like you are not that sick.” The invisibility of CRMO/CNO is a concern that continues to linger for Sara as well as other participants.

For three of the participants (Olivia, Dana, Sara), this fear of “looking healthy” was coupled with the obstacle they faced with needing to teach others about CRMO. Participants described CRMO as a rare or challenging disease that others know nothing about. Therefore, caregivers felt challenged to teach others, particularly those their children interact with at school, about CRMO. All participants described teaching others about the pain or fatigue associated with a CRMO diagnosis and the medication reactions that are often inherent in disease management for CRMO patients.

Additionally, three of the five participants discussed the social obstacles they felt their children faced due to their disease. Olivia described the desperation her daughter had to stay in school so she could be a "normal" teenager. Around this time, her daughter was missing so much school that Olivia approached her daughter about homeschooling. Olivia calls that talk "the kitchen table conversation." She says her daughter sobbed and said, "CRMO has taken everything away from me. If you take going to school away from me, that's the only normal thing I have that says that I am a normal teenager." Mary explained her daughter's desire to tell the other children in school that they could still play with her while Dana expressed fear that her daughter's peers might not understand she was just like them "just a little bit different."

Table 2 illustrates the additional obstacles that parents described encountering as they advocated for their children or themselves between school and medicine.

Table 2

Obstacles Identified by Participants

Participant	Laura	Olivia	Dana	Mary	Sara
Attendance	X	X	X	X	X
Disease invisibility, Healthy "look"—presents well, does not look sick	X	X	X		X
Rare/challenging disease		X	X		X
Social aspects—not wanting to leave school, wanting to explain to peers and playmates		X	X	X	
Fear of cancer	X		X		
No formal support plan	X		X		X
Concerns about management as student moves into higher grade levels	X			X	
Unskilled case managers at some point in the educational journey		X	X		
Specific accommodation requests				X	
Financial concerns					X
Number of people to communicate with				X	X
Lack of trust					X

Strategies used by participants to overcome obstacles. The case studies helped yield a variety of strategies that participants used to overcome the obstacles they identified. All five participants have utilized face to face communication as an effective strategy to overcome the disease barriers they have faced in the advocacy roles. Laura says, "I can say hey Coach her legs are hurting her" when I see him at drop-off. Laurie explains that she is a room parent and volunteers at her daughter's school frequently. She says that "face to face [communication] is the key." However, Laurie expresses concern about relying on the face to face communication method of advocacy as her child gets older and moves into larger schools. Olivia says, "There is nothing better than that face-to-face sit down meeting at the beginning of the year." Dana says she is at school often so that "they know who they have to answer to . . . everybody knows I'm her mother." Mary said, "get up and go" to the school to meet with the educators to help solve any concerns. When problems arise, Mary said she believes in face to face communication.

“Sometimes it’s just faster to just go and sit in the office and say, hey, you know if the principal has five minutes, can you have her come out and talk to me.” Sometimes she says you “have to go over there, get up and, you know, don’t go to work today. I am just going to go to school and talk in person.” Sara stated that communicating with a “professor that you are a person with a disability” even if you are not required to do so goes a long way in helping them understand you as a student.

Although case managers choose to use a variety of communication tools such as email and written notes, they overwhelmingly prefer to meet with educators face to face to problem solve as a team how to overcome challenges. Three out of four participants who were diagnosed as elementary school children used one-to-one parent-teacher meetings to address all needed supports informally. Participants Laura, Dana, and Sara either currently do not have or did not have a formalized educational support plan to work with their teachers to support their children with chronic diagnoses. Dana has a middle school-aged child and also utilizes one-to-one communication to manage her daughter's school needs. Olivia says, “We were working with our school teachers really well, just one-on-one. Elementary school is pretty easy.” The fact that face-to-face communication is the primary strategy utilized by all advocates is a reliable indicator that building relationships between all care-givers can be urgent for these children with chronic illnesses.

Despite having faced challenges in their advocacy, four of the five participants described their school relationships using positive language. “Partnership” (Mary, Olivia), “team effort” (Dana), “groups decisions” (Olivia) and “fortunate” with her “great” school (Laura) are just some of the descriptors used by participants to explain the relationships they have developed with their children’s schools. Two participants’, who were interviewed separately, go so far as to say they want to make educators “their best friends” because they are the difference makers in their children’s lives. Mary says, “If you’re going to be best friends with somebody, don’t even worry about the principal.” The people Mary finds helpful are the guidance counselors and the school psychologist. “Talk to those ladies,” she says because when your child is having a bad day, that is “the person who is going to make the biggest difference.” This approach to relationship building is a crucial factor in Mary’s advocating success. The optimistic view of parent-school partnerships described by participants is impressive.

Many of the participants acknowledge that other parents do not have the same positive relationship with the school as they do. Olivia says parents think they are going to “force their way through the 504 process” to make the school do what they want. Mary says she has worked with parents who have a much more “adversarial approach” that she often tells others will not work. Olivia says she believes she did not need a formal support plan for her daughter because she was not “fighting [with the school] right now.” This perception implies that many parents may wait to formalize plans until they are fighting. Four of the five participants express their relationships with their children’s school, so positively, it leads me to think that positive perception, may make the burdens parents face, seem solvable rather than something to “fight.” Additionally, all four parent participants in the study use words like lucky, blessed, or fortunate when describing the current disease status their children face. The positive attitudes towards disease management and school relationships were unexpected findings in these four case studies.

Additional strategies that a majority of the participants used included educating others about CRMO and utilizing CRMO specific resources such as the CRMO Facebook page and CRMO awareness website. Dana says multiple times, “Oh my gosh, definitely be on that CRMO

Facebook page." Due to the rare nature of CRMO, many parents utilized resources on the Facebook or CRMO awareness website to teach themselves, educators, family members, and their children's peers about the disease. Additionally, parents utilized the social media site to ask questions and gather information about disease-specific concerns, including how to develop formal educational plans. Two participants also sought resources from their university resource center or read books to teach themselves how to manage CRMO in their educational settings. Two participants also relied on educational professionals to teach them how to create formalized educational support plans such as a 504 or an IEP. Finally, two participants felt that their geographic connections in southern California and the Texas Medical Center provided them access to tremendous resources at their hospitals and schools, thereby making their advocacy easier because they had increased access to information.

Table 3 identifies the variety of strategies each parent used to overcome the obstacles CRMO presented.

Table 3

Strategies Identified by Participants

Participant	Laura	Olivia	Dana	Mary	Sara
Communication, specifically face-to-face	X	X	X	X	X
Problem-solving one on one with teachers (elementary-specific)	X	X			X
Creating a partnership with the school		X		X	
"Making them your best friend"		X		X	
Educational professionals teaching the caregiver the formal processes (IEP or 504)		X		X	
Geographic location providing access to teaching hospitals or supportive school districts	X			X	
Self-learning through books or seeking resources about formal processes (IEP, 504, or college disability services)				X	X
Educating others about the disease	X	X	X		
Joining social media or advocacy groups	X	X	X	X	
Positive attitude, identifying as blessed, lucky, or fortunate	X	X	X	X	

After analysis of the case study data, I identified a variety of obstacles encountered by parents in their role as an advocate for their child in the educational setting. The case study data also presented a variety of strategies to overcome these obstacles to ensure academic support for children diagnosed with CRMO. However, despite explicitly asking how parents coordinate or manage CRMO between the medical and school communities, only one participant provided insight into this question. Olivia said that the two communities are not "connected enough to really know the needs" of her child in different settings. She went on to say, "I have gone in and asked for things," but "it never came from the doctors or the hospital." Laura described a time in which she was acting as a key communicator between her child's pediatrician and the rheumatologists. She explained that Texas Children's Hospital does an excellent job of sending information electronically between her specialist and primary care doctor. Despite this, when Laurie took her daughter in to see her pediatrician for the regular ten-year-old check-up, Laurie told her pediatrician that her daughter could not have live vaccines due to a medication that was prescribed by her rheumatologist. Laurie says the pediatrician said, "They didn't share that with me, so email me whatever they sent you, and then I will put a note in her file for the future." Dana stated that the doctors asked her what she wanted to include in the medical forms they sent to the school. Dana requested, "gym as she can do it" she also included that she or her husband would chaperone all "overnight field trips." This data indicates that further research needs to be conducted in how medical doctors determine the data they are sending to schools as well as what role the medical community expects parents to play in that process. These exchanges show how critical the role is of a parent communicating on behalf of their child.

Research Question 2

What are parents' perceptions of their advocacy role? What factors contribute to parents' feelings about their advocacy role?

All of the participants in this study can identify their advocacy roles in either their children's lives or their own life. All five participants identified their primary job within their advocacy as communication. They each broke communication down differently. For example, Laura said that a parent "[has] to really be an advocate for your kid," to "educate whoever" is going to spend time with your child. In her case, this meant that Laura first had to learn all she could about CRMO. Her communication includes sharing disease knowledge with anyone who will be spending time with her daughter. Later she adds to this by stating that, "it's just about really educating those who spend the most time with your child so that they understand what

[CRMO] is." During the final question of the interview, when asked if there was anything else she would like to share, Laurie says, "learn everything you can and really talk to the teachers," "really educate yourself." In addition to the communicator role, she described herself as "managing the medical condition."

Olivia says, "no one else" sees a child's "daily needs like a parent." She uses this unique vision as she educates those around her about her daughter's illness. When asked how she views her advocacy role, Olivia responded, "Oh, wow, that's a big one." She called herself a "case manager" and the "main advocate for her child." Olivia also said she often acts as the "bridge" between medical and educational communities for her daughter. She seeks to listen carefully to her daughter's desires, and she described a "constant" quest to share information with others. Olivia not only serves as an advocate for her daughter, but also works with leading CRMO organizations to share information with as many CRMO families as she can.

Dana described her advocacy as "ultra, ultra-involved." She, too, finds herself working to educate people on the rare disease faced by her daughter; when she tells people it is an "autoinflammatory" disease, they often want to correct her and say that it is "autoimmune." Dana said she explains how high her child's pain tolerance is by saying, "if she looks like she is in pain, the chances are it is ten times worse than you could even really think of." When asked how she views her role and what she would like to share with other parents, Dana stated, "I feel like what really works for me is the fact that I am so involved in her school."

Mary sees her advocacy as a partnership with others in doing what is best for her children. She called herself the "manager" who is determined to "delegate" medical care to her children. Mary does this to ensure that as adults, her children will be able to manage their chronic conditions independently. She says that both of her children know what medications they take and when. Both children know the basics of their IEP plans and can communicate those to the adults around them. “They need to know why” we make the medical decisions we make. “They participate in their treatment plans so they should be aware of what they can and can’t do.” Mary described “priming” her children before meetings by asking, “at the end of this appointment or meeting, what do you want to know? What do you want to leave with?” to ensure they are actively involved in their plans. Mary explained that she teaches her children what accommodations they should be receiving in school. If the children feel like they are not getting those accommodations, she tells the children, “you don’t have to fight with the teacher, but tell me so that we can talk about it.” She went on to explain that even though her children do not participate in their meetings, yet she used feedback from her son to make decisions. Mary explains they have “taken the aid out of some of his unstructured time, lunch, and other things because when he says, I feel like I don’t need it. I feel like it is hurting more than helping” we take that seriously. Mary says, “I am managing” for them but I am “delegating” the responsibilities to them as well.

Finally, like the four parents participants in the case studies, Sara sees herself as a critical communicator to an unknowing public about her disease. Additionally, she is focused on self-care and long-term management of her disease. Sara said she also sends emails at the start of the term that is a “form email.” The email states her condition and symptoms and what she will do to mitigate those symptoms. Sara said that she has learned to “overcome by being an over communicator because that is what it sometimes takes to set yourself up for success in the beginning” of a semester. Sara also said it is essential to take care of her needs by ensuring she knows where campus resources are. She scouts out comfy places to rest and refuel between classes, “places where you can just go sit when you’re feeling exhausted.” Sara said that “being able to take a nap somewhere was huge." She is the first participant who discusses a need to focus on self-care likely because she is self-advocate. Sara is studying public health in a desire to ensure that "good science" is done in the future for others like herself. Although participants clearly articulated the factors, including the rare often hidden nature of CRMO, that have lead them to their advocacy approaches, I was struck by the fact that all five participants are women managing the illnesses of themselves or their daughters.

The second research question in this study has been answered. However, the all-female nature of both participants and children leads me to ask if male advocates view their role similar to their female counterparts. It may also be possible that women continue to bear the traditional role of primary caregiver in the modern family structure, thereby decreasing the likelihood of finding male caregivers. Additionally, I wonder if female caregivers advocate differently for their male children who have been diagnosed with CRMO.

Research Question 3

What type of guide can bebe developed to help parents navigate their advocacy role between the school and medical communities for their ill child?

Multiple interview questions were asked and answered by all participants to determine if a guide could be developed to help parents navigate their advocacy role Interview questions were designed to elicit responses in which the researcher could look for commonalities or patterns, such as "What do you wish you knew prior to your child's diagnosis that could have helped you work with the school?" "What common accommodations or supports does your child use?" "What advice would you give parents with newly diagnosed CRMO children?" and "What additional information would you like to share about working with your child's school?" It became apparent after the first two case studies that CRMO affects children in different ways to differing severities. There were relatively few patterns of specific accommodations or supports utilized by multiple participants. Several participants even highlighted how different cases were from one another. For example, Olivia said that she is often asked to share a copy of her 504 plan and does not like to do so because parents need to sit at the "table and figure out what works for your kid." Mary described what works for her two children as being vastly different. She works with two separate IEP committees for children with two different chronic illnesses. The power in those meetings is "sitting down and discussing what is working and what isn't" with all the stakeholders. Although all five participants discussed the need to create a plan that works for each child independently, specific accommodation, or communication patterns across all cases in this study are non-existent.

Only two of the five participants interviewed have a formal educational support plan in their K-12 school, though all expressed a desire to create such a plan. When asked if she thinks a tool to help her create a formal plan would be useful, Dana said, "Absolutely, because for one, I've never had, I don't even know what a 504 meeting is." The doctor just asked her, "'What do you want your 504 documents to say?' and faxed it over to the school." Laura asked, "When she goes off to high school, and it's a bigger school, do I need to get something written in place?" The two parents who have formal plans in place, Olivia and Mary, rely on those plans to help create face-to-face communication to support their children. Throughout all five interviews, I was struck most by this quote from Olivia, "I don't feel like the power [of a formal written educational support plan] is in legality. I think it's power is in connecting." A guide is needed to help CRMO diagnosed families navigate formal education supports. However, both Olivia and Dana believe that the most useful artifact that could be supplied to families would be a video sharing how their child's diagnosis makes them "just a little bit different" (Dana) and showing how to help facilitate “a perfect 504 meeting” (Olivia). As such, the written artifact and video link included in the appendix of this study are geared towards helping families create partnerships with their schools rather than focusing on specific successful accommodations.

Interaction Between the Research and the Context

Because of the rare nature of the disease included in the context of this study, all participants were interviewed utilizing the Zoom web-conferencing platform provided by Texas A&M University. Four out of the five participants chose to utilize the camera features included in the software so that the researcher and participant could see one another for the duration of the interview. One participant elected to participate in the interview utilizing the audio feature so that a phone interview was conducted. Before being interviewed, all participants completed an informed consent document to participate in the study. Additionally, before recording the interview, participants verbally agreed to have the interview recorded. All participants were interviewed utilizing the semistructured interview guide detailed in Chapter III of this work. While closing the interviews, the member-checking process was explained to participants. Shortly after the interview, each participant received a transcript of the interview. Participants were asked to member-check the transcripts to ensure the accuracy of the transcription. Each participant returned the transcript after completing an accuracy review.

How the Context Impacted the Findings

As the parent of a child diagnosed with CRMO, I felt that it was important to introduce myself as such during the interviews with all participants. After that initial introduction, I was careful to follow the semistructured interview guide to ensure that researcher bias did not affect the nature of participant responses. The geographical range of the participants included in this study allowed for a unique picture of parent advocacy across the United States. Two participants live in the Pacific Northwest, one participant with two differently diagnosed children lives in Southern California, one participant lives in urban Texas, and another participant lives in North Carolina. This geographical range allowed for a variety of school systems, obstacles, and strategies to be included in the study.

Stakeholders who participated in the study all expressed excitement in their ability to share their knowledge. One participant posted a message about the positive interview experience. The positive posting resulted in interest from additional participants. All participants expressed a desire to be part of an information exchange that would help other CRMO-diagnosed patients or parents. Though it was not my original intent to include an adult CRMO patient in the study, the addition of the college-aged participant who wanted to participate as her own advocate in a higher-education setting will be useful to parent advocates as their children begin to transition into higher education. One person interviewed chose not to continue their participation in the study after receiving the transcript from the interview, citing a dislike of their responses as the rationale to discontinue participation.

How the Research Impacted the Context

The results of each interview were shared with individual participants through the review of their transcribed interviews. All participants agreed that the transcripts were accurate reflections of the data collected during the semistructured interviews. As participants suggested the idea to create a video artifact, I shared that suggestion with participants in future interviews. All five participants felt that a short video capturing the unique qualities of CRMO, as well as an instructional segment on how to develop collaborative support plans, would benefit them in their advocacy role. A Google document containing a script for the video, as well as all resources included in the video, was shared with participants. Additionally, the written artifact was shared with participants. Two participants added suggestions and corrections to improve the script. Participant Olivia, who facilitates the CRMO awareness webpage, supports the CRMO research foundation, and acts as an administrator on the CRMO Facebook page, requested a final copy of this record of study, artifact, and video to include on the aforementioned resource sites. (The video can be accessed with permission at https://drive.google.com/file/d/1T71dFgv8s5a-8vKHGNBT178LKYjG9Jgy/view?usp=sharing/.) Furthermore, the artifacts produced in this study have considerable transferability and could be used by a wider group of parents working to set up educational supports for their children in a variety of circumstances.

Although most of the research questions in this study were answered, the question related to family roles in connecting the medical and educational communities should be further studied. Only one participant articulated her advocacy approach when going between these two communities. Olivia was the only participant who described her role as a “bridge” between medicine and education. Additionally, the female-centric nature of this study leads to questions about gender differences in advocacy. Do fathers take on the role of caregiver? Would male caregivers have similar approaches in advocating for their children, or would they use different methods to support their children diagnosed with chronic illnesses? Future studies of parent advocacy should work to include all genders to determine if advocacy differs between male and female parents.

Summary

This phenomenological study used a small sample representing five unique school systems to understand the phenomenon of parents advocating for their children who have been diagnosed with CRMO, an uncommon chronic illness. The five participants interviewed in this study have faced a variety of obstacles in their advocacy role. The participants have also found ways to overcome common barriers such as attendance concerns and educating others about the rare diagnosis their children (or they) have received. Rather than a set of standardized tools that others might replicate, the participants in this study have all developed strong communication skills to create close relationships with essential personnel in the school setting. The advocates then rely on the strength of their ties with the school system to develop intervention plans that can be adjusted to meet the changing needs of their children's (or their) symptoms. Despite the substantial geographical differences in the families represented in this study, school connectedness and face-to-face communication have been utilized to overcome a variety of barriers faced by advocates.

CHAPTER V

SUMMARY AND DISCUSSION OF FINDINGS

Summary of Findings

The analysis of this phenomenological study resulted in the creation of five individual case studies of parent advocacy and self-advocacy for those who bear the disease burdens of CRMO/CNO. The creation of individual case studies over a wide variety of geographical locations aided in the creation of a phenomenological picture of CRMO advocacy. Through the use of cross-case comparisons, patterns of successful advocacy took shape. Of particular interest, all five participants in this research study can be defined as action researchers. All of the participants are actively engaged in active research about CRMO/CNO and utilize a variety of methodologies to ensure successful outcomes for themselves and their loved ones. Of further interest, these advocates utilize a social media site as their primary means of engaging in action research. The CRMO Facebook page, closely followed by the CRMO awareness website, is the primary tool used by all participants to seek information. The use of these resources is particularly impressive when taking note that both are grassroots movements created by parent advocates to help other parents understand this disease.

Study participants have faced obstacles such as school attendance, physical appearance of health, social and emotional concerns, lack of information available about CRMO, fear of school transitions, lack of trust, unskilled educational professionals, and financial concerns when navigating their advocacy role. To overcome these obstacles, participants have used a variety of tools including face-to-face communication, one-on-one problem-solving, relationship- and partnership-building, educating those around them about CRMO/CNO, social media and advocacy groups, and maintaining an overall positive attitude about their circumstances to produce useful advocacy.

The study's parent advocates and self-advocate all described their primary responsibilities as relating to communication. This communication takes on many forms, most commonly, that of the educator. Advocates feel compelled to teach those spending large amounts of time with the CRMO/CNO-diagnosed student about the disease. This task often proves difficult given the rare nature of CRMO/CNO. Additionally, advocates utilize their social media channel and the CRMO awareness webpage to gather resources to add legitimacy to their education efforts. Further compounding the struggle to educate others about CRMO/CNO is the variety of ways in which the disease manifests itself. Because CRMO/CNO can affect any bone in the body, disease symptoms vary across those diagnosed. Additionally, disease sufferers may experience changing symptoms within themselves as the disease progresses over time. Therefore, the communication role is continuously changing and requires frequent communication to ensure that all stakeholders are up to date.

Discussion of Findings Related to the Literature

The findings in this study both extend and counter several ideas previously addressed in the literature. The parent advocacy role, barriers to successful advocacy, absenteeism, school supports, and student voices are all findings from this study that connect to the literature.

Parent Advocacy

As discussed, participants in this study all felt the overwhelming burden to educate others about CRMO/CNO. Cunningham and Wodrich (2006) determined that 92% of educators in their study reported wanting disease-specific information to help those students they serve suffering from a chronic illness. Educators lacking disease information can harm students (Irwin & Elam, 2011). CRMO/CNO advocates intuitively know that educators armed with more information about this rare disease can have a positive effect on their children. All of the participants in this study explained how educating those around them about the disease is of primary importance. Two pieces of literature previously discussed identify optimism and school connectedness as crucial success factors for children with chronic illnesses (Ferguson & Walker, 2014; Maslow, Haydon, McRee, & Halpern, 2012). All four of the parent participants in this study identified positive relationships with their schools. They all described feeling fortunate regarding their child's current situation and a strong desire to keep their child connected to the school. Thus, this study supports previous findings that optimism may be beneficial in advocacy. Several participants in this study expressed fear of school transitions as their child ages. These expressions align with the coping model found by Melnyk et al. (2001), who described school transitions as a time of increased parent stress (2001). Finally, this study's finding that parents most often utilize face-to-face communication to build partnerships with their children's schools is a prime example of the agency-building discussed in the literature (Marshall & Oliva, 2010). While this study examines the advocacy roles of parents, it primarily focuses on those who feel they have been successful. Further study is needed to determine if the findings would support the literature if advocates who have a more adversarial relationship with their children's schools had been included in this study.

Barriers to Successful Advocacy

All of the participants in this study identified a level of social anxiety related to the CRMO/CNO diagnosis. Parent participants discussed fear for their children's safety and social relationships while at school. Some participants described breakdowns in the office as they explained the illness to school personnel, affirming the parent coping models addressed by

Melnyk et al. (2001), who also suggested that parent stressors increase as they give up primary care of their children to the school system (Melnyk, Feinstein, Moldenhouer, & Small, 2001). All participants discussed the fear of isolating the student while balancing unique needs to protect those on immune-suppressant therapies. Parent and student fears of isolation found in this study correlate almost identically with those described in the literature: “Many environments can feel inaccessible and constraining when managing the effects of a child’s chronic illness” (Boles, 2017, p. 305). Three of the four parents interviewed for this study shared stories of going to their child’s school to share information with their child’s peers about disease manifestations. Often this action was at the request of their child. The concerns of parents for their child’s social well-being were described through the parents’ and children’s fears of using walkers and wheelchairs at school, as well as the children’s desires to have their parents read CRMO/CNO handouts to the class. These parent advocacy actions can be tied back to studies in the literature related to the necessity of creating a school-based support model (Gan et al., 2018). Although the majority of the parents described fear related to the isolation experienced by their child, they all explained the strong desire of their child to attend school. Though the children (as well as the adult self-advocate) struggle with disease management and fear of social rejection because of their disease, all six students who are chronically ill want to attend school. The desire to attend school is a finding opposed to previous research indicating that students with chronic illness may miss school due to social maladjustment or school-phobic attitudes (Shiu, 2001). Though Shiu’s (2001) study may hold true in other situations, school-phobic attitudes were not seen as reasons for nonattendance at school in this study.

Absenteeism

Although this study found attendance to be a barrier to successful advocacy in every case studied, the rationale of the problem differs from the attendance issues described in the literature. The findings of this study and the previously discussed literature agree that the length of absences required to necessitate school interventions and the adverse effect litmus test are areas of concern for parents (Clay, 2004; State of Texas, 2019; Texas Education Agency, 2019). The literature primarily has focused on how absences impact the academic outcomes of children with chronic illnesses (A'Bear, 2014; Boles, 2017; Gan et al., 2018; Irwin & Elam, 2011). Study participants described the attendance barriers they have struggled to overcome in terms of damaging their relationship with the school rather than in terms of their student's academic success. Participants described how they felt with phone calls asking for medical notes or truancy letters they received from the school. Sara, the adult participant, described teachers losing faith in her abilities as a student and went on to describe an excellent GPA, explaining that she maintained honor-roll status while in high school. The meta-analysis conducted to determine the relationship among chronic illness, absenteeism, and achievement suggests that academic concerns exist in the broader view of chronic illness, even if they were not seen in this small study (Lum et al., 2017). The misalignment of the literature to the finding of this study could be caused by what Mukherjee, Lightfoot, and Sloper (2000) articulated as parents being an unreliable source of information when discussing the academic performance of their students. Parent and self-advocates may not be able to see the academic impacts of chronic absenteeism on the educational careers of the student. The small sample size included in this study might not be large enough to find CRMO/CNO patients who have struggled academically because of their attendance. Even though the rationale for attendance concerns differs between the literature and this study, attendance issues and school management of this issue are a burden to successful advocacy.

Disease Invisibility (Student Voice)

This study identifies disease invisibility as a significant burden or obstacle to be overcome, yet there is minimal evidence of this finding in previous literature. Four out of five participants in this study describe how looking “healthy” to others while internally facing severe disease symptoms creates a misalignment of perceptions for those who interact with children who may be diagnosed with CRMO/CNO. In this study parent and self-advocates used language such as my daughter “looks healthy,” “presents beautifully,” “is in 10 times more pain than you can imagine,” “does not look sick,” “you are not that sick” and “can hide pain like nobody I’ve ever met” to justify the differences between what you can see on the outside versus the internal struggles created by a CRMO/CNO diagnosis.

Despite this significant finding, there is little evidence of the impact of disease visibility in people with chronic conditions in previous literature. Although Pinquart has completed extensive work on the social aspects of chronic conditions in his 2013 metaanalysis on chronic illnesses, he primarily identifies that social maladjustment of children with chronic conditions is due primarily to issues related to self-esteem. Decreased self-esteem in children who have a chronic condition is attributed to feeling behind or different than peers. Perhaps the struggles he finds in adolescents to achieve positive self-image could be due in part to the finding of the struggles related to disease invisibility identified in this study with children diagnosed with CRMO/CNO. Do adolescents with chronic self-image struggle to create a positive self-image because they are continually fighting a battle to get people to understand what they are going through despite the outward appearance of health? Is this the feeling of difference from peers that Pinquart identified?

Additionally, A’Bear (2014) and Boles (2017) discuss the social implications of isolation on children with a chronic illness. Compas et al., 2012 identify that children who suffer from chronic illnesses also suffer from chronic stress, which can decrease their social functioning in school. However, the Compas et al., study identifies falling behind academically and increased absences as the root causes of chronic stress. Based on the findings of my study, I believe that student and parental stress is related to the burden of teaching others how damaging a CRMO/CNO diagnosis can be to children’s bodies despite the outward appearance of health. Lum (2017) identifies that students with chronic conditions who can connect to their social environment in school are more successful academically than students with chronic conditions who can not connect to their school environments. This large study does not identify why there are differences in connectedness. Perhaps Mukherjee’s 2000 findings that students with chronic conditions need their teachers to understand and explain their chronic conditions to their peers could be a direct result of the invisibility of their chronic conditions. Although there is significant evidence in the literature that children with chronic conditions undergo increased stress and feelings of isolation, the rationales given in the previous literature for these findings differ from this study. Further study on the impact of the often hidden nature of chronic conditions has on children who have been diagnosed with a chronic condition is needed.

Supports

Nearly 40 years ago, researchers identified parents acting as key communicators on behalf of their children with chronic illnesses (Baird & Ashcroft, 1984; Baird, Ashcroft, & Dy, 1984; Walker & Jacobs, 1984). The finding in this study suggests that the role of key communicator continues to be one of primacy in the advocacy role had by many parents today. This study aligns further with previous research with the participants in this study adding to their role by serving as the principal educator of their rare diagnosis (Nabors, Little, Akin-Little, & Iobst, 2008). The literature has suggested that teachers who have more information about the diseases they may encounter are more confident in providing support to the chronically ill students in their classrooms (Cunningham & Wodrich, 2006). Parents acting as education agents for teachers regarding their child's illness would support the work done by Cunningham and Wodrich (2006). Some researchers have suggested that advocates take on the roles of communicator and educator as a way to ensure that caregivers create social justice and agency for their child and themselves (Marshall & Oliva, 2010). The participants featured in this study all reported a desire to create partnerships; some even called school personnel "best friends" in caring for their children. This parent description extends the idea of the agency explained by Marshall and Olivia (2010).

Additional examples of connections between this study and the literature can be found as parents work to set up educational plans in schools. Similarities exist when comparing the descriptions used in Hewitt-Taylor's (2009) study of parents battling the school with this study's participant description, "I am not fighting [the school] right now." Additionally, the advocates who participated in this study either worked to formally set up educational supports for their child or were actively engaged in establishing informal methods of support. The use of both informal and formal supports by all participants aligns with the literature, indicating that parents may need assistance in learning the methodologies for implementing formalized plans to support their children with chronic illnesses in the school setting (Clay, 2004; Oliver et al., 2018). Though parent advocates had varying levels of skill in setting up school supports, it is essential to note that all participants in this study expressed a desire to understand how to implement formal educational support plans as they navigate their educational advocacy role.

Participants in this study expressed the value of locating helpful school personnel in establishing school support plans for the chronically ill. However, this study did not produce consistent findings on who those key school personnel are who could be of assistance to parent advocates. Although studies have been performed suggesting the critical roles of both the school nurse and school counselors, participants in this study reported utilizing those resources with varying degrees of success (Kaffenberger, 2006; Nabors et al., 2008). While some participants have relied heavily on the school counselors, another called their counselor “useless.” Only one participant in this study described relying on the school nurse. While this study could not identify a consistent person with whom parent advocates could connect at school, each participant discussed finding the person on their child’s campus who would see the good in their child. They have all searched for a person who sees their child for what they can do rather than focusing on their child’s disability, which aligns with the capability framework establish by Terazi (2008) in the literature.

Implications for Practice

Connections to the Context

CRMO/CNO is a rare, often invisible, isolating disease. CRMO/CNO has implications on not only the individual diagnosed with the disease, but also with the multiple communities within which a person with CRMO/CNO interacts. Unlike other chronic illnesses that may be more well-known, CRMO/CNO patients must take on the burden of teaching others about their illness. Thus, those diagnosed with CRMO/CNO and those who act as caregivers have to become educated in their diagnosis before they can teach others about it. The rarity of this disease results in a lack of resources that can be used by individuals to educate themselves. The primary method used by the CRMO/CNO community to gather information is social media. Each resource used by the parents and student interviewed for this study to educate themselves was created and is maintained by members of the community. A small community of parent activists has established the CRMO Facebook page, CRMO awareness website, and CRMO research foundation.

The grassroots movement created by the CRMO/CNO community to establish connections and help educate one another is impressive. Additionally, the grassroots ideology has implications on how to provide tools to this community. Each participant discussed seeking knowledge via the CRMO Facebook page and CRMO awareness website. Therefore, any resources generated by the community, including this study and its artifacts, need to be housed in these two places. Thus, any information shared with parents is often not considered useful until other parents validate it. Also, parents always add ideas and provide useful tips and strategies to other parents in similar situations. Therefore, the artifacts produced by this study need to be housed such that open-forum discussions can occur in order for other parents to find them useful.

Connections to the Field of Study

The five case studies included in this record of study produced compelling results. Primarily, the participants in this study view their partnerships and relationships with the school system as critically important. Overall, they have a positive perception of their school systems in educating the student with a chronic illness. They are hopeful and engaged in the process of creating a situation that will allow for the student's academic success. Each participant interviewed expressed their approach to building relationships for face-to-face communication.

Sitting down together with all of the stakeholders in a student's education is of vital importance to these participants.

Furthermore, parents did not report seeing their child's medical professional as vital to the educational success of their children. One participant stated that the medical community did not see the impact of the medical condition on the nonmedical aspects of her daughter's life. The positive belief in the school systems educating their children has vast implications for educational professionals. Schools must make time for face-to-face meetings as the participants of this study described. Failure to provide parents with this type of platform will result in a loss of trust that will damage the positive perceptions currently held by these parents.

Parent and self-advocates are using a form of action research to establish a positive advocacy role in educational supports. The CRMO/CNO community has established grassroots educational forums for one another in which they can create a knowledge base that all participants can utilize. It would benefit educators who interact with students diagnosed with CRMO/CNO to become members of these online communities to become better educated themselves.

Discussion of Lessons Learned

Personal Lessons

The record-of-study process produces a tremendous amount of personal lessons to be learned. First, the design of a research project is critical. I desired to understand the phenomenon of parent advocacy for children diagnosed with CRMO/CNO. I wanted to create a research design that would allow me to understand how other parents had successfully navigated their advocacy role while also creating tools that would benefit the CRMO community and the educators who serve it. My connection to this research required that I carefully acknowledge researcher bias and develop systems to overtly state that bias and move beyond it. While I was careful to stick to the script I produced for the semistructured interviews, I was surprised at how hard it was to hear other parents' stories during the data collection phase of this project. I found myself moved to tears many times during the interview, transcription, and data analysis phases of the study. My goal in including the autoethnography framework in this study was to use my school administrator lens to evaluate the strategies used by parents in their advocacy role for the ability to apply useful strategies more broadly. What I found instead was myself being inspired by the faith placed in educators by parents and pride in my membership in a community of parents working so hard to educate and ease the burdens of one another. The case studies found in this work represent optimism despite difficult circumstances. Though I had previously read about the objectivity-subjectivity obstacles inherent in autoethnography and action research, the experience was more intense than I anticipated. I did not expect how inspired I would be in creating the cases or how emotionally attached I would become to the quotes I used from parents to describe their situations.

Additionally, I learned how consuming case study research can be. I faced struggles in finding participants (despite the high number of interest emails I initially received) and was shocked at how time-consuming transcription is. Each one-hour interview took me four to five hours to transcribe. I was surprised by how engrossed I became in the transcription process, as well as how much I thought about developing each case. I often woke up in the middle of the night thinking about the similarities and connections among the case studies and how they relate to the research questions in the study. I was surprised by how completely consumed I became with other people's stories, often neglecting other tasks that needed to be accomplished while analyzing the data.

By nature, I like organization and structure. Although I started this record of study with a solid plan, I learned a valuable lesson about flexibility through this project. I began this project believing that I could create a tool or a form to help parents navigate the educational process. What I learned, though, is that there probably is not one form that can help all parents. Overwhelmingly, participants told me that they prefer videos and clips to facilitate their learning. Participants want something that can be posted on an open forum and added to by other successful advocates. I learned that participants' stories lead to an unexpected outcome, and that is okay. It is part of the qualitative and action research process. The study and my artifacts are robust because I was open to participant suggestions.

Record-of-Study Lessons

This record of study provided various lessons on the role of parent advocate. First, CRMO/CNO parents are action researchers. Parents utilize a variety of tools, including social media, websites, and relationships with their neighborhood schools, to implement strategies and study what works for their children and themselves. The initial goal of this study was to create a communication tool to aid parents in their advocacy role. Participants indicated that in addition to static tools, they need visual tools that can be placed on open forums where the CRMO/CNO community can post additional suggestions or tips. The rationale for this type of artifact is the volatile and evolving nature of a CRMO/CNO diagnosis.

Although there is a strong parent support base in the CRMO/CNO community, the individualized symptoms and disease development of CRMO/CNO make parents hesitant to share formalized educational plans with one another. Intelligently, parents recognize that support plans must be developed with communities that support their individual children. No one strategy or accommodation was common across all five participants in this study. Thus, parents have developed a unique understanding that their advocacy can support one another but cannot be replicated to produce identical results for other families.

Finally, parents are acutely aware that the relationships and trust they place in those who care for their children must be cultivated to create a positive environment for their children. The participants of this study recognize that this approach to positive relationships is not universal, and they instead choose to build trusting relationships because they have found it the most beneficial method to support their children. The participants in this study reported hoping that a tool can be developed to teach other parent advocates how beneficial this approach can be.

Recommendations

This record of study included a small sample of active parent advocates. The small sample size creates limitations in this study. The parent participants in this study are all female with female children, thereby eliminating a male perspective from this research. Further study should seek to include male caregivers, if they can be found in this non-traditional role, to determine if gender differences change perceptions of advocacy roles. Additionally, there are several other missing voices in this study. To provide a more thorough picture of parental advocacy between the medical and school communities, educators and medical voices should be included. This study relies solely on parent perceptions. While the participants in this study share compelling information on how they have successfully navigated their roles between school and medicine, it would be fascinating to talk with the doctors and teachers involved in these case studies to see if their perceptions align with the parental self-reports.

Additionally, the student voice added by Sara creates a unique dimension to this study. Her perception is less optimistic than many of the other participants when referring to trusting educational professionals. Several factors could contribute to this difference, one being that she is an adult with financial obligations who is managing a collegiate educational setting. However, her voice brings an interesting angle to this study. I wonder if adding more student voices, particularly younger children, would provide a different perspective on how successful their parents are in advocating for their needs. Would the children be as optimistic about their disease burdens as their parents? The inclusion of multiple perspectives would strengthen the study of parent advocacy of ill children in the future.

Closing Thoughts

Parents whose children have been diagnosed with CRMO/CNO are acting in the role of key communicator to be the primary advocate for their child. This role requires the parents to bridge the gap between their child’s school and medical communities. Although the participants in this study may not see themselves in the role of building a bridge between medicine and education, their willingness to act as disease educators for those who surround their children indicates that the parents do serve in this role. As bridge-builders and advocates, the parents in the CRMO/CNO community have developed a number of grassroots efforts to help one another, despite the geographic distance between them. The use of a parent-developed website and social media page for vetting ideas and approaches to disease management increases the strength of these efforts. The creation of tools using the themes developed by this study’s participants creates additional resources that the more comprehensive CRMO/CNO collaborative can use to increase the success of its advocacy.

The five participants in this study have optimistic views of their educational settings despite the obstacles they have overcome in working with their school systems. School districts, administrators, and teachers would do well to create procedures to enable parents to advocate in the face-to-face manner described by these participants. Additionally, because of the rare and changing nature of CRMO/CNO, schools can utilize the parent resources to help them develop accommodations that fit the physical symptoms experienced by individual students, as well as to develop social, emotional, and academic supports for students with this rare diagnosis. The participants of this study place immense trust in their children’s schools. That trust has been earned by a true collaboration that benefits the student in each case. Schools need to work with parents to nurture that collaboration, especially as students move into secondary schools where parents fear decreased communication.

REFERENCES

A'Bear, D. (2014). Supporting the learning of children with chronic illness. *Canadian Journal of Action Research, 15*(1), 22-39.

Anderson, G. L., Herr, K., & Nihlen, A. S. (2007). *Studying your own school* (2nd ed.). Thousand Oaks, Calif: Corwin Press.

Baird, S. M., & Ashcroft, S. C. (1984). Education and chronically ill children: A need-based policy orientation. *Peabody Journal of Education, 61*(2), 91-129. doi:10.1080/01619568409538439

Baird, S. M., Ashcroft, S. C., & Dy, E. B. (1984). Survey of educational provisions for chronically ill children. *Peabody Journal of Education, 61*(2), 75-90. doi:10.1080/01619568409538438

Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, N.J: Prentice Hall.

Basch, C. E. (2011). Asthma and the achievement gap among urban minority youth. *Journal of School Health, 81*(10), 606-613.

Boles, J. (2017). The children's corner: Perspectives on supportive care. School attendance for children with chronic illnesses. *Pediatric Nursing, 43*(6), 305-306.

Bonaiuto, M. M. (2007). School nurse case management: Achieving health and educational outcomes. *Journal of School Nursing, 23*(4), 202-209.

Boonen, H., & Petry, K. (2012). How do children with a chronic or long-term illness perceive their school re-entry after a period of homebound instruction? *Child: Care, Health & Development, 38*(4), 490-496. doi:10.1111/j.1365-2214.2011.01279.x

Chang, H. (2016). *Autoethnography as method*. London; New York: Routledge, Taylor & Francis Group.

Clay, D. L. (2004). *Helping schoolchildren with chronic health conditions: A practical guide*. New York: Guilford Publications.

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology, 8*(1), 455-480. doi:10.1146/annurev-clinpsy-032511-143108

Creswell, J. W. (2014). *Research design* (4^{th} ed.). Los Angeles; London; New Delhi; Singapore; Washington DC: SAGE.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Los Angeles: SAGE.

Cunningham, M. M., & Wodrich, D. L. (2006). The effect of sharing health information on teachers' production of classroom accommodations. *Psychology in the Schools, 43*(5), 553-564.

Denzin, N. K., & Lincoln, Y. S. (2018). *The sage handbook of qualitative research* (5th ed.). Los Angeles: Sage.

Erkolahti, R., & Ilonen, T. (2005). Academic achievement and the self-image of adolescents with diabetes mellitus type-1 and rheumatoid arthritis. *Journal of Youth and Adolescence, 34*(3).

Ferguson, P., & Walker, H. (2014). ‘Getting on with life’: Resilience and normalcy in adolescents living with chronic illness. *International Journal of Inclusive Education, 18*(3), 227-240. doi:10.1080/13603116.2012.676082

Fowler, M. G., Johnson, M. P., & Atkinson, S. S. (1985). School achievement and absence in children with chronic health conditions. *The Journal of Pediatrics, 106*(4), 683-687. doi:10.1016/S0022-3476(85)80103-7

Gan, L., Lum, A., Wakefield, C., Donnan, B., Marshall, G., Burns, M., . . . Fardell, J. (2018). The school experiences of siblings of children with chronic illness: Australian parents' perceptions. *Educational & Developmental Psychologist, 35*(1), 36-50. doi:10.1017/edp.2018.3

Hewitt-Taylor, J. (2009). Children who have complex health needs: Parents' experiences of their child's education. *Child: Care, Health & Development, 35*(4), 521-526. doi:10.1111/j.1365-2214.2009.00965.x

Hosking, D. The theory of critical disability theory. Paper presented at the *4th Biennial Disability Studies Conference at Lancaster University,* 1-17.

Irwin, M. K., & Elam, M. (2011). Are we leaving children with chronic illness behind? *Physical Disabilities: Education & Related Services, 30*(2), 67-80.

Kaffenberger, C. J. (2006). School reentry for students with a chronic illness: A role for professional school counselors. *Professional School Counseling, 9*(3), 223-230.

Kish, A., Newcombe, P., & Haslam, D. (2018). Working and caring for a child with chronic illness: A review of current literature. *Child: Care, Health & Development, 44*(3), 343-354. doi:10.1111/cch.12546

Leroy, Z. C., Wallin, R., & Lee, S. (2017). The role of school health services in addressing the needs of students with chronic health conditions: A systematic review. *Journal of School Nursing, 33*(1), 64-72.

Lum, A., Wakefield, C. E., Donnan, B., Burns, M. A., Fardell, J., & Marshall, G. (2017). Understanding the school experiences of children and adolescents with serious chronic illness: A systematic meta-review. *Child: Care, Health & Development, 43*(5), 645-662. doi:10.1111/cch.12475

Marshall, C., & Oliva, M. (2010). *Leadership for social justice* (2nd ed.). Boston: Allyn and Bacon.

Martire, L. M., & Helgeson, V. S. (2017). Close relationships and the management of chronic illness: Associations and interventions. *The American Psychologist, 72*(6), 601-612. doi:10.1037/amp0000066

Maslow, G., Haydon, A. A., McRee, A., & Halpern, C. T. (2012). Protective connections and educational attainment among young adults with childhood-onset chronic illness. *Journal of School Health, 82*(8), 364-370.

Massie, R. K. (1984). The constant shadow: Reflections on the life of the chronically ill child. *Peabody Journal of Education, 61*(2), 16-27. doi:10.1080/01619568409538436

Melnyk, B. M., Feinstein, N. F., Moldenhouer, Z., & Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing, 27*(6), 548.

Meuleners, L. B., Binns, C. W., Lee, A. H., & Lower, A. (2002). Perceptions of the quality of life for the adolescent with a chronic illness by teachers, parents and health professionals: A delphi study. *Child: Care, Health & Development*, *28*(5), 341-349. doi:10.1046/j.1365-2214.2002.00283.x

Minier, M., Hirshfield, L., Ramahi, R., Glassgow, A. E., Fox, K., & Martin, M. A. (2018). Schools and health: An essential partnership for the effective care of children with chronic conditions. *Journal of School Health, 88*(9), 699-703. doi:10.1111/josh.12671

Moses, M., Gilchrest, C., & Schwab, N. C. (2005). Section 504 of the rehabilitation act: Determining eligibility and implications for school districts. *Journal of School Nursing, 21*(1), 48-58.

Mukherjee, S., Lightfoot, J., & Sloper, P. (2000). The inclusion of pupils with a chronic health condition in mainstream school: What does it mean for teachers? *Educational Research, 42*(1), 59-72. doi:10.1080/001318800363917

Nabors, L. A., Little, S. G., Akin-Little, A., & Iobst, E. A. (2008). Teacher knowledge of and confidence in meeting the needs of children with chronic medical conditions: Pediatric psychology's contribution to education. *Psychology in the Schools, 45*(3), 217-226.

Oliver, M., Lee, T., Halpern-Felscher, B., Murray, E., Schwarts, R., & Zhao, Y. (2018). Disease burden and social impact of pediatric chronic nonbacterial osteomyelitis from the patient and family perspective. *Pediatric Journal of Rheumatology Online, 16*(1), No pagination. Retrieved from https://www-ncbi-nlm-nih-gov.srv-proxy1.library.tamu.edu/pmc/articles/PMC6295

Patton, M. Q. (2015). *Qualitative research & evaluation methods* (4th ed.). Thousand Oaks, CA: Sage.

Perrin, E. C., Ramsey, B. K., & Sandler, H. M. (1987). Competent kids: Children and adolescents with a chronic illness. *Child: Care, Health & Development, 13*(1), 13-32.

Pinquart, M. 1. (2013). Self-esteem of children and adolescents with chronic illness: A meta-analysis. *Child: Care, Health & Development, 39*(2), 153-161. doi:10.1111/j.1365-2214.2012.01397.x

Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). Los Angeles; London; New Delhi; Singapore; Washington DC: Sage.

Sexson, S., & Madan-Swain, A. (1995). The chronically ill child in the school. *School Psychology Quarterly, 10*(4), 359-68.

Shiu, S. (2001). Issues in the education of students with chronic illness. *International Journal of Disability, Development and Education, 48*(3), 269-81.

Texas education code chapter 38, (2019). Retrieved from https://statutes.capitol.texas.gov/SOTWDocs/ED/htm/ED.38.htm

Terzi, L. (2008). *Justice and equality in education*. London: Continuum.

Texas Department of Health and Human Services. (2019). School health services. Retrieved from https://www.dshs.state.tx.us/schoolhealth/schnurs.shtm

Texas Education Agency. (2019). Proposed 2019-2020 student attendance accounting handbook. Retrieved from https://tea.texas.gov/sites/default/files/Entire%2019-20%20Proposed%20SAAH_master.pdf

Thies, K. M. (1999). Identifying the educational implications of chronic illness in school children. *Journal of School Health, 69*(10), 392-397. doi:10.1111/j.1746-1561.1999.tb06354.x

Walker, D., & Jacobs, F. (1984). Chronically ill children in school. *Peabody Journal of Education, 61*(2), 28-74.

Yin, R. K. (2018). Case study research and applications: Design and methods. Los Angeles: Sage.

APPENDIX

EDUCATIONAL SUPPORTS: AN INSTRUCTIONAL GUIDE FOR PARENTS

First Steps – What you will need to get started:

- ☐ Know your goal –
  - ➢ Any educational support meeting is designed to help build a relationship between yourself and your child's school. The power of a support meeting is in the collaboration you will create between your child's caregivers.
- ☐ A written diagnosis –
  - ➢ Check with the school system to see if they have a particular form.
    - ➢ Parent tips: Contact nurses, office managers, or your child's primary care doctor for necessary forms if the specialist is difficult to reach or to schedule appointments with.
- ☐ Share info about CRMO. The educators who work with your child will need information about this rare disease.
  - ➢ The CRMO Awareness website has a great brochure: http://crmoawareness.org/wp-content/uploads/2019/07/CRMO-Brochure-final-draft.pdf
  - ➢ The CARRA flyer can be found here: https://crmofoundation.org/newlydiagnosed/

How to set-up the meeting:

- ☐ Send an email requesting a meeting. Ask that these people be involved:
  - ✓ a school administrator
  - ✓ counselor
  - ✓ nurse
  - ✓ most if not all of your child's teachers
    - ➢ Parent tips: Face to face communication is a critical component of success! Remember, this is a collaborative plan. If you have to wait a few days to get all the stakeholders there, do it! Everyone sitting at the table at the same time is a critical factor in the success of the meeting.
- ☐ Note: In most locations in the United States, you are asking for a 504 meeting. However, you could also have an individual education plan meeting or health support meeting.

Use this space to keep notes on how you are setting up your meeting. Who did you email? When? Date, time, and location of the meeting.

Starting the meeting off: -The educators involved are going to lead the meeting. Ask if you can start the meeting by addressing two topics:

- ☐ 1. Introduce CRMO & tell your child's story.
    - Parent tip – Write down your child's story and read it to the team. Stick to what your child has endured and how it may impact their schooling. If this will be difficult for you, then share Faith's story. Here is the video link: https://www.youtube.com/watch?v=8A4bmVXZjkA
- ☐ 2. Attendance - In the recent parent interviews, I conducted almost every parent discussed their child's school attendance as an obstacle they had to overcome in dealing with the educational system for their child. Many parents received truancy letters or phone calls that upset them while worrying about their child's health. I suggest you tackle this topic head-on. In many states, there are strict attendance laws, and often automated systems generate the letters and calls you are receiving. Ask a few questions so that you understand this process better:
    - What are the attendance laws/rules/procedures here?
    - What can I do to help ensure that my child receives credit for attendance?
    - When things are tough and my child can't come to school, how can we ensure he gets the necessary materials.
    - How does the school prefer you to notify them of an absence?
    - If you happen to get one of those attendance letters or calls, when should you be concerned? Are they just all automated? What would they like your process to be?

Keep notes here for your agreed-upon attendance plan:

What could the rest of the agenda look like?

- ☐ Educational strengths & weaknesses
    - ➢ Parent tip: Be prepared to listen to this. You know a lot about your child, but so do your child's teachers. They know the child as a student; they see your child interacting with their peers and can give you valuable insight into how they are tolerating school.
- ☐ 504/IEP Qualifications
    - ✓ The educators are likely to discuss things like eligibility and qualifications. This portion of the meeting generally re-states the diagnosis documentation you requested from your doctor. It is stated out loud so that all members of the team have heard it, and it can be included in the meeting notes.
        - ➢ Parent tip: Take a notebook. If they say something, you don't understand write it down so you can ask questions later.
- ☐ Accommodations and Supports – This is an essential part of the meeting. You will be determining what the school can do to help your child in their daily functioning.
    - ➢ Parent Tip: Before the meeting, complete at least the 1st two columns of this chart. Additional ideas and resources to complete the chart can be found here: http://crmoawareness.org/504-2/.
    - ➢ Parent Tip: It is critical to realize that this plan is individualized to your child and their symptoms.

Disease characteristics or symptoms:	Impact on my child's life or education	Possible strategies
Ex: Severe pain in hips	Ex: Inability to sit still or participate in PE	Ex: Frequent breaks; goes to art rather than PE

Complete your chart here:

Disease characteristics or symptoms:	Impact on my child’s life or education	Possible strategies

Final Parent Tips:

- Be sure to follow the notes you have made on your chart so that you address your concerns.
- Meetings can get overwhelming, especially when we are discussing topics as emotional as the health of our children.
- Having a plan about what to discuss is essential! Stick to it.
- It is important to remember that this plan is fluid. There will be changes often, and that's okay. Remember your goal is to build a relationship with your child's caregivers at their school.

Closing

☐ Have the note-taker repeat the supports your child will receive.
☐ Find out who your primary contact should be in case of changes in your child's health.
☐ Determine the next meeting date.

Keep the follow-up meeting dates and next step here:

**Important Note – This guide was created by a CRMO mother who is a school administrator. It is designed as a how-to-overview to help you set up educational supports for your CRMO Warrior. The guide and corresponding video were created during a doctoral research project with the help of many CRMO parents. It's just a guide. The processes, procedures, and forms in your local schools may look different than what you see here.