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An Exploration of Parental and Health Professional Perceptions of Transition for Chronically Ill Students

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by

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Declaration of Originality

I do hereby declare and attest to the fact that this is an original study based solely upon my own scholarly work here at Lindenwood University and that I have not submitted it for any other college or university course or degree here or elsewhere.

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Abstract

When a young person is diagnosed with a chronic illness, it impacts every phase of the person's life. During the stages of childhood and adolescence, school is the central socialization site for the student's developmental and personal identity. That is why it is difficult to replace school as one of the maturing spaces for young people's transition to adulthood. Chronic illness interrupts the normative life process for an extended period or permanently.

Engaged parents, legal and social advocacy, innovative medical research, public policy, educational workshops, and finally, the consortium of family, health, medical, educational and community support have been advocates for the chronically ill student. All of these factors have compelled the health and educational establishments to consider the serious nature of the chronically ill student. However, while the chronically ill student has been recognized in the school system, gaining equitable resources and dealing with the educational life of these students has remained a challenge. Absenteeism, academic and cognitive difficulty, educators' limited professional knowledge and understanding, social and personal dislocation, and a sense of isolation characterize and affect the lives of many of these students.

Interviews and focus groups were conducted with a limited number of parents/guardians and health professionals to consider the parental/guardian perspective as a major contributor to ascertaining the most effective transitional school options for chronically ill students. The results provided four major concerns from both parents/guardians and health professionals:

1. The lack of communication with the major parties and/or the breakdown of communications among the major parties
2. A care team that is needed to be functional and effective that includes several entities, hospital, school, family and community
3. Better informed entities; health professionals need to do a better job in conjunction with parents/guardians in getting medical and health information to teachers and other educators
4. The experience of the chronically ill student and the care has unique but universal features.

The purpose of the study was to ascertain and provide effective and adaptable transitional strategies for the unique needs of the chronically ill student.

Table of Contents

List of Tables

Chapter One: Introduction

Introduction

The researcher’s world stopped the day her daughter was diagnosed with a chronic illness. After she had absorbed the diagnosis and began to accept the new and strange reality that would define the family setting. The next step was to deal with the school; both the socialization process, from regular to chronically ill student and then address the academic aspect. It was also necessary to inform and assist the school environment of administrators, nurses, counselors, and teachers about her condition and her needs (Thies, 1999). There was a feeling of helplessness, because the researcher knew that her family could not always be there to support or assist with situations that presented themselves (Kliebenstein & Broome, 2000). Hovering closely to the researcher’s heart also were the challenges that her daughter would have to confront and encounter alone. The other concern was the low-level stares of her school peers, because she initially looked different. However, something changed in the researcher as a parent and then eventually, as an educator and researcher; a helpless feeling was replaced by a feeling of empowerment, to be used to assist her child. It was necessary to overcome the obstacles that her child had to traverse to get her to the point of maintaining educational and social achievement (Goldblatt, 2011). The researcher took her empowered hope and advocacy and started on a research journey that led her to this thesis. Fear, dismay, and a committed hope motivated the researcher within the context of advocacy within the educational environment. The objective became to try to understand the challenges of the chronically ill student who would have interruptions and extended absences from school. The researcher started to explore resources and transitional strategies and attitudes of schools that had been reasonably effective in welcoming chronically ill students back into school environments. The role of each educational entity was explored. Whether administration, nurses, counselors, teachers, and fellow students and how they would play in the lives of chronically ill students (Kaffenberger, 1999; Thies, 1999).

Like most families with a chronically ill child, the question was posed as to whether she should try to continue as a student in a regular educational institution or should other educational instruction for the student be sought. Then there was homebound education, which was known to be an option, and that some of her educational work would have to take place; but the intent was not isolate her child as a student (Joachim & Acorn, 2016; Shaw & McCabe, 2008). Therefore, if homeschooling was necessary, it had to be integrated within the actual school setting. “I want my child to be as normal as possible,” was the insistent logic of her father. As an educator and somewhat knowledgeable about the challenges of disabled children pursuing educational goals, the researcher wanted as much normalcy as possible for her daughter. However, even if normalcy was the intended goal, it would not be the same kind of normalcy that she had experienced so effortlessly as a teenage girl. One of the clear but ambivalent themes in the interviews with parents of chronically ill students was the insistence they wanted their children to be considered normal, but they also understood that it would be a new kind of normalcy. Even after this research, neither the researcher nor the parents that were interviewed could answer the question, “what is the new normal,” satisfactorily (Joachim & Acorn, 2016). The crucial point here is that just as medical researchers find new treatments for diseases, parents/guardians and families too encounter their own discoveries about the diseases regarding the educational challenges, the support system, and the healthcare system that is responsible for their managed care. Advocacy becomes a necessary engagement for many parents/guardians.

Born from frustration and curiosity, this topic incubated in the researcher's heart and soul for a long time. After experiencing the trials and tribulations of dealing with a chronically ill child, the researcher wanted to know if there was a community of parents/guardians and families like hers with similar, near similar and/or different experiences. The researcher also wanted to identify and explore a consortium of support for the chronically ill student; the legal boundaries and definitions that separated or connected the disabled, and the chronically ill student, and how the chronically ill student is situated in state and federal law. The researcher was also interested in the role that health professionals along with the parents/guardians play and how these two entities have the most significant and effective influences on the physical and mental health of the chronically ill student.

Besides the families and parents/guardians, the health professional is an integral caregiver for the child. He or she plays a crucial role in finding resources, from healthcare to insurance benefits to educational opportunities for children and their families. In the interviews with parents/guardians, the healthcare professional is a recurring theme of support and understanding even though parents/guardians admit that they have bumped heads with them. However, unlike any other professional in the consortium of care for the chronically ill, health professionals are well versed in their knowledge, compassion, and at times become advocate for them (Eaton, 2012). In this study, the researcher found that their knowledge about the most effective re-entry school programs and the attitudes and strategies needed for a successful welcoming for these students rival the parents/guardian's information and experiences about re-entry school programs. It was imperative that health professionals be included in the interview protocol, and many times both the parents and health professionals started a dialogue in the focus group that could be somewhat contentious, but always ended up collaborative.

Both parents and health professionals signify the most important themes about the chronically ill students, and the needed understanding of the care necessary to become successful students are resources to sustain the good rapport that a chronically ill student had previously with a supportive school and/or school district. The researcher had the distinct impression that the health professionals deemed the parents/guardians as heroes and heroines, but the parents/guardians felt the same sentiments about the health professionals. Parents/guardians acknowledged in the interviews that the key element that could make a consortium of care work effectively is the central role of health professionals in conjunction with the parents/guardians to deal with transitional strategies, re-entry school programs, academic performances, compassionate health watch and care, and the school socialization process. These crucial elements can be brought together with the use of the health professionals who know more about the student than anybody, except the parents/guardians.

The experiences of serving and advocating for a chronically ill child/student, the research, the intense, sometimes heartbreaking interviews, the study and reviews on educators, and the academic and social school environments that students encounter after they are diagnosed with an illness motivated and sustained this study. The educators' genuine humility and indifference at times, primarily due to frustration, and circumscribed resources kept the researcher digging deeper for solutions. Clay et al.

(2004) explained that educators want to help but are short on guidance and knowledge necessary to effectively assist the student. The researcher can relate to that feeling of being overwhelmed and not helpful enough to the situation, especially with so many different categories of the chronically ill. The challenges are real and impressive, and the discovery of effective and creative transition strategies and re-entry options, gave the researcher hope, insight, awareness, and committed her parental and professional life to identify reasonable options to help these children fulfill again their student status. The empowering spirit that the researcher developed substantiates the fact that the conditions, resources, understanding, and effective action that is needed for the chronically ill child/student has improved and is improving for future generations of chronically ill students and their families.

Rationale of the Study

The researcher, as a teacher and parent of a student diagnosed with a Chronic Illness, experienced frustration and difficulty while attempting to ensure necessary services, accommodations, and resources for non-problematic student school re-entry. Throughout the process, the researcher followed the directive of the appointed lead - the school nurse. However, after re-entry, the student, who had previously been at the top of the academic scale, could not handle the workload or stress associated with completing missed assignments, and was therefore, in danger of receiving failing grades. According to Hamlet, Gergar, and Schaefer (2011), the difficulties incurred while coping with chronic illness impacts students' academic, social and emotional development, thereby underscoring a greater complexity and school involvement with the chronically ill student. When posed with the question of serving the needs of a chronically ill student, the nurse admitted she was not immediately prepared to offer input, and was unfamiliar with any standard procedure or protocol to meet the academic needs of a chronically ill student. Hence, the natural progression of the thought process was “How many other parents are having the same frustrating experience?”

Chronically ill students are experiencing school related problems and the information exchanged between the trinity of professionals, which includes educators, medical professionals and mental health professionals, to families, is inconsistent and confusing, thwarting access to resources (Lanin, 2014). One of the major issues is the inability for the chronically ill student to maintain consistent attendance. Students missing school because of illness is not a new issue. According to Eaton (2012), over one million children five through 17 years of age are hospitalized in the United States each year (p. 271). Prior to hospitalization, students may have missed school days as a result of their medical needs and will miss additional days as they recover after being discharged. Any school time missed as a result of chronic illness disrupts the student’s ability to remain on track and in good standing academically. According to Theis (1999), students with chronic illness experienced more academic difficulties than their healthy peers.

Throughout the current literature, parents reported having gone through a series of challenges that left them both frustrated and empowered (Goldblatt, 2011; Kliebenstein & Broome, 2000). Through their own explorations and interactions with professionals, in medical, counseling, and educational fields, and having a comprehensive sense of their child, parents started to create their own opinions and quality standards for strategies to transition their child back to school. Some parents were impressed with the work of the trinity of school professionals, medical, and health support systems. Other parents found the perspectives and experiences too insular and fragmented. Transitional approaches are distinct and they work for different purposes and with different persons. Therefore, the parent becomes a central determinate in discovering the best and most effective strategies.

This study examined parent experiences, perceptions, and assessments of transitional school strategies and compared them with health professionals' resource availability and recommendations. The information from this study could provide insight into themes and commonalities regarding expressed experiences of parents with chronically ill students in the metropolitan area.

Purpose of Study

The researcher studied the responses and practical advocacy of the parents with chronically ill children/adolescents who have successfully transitioned their children back into a normal school setting. The researcher examined interviews and responses of focus groups of parents and health professionals who have had the experience and involvement of transferring school transition for a chronically ill child. The information and knowledge from the variety of parental experiences and responses in dealing with a sick child and the school system will contribute to educational teaching and the health field. In the circle of care for the ill child/student, the parents are central role models that affect the child's health and educational adjustment. It was important to study and understand the support system, professionals, education, health, friends, and family network that were helpful to the parents in making decisions concerning the child's health and intellectual readiness.

The other advocate within the parental strategy is the health professional. In the researcher’s experience and in previous discussions with parents/guardians, the health professional is central to the created strategies and support system. The health professional almost equals the authority of the parents because the health professional monitors a major part of the chronically ill child’s life: the physical challenges. While the parent is certainly more knowledgeable regarding the life of the chronically ill child (i.e. mental, emotional, the everyday process of survival) the parent/guardian claims a major role for health professionals in helping the chronically ill child transition back to school. In the end, parental strategies include collaboration with health professionals. The researcher studied the role of health professionals and their responses, advice, and practical recommendations that help transition Chronically Ill students back into school. For the purposes of this study, health professionals included a social worker, nurse, and child–life/humanities specialist, who were interviewed and then participated in a focus group. The expected outcome from studying the role, responses, advice, and recommendations (in tandem with the parent) is a comprehensive understanding of the health professionals’ impact in assisting the parents/guardians as they transition the chronically ill child back to school.

Research Questions

1. In what ways do parents and health professionals perceive the quality of transitional school strategies available to them for Chronically Ill students? How do the selected strategies vary by age level, school district, or geographic area?
2. What supports have parents received from parental and/or family groups that have assisted in transitioning Chronically Ill students back to school?

3. What are the perceptions of each parent and health professional regarding the challenges that Chronically Ill students face in the school setting?
4. What are the differences and similarities between parental and health professional transitional school strategies for the Chronically Ill student?

Definition of Terms

Advocacy: the act of or process of supporting a cause or proposal; the act or process of advocating (Advocacy, n.d.).

Chronic Illness:

> a physical health problem(s) that last over three months, affects a student's normal activities and requires multiple hospitalizations and/or home health care and/or extensive medical care. Students with chronic illness may be ill or well at any given time, but they are always living with their condition. (Boyse, Boujaoude, & Laundy, 2008, p. 3)

Health Professional: a person who helps in identifying or preventing or treating illness or disability (Health Professional, n.d.).

Strategy: an adaptation or complex of adaptations (as of behavior, metabolism, or structure) that serves or appears to serve an important function in achieving evolutionary success (Strategy, n.d.).

Transitional: marked by transition; involving, providing, or consisting of a passage, movement, or change from one state, condition, subject, place, etc., to another (Transitional, n.d.).

Summary

The study aimed to explore the educational challenges of identifying and examining the conditions of chronically ill students in school settings. The study explored the psychological and emotional burdens that chronically ill students and their families experienced when these students are diagnosed with a chronic illness and still have to be involved in the educational system.

The study focused on the parents/guardians and health professionals and their various perspectives on the chronically ill student as a child and patient trying to achieve educational success in school. The study conducted interviews with parents/guardians and health professionals, to ascertain their experiences and recommendations of the most effective transitional school options and strategies for chronically ill students and their unique needs for succeeding in school settings.

Chapter Two: Review of Literature

This chapter includes an overview of the definitions, development, and increase of chronic diseases among children under the age of 18, and the effects these diseases have had on children as students and their families. Personal experiences and deep concerns about the situation and treatment of their children in the school systems started the chronic student advocacy movement organized by parents/guardians and their allies. Along with professional advocates in the health field, the community and the academy, parental/guardian advocacy has challenged traditional, strategies for developing and sustaining transitional program strategies for chronically ill students.

A significant and increasing number of students have chronic illnesses that affect their academic status, school attendance, family/guardian interactions, emotional/social peer development, and mental/self-esteem attitudes (Cole & Reiss, 2013; Eaton, 2012). The challenges of helping students to effectively transition back into a normal school setting are multiple but interrelated (Denny et al., 2014; Shaw & McCabe, 2008; Theis, 1999). Parents/guardians, health professionals, educational staff, student peer groups, and general communities all play important roles in the collaborative help that is given to students with chronic illnesses (Jackson, 2013; Jung, 2002). The central narrative in exploring the challenges with school systems and chronically ill students is to help define, organize, individualize, and produce a consortium of professionals that will review and enact important programs, understanding, and re-adjust attitudes for chronically ill students in assisting them to comfortably adjust back into normative, school settings (Kaffenberger, 2006; Sexson & Madaan-Swain, 1995; Smith, Lutenbacher, & McClure, 2015). Experts might disagree on how to proceed to resolve some of the challenges about chronically ill students and school re-integration. However, they agree on two major points for effective school transition attitudes and programs for chronically ill students: sustain comprehensive, collaborative, communicative and integrative approaches, and workable programs that include full participation of four major elements: chronically ill students/families, medical and health professionals, educational staff/professionals, and community support (Bessell, 2001; Houlahan, 1991; Prevatt, Heifer, & Lowe, 2000; Shaw & McCabe, 2008; Shiu, 2001).

In the late 1970's and onward, the medical practitioners became concerned about the increasing rate of childhood chronic illness and the impact on their health and educational pursuit. Educational leadership slowly started to understand that special education and disabled students differed from the chronically ill student. Recognition and consideration of the chronically ill child's issues was a relatively new phenomenon. Adults with chronic diseases understood that children with chronic illness would most likely be an issue throughout their life. The increased concern with the number of children affected with a chronic illness gained attention in the latter part of the 20th century and became a dominant theme in the 21st century. More children were being diagnosed as chronically ill and educational mainstream policies and beliefs were becoming aware of a new educational challenge (Bessell, 2001; Shaw & McCabe, 2008; Tseng & Pluta, 2016).

Two broad approaches, the integrative and communicative models, have made a difference in transitional re-entry programs for chronically ill students; as well as the two major role model groups, parents/guardians and health care professionals, within the care consortium, their expertise, advocacy and knowledge. Both model groups have been innovative and helped engage educators, school counselors and other partners in the care consortium for chronically ill children as students (Kaffenberger, 2006; Lanin, 2014; Nuutila & Salatera, 2006; Smith, K. et al., 2015; Smith, Cheater, & Bekker, 2015; Sullivan, 2017).

In order for the major elements to work within the integrative approach, parental/guardian advocacy and the allies had to organize, and develop strategies, and actions for students who were chronically ill. First, advocacy compelled the schools to acknowledge the existence of a new kind of student, the chronically ill, and then they encouraged studies of these new students. They fought to introduce IEP's that would help chronically ill students receive customized attention from the school. When you review statistics of state, city, and county school systems, what is apparent is the problematic nature of the actual cases and percentage of these students. In addition, viewing the statistics indicates a sense of overwhelming isolation and loneliness for the students who suffer chronic health conditions (Eaton, 2012; Jaress & Winicki, 2013; Kaffenberger, 2006).

In the United States, 50 million students attend elementary and secondary public schools (National Center for Education Statistics [NCES], 2016; Shaw & McCabe, 2008; Tseng & Pluta, 2016). In the state of Missouri, viewing statistics from 2014 to 2017, starting with 2014 figures, the estimates of the public-school student population were 917,900; enrolled in a total of 2,406 schools in 567 school districts, with 66,248 teachers (Ballotpedia, 2014). In the city of St Louis, using 2016 figures, despite the two-year differences, the numbers remained steady, the public-school population, elementary and secondary, is 30,831; while in the county school districts, the figure is 144,919

(Ballotpedia, 2016; Public School Review, 2016). Of the combined student population, from St. Louis City and St. Louis County, of 175,750, the percentage of chronically ill students ranged from 3% to 6% (NCES/State Education Data, 2016). Therefore, there exists between 1,707 and 3,414 students in the St. Louis school systems, city, and county, whose condition is defined or potentially defined as a chronic health condition (NCES/State Education Data, 2016). The growth is significant and school districts are becoming engaged. However, the need for new standards and fresh, individualized approaches for effective results continues to be discussed (Jackson, 2013; Prevatt et al., 2000; Sexson & Madan-Swain, 1995).

National estimates of chronically ill students reflect the growing gain for chronic illnesses and the growing focus of these illnesses regarding children as students. National estimates vary, but the consensus claimed between 17% to 20% of children and adolescents suffer from some type of chronic illness (Kaffenberger, 2006; Sexson & Madan-Swain, 1995). Some estimates suggested that one out of every five children under the age of 18 suffers from some form of chronic illness, and in some cases, multiple chronic illnesses (Jaress & Winicki, 2013). And, nearly one-third of those chronically ill students experience such extreme effects from their health conditions that at times, regular school attendance, student socialization, student functions, and academic performances become great challenges for the students (Graff & Ault, 1993; Jaress & Winicki, 2013; Tseng & Pluta, 2016).

As mentioned earlier, the relationship between the educational and medical establishment with regard to the chronically ill student was problematic at the beginning. There was mistrust and uncertainty of where the educational system and medical models would situate the new phenomenon. In the late 1980s and onward, the medical establishment became alerted and systematic about chronic illness in children and the impact on their health and educational pursuit. Educational leadership slowly started to understand that special education and disabled students differed from the chronically ill student. Recognition and consideration of the chronically ill child was a relatively new phenomenon. Adults with chronic diseases understood that children how chronic illness would most likely be an issue throughout their life. The increased concern with the number of children effected with a chronic illness gained attention in the latter part of the 20th century and became a dominant theme in the 21st century. More children were being diagnosed as chronically ill and educational mainstream policies and beliefs were becoming aware of a new educational challenge (Bessell, 2001; Shaw & McCabe, 2008; Tseng & Pluta, 2016).

Definitions

A chronic illness is an illness with no cure, but is not fatal (Huegel, 1998; Kaffenberger, 2006; Shaw et al., 2010). It is a disease that has a permanent time frame after symptoms persist three months or longer. Illnesses that require managed medical and health care intervention, whether for adults or children and youth. For a long time, authors Thompson and Gustafson (1996) produced a definition that experts agreed with and still do, except for some minor exceptions. Chronic illness is defined by these authors as:

> a condition which lasts for a considerable period or has a sequela which persists for a substantial period and/or persists for more than 3 months in a year or

> necessitates a period of continuous hospitalizations for more than a month.
> (Thompson & Gustafson, 1996, p. 4)

Secondary educational expert Shaw and his team (2010), in an article on educational leadership and the challenge of educating chronically ill students, provided a much simpler definition for parents and students. For these researchers, a chronic illness is a "long-term or permanent medical conditions that have recurring effects on everyday life" (Shaw et al., 2010, p. 12). The official medical definition of chronic illness, provided by U.S. National Center for Health Statistics (2016), is a “disease that persists for a long time. A chronic disease is one lasting 3 months or more. Chronic disease generally cannot be prevented by vaccines or cured by medication, nor do they just disappear” (p. 1).

Therefore, both the layperson and medical definitions of chronic illness define the chronic conditions with one or more of these following characteristics: “long-term or permanent; it leaves a residual disability; its causes, natural course, and treatments are ambiguous; it is degenerative; it requires special training of the patient for rehabilitation; and it requires a long period of supervision” (Chronic illness, 2003, p. 1; National Commission on Chronic Illness, 1954).

Chronic Illness

Present statistics indicated that over 80% of adults 65 years and older suffer from a type of chronic illness (Center for Disease Control [CDC], 2017, p. 1; Ory et al., 2003). Chronic illnesses have been developing for several decades, starting with the 1960s, replacing acute illnesses as the leading causes of death. Experts in the medical, health, and insurance establishments began to take notice of this dramatic shift in people’s health in developed countries where the medical and health establishments were moving from an acute to a chronic sick model. “People in developing countries have experienced the ‘epidemiological transition”-a shift in the disease burden from high rates of death from acute, parasitic, infectious disease, and short life expectancy to longer life expectancy and high rates of chronic diseases” (Mishler, 1981, p. 3). The medical model on developmental diseases was transformed; replacing the focus from acute to chronic. The reasons for the change came from the great improvements in the society of “hygiene, sanitation, living conditions, and nutrition”. The advancements were connected to the major breakthroughs in medicine (Blum et al., 1993; Lorig & Holman, 2003).

While acute diseases had a rapid onset and normally, a short course, chronic diseases were completely different. The acute illness model recognized short periods of sickness, at times intense sickness, but within a reasonable time limit, the sickness could be cured. Patients would come to the hospital and be diagnosed and then experience a quick cure and return home or sent home, sometimes with temporary medication. Acute illnesses include colds, flu, or a childhood disease like measles. Chronic diseases, however are persistent with long-lasting effects. The National Commission on Chronic Illness (1954) wrote about the variety of causes and treatments for these diseases and the uncertainty of some of the diagnoses. Examples of chronic illness include the obscure, as well as the well-known ones, such as asthma, allergies, cancer, congenital heart problems, diabetes, sickle-cell anemia, arthritis, cystic fibrosis, epilepsy, spina bifida, and certain types of mental illness (CDC, 1954-2017). Chronic illnesses can range from mild, where the diseases can be managed with appropriate medications and therapies to severe, where the diseases can prove to be terminal or degenerative, and therefore, disrupts the normal activities and life of the person. The causes can be genetic, social, nutrition, physical or environmental. Often, both the diagnoses and treatments are conditional, and, in some cases, the specific causes are unknown (Hertzman & Siddiqi, 2000).

In the late 20th and early 21st centuries, the top leading causes of adult deaths were due to chronic diseases. These diseases account for 7 in 10 deaths in this country (CDC, 2016, p. 1). Even more alarming was the increase of chronic diseases in children and the growing fact that these children would need lifelong managed care. This was a relatively new phenomenon and it challenged the traditional notion of taking care of sickness. Acute and contagious diseases were being mastered with new medicines and procedures and thus assuring a longer life span for patients than previously thought. However, as the types of diseases were decreasing, the rate of chronic diseases were increasing. At present, they are the dominant diseases in developed countries (Eiser & Morse, 2001). The traditional medical model was being challenged by experts, as well as by experiences (patients suffering more from chronic rather than acute diseases). The late 20th and early 21st centuries were introducing a new model to deal with illnesses that were chronic and not acute (Blum et al., 1993). It would be a great challenge not only for medicine and health care practitioners but for two other groups, families and educators, that had to face the challenge, as well (Rolland, 1994).

Children and Chronic Illness

In a journal article on chronic conditions in children and youth, the authors, Van Cleave, Gortmaker, and Perrin (2010), studied four categories of chronic illnesses among children and youth. The four categories examined were obesity, asthma, other physical conditions, and behavioral/learning problems (Van Cleave et al., 2010). Evaluating three different periods, 1988-1994, 1994-2000, and 2000-2006, from a National Longitudinal Survey of Youth-Child Cohort study, the authors found “chronic illnesses in children doubled from 12.8% in 1994 to 26.6% in 2006, with low-income, racial, and ethnic minority children being disproportionately affected” (Van Cleave et al., 2010, p. 623). Other studies indicated similar numbers and the most recent studies have confirmed that chronic illnesses among children are still rising. Studies found that one out of five children under the age of 18 suffered from a chronic illness. Their illness or disease significantly interrupted their daily lives and negatively impacted regular attendance in school (Jaress & Winicki, 2013, p. 3). Of the four categories mentioned earlier, each one has a group of students whose chronic illness becomes severe enough to cause dramatic absences. The extreme absence experienced by these students is unfamiliar to educational administrators, as the common theme for absence is connected to truism. (Tseng & Pluta, 2016). Some students could miss up to 30 days or more at a time; absences could be more extreme depending on the sickness and the condition (Van Cleave et al., 2010). The most common childhood chronic illnesses were digestive disorders, asthma, seizure disorders, (epilepsy), cancers, allergic disorders, heart conditions, mental disorders, and central nervous system disorders (Newacheck & Halfon, 1998).

The authors noted that the trend to understand more about chronic diseases in children was increasing along with the cost, due to the longevity and repeatable features in diagnoses, medication and treatment protocols. The authors agreed with other studies that suggested that U.S. children are sicker today than their parent’s generation (Van Cleave et al., 2010). The numbers are disturbing. For instance, cancer is now the leading cause of death among children. Over 15,000 children were diagnosed with cancer in 2014 (World Health Organization, 2015). That number will increase. Asthma accounts for 1 in 10 children while allergic reactions claim 1 in 13 children. Heart Disease is the fifth leading cause of death in children.

> ADHD is the most commonly neurodevelopmental disorder and affects 1 in 10 children. And 1 in 6 children has a Developmental Disability. Another chronic illness, Epilepsy Seizures, account for 1 in 20 children while Juvenile Diabetes have increased 23% between 2001-2009 and is still rising. (Thompson & Gustafson, 1996, p. 432).

Chronic illnesses among children present a critical crisis for the medical and health care professions. However, the crisis is a democratic one. Chronic illnesses affect not only the health, physical, and mental state of the children and their daily lives, but also the chronically ill child creates new roles for families and educators. Parents/ guardians and educators are still searching for better ways to serve chronically ill students. Parental advocacy for the chronically ill student along with educators is becoming more involved with both school and the medical/health care establishments.

With the traditional model of dealing with sickness, parents were involved with their children’s doctors and health care practitioners in very limited ways. Educators were never significantly involved with sick children, since most had acute illnesses and not long-term illnesses. In most cases, the family and the health care and medical professions could take care of the sick child. The same way that parents/guardians were looking at short-illnesses and accidents among their children, educators in schools were trained to focus on temporary illnesses (Shaw et al., 2010). The medicine and health care mainstream professions had to change and that necessitated changes in roles for parents/guardians and educators. Parents/guardians' roles no longer just meant to follow the instructions of the doctors and nurses. They had to become completely involved in their chronically ill children's medical and health lives by becoming different kinds of experts. The diseases are so comprehensive that parents/guardians had to change and avail themselves to being doctors, nurses, psychologists, friends, and teachers to their children; as all-around helpers. Educators had to change, since these children by law had a right to be in normative schools and to be given equal rights as chronically ill students. They had some experience with the unusual or different students with special needs and disabled students. However, with chronically ill students, the situation became more complicated for educators and schools, since the diseases were not clear cut like many other disabilities. Many chronically ill students appeared like regular students and could not be distinguished from regular students at times. Unlike some students with manifest disabilities, some chronically ill students did not show their illnesses; having clear signs of illnesses made it harder for educational professionals to identify chronically ill students and thus to serve them better (Shaw et al., 2010).

One of the perennial questions was: were the chronically ill students the same as special needs students? Or did they have more in common with some students with explicit disabilities? Should medicine, educators and parents/guardians insist upon a distinction between these categories? And the stigma that might come with a new category, did parents want their children to be labeled and have those categories to define their children for the rest of their lives? Should parents/guardians then demand a distinction between their chronically ill student and other unusual or different students? Would a chronically ill child be better at a hospital school or homeschooling? Should we further isolate chronically ill students or place them in a regular school situation and with a support team to help them transition back into classes and social interactions? How do we cure bullying against chronically ill students?

Research showed that there are many questions that must be addressed when dealing with a chronically ill student. It also showed that sustained interactive, comprehensive, collaborative, strategic attitudes, efforts, and support are the characteristics of outcomes that define effective, transitional school programs (Jackson, 2013; Prevatt et al., 2000).

School and the Chronically Ill Student

As medicine and health care advanced, innovative treatments were discovered. The treatments improved many children's diseases that were previously considered fatal. However, the treatments were not yet able to completely cure the child. Modern medicine changed the sick model from acute to chronic (Mishler, 1981). Children who previously had fatal or severe diseases could be taken care of and experience an improved quality of life. Medicine was now prolonging their lives. However, with the constructive changes created by medical and health care for chronically ill children, the roles of both parents/guardians and professional educators had to change, as well. Roles had to be more inclusive and comprehensive in their care of the student. Roles that had been restricted in the past for parents/guardians and professional educators in dealing with sick children/students, as defined by the acute illness model were now being revisited and fitted into the chronic illness model. The two groups were central to the chronically ill child in ways that they were not with acute illness children. In the past, their roles had been limited because the chronically ill child was either too sick to attend regular school or lived a short life. Besides those two groups, parents/guardians and educators, peer groups for chronically ill children became important component to their well-being and transitional school success (Jackson, 2013).

As school began to enroll chronically ill children, resources to meet their needs were not available. One of the initial reasons for this lack of resources was uncertainty of the number of students that were being defined as chronically ill in the school systems. The numbers were negligible at the time and the medical term was still evolving. Second, educators had some experience with special needs and later, disabled students. Yet a protocol for the types of students that would come under the banner of chronically ill students were driven not by administrators and teachers but by state and federal policies.

Society wanted educators to teach and schools were traditionally treating and teaching all students the same, healthy or not. This was a part of the new climate of opinion that embraced the inclusive, student approach (Jackson, 2013; Prevatt et al., 2000). Third, while the medical and health professionals knew about the increase of the chronically ill students, educators were aware, but not professionally informed. Educators were not also completely familiar how these students would fit into their systems and institutions as students, between normal and abnormal school setting. In fact, this remains a great challenge. Several survey studies of teachers and school counselors indicated that they were not informed on the etiology nor the protocol of many of the chronic diseases that their students might suffer (Jaress & Winicki, 2013; Prevatt et al., 2000).

Behavioral Problems

To ensure that overall health is maintained, it is customary for the chronically ill student to routinely visit the doctor. Many of the visits are scheduled during school time. Therefore, the chronically ill student is in an ambivalent situation, defined as a student who is enrolled full-time in school but involved in part-time status. Studies have shown that half of all children diagnosed with a chronic illness experience absence from school up to four times more than their healthy peers (Jaress & Winicki, 2013; Wideman-Johnston 2011). In addition to doctors' visits, absences are a result of emotional and physical exhaustion, embarrassment of appearance, fear of being bullied, and decreased interest attending school, due to the amount of missed assignments and the stress playing catch up. Furthermore, students with chronic illness sometimes experience prolonged periods of absence and with little peer contact, which creates social discomfort.

Asthma, one of the leading causes of school absence, impacted 10 of every 100 students when considering the absenteeism profile (Kaffenberger, 2006). This challenge is also complicated because the chronically ill student status is confused, since many times, the absentee figures are conflated with the general absentee school rate, which is already high in public schools (Zinshteyn, 2016). According to experts, just two days of school absences within a month's time challenges students' academic performances, no matter their health status. The absences could place them into conditions of intellectual and academic difficulties. The obstacles reflect lowering of reading levels and math comprehension scores and continued academic difficulties might discourage the student if she/he does not have a solid support system (Clay et al., 2004; Kaffenberger, 2006).

There are also difficulties adjusting to the social demands of school. Frequent school absences challenge the chronically ill student’s social exchanges and connections with other students, the majority of whom are healthy. Dealing with unpleasant experiences upon returning to school is not uncommon. The experience includes being teased, self-conscious about appearance, and re-establishing friendships (Suzuki & Kato, 2003). The socialization process is extremely important for all students. It becomes especially important for chronically ill students, who might have been quite involved in the social activities of school before they were diagnosed.

In an essay dealing with resilience of chronically ill students, Wideman-Johnston (2011) contended that social integration of chronically ill students when they return to school is central to any effective school transition program. Studies have confirmed that chronically ill patients do better as students when they have clear opportunities available to help them participate in the school community. Social exchanges with their peers and full involvement in the school curriculum, as well as extracurricular activities are a benefit to the student. For the chronically ill student, having that social support from friends and fellow peers can be crucial in helping the student keep up good grades (Jackson, 2013). Social isolation is not a good condition for the chronically ill student. Being in school with their peers and with a professional group, counselors and teachers that will teach, encourage, and support them as students, and not solely as a patient, is beneficial for them (Shaw & McCabe, 2008; Wideman-Johnston, 2011).

Peers may have fears and may shun the chronically ill student because they are concerned that the student’s disease is contagious, and their peer ignorance could make awkward social contact (Kaffenberger, 2006). The chronically ill student has much to fear because of the seriousness of the diagnosis, and in many cases, the chronically ill student's entire life is interrupted and now must re-adjust and change for a set of major challenges. Research suggested that the chronically ill student will be looked at differently and, in many cases, will be a victim of bullying; what experts call peer victimization (Sentenac et al., 2011). The chronically ill student can avoid some of this bullying or social isolation through hiding chronically ill appearance or behavior. However, that can be hard for many chronically ill students. While self-esteem is key to the development of the chronically ill students, worse for self-esteem is the feeling that they must hide what they are going through when the disease symptoms strike and surface. Denying what they are experiencing out of fear of social disapproval will not help chronically ill students and the stress that they are feeling as patients and students in the real world. The important factor to remember is that the chronically ill student is not alone.

The fear of the thought that other students think the disease is contagious is common with this situation; however, the undermining of these myths is the responsibility of the school and its professional staff by finding ways to convey the medical conditions of these diseases to the entire school. The chronically ill student should not have that burden by herself/himself in the school. It is necessary for individuals with authority and school professional staff to help the chronically ill student feel integrated into the school community. Professional staff along with peer students could do an excellent job with the new challenge in their schools by confronting and overcoming the myths that have been used to foster misunderstanding and half truths about these diseases (Kaffenberger, 2006; Jaress & Winicki, 2013; NIMH, 2016).

Some pre-teens and teenagers avoid interaction for fear of associating with someone who is different. The feelings and reactions of the peer student group is crucial and can make or break the chronically ill student at school. Whether the chronically ill student has support from mom and dad and/or assistance from health and school professionals, it does not matter in the end if all of that support does not promote positive peer student group exchanges (Jackson, 2013; Jaress & Winicki, 2013). The chronically ill student needs the acknowledgement of her/his fellow students and many times, the regular student is too invested in mainstream thoughts, feelings, and behaviors and therefore ambivalent about the chronically ill student (Prevatt et al, 2000; Wideman-Johnston, 2011).

Ambivalence from the chronically ill students' peers is a part of the overall mental and emotional anguish that chronically ill students have to confront frequently in their school experiences. The constant awareness that their peers may or may not know of their illness; comparative fatigue where they are contrasting themselves with healthy students; trying to avoid being bullied or misunderstood; trying to play mainstream but feeling marginalized are many of the concerns of these students. Being a topic of gossip, curious or vicious, are ongoing and constant concerns for the chronically ill student (Wideman-Johnston, 2011). Chronically ill students' behavioral attitudes, problems, and patterns include types of depressions, anger management, “acting out,” certain obsessions, withdrawal symptoms, emotional confession and mental anguish (Kaffenberger, 2006; Thies, 1999; Wideman-Johnston, 2011). However, the challenges are not only reserved for the chronically ill student. Challenges are multi-faceted, so the chronically ill student would require a consortium too that will help adjust both the chronically ill and regular students to a school environment that will make the chronically ill student comfortable and welcome.

Chronically ill students are always aware of the physical symptoms that are apparent while trying to navigate the daily school routine. Some of the challenges are:

a. Hair loss
b. Face disfigurations; pimples, sores, burns, and warts
c. Amputations
d. Ambulatory devices (wheelchairs, walkers, canes, electric scooter)

Some symptoms/issues can be covered and some symptoms only surface at particular times during the lifetime of the disease. However, the chronically ill student is the product of inevitable sickness/symptoms and many times have no control over how her/his body responds. They are a part of the managed care team for their illnesses. Medication is a part of that managed care and must be taken at the appropriate time. Medications indicate the direct connection needed between the chronically ill student and teacher/health care school specialist (Jaress & Winicki, 2013). The student might need a certain time certain health care expert to administer the medications or the chronically ill student might need a private place to take the medications. The real situation of mental and physical fatigue happens often with chronically ill students in school and will affect their cognitive efforts and even the completion of homework assignments.

Pain is constant in some chronic diseases and short, but intense in other chronic diseases. It should also be noted that for chronically ill students, pain can sometimes define physical limitations and movements. These factors have a profound influence on the behavior and thinking of the chronically ill student. Some of the challenging concerns dealing with chronically ill students are how they look to themselves and how do they think they look to other students and adults (Jaress & Winicki, 2013; Prevatt et al, 2000).

In an article on the educational support services for chronically ill students, the authors, Tollit, Sawyer, Ratnapalan, and Barnett (2015) contended that chronically ill students have suffered stress and anxiety at serious levels. They insisted that “high levels of intense stress and anxiety, if not managed, can affect functioning and impede learning, with the risk of negatively affecting school functioning and academic performance” (Toillit, 2015, p. 5). Feelings of isolation and discomfort are emotional/mental staples of chronically ill students. Since school remains an important part of chronically ill student’s world, even though shrouded with uncertainty, it makes sense that school phobias or separation anxieties would be a part of his or her emotional/psychological make-up.

In a study on chronic illness and its effect on children, the National Institute of Mental Health (2016) indicated a number of factors that many chronically ill patients, including chronically ill students confront daily in life and school:

- Feeling sad, irritable, or anxious
- Feeling empty, hopeless, guilty, or worthless
- Loss of pleasure in usually-enjoyed hobbies or activities, including sex
- Fatigue and decreased energy, feeling listless
- Trouble concentrating, remembering details, and making decisions
- Not being able to sleep or sleeping too much. Waking too early

- Eating too much or not wanting to eat at all, possibly with unplanned weight gain or loss
- Thoughts of death, suicide or suicide attempts
- Aches or pains, headaches, cramps, or digestive problems without a clear physical cause and/or that do not ease even with treatment (NIMH, 2016, p. 1)

Any of these factors, characteristics, symptoms can happen to anyone with a chronic disease, and it can happen suddenly and unexpectedly. Many of the symptoms are either temporary or sustainable, depending upon the person and the disease. Research indicated that the psychological/mental aspects of chronic illness is a challenge for parents/guardians and health care professionals, but also to school professionals Karrenberger, 2006; Jaress & Winicki, 2013). For school professionals, the need to balance the responsibilities and information among the collaborators, medical, family, and school, are effective strategies to helping chronically ill students to re-adjust to the school environment (Haverman et al., 2013; Kaffenberger, 2006; Van Cleave et al., 2010).

School Absenteeism

School absenteeism was previously mentioned, but there was no emphasis on how crucial school presence and absence determines whether the chronically ill student will be successful. Absences can predict reasonably well whether the student is going to complete the course work or not. School absences provides some indication of the nature and quality of the chronic illness, and can also signal the need for communication among the student's collaborative team (Jaress & Winicki, 2013; Zinshteyn, 2016). The team can help the students to adjust and start fresh with re-assuring student peers that will support these students, as well as the school consortium who will be available for assistance.

Traditional school attendance is critical for the student's emotional academic well-being, which is why school transition programs and educational support systems for chronically ill students are so important. They are important for several reasons; they provide: opportunities to learn; socialize with peers; experience success; develop increased independence and control over their environment, and it is the only place where they are viewed as children rather than as patients. Research showed that chronically ill students are constantly trying to balance school lessons and assignments with the obligatory absent days because of their illnesses (Shiu, 2001; Wideman-Johnson, 2011). Inability to attend school may lead to decreased self-esteem, and hopelessness about the future (Jaress & Winicki, 2013).

Research confirmed that continued absence from school will create educational challenges and in turn, frame these complications to educational adaptations by not only the chronically ill students but also the collaborative teams that must be produced and organized for these kinds of students (Jaress & Winicki, 2013; Tollit et al., 2015). Significant disassociation from the academic and socialization status of school will create negative outcomes that have been confirmed in research: poor academic performance, bad emotional behavior, and limited career choices. If the chronically ill student's attitudes to school is a persistent negative one, that is a good predictor for disengagement from school and academic work (Jaress & Winicki, 2013; Tollit et al., 2015).

Academic Difficulties

The chronically ill student must make the choice of whether she/he wants to be a part of the school environment again. No one can make that decision for her/him. This is a difficult situation for many in the consortium. No one wants a child to be isolated as a student. No one wants a child's social maturity to be affected due to their condition. Even with home-school, parents/guardians try to make sure their children have peers or family members that can relate and understand so that the child does not feel marginalized. Health care professionals want chronically ill students back in school; a robust picture of the chronically ill student interacting with their school peers; parents/guardians are rooting for their child to become an exemplary academic student or the normal student again. The school professionals want to make these students' experiences the best possible one when they return (Prevatt et al., 2000). However, in the end, the choices must be made by the student in consultation with the people in the consortium. Whichever decision the student makes about their life, the role of the consortium is to support them with a customized treatment plan. Each case is different and has to be treated as such though this may exhaust or strain resources. As both physical and emotional factors contribute to the academic challenges that a chronically ill student may experience.

A child could be academically sterling, sociable, and well-integrated into the school environment; diagnosed with a chronic illness, their grades plummet, socially they withdraw, even though students reach out to them; exemplary chronically ill students need encouragement and understanding (Kaffenberger, 2006; Jaress & Winicki, 2013; Jackson, 2013).

There is also the question of limited resources which can impede the student's academic progress. Resources are limited further in terms of the number of studies, strategies and programs that have been earmarked for chronically ill students (Kaffenberger, 2006; Wideman-Johnston, 2011; Tollit et al., 2015). Besides the lack of resources in public schools, including scarce, monetary funds, to develop school transition programs or sustain them, the other challenges are the low tolerance of school professionals who deal with chronically ill students, minimum co-operation of student peer groups, communication imbalance between parents/guardians and the school, and the absent or limited dialogue between the school and health care professionals (Clay et al., 2004; Kaffenberger, 2006). This is where parents/guardians and school must work together and where advocacy is necessary to start the conversation with schools, bringing the health professional groups along.

Students demonstrate difficulty meeting curriculum requirements that ultimately place them in a position where they are unable to meet curriculum requirements. They are in an on-going state of trying to play "catch up," and experience increased anxiety, which complicate academic difficulties (Jaress & Winicki, 2013). There are also certain medical treatments that affect academic functioning: Drowsiness, fatigue, nausea, increased irritability, and decreased attention span, and impaired learning (Jaress & Winicki, 2013; Thies, 1999). Finally, many students have average intelligence, resulting in significantly lower achievement test scores, with no known cognitive impairments that are correlated with school absences (Newacheck, 1992; Sheidow et al., 2014)

The research showed that when a student is diagnosed with a chronic illness, the change comes initially from everybody around the student. The student begins to change when she/he sees the changes that are happening to friends and school peers. The difference between siblings, parents/guardians and other persons are evident and does not contain the intimacy that is characteristic of the relationship between the chronically ill student and his/her family, particularly the parents/guardians and siblings (Kaffenberger, 2006; Sexson & Madan-Swain, 1995; Shaw et al., 2008; Wideman-Johnson, 2011). Some experience diagnosable learning disorders: increased incidence of severe reading problems, illness may exacerbate prior history of learning problems (Newacheck, 1992), and teachers attribute problems to effects of illness, thereby overlooking real academic difficulties or deficiencies.

Chronically Ill Student and the Law

The complications that arise in not defining but in categorizing chronic illness and in situating chronically ill students between students with disabilities and special needs students emerge in laws. One of the ways that experts and public policy advocates have dealt with this challenge is introducing the term “hidden disabilities” and establish protocol in both definitions and categories (Longmore, 1987). Other professional experts have called them “hidden illnesses” as opposed to “invisible disabilities,” but for many parents/guardians, chronic illness advocates, and health care professionals the term “invisible disability” is not the best description. However, it does help in understanding the subtle difference and challenges that people may experience (Davis, 2005; Invisible Disability Association, n.d.). The invisible or hidden diseases can range from chronic fatigue syndrome to sickle cell anemia to various forms of cancer to rheumatoid arthritis to cognitive dysfunctions (brain fog) to fibromyalgia and chronic myofascial pain to severe headaches/migraines to lupus to heart conditions and many others (Disabled

World, n.d.). Most of these invisible chronic conditions are not visible to the observer, however they can circumscribe the activities and the expectations of the chronically ill student.

Definitions and categories are important, but for children and the parents/guardians of children with chronic illness, categories can restrict and damage a child's self-esteem, especially if the illness is, as many are, not noticed, not acknowledged, and therefore, remains invisible. This is a recurring theme in the experiences of the chronically ill child. Many of them cannot be identified by their sickness unless they are interrupted by the sickness at inopportune times, i.e., sitting in a classroom or playing during social school activities. Furthermore, handicapped, or even disability as a term, is still not mainstream enough to exclude them from negative connotations. The whole disability movement started off fighting for the right of not only equal education for people disabilities, but integrative education. The idea was not to exclude the disabled, but to situate them alongside the regular students, whether in school, the school setting, or on the job. Yet in the end, many policy experts and advocates succumbed to the reality of separation spaces, though they won a significant victory just to have them in the general school environment (Fleischer, Zames & Zames, 2012). The story of the chronically ill student is different than the normative of the disabled student in general or special needs students. Unlike the special education and/or disability student, often the chronically ill student shares his/her chronic condition with the general population. There are far more people with chronic illness than disability in society. According to the Center for Disease Control (2017), as of 2012, half of all adults in this country, 117 million people or more, suffer from one or more chronic health conditions. That is translated as one in four adults who had two or more chronic health conditions. Seven of the top 10 causes of death in 2014 were chronic diseases. And the two major chronic illnesses, heart disease and cancer, account for nearly half of all deaths in this country (CDC, 1954-2017). Among children, chronic illness is not as impressive in numbers, but the number rate is rising. Though not definitive, children's chronic illness estimate range between 17% to 20% and in some cases, higher but experts suggest that one in five children suffers from some kind of chronic illness (Sexson, & Madan-Swain, 1995). Of that general percentage, 6.5% experience chronic illness to the degree that interrupts in major ways their school performances (Kaffenberger, 2006).

How do we transmit rights into laws derived from invisible diseases? So many times, the criticism of the external environment is what people, meaning no harm, see when looking at the chronically ill student thinking or saying, "but you look so good," without understanding the nature of chronic illness. However, that comment can also be uttered by teachers, counselors, and educators, as well as non-chronically ill students. It is one of the great challenges of a sickness that cannot be seen. It is also a challenge that makes parents/guardians maintain that their chronically ill children are normal, except at infrequent intervals. But, the most important reason besides the emotional and psychological alienation that these children can face and feel, is that they are normal because their illnesses are shared by a large majority. Additionally, with advancement in health care, children with chronic illness are increasingly coping with the challenges of their illness and a typical school day (Hamlet et al., 2011). Medicine and medical technology also have allowed children who had to withdraw as students to be reinstated back into school environments sooner than previous school protocol. The big difference is the limited research that has been done so far on these students, as the chronically ill is a thin minority, even among the disability population. Alternative options were created by the reality that chronically ill students were returning to the classroom sooner. The best way to cope and cater to their conditions and their needs included homeschooling, school administered tutoring, hospital schools, classroom/homeschooling, and certain forms of community schooling, are being considered (Newacheck & Halfon, 1998). Chronically ill children are even minorities within minorities in civil rights law, because initially and at present, the laws focused mostly on the disabled and handicapped. The chronically ill student is a relatively recent phenomenon. In the decades past, before the 1970's, children, except for rare occasions, had a sickness that was defined as acute. Children would get sick, chicken pox, measles, a cold, a physical accident, but they would in no time be back with their classmates. Chronic illness was for the most part, an adult disease. Then starting in the late 1960's, and definitely in the 1970's, the chronic illness gradually started to encompass a small group of children, and then as the years and decades progressed, more and more children were experiencing chronic illness. As mentioned earlier, this happened simultaneously with the improvement of medicine and medical technology; the same way that this change allowed adults to live longer, it allowed children to live longer, as well. The chronically ill child was now able to resume what children do: play and attend school. While mainstream society knew of the acute model of illness and had some information of children with special needs and disabilities, the chronically ill model for children was not a familiar landscape. Once these children had the opportunity to re-enter school settings, many experts and parents/guardians were trying to integrate them with traditional attitudes and models. However, they found out that these chronically ill children were not so easily placed into the category of special needs or disability (Huegel, 1998). Granted, some might have had what in the broadest sense could be termed a disability; this was a new phenomenon. Advocacy in both the health and education fields started asking for research and studies; then of course, law started to understand better that these children were not in the existing laws and had to be reflected in a new way in laws that dealt with the civil rights of children and students who had disabilities. Thus, the term “hidden disabilities” was invented for those children and their advocates who rejected separation in classroom settings. They insisted upon being integrated in regular classroom settings, unlike the children with traditional, exposed disabilities. Yet they were not quite regular or normal. What was certain is that something different was evolving. The medical status quo and health care fields started to identify these children and their conditions and some of their needs. The educational entities had some familiarity with disabilities and the accountability that was garnered through knowledge, compassion, advocacy, and law, but children with chronic illness was a new phenomenon. Law along with schools had experience with the conditions and struggles of disabled children and had codified their rights and needs. But the legislative system saw something new and insisted upon trying to adapt to children who were normal, because their sickness mostly was hidden, and yet not normal because they increasingly needed some form of managed care. The chronically ill child and their advocates compelled these forces to recognize children with chronic illnesses. Whether they were viewed as students with the status of integrative normalcy or integrative marginal normalcy, they had rights, and the law needed to consider and protect them.

In a pamphlet exclusively devoted to student with hidden disabilities. The Office for Civil Rights insists first that students with hidden disabilities have the same rights as students with apparent disabilities. The Office insisted that ultimately the both hidden and exposed disabilities are based on criterion of both having interruptive experiences that impedes their daily activities. Hidden and ostensible disabilities are recipients of

> physical and mental impairment [that] results in a substantial limitation of one or more major life activities. Major life activities, as defined in the regulation, include functions such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. (Office for Civil Rights, 1995, p. 1)

This definition is gleaned from Section 504 of the American Disabilities Act (1990). Yet within this broad definition, the Office suggested that Section 504 still protects individuals, like many students who do have chronic illness, but is not completely handicapped or whose handicapped condition does not completely define their life activities, including school engagement. Section 504 in considering hidden disabilities, protects students that fall into two groups. The first one is that a student is treated as though they do [have a major handicap], because they have a history of, or have been misclassified as having, "mental or physical impairment that substantially limits one or more major life activities" (OCR, 1989). For example, if a person has a history of a handicapping condition but no longer has the condition, or has been incorrectly classified as having a condition, they too are protected from discrimination under Section 504. Frequently occurring examples of the first group are persons with histories of mental or emotional illness, heart disease, or cancer; of the second group, persons who have been misclassified as “mentally retarded” (Office for Civil Rights, 1995, p. 1). Disability laws, when it comes to chronically ill children maintain necessary fluidity of the categories and definitions. It is a scientific fact that hidden disabilities can only be validated and categorized by administering diagnostic tests.

Laws, Disability, and Education

The Civil Rights Movement, in its quest to fight for the full rights of minorities helped spurned advocacy for other minority populations in the United States that were invisible and underrepresented in civil society, People, which included children, with handicapped and certain disabilities were isolated with few individual rights. Even the first comprehensive civil rights laws that were enacted to protect the rights of minorities in education and employment, the Civil Rights Act of 1964, excluded people with disabilities as a specific group status. However, the awareness of disabled people being isolated and underrepresented in society gave momentum, because of forces that had fought for the rights of black people and other minorities in society. It was in the early 1970’s that the first act to specifically address the civil rights of people with disabilities, 1973, compelled society, in the form of education and employment opportunities, to confront the invisibility and unfairness experienced by people with disabilities. That law was the Rehabilitation Act of 1973, featuring Section 504, which explicitly makes discrimination against people with disabilities a crime. Section 504 stated that “no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination” under any program or activity that either receives Federal financial assistance or is conducted by any Executive agency or the United States Postal Service (OCR, 2016, p. 1). Furthermore, this statute addressed accountability and insisted that all those seeking federal funds would have to be compliant with this mandate. Research shows that since the 1970's the laws have tried to identify, defend, accommodate, and adapt to the times, to the medical and health professional experts, to parents/guardian's advocacy, and to the direct concerns of the students with disabilities (OCR, 2016). As seen with the new accommodations of the two groups under the hidden disabilities' status in Section 504, both groups, including the chronically ill student, challenged then are still addressing the advocacy of new laws. Through examination of legislative action that has taken place since the 1970's, a lot of ground has been covered. The challenges surround a need to build up communication with:

1) The various entities that make up the consortium of support for the Chronically Ill students,
2) The debate between a uniform protocol for students or a singular customized treatment for each student,
3) Marking a chief mediator as a professional to translate both laws and intervention strategies for the school environments or acknowledging health professionals as the chief mediator because of their experience and information concerning conditions and resources.

Federal laws concerning students with disabilities have encouraged and supported cooperative entities to work together, and for parent/guardian involvement. Major federal laws have mandated procedures for state administrations to apply and measure accountability standards to make sure that public schools organize a professional and family consortium of care and support for students with disabilities, including children with chronic illnesses (Sexson, 1995; Gannon, 2014). However, some public-school systems insist that this kind of mandated arrangement could drain their resources and limit the main responsibility for teaching regular students. The laws are there, but research has shown that laws are not enough in finding genuine solutions to a growing group that are not adequately defined as children with disabilities and yet sharing many of their disabilities with the larger population (Bagenstos, 2009). There is a set of children with chronic illness, living a double reality, disabled and yet not disabled, that has advocates suggesting that new laws might have to be enacted to comprehensively recognize this unique situation between chronically ill students and the larger society.

Major Laws

Elementary and Secondary Education Act (ESEA)- April 11, 1965

The Elementary and Secondary Education Act (ESEA) was an important milestone for the disability movement because it insisted upon the full equality of all children have the right to learn with supported programs and resources, including children with disabilities. Enacted in 1965, it was the first federal grant program to finance the education of children with disabilities earmarked for state-operated schools and institutions under the mandate of equal access for everybody. The specific status was provided for children with disabilities in the provision title a year later in Title VI-Aid to Handicapped Children (1965 Title VI becomes Title VII). The Act was beneficial to underserved communities and groups and produced Title I, Head Start and bilingual education. An achievement of the Lyndon Johnson War on Poverty initiative, it also introduced important innovations that became useful to the disability movement and helped parents/guardians advocate for children with disabilities late in the 20th century and the early part of the 21st century. The Act insisted upon raising the educational standards of students with disabilities, using equal access, but more than that, the act delineated a set of mandates that brought in professional assistance, instructional teaching materials, even encouraging new learning tools and programs and especially important, was the Act’s insistence upon allowing and supporting parental/guardian involvement in their child’s educational experience (Gallagher, 1989).

The Rehabilitation Act of 1973

The Rehabilitation Act of 1973 was the first significant federal law that codified educational rights for children with disabilities. The Act in part derived from the growing awareness of the isolation and unequal treatment of many of these students who had been underserved and underrepresented in civil society and in education. The law was enacted in 1973 as a replacement for the Vocational Rehabilitation Act of 1973 and it reconfigured the existing programs at the time and proposed new guidelines for schools and other institutions that received funds from the federal government. The emphasis was on greater service for those with disabilities. The Act wanted to expand research on these citizens and training programs. This law paved the way for the Americans with Disabilities Act (1990) with its first mandate in Section 504 prohibiting discrimination against people with disabilities in governmentally funded programs and services, which include schools as well as in employment. Section 504 was carried over to both ADA and IDEA, which came later but with the same purpose: to protect children and adults with disabilities from isolation and discriminatory treatment in schools, jobs and the larger civil society. There were four main features of the law:

1. to extend and revise the authorization of grants to states for vocational rehabilitation services, with special emphasis on services to individuals with the most severe disabilities,
2. to expand special federal responsibilities and research and training programs with respect to individuals with disabilities,
3. to create linkage between state vocational rehabilitation programs and workforce investment activities carried out under title I of the *Workforce Investment Act* of 1998,
4. to establish special responsibilities for the Secretary of Education for coordination of all activities with respect to individuals with disabilities within and across programs administered by the federal government (U.S. Dept. of Education, 2015).

This law was amended the following year and the most significant change was expanding the definition of people with disabilities. The previous definition was too restrictive:

> any individual who (A) has a physical or mental disability which for such individual constitutes or results in substantial handicap to employment and (B) can reasonably be expected to benefit in terms of employability from vocational rehabilitation services provided pursuant to titles I and III of this Act." (U.S. Department of Education; Pub. L. 93-112, p. 1)

However, the new definition would have potential and actual advantage in producing a greater inclusion:

> any person who (A) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (B) has a record of such

> an impairment, or (C) is regarded as having such an impairment” (Independent Living Institute; Pub. L. 101-336). The new definition favored a more extreme condition or disability while the second definition adapts to different degrees of disabilities as eligible status. The new definition would help the future trend of hidden illnesses by adults and then children defined as chronic and therefore may be long lasting managed care. The new definition fit well into the future ADA and IDEA legal acts. (ADA, 1990, p. 6)

The Family Educational Rights and Privacy Act of 1974-August 21

The next important law for children with disabilities was the Family Educational Rights and Privacy Act of 1974 that paved the way for more parents/guardian’s involvement with their children’s education. The act gives parents/guardians formal access to the child’s education records and how these records can be used. This is important for children with disabilities and how they are treated and reviewed in an educational setting. It also will point out the crucial importance of the parents/guardians being a crucial member of the consortium of care and support for the child with chronic illness (U.S. Dept. of Justice, Privacy Act 1974).

Education for All Handicapped Children Act-November 30, 1975-1990

After this law, which included all students’ rights to equal education resources, the next legislation dealt specifically with children with disabilities, a 1975 law-Education for All Handicapped Children Act. This was a major achievement and its provisions have been used by many parents with children with disabilities and has had a major influence on avocation for students with chronic illness. The most profound contribution of this legal Act concerning students with disabilities was the mandated

Individualized Education Program (IEP) provision. It is required from any educational institution that receives federal and state funds. Special education and related services for students with disabilities must be a part of their educational experience. The Act covered children and youth from 3 to 21 years of age. The other important provision, central to the unique challenges of children with chronic illness, was the Act's support of placing disabled children in classrooms with non-disabled children. This option became difficult for some of the children with disabilities, but for children with chronic illness it was crucial to them and the parents/guardians to maintain some sense of normalcy and a way to separate them from special education and certain disabled students. However, the IEP was an important provision for children with chronic illness in their bid to stay in school and maintain normalcy and in their parents/guardians demand to develop customized procedures for their children.

Individuals with Disabilities Education Act (IDEA)-1990

The law's name was changed however, being sensitive to the word handicapped in a new climate of opinion. P.L. 94-142, or the Education for All Handicapped Children Act of 1975, was changed to The Individuals with Disabilities Education Act (IDEA), in 1990 which "requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs" (IDEA, n.d., para. 6). This was a powerful law in favor of the child with disabilities and used to advocate more widespread for children with chronic illnesses. The Act mandated that an individualized and creative set of procedures be developed by a team of knowledgeable persons and must be at least reviewed annually (Include NYC, 2021). The team includes the child's teacher; the parents subject to certain limited exceptions; the child, if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents or agency's discretion. This was an Act that favored not only children with disabilities, but mandated a support team and changed the game for many parents/guardians and their children. The Act also gave parents/guardians the right to reject the IEP developed by the team and appealing through a series of due process hearings. This certainly galvanized the support team surrounding this unique group of children with disabilities, the chronically ill and they used the Act to support their children and, in some cases, start insisting that this law should be used to create new laws. There was confusion from families, health professionals and educators on similarities and differences between Individualized Education Program (IEP's) and 504 Plans. A chart providing clarity and valuable information on what each one provides for the recipient and their families is located in Appendix G.

Missouri State Laws and Student with Disabilities

In reviewing the Missouri situation concerning students with disabilities, the rhetoric is impressive in terms of protecting students. Three major departments work together to assure programs and services for these students: Department of Elementary and Secondary Education; Division of Learning Services, under the Vision entity, and Office of Special Education. In the Office of Special Education, the Compliance Section focuses on making sure that students with disabilities and their families have access, consistent standards, and improved outcomes for students with disabilities. This means having an understanding of the federal laws and the varieties of ways of interpreting these laws and applying them. Federal statutes allow individual states to creatively, but professionally apply the laws to their particular situations. According to the Department of Elementary and Secondary Education, the department establishes consistency in the procedure's public agencies, implement for meeting compliance with state and federal regulations. Their Compliance Section works and supports local educational agencies (LEA's) to comply to laws and regulations concerning individuals with Disabilities Education Act (IDEA, n.d.).

Compliance is provided through three main functions among others (U.S. Dept of Education, Special Education, 2015)

1. Monitoring special education programs for disability students, age range 3-21
2. Provide technical assistance
3. Investigate child complaints view them and/or family

There is an active roster of activities, literature, special programs, and data research concerning students with disabilities. For instance, there have a subsection entity, called Effective Practices whereby they study and review the best and quality programs for students with chronic illness. There is also a transition section where information on scholarship, research studies and evaluative studies, practical information in the forms of pamphlets, surveys, and assessments is available. This information is organized and target beside the student, the parents/guardians, families, educators, and other professionals.

However, in reviewing Missouri's compliance, it seems that the number one problem is a lack of communications, in terms of promoting and reaching out to parents/guardians and families, even schools and educators, to make them aware of so many available and influential resources that these groups and individuals can access in their state.

Publicity, communications, and the need to bring a consortium of advocates and scholars and advertisers to try to gain this information and information data to a wider range of people. This was a recurring theme in the interviews and focus groups that many times parents/guardians were not aware of all of the rights and the available resources associated with Section 504 or IEPs.

Conclusion

The review of literature provided evidence of the challenges of living with a chronic illness. The difficulties associated with living with a chronic illness impact every aspect of the student’s day-to-day existence. This includes visible challenges; such as inability to function physically, side effects from treatment, which render you immobile, delayed motor skills, extreme absenteeism, and hair loss. The invisible challenges are primarily social emotional, which include depression, isolation, thoughts of suicide, memory and sensory (academic) issues, and fatigue. Imagine being a student, who is already frustrated, due to their inability to perform daily life activities, being expected to successfully transition back to the school setting, without a coordinated team effort amongst the key leaders to ensure the needs of the student are met. This study will add to the body of knowledge about the perception of health professionals and parents/guardians as it relates to transitioning the student back to school.

Chapter Three: Research Method and Design

Qualitative methods were used to examine parent experiences, perceptions, and assessments of transitional school strategies and compare them with health professionals' resource availability and recommendations. Data were collected through interviews and focus groups conducted with parents and health professionals (volunteers), who were familiar with students who were impacted by a Chronic Illness. In this chapter, four different research questions are restated. In addition to the research questions, the population, sample size, instrumentation, data collection procedures, data analysis, and summary are presented.

Problem and Purpose Overview

The researcher, as a teacher and parent of a student diagnosed with a Chronic Illness, experienced frustration and difficulty while attempting to ensure necessary services, accommodations, and resources for non-problematic student school re-entry. Throughout the process, the researcher followed the directive of the appointed lead – the school nurse. However, after re-entry, the student, who had previously been at the top of the academic scale, could not handle the workload or stress associated with completing missed assignments, and was therefore, in danger of receiving failing grades. According to Hamlet et al. (2011), the difficulties incurred while coping with chronic illness impacts students' academic, social and emotional development, thereby underscoring a greater complexity and school involvement with the chronically ill student. When posed with the question of serving the needs of a Chronically Ill student, the nurse admitted she was not immediately prepared to offer input, and was unfamiliar with any standard procedure or protocol to meet the academic needs of a Chronically Ill student. Hence, the natural progression of the thought process was “How many other parents are having the same frustrating experience?” This study examined parent experiences, perceptions, and assessments of transitional school strategies and compared them with health professionals’ resource availability and recommendations.

Research Questions

The information from this study could provide insight into themes and commonalities regarding expressed experiences of parents with Chronically Ill students in the metropolitan area. The following research questions guided the study:

1. In what ways do parents and health professionals perceive the quality of transitional school strategies available to them for Chronically Ill students? How do the selected strategies vary by age level, school district, or geographic area?
2. What supports have parents received from parental and/or family groups that have assisted in transitioning Chronically Ill students back to school?
3. What are the perceptions of each parent and health professional regarding the challenges that Chronically Ill students face in the school setting?
4. What are the differences and similarities between parental and health professional transitional school strategies for the Chronically Ill student?

Research Design

The research design used for this study was qualitative. In general, qualitative exploratory methods are particularly useful in finding the importance people give to events they encounter (Yin, 2015). The purpose of this study was to determine how parents and health professionals perceived the quality of transitional school strategies available for chronically ill students. Creswell (2013) further explained the approach:

> Qualitative research begins with assumptions and the use of interpretive/theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is both inductive and deductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of researcher, a complex description and interpretation of the problem, and its contribution to the literature or a call for change. (p. 44)

For the purpose of this study, the experiences and perceptions of parents and health professionals were explored in relation to four research questions. According to Yin (2015), a qualitative study allows the exploration of experiences, such as feelings or thought processes that are often complicated and difficult to learn about through conventional research methods. Although transition strategies for students with chronic illness has been examined, the perception of parents and health providers has not been specifically examined. This research explored participants' perceived quality of transitional school strategies available for students with chronic illness.

The researcher studied the resources and practical advocacy of the parents with Chronically Ill children/adolescents to try to successfully transition their children back into a normal school setting. The researcher studied the literature, interviews, and responses of focus groups of parents and health professionals who have had the experience and involvement of transferring school re-entry for a Chronically Ill child.

The information and knowledge from the variety of parental experiences and responses in dealing with a sick child and the school system may contribute to educational teaching and the health field. In the circle of care for the ill child/student, the parents are central role models that affect the child's health and educational adjustment. It will be important to study and understand the support system, professionals, education, health, friends, and family network that were helpful to the parents in making decisions concerning the child's health and intellectual readiness.

The other advocate within the parental strategy is the health professional. The health professional however, is a more objective and neutral advocate, even though still with concerns for the Chronically Ill child/student. In previous discussions with parents/guardians, the health professional is central to the created strategies and support system. The health professional almost equals the authority of the parents, because the health professional monitors a major part of the Chronically Ill child's life: the physical challenges. While the parent is certainly more knowledgeable regarding the life of the Chronically Ill child (i.e. mental, emotional, the everyday process of survival) the parent/guardian maintains a major role for health professionals in helping the Chronically Ill child transition back to school. In the end, parental strategies include collaboration with health professionals. The researcher studied the role of health professionals and their responses, advice, and practical recommendations that help transition Chronically Ill students back into school. Health professionals included a physician, social worker, nurse, and child-life/humanities specialist, who interviewed and participated in a focus group. The interview was conducted face-to-face or via telephone conference call to collect information that was assessed and evaluated, in conjunction with information revealed from the focus group. The expected outcome from studying the role, responses, advice, and recommendations (in tandem with the parent) was comprehensive understanding of the health professional's impact in assisting the parent as they transitioned the chronically ill child back to school.

Population Sample

The participants were recruited through attendance of scheduled functions and meetings with Friends of Kids with Cancer. The organization is attended by parents who have a child with a Chronic Illness. Health Professionals are routinely invited and in attendance at scheduled functions/meetings. The researcher encountered parents and health professionals from the hospital setting met during her daughter's illness; however, this did not influence the results of the study, as the researcher was not personally acquainted or familiar with any of the participants prior to the study. Parents and health professionals were interviewed and participated in a focus group, but from a different context. The researcher drafted a letter and presented an oral presentation that addressed each group, outlining the initial need to identify several parents/guardians and health professionals and the nature of the research study (see Appendix E). Individuals from either group who agreed to participate in the study provided their contact information. Once this piece was completed, a face-to-face meeting was scheduled to complete the interview and focus group portion (see Appendices C, D, F). Participants were informed that there was no compensation for interviewing or involvement in the focus group and no resultant harm to children if they participated. Before beginning the focus group meeting, the parent and/or health professional signed consent for their audio-recorded focus group responses (see Appendices A, B). The location, date, and time for each interview and focus group meeting was arranged with the participant via email and/or phone conversation.

Sample

For this study, purposive convenience sampling was used. Researchers use their judgement to select a sample that they believe, based on prior information, would provide the data they need (Fraenkel, Wallen, & Hyun, 2016). Parents and health professionals were interviewed to gather their perspectives on experiences, perceptions, and resources available to parents with Chronically Ill students. According to Fraenkel et al. (2016), a sample should be as large as the researcher can obtain with a reasonable expenditure of time and energy. As such, the researcher set the minimum of parents surveyed at eight and health professionals at four.

Data Analysis

In order to analyze the qualitative data (interviews and focus groups), the following procedure was used. The researcher received IRB approval from Lindenwood University Review Board. Upon approval, the researcher attended scheduled functions and/or meetings at Friends of Kids with Cancer. This organization consists of parents who had a child with a chronic illness. Health Professionals were also routinely in attendance at the functions/meetings as well. The researcher was introduced and presented details of the research study to attendees. Interested individuals were recruited upon expressing interest (see Appendix E).

Interviews were held at designated and formal areas, in workplace, home, and other neutral areas. Interviews were both in written, as well as recorded, formats. Formal conversations about the experiences, the ideas, and lessons from the parents and health professionals were held. In addition, the investigator noted and reflected the practical recommendations of transition for the chronically ill child/student. Responses from the interviews and focus group were typed, coded, and documented. Congruent themes were discovered by analyzing responses. Qualitative data were organized by theme and commonality and presented in the dissertation as similar experiences and problems.

Thirteen one-on-one interviews were conducted involving parents/guardians of children with chronic illness and health professionals, after approval by Lindenwood University's Institutional Review Board (IRB). The interview environment remained constant by holding most interviews in workplace, home, or an office space. The interviews were audio-recorded to ensure accurate representation of what was expressed. To maintain anonymity of all participants, they were informed prior to the interview that confidentiality would be maintained by being described using pseudonyms. Once all interviews were completed, two focus groups were held (accommodating scheduling needs) with all participants. The questions were open-ended to allow participants to explain their perceptions and elaborate on answers with limited interjection from the interviewer.

Summary

The focus of this research was to explore participants' perceived quality of transitional school strategies available to students with chronic illness. A purposive convenience sampling was used to select a sample that is believed, based on prior knowledge, would provide the data needed. A common set of interview questions was used, and responses were coded and analyzed to determine emergent themes. The data analysis process and findings are described and explained in Chapter Four. Chapter Five provides a summary and suggestions for future research.

Chapter Four: Analysis

The purpose of this study was to examine parent experiences, perceptions, and assessments of transitional school strategies and compare them with health professionals' resource availability and recommendations. The information from this study could provide insight into themes and commonalities regarding expressed experiences of parents with Chronically Ill students in the metropolitan area. The research was completed to answer the following research questions:

1. In what ways do parents and health professionals perceive the quality of transitional school strategies available to them for Chronically Ill students? How do the selected strategies vary by age level, school district, or geographic area?

2. What supports have parents received from parental and/or family groups that have assisted in transitioning Chronically Ill students back to school?

3. What are the perceptions of each parent and health professional regarding the challenges Chronically Ill students face in the school setting?

4. What are the differences and similarities between parental and health professionals Transitional school strategies for the Chronically Ill student?

The findings from the interviews and focus group are discussed in this chapter. Questions guiding this study were based on parent and health professional experiences, perceptions, and assessments of transitional school strategies. Participants were asked to voluntarily consent to join the study. Parents and health professionals who chose to contribute their opinions did so by responding to a series of interview questions, as well as participating in a focus group. Pseudonyms were used to maintain confidentiality.

Nearly all qualitative studies contain information about the actions and voices of individual participants (Yin, 2015). Qualitative analysis involves labeling and coding of the data to recognize similarities and differences (Fraenkel et al., 2016). The analysis of data in this qualitative study was ongoing, and conclusions were drawn continuously throughout the data collection and analysis process (Fraenkel et al., 2016).

The first instrument utilized in this study included interview questions exclusive to the parent. Semi-structured interview protocol guided the conversation between the researcher and each parent, allowing meaningful conversations to take place utilizing the parents' own words (Magnusson & Marecek, 2015). Open-ended interview question format was also used for health the professionals interview session. Questions allowed the health professionals to express their own perceptions of experiences, perceptions, and assessments of transitional school strategies in their own words and not the researcher's terminology (Creswell, 2013). Each health professional had the opportunity to communicate experiences in a conversational mode, allowing natural routine spoken communication (Magnusson & Marecek, 2015).

The second instrument utilized in this study included semi-structured questions, which were used in focus groups for both parents and health professionals. Ten questions were presented to the participants of the focus groups, with an additional final bonus question, which asked if there was "any additional information that you would like to add?" The participants of the focus group provided rich data representing parent and health professional experiences, perceptions, and assessments of transitional school strategies. According to Yin (2015), focus groups allowed the researcher to adjust and adapt the situation without altering the original context of the data.

Parent/guardian interviews. In this section, parent/guardian interview questions are presented. Questions 1-6 will provide insight into the participants, the students illness, the day-to-day struggles, and more context to why attending school is not only difficult physically, but mentally as well, and the burden this puts on the families.

Interview Question #1: What is your child's illness and age?

There were nine parental participants with children of the following ages:

Table 1

Parent Participant – Children Demographics

Parent	Child's Age	Child's Sex	Chronic Illness	School District
Participant #1	13	Male	Autoimmune Dysfunction	Ritenour
Participant #2	14	Male	Cancer	Melville
Participant #3	9	Male	Cancer	Private St. Louis City
Participant #4	12	Male	Cancer	Jefferson County
Participant #5	16	Female	Cancer	Francis Howell
Participant #6	11	Female	Cancer	Webster Groves
Participant #7	15	Female	Cancer	Parkway
Participant #8	11	Male	Cancer	Ritenour
Participant #9	17	Female	Cancer	St. Louis Public

Ninety percent of the parents responded that their child's chronic illness was due to a form of/or either a cancer related illness, with the exception of one parent whose child had a diagnosis of autoimmune dysfunction, which caused debilitating chronic migraines daily, to include vomiting, diarrhea, nose bleeds, temporary blindness, and passing out. He received the diagnosis at the age of 11, however, at the time of the study he had reached the age of 13.

Interview Question #2: What school district does your child attend?

The responses are listed in Table 1. Review of the responses indicated children with chronic illness are geographically located throughout the metropolitan area, and attended public as well as private schools.

Interview question #3: Do you consider his/her illness chronic?

The participants agreed that the condition or diagnosis received was considered chronic. Most of their children were and had undergone treatment in attempts to save the life. The condition itself and drugs utilized in the treatment always have side effects that alter the child's life in some form or fashion. The illness and chronic side effects, in many cases, critically impacted the child's life in an on-going basis. Effects from the treatment and medications caused unpleasant effects, such as hair loss, exhaustion, low blood counts, inability to concentrate/focus, anxiety, stress, and several other conditions that ultimately crossed into the boundary of their social life; whereby, negatively impacting this aspect of their complicated and complex life and condition.

Participant 1 stated, "It's diagnosed as chronic migraine. Anytime you have more than 15 a month, then that's chronic." Participant 3 added, "There are so many associated symptoms that chemotherapy can bring, even if you make it through the treatment which has been three and a half years. There are a lot of secondary illnesses." Participant 5 lamented that it is something that you never recover from, this is a life long illness. Participant 6 "Yes, because it keeps coming back. We hope that it's gone for good, but it keeps coming back". Participant 8 indicated that her child's illness is long-term and that he will be on antibiotics for the rest of his life.

Interview question #4: When was your child diagnosed and did you seek a second opinion?

The responses to this question were equally split, with the exception of a parent who conducted research regarding the protocol of the suggested treatment. After, intensive research and summation of the options available, the family determined that a second opinion was not necessary, as the protocol and suggested treatment plan was universal. Therefore, no matter where her child received treatment, the oncology centers would follow the treatment plan initially suggested by the first physician.

Of the remaining participants, four sought second opinions and four others did not. The rationale for each family's choice were varied. Participant 1 indicated that it was difficult to receive a correct diagnosis as a result of how complex and rare of a condition they were dealing with. She stated that "depending on which neurologist you go to, you may get a different diagnosis." After seeing several different neurologists in the state of Missouri, her son was referred to a specialist at Diamond Head Clinic in Chicago, Illinois. Because he had seen so many neurologists, his condition was finally pinpointed and correctly diagnosed. At this point, because his condition (Autoimmune Dysfunction), was "chronic," and would never change, the treatment plan was rehabilitation or learning how to live with it. Participant 8 felt compelled to seek a second opinion due to long term issues from age zero through five. It was not until the age of five, that they were informed that he had been born with his condition, which was initially misdiagnosed. Participant 5 indicated that they sought other opinions to what it was, and how to best treat the condition. Participant 2 stated that because it was a brain tumor, they sought four or five different opinions. “They all said the same thing; one place, Phoenix, said they could try to remove it, but then our doctor advised us against it.”

There were justifiable reasons why other parents opted not to seek other opinions regarding their child’s condition or diagnosis. An emerging theme from this interview question was “time.” As a result of the circumstance, the seriousness of the condition, and the fact that parents are dealing with life and death matters, time seems to fly. Time was of the essence and the option to seek opinions from other health professionals was a choice they chose to pass. Participant 3 commented that after lumps were felt on her son’s neck, they had blood drawn. They were informed that his white cell count was extreme. They went to Cardinal Glennon Hospital later that day and “we were there for a month. Everything happened very quickly.” Participant 4 after diagnosis, proceeded directly to Children’s Hospital. She had another son with a disability and was familiar with the quality of services. While contemplating what to do, “there was literally a sign hanging on the wall, that said it was number one in neurosurgery. So, you can’t really go wrong with that.” She indicated that she inquired as to whether she needed a second opinion, but was informed that the protocol for his type of cancer is the same at every hospital. Another participant stressed the urgency in making a decision in the moment. Her daughter was paralyzed from the waist down, when she was diagnosed with spinal cord cancer. Participant 7 stated, “There was no time, because they had to immediately decompress her spinal cord.” Participant 9 explained that “my child was in a lot of pain and the cancer had spread to the point where we really didn’t have time for a second opinion.”

Interview question #5: How long has your child been dealing with their chronic illness?

Of the nine participants, there were three children who had been dealing with chronic illness for an extended period of time. Participant 6 whose daughter was two and half years old upon diagnosis with cancer and at the time of study, she was 11 years old and had been dealing with chronic illness for a total of eight years. The other individual who had been what is called in the cancer world on “the journey” that had been dealing with chronic illness was the daughter of participant 7.

> She was actually born sick…we do not know what happened, but it took us five and a half months until she became paralyzed to figure out what it was. I don’t think the tumor was visible because she had had a scan….so we would go to the doctor every week, every two weeks, every two days to try to figure out what was wrong…she was just not well.

She continues to face long term chronic health issues as a result of her condition and has had 11 surgeries and is 16 years of age. Participant 8 expressed that “on paper,” her son who is 11 years old, had been dealing with chronic illness for eight years. The “on paper,” comment alluded to the fact that he was not correctly diagnosed until he was five years of age.

The other participants’ children had been struggling with chronic illness on an average of three years.

Interview question #6: What was your and your child's reaction to the diagnosis?

The responses reflected three main ideas regarding their child's reaction to their diagnosis. Surprisingly, there was a feeling of "Hope." One participant's child had received several different diagnoses along with treatment plans that did not offer long term relief from his chronic illness. Therefore, when he was presented with a diagnosis that explained all symptoms and issues, he was hopeful that medication and a treatment plan would allow a return to living a normal life. Participant 1 said:

> Most kids are looking for hope. So, each time a doctor gave him hope, he would grasp it. He was praying that this was the answer. But after a while they become numb, they don't trust because they have been offered so many false hopes that they no longer believe anything is going to work……it's a hopeless feeling for a kid who knows that this is their new life. Especially, if they lived a normal life.

Participant 4, 5, and 9 child's reactions were reflective of emotions of anger, fear, and devastation, as they were knowledgeable enough to comprehend the seriousness of their illness. They were aware enough from life experience and exposure that many people die from cancer. According to Participant 4:

> I don't know if he was so angry at his diagnosis, as he was angry about the situation. He was upset because we had plans to go to the zoo, get ice cream and movie. We went to the hospital and didn't go home. However, once he had a friend at the hospital, he wasn't angry anymore. Really didn't have a reaction to it – he just went with the flow.

Participant 5 expressed the level of confusion associated with the unknown factor of what was going to happen to her child. It was stated that:

> I think probably just fear, really. It's hard to really understand what's really happening and what's going to happen, so my eleven-year-old was about to start puberty. It was just confusing and scary.

Another participant briefly shared information reflective of the world coming to an end. They were completely taken by surprise by the diagnosis. Participant 9 stated "complete devastation, our world had ended. Why did God do this to us."

There were various other responses to the question from participants interviewed regarding their child's reaction to their diagnosis. Participant 2 stated, "He is very easy-going, he never really complains. One time he did cry when they told him the tumor was back."

Participant 3 spoke to a reaction of disbelief, "He knew cancer was bad and we did not use the word cancer. But it was forced on us…because we were at the hospital….as soon as they said cancer, he knew that it was serious."

Participant 8 recalled that her child was "used to it" in terms of the treatment plan for dealing with a chronic illness for an extended period. He did his best to manage his symptoms so that it would not result in a trip to the hospital. "We cry about it, but at the end of the day, he's just happy to be alive." In contrast to the other participants whose children had some type of emotional reaction. Participant 6 and 7 shared that their children were too young at the time of the diagnoses and could not comprehend the seriousness of their condition.

Interview question #7: At what point did your child start to be absent from school?

The responses pertaining to question seven varied. One third of the participants (3, 5, and 9), indicated that their child started missing school immediately. While the other participants expressed different time periods that were situation based.

Participant 3, stated "we were on spring break, so we had time to regroup and by the end of the week he was gone for the rest of the year." Participant 5 shared that while on Christmas break her child had a port inserted and started chemotherapy treatment. She did not return to school after break. "By the time she returned she looked like a different kid. She had hair loss and was really sick from chemo." Participant 9 commented, "Immediately, December 13, when she was diagnosed, she went in the hospital and was absent for the next 365 days." She was absent her entire sophomore year.

Participants 2 and 7 expressed similar situations that required their child to be absent from school as a result of medical appointments, tests, and scans. Participant 2 noted that radiation treatments were every day. Which resulted in many absences; however, in contrast, it is difficult to say how much he has missed. It was stated that "he's been out more than he's been in." Participant 7 spoke of absenteeism as a result of several surgeries. She felt that her child never had the potential to regularly attend school due to numerous doctors' appointments, testing, scans, and surgeries.

Participants 1 and 8 both referenced the child's grade, regarding the question of when the child started to be absent from school. Participant 1 reported that her child was in Children's hospital all the time, and most of sixth grade he was not in school. On the same note, participant 8 vividly remembered the struggle in kindergarten, but it was not until “first grade, that we were in and out and really missing school…we were out at least 90 days per year.” It was also shared that at one point her child missed six consecutive weeks and was assigned a homebound teacher. Participant 4 was specific in her response, “June of 2014…because he was going through full treatment, he missed a lot.” The hospital’s direction was, send him whenever you can, to keep him happy.

Participant 6 indicated it was in September at the age of five that her daughter started to consistently miss school. She stated, “She started school in September and the at the end of November she was sick again and started treatment again. But she was in and out.”

Interview question #8: Overall how much time has your child missed due to their illness?

All participants indicated that their child had missed a significant amount of time from school due to their illness. Some instances were continuous blocks of time missed, some were sporadic and in two cases the amount of time was so significant, that the parent lost track. Because some of the children have dealt with chronic illness for an extended period.

Participants 2 and 4 found it difficult to quantify the amount of time their child missed. Participant 2 stated, “In the past three years he’s missed a lot…I really can’t say how much time he’s missed overall…it’s really hard to say because it’s been so long. But he’s been out more than he’s been in.” Participant 4 had the same sentiment, “He was going through full treatment, he missed a lot. I can’t even tell you how much time he missed.”

Participants 1, 3, 5, 6, 7, 8, and 9 expressed similar experiences with regard to the overall amount of time their child had missed. The recurring theme being, absenteeism in excess of 30 days in any given school year. Participant 1 said her child missed his sixth-grade year, three quarters of the seventh-grade year, and all of his eighth-grade year. Participant 2's response was absenteeism in the amount of four months in the last two and a half years. Participant 5 indicated that ability to attend school consistently was extremely difficult. Freshman year attendance was 60% of the time, sophomore year her child was withdrawn due to continuous complications and illness. Participant 6 again expressed absence as "way more than 50%...when she felt good, she would go and somedays she would go a half day." Participant 7 in conjunction with other participants indicated that from the first through the sixth grade her child missed about a third of the school year. The child of Participant 8 missed the same amount of time as participant 7, a third of the year. Participant 9 estimated that his child had missed one year to a year and a half, in three to four years of school.

Interview question #9: Has your child been able to return to school?

The intent of each parent is to successfully transition their child back to school to an environment that resembles normalcy, to reconnect with friends, peers, and to continue to receive educational services. Participant 1, briefly stated that returning to school was the plan. Participants 2, and 4 indicated that their child had returned to school and was "back to normal." Participant 3 was not expressive in regard to this question, only remarked that their child was able to return to school. Participants 5 and 7 referenced similar difficulties and outcomes. Although their children had returned to school, they continued to experience consistent, sporadic interruptions and absenteeism as a result of chronic illness and/or side effects of their treatment plan. “She was able to return to school for a short period of time in the ninth grade. And then in the 10th grade, we pulled her back out because her vision was so bad, and it was causing so much anxiety…spent pretty much of her 10th grade year with a homebound teacher.” According to participant 5, Participant 7 shared the same sentiments as participant 5. In ninth grade, her child was well enough to regularly attend school; however, scheduled medical appointments, treatments, and illnesses caused expected and unexpected continuous absenteeism. Participant 8 had a similar experience to participant 5. Although participant 8’s child was initially able to return to school, part of a treatment plan required medication (morphine drip) that left him semi-conscious and sedated. Therefore, he was assigned a homebound teacher for the purpose of providing educational services, as required by state law, for an approved period of time. Participant 9 had a teenaged child who was close to graduating from high school. Although his child was able to return to school, it was never on a full-time basis, but enough to complete high school to graduate.

Interview question #10: When the school was informed of your child’s illness, what did they do?

Several of the parents provided positive feedback regarding their experiences with the educational system, after they were informed of a current or ongoing medical condition or issue. The common threads were expressions that the school was receptive and attempted to accommodate the needs of the student while providing quality educational services.

Participant 4 expressed appreciation of the school's response and stated, "The school immediately reacted…they did a really good job of reaching out to me…they had a school liaison…I got very lucky to have her." Participant 5 detailed a similar positive experience; "they immediately reached out to us about what her needs would be…apparently, they had dealt with a couple other kids who had similar situations, so they were better prepared and knew the routine. So, we benefited from someone else's trial and error." Participant 6 indicated that a very detailed care plan, similar to a 504 Plan was set up. Participant 2 stated that her physician outlined every accommodation needed and the school followed as closely as they could. Participant 3 commented that they were contacted and arrangements were made to receive information. Participant 1 felt that the great thing about the school district was that previous students had medical conditions that paved the way so that their problems were minimized.

In contrast to the positive experiences, there were two participants who felt that the reception and reactions of the school to their child's condition was disappointing. Participant 7 commented, "They were receptive, but there was no real understanding. I had to fill out all of the 504 paperwork. The principal told the lead social worker of the school district to call and ask me about the situation." Participant 8 believed the school was good initially, but felt as time passed, the teachers did not read or follow protocol, because it was a lot. Participant 9 emphasized that school staff were clueless. "They talked as if they were going to support us, but they didn't know what to do."

Interview question #11: Explain what role and/or support services the school offered to you while your child was absent?

Each parent had a reasonable expectation that the school would make available educational resources and/or support services to accommodate their child's absence due to medical issues. Most of the participants were offered the services of homebound instruction for their child in their absence, as well as the option of a 504 Plan. However, there were participants that stated that options to basic services were never offered.

Participants 1, 4, 5, 7 and 8 were offered the resources and support services of a homebound teacher. Participant 1 expressed satisfaction regarding homebound services and accommodations. The homebound teacher was great. When her child was visually impaired, the teacher would read out loud. "They worked with him on his weak point and let him go to classes in the areas that he was comfortable with." According to participant 4, the experience was positive as well. "They pulled the red carpet out, but I also knew they did not know what the heck they were doing." They were introduced to the school liaison, who assisted in coordinating and setting accommodations. The liaison ensured that any time school was missed, a teacher came to the house to ensure that the student remained on track. Participant 5 was pleased as well.

> They immediately reached out to us about what her needs would be as far as chemotherapy treatment, and making sure we had all the paperwork to get a Homebound teacher set up. Apparently, they had dealt with a couple other kids who had similar situations, so were the third in three years who had been diagnosed with cancer. So, we benefited from someone else's trial and error.

Participant 7 simply stated that they were offered homebound education, contingent on surgeries. Participant 8 expressed satisfaction with the fact that accommodations of a 504 Plan were offered along with the services of a homebound teacher. However, it was felt that the real support came in the form of the school secretary and nurse. As they expressed concern and would call and check on her child's condition. Participant 2 did not respond to the question, in terms of acknowledgment of established services and support, but focused on support in terms of the emotional aspect. "They sent cards and stuff. He received a booklet of cards from the kids at school. The kids wore team… shirts, they were very accommodating."

Participants 3, 6, and 9 did not have the same experience of being offered anything that provided a formal or structured outline. According to Participant 3, the school did not have a formal plan. However, there was a meeting held with the teacher, school nurse, special educator, and principal to figure out what needed to happen. They were open to assist as necessary. Participant 6 briefly stated that there was not much support when her child was absent. The teacher would communicate with the hospital teacher on what to do, but there was not anything special about the service. Participant 9 frankly stated that they reached out to the school to initiate and demand the services that the law requires for disabled students.

Interview question #12: Where the options clearly communicated?

The response was close to an even split regarding clarity of communication of options. Several participants were adamant that options available for their child were definitely "not" clearly communicated or information made available. Participant 9 specifically states:

> I personally don't feel anything was clearly communicated to us. My wife was a teacher and was able to try to push and weave our way through the system to get whatever form of support we got from the school district.

Participant 8 was full of emotion when explaining that no options were made available, they were responsible for gathering all necessary paperwork, and had to throw a fit and fight to receive appropriate services. Participant 2 explained that because her child attended a Catholic school, the school was not required to abide by a 504 Plan. They were told that instruction from the physician overrode every other legal document. Therefore, there was nothing to explain. Participant 6, whose child also attended a private school commented "They didn't really have much in regard to options."

In contrast to participants who felt that communication was an issue, Participants 1, 3, 4, 5, and 7 felt that communication of services available was clear. Participant 1 found it necessary to complain about a different issue. Because, the school was aware of the initial complaint, they were hypersensitive in trying to minimize additional conflict. As such, great care and concern was taken on behalf of her child. Participant 4 referenced the meeting held where a Procedural Safeguard document that explains the student's legal rights to free and appropriate education was made available. Participant 5 believed that options were clearly communicated, however, they struggled with getting teachers to honor the accommodation that were outlined:

> Teachers would give her zeros and/or "F's" in class, because they refused to follow the 504. It got to the point where the principal was contacting the teacher and they would change it.
>
> Participant 3 and 7 were also in agreement that information regarding options were clearly communicated.

Interview question #13: What did you think about the transitional strategy?

The responses to this question were interesting as, they fell into three different groups. Participants in the first group were extremely pleased with the transitional process for their child and made positive comments. Participants in the second group expressed a feeling akin to being lukewarm. “The process or experience was O.K., but it could have been better.” Participants in the final group expressed a level of dissatisfaction with the fact there was not a formal process or strategy in place to accommodate the needs of their child. There was a participant who expressed conflicting emotions. On one hand, it was fine, then on the other, there were concerns of dissatisfaction of the process in its entirety. That eventually worked itself out.

Participant 1 commented that they were “pleasantly surprised,” with the transition strategy. They felt that the school staff took the child’s illness at face value, based on the medical documentation and did not try to read anything into it.

Participant 3, was extremely pleased:

> It was amazing, it was what we needed. I do not know what we would have done without it. It took a lot of self-initiative to be able to keep up with the plan, and self-responsibility on the parent’s part, but they were open to aid wherever we needed it. It was good, it’s something that I would not change.

Participant 4 expressed satisfaction in terms of the strategy being “good,” as her child, like many students who are in chemotherapy treatment, appeared to be extremely ill. Because her child was so sick, the level of empathy from school staff was high. The attitude of the staff was to do whatever they could to help. Participant 5 also expressed satisfaction of the strategy as “it worked out well.” However, that was not without several bumps in the road. Elementary school was laid back, but middle school was more difficult because of the changing of classes and the complications associated with chronic illness. Initially, they received phone calls to the home each time her child was absent, and the principal pulled the child from class 3 or 4 times and summarized her attendance history and how many absences she had. She would remind the principal that she had a written 504 Plan and he would retreat. It was not until her child was homebound and receiving services that they were happy, because they did not have to essentially be harassed anymore. This was participant 5's definition of "it worked out well."

Participants 2 and 6 fell into the category that expressed feelings that equated to being "lukewarm." The impression was it was not the best or worst; however, it was satisfactory. According to feedback, the school was making appropriate accommodation, as far as the parent could tell. But because she (parent) was not there and her child could not verbalize the specifics of the daily routine, "everything they did seemed to be fine." Participant 6 stated that they "did the best they could," based on the fact that her child was transient and missed a significant amount of school. However, they were able to meet with the teacher over the summer to prepare and discuss the upcoming new year. Since her child never consistently attended school or was able to fully return, Participant 6 had a limited opinion of the strategy.

The final group of participants were adamant that there was not a strategy or had a negative opinion of their experience. Participant 7 felt that a strategy did not exist:

> There really wasn't a transition strategy. She returned to school and she was expected to participate just like any other student. It was difficult for her because she missed so much school, her education was like Swiss Cheese. You miss

> certain letters of an alphabet, there is no way to fill in the gap…no options or supports to minimize stress were offered by the school.

Participant 9 was also displeased that there was no strategy. It was a situation of stumbling to find your way. It required persistence to receive information about the 504 Plan and homebound services. They were surprised at the counselor/nurse’s lack of knowledge on how to proceed with providing services to a child with a chronic illness. Participant 8 echoed the same sentiments.

Interview question #14: Was the approach or service explained with regard to transitioning your child back into school?

Over half of the participants’ reactions to this question were negative (no). The expectation of the participants, was that someone. either school administration, or at best a teacher, would evaluate the situation of the chronically ill child and attempt to offer guidance, structure, or an outline to facilitate the transition back to school. Contrary to their belief, there was not a formalized method of communicating information deemed necessary for a smooth transition back into the school setting. Many of the participants asserted that their child was expected to perform the same as any other student. Participant 7 commented that there was no transition, just a regular return to school. There were teachers who complained about the fact that her child was allowed additional time to get to class as a result of her illness. “Some of the teachers did not like that, they didn’t like that she had extra time or was late to school. She was interrupting their class, by coming a little late.” Participant 8 expressed disappointment and anger in the fact that there was no transitional strategy: “No, he came back from the hospital and he was home for two months, and he went back into class as though he was never gone. They did not do any transitional strategy at all."

Participant 9 echoed the same sentiments:

> No, I don't even know if they even had an approach. We flew by the seat of our pants, trying to fight for our child. They were not resistant on the surface, but they weren't a lot of help, because they didn't know.

Other participants were fortunate enough to have had a positive experience. Participant 2 was pleased that the process was explained, however, it was expressed that they her son never really returned. And on the occasions that he was able to go to school. It was agreed upon that he would not receive "a lot of work, it's just dumb, and it's just busy work." This sentiment was based on being informed that his condition was terminal, and the intent was to not add any additional stress. Participants 4 and 5 agreed that the process was explained; however, participant 5 recalled feeling confused, because every year the process was new. Each year a meeting was held to review the plan for educating her child. She felt that it was fine in middle school but in the ninth grade it was difficult, because the approach was different. Instead of meeting before school started, the school decided to wait 2 to 3 weeks after school started to meet with teachers and parents. Participant 5 also added:

> It seems sort of backwards to me. Just because 3 to 4 weeks and if they are having problems, then you could let me now then, but now the time already passed. I felt frustrated, because she was having some problems…I would email them and they would say "just wait," the first 2-3 weeks is a very busy time.

Interview question #15: Was there a team approach to transition your child back into school? If so, who was involved and what support did they offer?

The response to this question was akin to the previous question, in that over half of the participants were in agreement that a team approach to transition was implemented. The commonality of each response was that professionals who attended meetings to discuss and coordinate services, routinely included the principal, teacher, and the nurse. Other occasional attendees identified were the Homebound Teacher, Social Worker, and Counselor. One participant's characterization of events stood out. The analogy used by the school liaison to convey the seriousness of the condition and emotional state of the child, could be considered extreme. Although the intent of the school liaison was to educate staff, Participant 5 illustrated the content of the information used to get the staff's attention. It was described as being a pretty dramatic discussion, because the school liaison was trying to get the staff to understand that what kids with cancer go through is "considered as the same emotional trauma as a child who was raped." They do not get to choose to say "yes or no" to the things that are happening to them. Although the treatments are administered to heal and hopefully cure, there is extreme trauma, due to the lack of choice and the inability to comprehend or understand what and why things are happening. The intent of the school liaison was to say something, to emphasize in strong language to the teachers and staff, to get them to understand that this is a real trauma. There is a reason for an IEP or 504 Plan. That an educational contract is in place to lessen, if possible, additional trauma in the school setting. "It shook them up," stated participant 5. Participants 7 and 8 expressed similar feelings in reference to this question.

Both participants felt that there was not a coordinated attempt to transition their child back into school when they returned. According to participant 8:

> The only team we had was the school nurse and the secretary who informed me of things that I could get together for him. In fifth grade, we had the behavioral person who assisted us. We had one meeting every year just to go over the paperwork. Other than that, there was no team approach.

On the positive side, participant 3 answered the question in terms of the level of humanism, the use of an individualized approach versus the common answer, of which professionals were in attendance for a team approach meeting:

> Very humanistic, a lot of empathy was there. They were very supportive and they looked at the child as an individual and what were his needs. They were very supportive of his needs such as having a water bottle at your desk, or sanitizing your area or needing to vomit and then come back to class. They didn't seem to believe those things were so outlandish.

Interview question #16-18: What was it about the strategy that was effective and why? Did anyone follow-up with you and was there a formal system in place?

Effectiveness of the strategy for 80% of the participant responses were positive. It appeared that initiation of any form of communication to the parent, with the intent of providing information or feedback on the welfare of the child was greatly appreciated. It was also perceived as taking proactive measures to ensure the child was treated equitably in spite of their illness, limitations or circumstance. Participant 1 lamented:

> The fact that you had all of these professionals working together, and everybody had input, his neurologist, and a doctor at the Mayo Clinic, even his pediatrician.

> With all those people being involved, everything had been taken into consideration and covered.

Participant 3 commented that the staff was very supportive and considered her child as an individual, with regard to what needs, needed to be met. Participant 4 expressed her satisfaction with the strategy of utilizing the hospital liaison to present and represent her child’s best interest. She stated, “I don’t care what school district you’re dealing with or what person is sitting there, but when you bring in a medical professional, who was going to tell you what’s going on, it’s going to elevate everything to another level.” In contrast, Participant 7 and 9’s comments were in effect reflective of a void to the question of effectiveness. Participant 7 indicated that they may have had a strategy; however, she was unaware of it, and didn’t know what they did. Participant 9 expressed dissatisfaction:

> We believed that the institution should have understood and been able to help us get through the strategy or create a strategy to help us…they were struggling. The negative was not having, as I stated, they had no subject matter expert to help us understand and navigate or even to create a strategy to manage through the 504 Plan, and help us integrate our child back into the school system.

Follow-up with the parents was not a problem for the majority of the participants. The member of the educational staff (principal, social worker, counselor, nurse, secretary), who provided on-going follow-up information varied by participant. Staff members were keenly aware of the child’s chronic illness and usually followed protocol and made accommodations accordingly. Most participants agreed that there was some type of acceptable feedback about their child.

On the other hand, one participant expressed disappointment with the nature of the follow-up. It lacked genuine concern. It resembled, the act of checking off boxes to remain compliant or going through the motions according to participant 5. Follow-up would usually be because of an incident. “It was not necessarily a proactive approach; it was because something happened. I would receive some sort of follow-up email or phone call.” This was the norm for this participant, and ended up being acceptable, because, any form of communication was better than no communication or feedback.

When to the question of whether the school had a formal transition plan in place, four of the participants indicated “no,” the school did not. Participant 9 was unable to definitively answer the question. If there was a formal plan within the district, school administration was not aware of it and did not effectively communicate its existence. Participant 8 stated that there was a formal transition plan in place for her child’s school, but described it as being “horrible.”

> There was a formal system in place, but trying to get people to adhere to the system was horrible. It looks good on paper, but behind the scenes it’s another story…They try to follow the plan of the special school district, but they lack the ability to follow through. It’s an afterthought. The only reason they do it, is because this is the law. They have a system that is supposed to be followed…but they don’t use it.

Participants 1, 2, and 4 explained their understanding of the formal plan from a different perspective. It was not a formal plan that was outlined by the district with specific protocol. It was the fact that basic common-sense instructions were followed. Participant 1 simply stated the stipulations of the IEP were followed, while participant 2’s definition of the formal plan was the nurse speaking with them and following her recommendations. “They had a plan, some sort of plan, not like an IEP it was just a school plan.” Participant 4 understood the 504 and medical plan outline to be the basis of a formal transition plan.

Interview question #19-21: Due to the nature of your child’s illness, have you participated in any support groups. If so, what was your experience and how has it helped you?

Ninety percent of participants had participated in a support group, all except Participant 8. Six of the remaining eight participants revealed that they participated in Friends of Kids with Cancer support group. This group was described as a safe place for parents who wanted to speak with and share experiences of caring for a child with cancer or a chronic illness related to cancer. Each participant described the experience of involvement in the support group in positive terms. Participant 5 described the group in the following terms:

> It is not necessarily counseling. It’s more the opportunity to talk with other moms and do activities together – who understand what you are going through. You don’t necessarily talk about your kid’s cancer, but you share something in common and it’s a very comfortable environment.

Participant 5 also described her experience as being “very good;” as being a nice place to feel supported. “You are able say things and people get it. It is not necessary to provide a deep explanation…it’s like family.” Participant 6 also provided glowing remarks. Stated that Friends of Kids with Cancer has been a wonderful support for the family. “They attempt to do whatever they can to assist the parent and child. They also go as far as offering educational, tutoring services and assistance with the 504 Plan if needed." Participant 7's comments were in alignment with participants 5 and 6:

> Friends of Kids with Cancer, even though it's not an official support group, we share stories, and we laugh, and cry – we understand that nobody has to apologize for anything that they say…nobody feels awkward because we get it…we can ask questions that nobody else would ask – about a child's death, or illness… there is no judgment. It's just a big warm hug every time.

Involvement and/or attendance in a support group, is primarily in person. With the new age of technology and social media, parents have additional options to meet their needs f community support, feedback and associations with others who have similar situations. Participant 1 and 8 spoke of participation in online support systems. Participant 1:

> I ended up finding out about support groups online through two other parents…otherwise, I would've never known… The online support groups are great because there are people all across the world… It helps to hear other people's struggles. It helps to get support from people that can relate to what you're going through.

Participant 8 spoke of association with a Facebook group for emotional support. It was described as a casual format with two other mothers who check on each other three times per week, via text or Facebook. Participants 2 and 4 were involved with a Brain Tumor support group. Both participants agreed that they were helpful; however, participant 2 described being hesitant, because "all the kids that you follow with these tumors have died. Then you hear people complain about dumb stuff." Although it was a slight irritant, she continued to attend the meetings, as it allowed the opportunity to speak with others to gain perspective and coping skills.

Interview question #22 -23: What are your perceptions regarding the challenges that chronically Ill students face in the school setting and what actions steps did you take to transition your child back into school?

There were several different reactions to this question. However, there were two common themes that stood out amongst five of the participants. The first being, concerns that the child was socially disconnected from their peers; therefore, they had little to no social life. Participants 3, 6, and 7 expressed similar feelings. They felt that their child was routinely isolated and usually not invited or included in social activities. The perception of the participants was not that it was intentional. It was as a result of frequent absenteeism of the child, who did not have the time necessary to develop those connections or bonds with others. There was also the inability to keep up with healthy peers, due to long term side effects and their conditions. This emotional component was also a struggle for many chronically ill students, as they found it difficult to comprehend or understand many of the social issues that their peers complained of. They felt they are living with the day-to-day stressors of life and death issues, and their peers were concerned about trivial issues regarding the way they looked or what to wear.

Participant 6 described the challenges of peers not understanding:

> She does not fit in socially because she is so mature because of what she's been through and she's immature, because she does not know how to socially interact with people her age, because she's in a world of adults for so long…she can't keep up with her friends and she physically can't run long distances.

Participant 7 mirrored the same sentiments:

> Socially is the worst… she is immature because she never knew those social norms or the rules, or the guidelines, or how girls work. She does not have a lot of patience because she is like – I have cancer, I have had surgeries, and people around me living and dying, and suffering, and you are worried about your toenail that doesn't have polish on it.

There is also the challenge of students who have hidden chronic illness. Those who did not appear ill, however, they have serious on-going health issues and challenges that impact their ability to function or remain involved in routine activities. Participants 1 and 4 had perceptions that were reflective that students who do not appear ill, are not taken seriously and/or treated different. Because they do not appear ill, the expectation is that they can keep up and function as a healthy child. Participant 4 said:

> The school doesn't understand it…he looked healthy, he felt healthy, he doesn't look like he's a cancer patient anymore, but not everything works…because he is strictly responding off of parts of the brain that are not working because of radiation or because of chemo.

Participant 8 recounted feeling that there was medical discrimination against her child:

> Discrimination, everybody thinks it's just a color thing. Discrimination on a medical level is so much more intense, because you're labeled the misfits and you as the "you can't do this kid." Even though mentally you're perfectly fine.
> It's just you are chronically ill and you're pushed aside because you're just too much to deal with.

Participant 5 partially agreed with participant 8 in terms that many chronically ill students did not receive the help they need, because it’s too much trouble. “Districts feel that there is not enough money, support or resources to help the students.” Most of the participants were in agreement that steps necessary to transitions their child back into school required clear two-way communication. Participant 6 provided a summary that was reflective of the majority of the participants’ feedback:

> The key is continuous communication. Keeping the line of communication open, making sure that everybody understands that it’s okay to talk about it, and it’s okay and necessary in order to help my child. As her treatment changes or as her needs change, continue to communicate. In today’s world, it shouldn’t be an issue because there are so many forms of communication that are instantly available.

Interview question #24: Did you express your concerns with the school and what actions/resolutions were offered?

Ninety percent of the participants communicated that it was necessary to make someone within the school system aware of their concerns. The participants did not necessarily go into any detail regarding the details of the complaint. However, the common thread was the avenue they chose to make their concerns known. Participant 1 explained that she wrote a nice long letter to the superintendent and forwarded it to his bosses and the board of directors, as well. Participants 3, 4, 6, 7, and 8 chose to make their concerns known in the form of phone calls, discussions, and letters. Participant 7 stated:

> In regard to my battle and fight – I would make phone calls, write letters, have conversations when I would pick her up from the nurse…this is what’s

> happening, this is what's going on, this is why I am picking her up. I would go so far as to show them her incision. This is where she had surgery, and this is why it is uncomfortable.

Participant 5 indicated that she was usually offered a meeting to evaluate the 504 Plan. She also emailed the teachers to discuss issues with them and they would usually do something to adjust or resolve whatever the problem was. Participant 2 was the only individual who commented that it was not necessary to express any concerns, as the school followed agreed upon protocol.

Interview question #25 -27: As your child transitioned ack to school, what were some of the social issues/challenges they expressed? What barriers did you have to face, and what are the most difficult parts of balancing school and the illness?

The lack of friendships, solid relationships and isolation was the reoccurring theme of social issue challenges. This was primarily due to chronic absenteeism, inability to keep up with peers and being bald/looking different. Therefore, solid bonds were not formed. Participant 5 explained:

> Being a teenage girl, being bald and being in school. Not being able to walk the steps and being forced to take the elevator, she felt isolated and out of place, she felt that all the things the kids at school were complaining about were insignificant. Students might see an issue as being major, but when you're facing life and death situations, they are insignificant to her. So, it was difficult for her to relate to her peers, and some of them found it difficult to be around her because she found it difficult to relate to them as well. So, it became very isolating to the point that she just didn't feel she had any friends.

Participant 7 stated:

> Socially, she was not the kid on the playground who could do anything, she sat with the teacher's aide…so socially, she wasn't really included, and then the minute she made a friend, she was gone again…when you are young you have not formed those bonds yet or understanding of empathy or sympathy…to this day, she still says that she doesn't have any friends, or that she doesn't feel like she is part of the group, and that she is excluded.

Participants 3, 6, and 9 echoed the same sentiments of lack of support, feeling left out and isolated socially. The feeling of being treated differently than the majority of other students was hurtful and discouraging. Participants 1, 2, and 8 spoke about hurtful comments. Participant 8 said:

> So, the teacher asked them to stand up and talk about themselves and he talked about the fact the he had an extra spline, and the teacher said in front of the entire class that he was a liar. He tried explaining that it's a rare condition. The teacher made him cry. I went to the school and told them that it was true and that he needed to do his research. Then I want you to formally apologize to my child in front of the class.

Participant 2 described a situation where her child's sister who attended the same school, came home and reported that students were saying mean things and making fun of her son. Another theme, was how appearance played a major role in how students with chronic illness are treated by their peers. As mentioned above, participant 5 was expressive in her quote regarding baldness. Participant 4 said:

> He is permanently bald in the back of his head from the extreme radiation. So, we

> strategically cut his hair that it looks like a hair flop. He does not like that to be messed with. Somebody asked him why he doesn't have any hair. I said tell that you had a brain tumor – that will kind of shut them up a bit. He just said, I just tell them don't worry about it. But I told him that they are curious. It's teaching him that, you don't' use your story as an excuse and you educate them. Because honestly when you say I had a brain tumor they shut up. They really do not know how to answer to that. That's his only concern that he's ever had.

Participants responded to the question of barriers faced, with several different experiences. Participants 7, 8, and 9 spoke of the underlying theme of acceptance, being heard, and acknowledgment of the difficulty of their child's struggles by the school system. Participant 7's description:

> I feel that they didn't accept her or understand or try to understand either one of us. So, the barriers were more unwritten, than written, because officially they gave her everything they needed to. It was those soft things that are not written in the official rules that made it difficult. Like being welcoming, and understanding and accommodating. The individual teachers probably did that more.

Participant 8's expressed barrier:

> Being heard and actually having the school district follow through. Getting the paperwork filled out. It was so difficult getting my child educated this year, it was so hard, we had to fight for everything. They continue to try to hold him back, the excuse was he's missed so many days. I told them that it was their fault because they did not complete the paperwork, and all of his absences should be excused because of medical reasons.

Participant 9 was disappointed that there was no subject matter expert to lead them through process of completing the paperwork, or to outline and define the process of the 504 Plan. In addition, not being received or welcomed was felt as being a barrier when considering the process of advocating for their child.

Participant 2 had an interesting take on the question. It was indicated that they were so caught up in the illness itself, and getting her child better that there were no other priorities. This is understandable when you do not know how much time your child has to live because of the uncertainty of their chronic illness. Therefore, the expressed barrier was being caught up in the illness to the extent that nothing else mattered. Educating individuals in close contact with her child was a barrier for participant 6 who stated:

> Educating the parents and the kids, so they would understand what she's been through and accepting of her returning to school. Also, coming back to school as a chemo kid you have to be very aware of infection, and you have to get the other parents on board to understand that you cannot send your kid to school with a cough or cold without telling me first. Especially, if I'm going to send my kid and you are going to send your kid, it doesn't work. In a private school it works because, its's small and we have open communication and we alert each other when a kid is not feeling well.

Other singular comments regarding barriers were issues attributed to the fact that one participant/parent was unable to maintain a full-time job, because of the schedule for medical appointments, scans, and illnesses of her child. The other was an issue of a child who did not appear ill; however, the expectation of teachers and staff was being placed upon him to keep up with healthy peers. Finally, a child who was coached by his parents to seek medical attention from the school nurse when necessary, was ultimately made to feel uncomfortable by the nurse each time services or attention for his health condition were sought.

As expected, having a child with a chronic illness presents unique challenges. One example is balancing school and the illness. Review of the commentary revealed that the primary concern was absenteeism and its impact on keeping pace with school assignments and the social emotional aspect of being left behind. Participants 3, 5, 6, 8, and 9 were concerned, because each absence created another level of unwelcomed anxiety, that was added to the endless list of issues that their child faced. Participant 5 spoke of the difficulty of getting school work done, and just the mere idea of the issue was tough for her child. Participant 6 expressed absenteeism as being a "gap," because of the significant number of days missed. It was a concern, however, because her child attended a small private school, there were no expectations or worries about missed assignments. This is considered the educational gap that would not be filled and/or the nature of the situation they must deal with. Participant 9 answered:

> Worrying about our child's mental stability. The whole gambit is bad. Her absenteeism, you wanting her to stay part of it, she wanting to stay apart of it, she's wanting to do all of her required work, but she's already behind. Not to mention how the effect of chemo on her brain, where she can't remember. There is no easy way to talk about what's required or what's needed. The whole thing is bad. You get the story your child's about to die and yet two months later, thank God your child is still here, but you're worried about French 101 or English 101. As a parent you should not have that battle.

In contrast to what was expressed by others, participant 2 found difficulty in balancing the communication aspect. People were interested in what was going on and were worried, but she did not want to talk about his condition all the time. Therefore, the solution was creating a Facebook page. As such, people had the option of updates without constantly bombarding the family. Participant 4 had the primary concern of ensuring that her son was not held back because of his illness and excessive absenteeism.

Interview question #28 -29: Did the process of the transition have any impact on your child's condition and did your child's school have any programs for students with chronic illness?

The majority of the participants felt that the transition process impacted their child's condition. However, the reason for the impact varied. Participant 1 said:

> lost his vision every day for weeks before he left [name omitted]. I believe this stress was aggravating his illness. It got so bad that he was sent to school in a cab. Sometimes he would get to school and he could not see to get out of the cab, and The cab driver would have to walk him up to the door. We do believe in hindsight, that the way he was treated made his illness worse.

Participant 4 expressed the difficulty of transition as a result of brain fog from chemo:

> He did struggle, he knows when he can't get it, he can't get 3 x 3, just because he is so frustrated, he will cry. He will say, I don't know why things aren't working. He has to learn to reset, and the teachers have to say to him – it's okay, just walk away. I think he has got a little bit better with that. We are very honest with him, we tell him everything, the hospital tells him everything, he signs his own consent, understands his chemo, he knows all the drugs. He knows his life

> expectancy, he knows everything, because it’s his body. We let him read his neuropsych report, why things are not working. Because it’s not his fault. So, as long as he knows that, then the emotion gets kind of pulled out of it.

Social issues impacted the transition process for participant 7’s child to the extent that she did not want to return to school. She complained of always feeling like an outsider, because she could not keep up with the academics and/or the physical demand of navigating through out the school building. Participant 8 felt there was a negative impact because her child refused to wear a face mask to school, he was bullied whenever he wore one. She also felt that the school failed them because her son was taken outside in 90-degree weather, which exacerbated his condition, failed to use sanitizer in the classroom, or required him to wear his mask in class. Participant 9 believed the transition process had a negative impact, strictly because it affected his daughter mentally, and that affected her ability to heal.

In contrast to the other participants who felt the impact of the transition process negatively impacted their child, Participant 3 believed there was a positive impact. She believed it made her son fight harder, “because there is anxiety associated with his illness, whether it is specifically linked to the school work or the friend connection or just the illness itself. It’s hard to determine.”

With regard to responses to whether programs for student with chronic illness were available in school, 80% of the participants indicated there were no programs available or they were not aware of them. On the other hand, comments from two participants indicated they felt the 504 Plan and Homebound were the equivalent of a program for students with chronic illness. Although they do not specifically cater to students with chronic illness, they felt it has provisions that allow students to continue their education through accommodations and modifications.

Interview question #30-31: Did you do any research on transition strategies and your options as a parent? Is there anything in the transition process that is missing or should be added?

The majority of the participants responded that they did not conduct any research on transitional strategies or options. However, participant 4 mentioned that her research was conducted years ahead of time, as result of her other son who was diagnosed as hearing impaired. She detailed how she was educated on the art of advocating. The fact that you should remove all emotion from conversations, as well as the term "you" in written documentation to prevent the feeling of pointing. Participant 9 simply stated, "We researched the 504 Plan and we researched the potential of doing Homebound." Participant 1 provided more detail on her experience:

> Yes, I tried to get help through lawyers and legal services. I tried many things to get assistance to help me with [name omitted]. Unfortunately, when your money tied up and trying to get your son healthy, you do not have the money to invest in going after a district to get them to do what they should do. So, the fact that he transferred to [name omitted] was the best thing that happened to him. I didn't have to fight for my rights as a parent with a kid who needed accommodations. They were willing to abide by the ADA laws and give him what he needed.

When answering the question if anything should be added or is anything missing from the transition process, surprisingly, several participants did not feel that anything was missing or should be added. Other participants were not in agreement. Participant 1 felt that a counselor should have contacted and evaluated her son, so that options could have been made available. Participant 2 thought that education for teachers and students regarding her son's issues would have been helpful. Participant 3 stated:

> I would have felt a little more secure if there were an outline. So, I didn't feel like we were writing the book, because I felt scared that nothing was written, so I did not know if we were doing what we needed to do. So, I was saying "what do we need to do?" and they were saying to me "what do you need for us to do?" And finally, it all came together, but in the beginning, it would have been nice if there was some sort of outline to follow.

Participant 4 was adamant:

> I think kids who are going through cancer treatments which is chemo or radiation, there needs to be a 504 or IEP, and there needs to be a medical plan that is written on top of it…there really should be an in-service medical plan. When you have a child that's going through something that is so dramatic, that is taken them out of their setting and altering them, and then they are going to eventually get better and come back. So, it's a part-time thing. That in-service is huge. It should be required that a hospital representative or somebody in that aspect with the parents sit with those teachers to have that one-on-one session…that is critical.

Participant 5 believed that follow-up and a Child Life Specialist is crucial:

> The following-up with parents is so huge, because we have so much going on and so much information being thrown at us. That trying to help our child transition into school with a chronic illness and dealing with everything else and tying to

> remember everything that they want us to know and want us to do in regards to school. It feels next to impossible. So, what if you forget something, that you don't remember to sign this form. I don't know how to resolve that, except making sure you have an advocate at the school…just having someone to help get you through the process. They have a Child Life Specialist in the hospital, so I wonder why they couldn't have a Child Life Specialist in the schools.

Participant 9 made the simple suggestion that each school or district employ a subject matter expert.

Interview question #32-33: How has your family and friend support system helped with transitioning child back to school and who was the most effective supporter in your child's transition process?

The recurring theme of all responses were that family, friends, and the cancer community provided lifesaving support needed when caring for a child with a chronic illness. It was not only expressed as lifesaving, but family was the driving force for encouragement, emotional support and meeting transportation needs for numerous doctors' appointments. Participant 1 commented:

> My family is a lifesaver, my dad takes him to all of his appointments at the Psychologist. I take him to all of his medical appointments and hospitalization. My father and I switch off with the hospital. Having retired parents allows my father to have time to deal with him and he's very patient, so he does very well with him and it's been very helpful. They have been very supportive … as well as with my daughter.

Participant 3 was extremely grateful when expressing the following:

> It’s everything, I do not know what we would have done. They have helped in every single imaginable way. My family, friends, and support at his school is everything to us. The support at his school, I consider them to be our family and friends, because through this whole process that is who made this all work. We will be forever indebted to these people. They are what made us not go crazy. They showed more love to us, we are Christian people, so I believe that the common thread is God, and their empathy towards us, and love is just what has made my child do so well. Because if we didn’t have that, I think that we would be lost. The out pouring of generosity towards my entire family. That meant everything.

Participant 6 primarily received help from friends:

> They have been wonderful, because I have needed my friends as far as picking up or dropping off. The friends and parents at school have been making sure that they have been calling if the kids are sick, they have been helpful there. Also, the teacher will call me and let me know if somebody is coughing and we decide what to do. They make the effort to make sure all students hand sanitizer when they walk in the door…the parents have been great with setting up play dates and bringing them to the hospital to visit Ari. So, she has some social interaction. We have been very lucky, because they have been very active getting other parents involved.

The question of who was the most effective supporter in the transition process, yielded titles of a variety of individuals who were in contact with the child or acted as an advocate. The majority of the titles included school personnel, be it Homebound, Special Education, General Education, or Vision teacher. Participant 1 felt that the education advocate Edna Campbell was without a doubt the best thing for her son. Participant 2 identified the principal, as well as the teacher as being effective. Participant 8 felt that the school nurse and secretaries' actions met the needs of both she and her child. Finally, participant 7 indicated that the Guidance Counselor and her mother should be credited with being the most effective supporter.

Additional Comments

Additional comments made were significant to the individual participant. For example, Participant 1, expressed disappointment over not qualifying for services of an Education Advocate, because of income. Participant 4 spoke on the importance having an advocate; that "everybody needs somebody on the outside to fight your fight with you." Participant 5 hoped that by speaking with other parents and exchanging ideas, the conversation would elicit change that will help other students with chronic illness in the future. Participant 7 was concerned about the lack of empathy, support, and love for parents who are having a difficult time raising a child with a chronic illness; believed that the school process was numbers and money driven, without real concern of what is best for the student. Participant 8 suggested that each parent complete thorough research on the school process and your legal rights as a tax payer. Finally, Participant 9 stated, "There needs to be a lead for every school district;" believed that the devastation of the illness on the child itself was too much, and that parents should have someone to assist with the integration of the transition process.

Health Professional Interviews

The other group of participants interviewed were the Health Professionals. They are woven and involved in the day-to-day actions and contribute to coordinating quality-of-life functions of students with chronic illness. Therefore, involvement in the study provided data that ultimately added insight into this research.

Interview Question #1: How do you define chronic illness?

All Health Professionals (HPs) were in agreement that chronic illness is a long-term condition. HP 1 stated that “it’s something that doesn’t have a quick easy cure, and they need care for a significant amount of time.” HP 2 commented that “it’s a lifelong condition that effects the patient’s ability to function within society.” HP 3 provided a detailed response:

> I define chronic illness, first there has to be documentation from the physician, so I would be looking at medical records from the doctor stating what the condition is. From there, it would let me know what type of services that individual would need and that we are looking at long-term, not something that’s going to go away in a week. We are looking at something that you’re going to live with the rest of your life.

HP 4 explained that “chronic illness is something that’s ongoing. It does not necessarily have a beginning or end date.”

Interview Question #2: How long have you provided services to students with chronic illness?

HP 1 has provided services for 15 months, HP 2 and 3 for six years, and HP 4 has provided services for three years.

Interview Question #3: What percentage of students are able to return to school?

Three of the HPs responded that 80% - 100% of their students with chronic illness were able to return to school at some point. HP 1 stated, “We try to have all of our kids go back to school. They might miss a short period of time or even sometimes a little bit longer, but I would say the vast majority return to school.” HP 2 said, “Our goal is hundred percent always…so I would say 80% are returning to full functioning.” HP 3 commented that “all students that I have worked with, with chronic conditions have returned to school with the exception of one student.” HP 4 was not comfortable with providing an estimation.

Interview Question #4: What are the expressed concerns of the parents, as they transition their child back into school?

The recurring theme within the responses was the parents concern over appropriate accommodations being made available to the student. What type of accommodations, would be made, how it would be communicated and if the accommodations be uniformly administered in each classroom? HP 1 stated:

> (I) would like to make sure that appropriate accommodations are made. So, a lot of our patients have accommodations such as; being allowed to have water at their desks, being able to go to the bathroom without penalty, not having to wait until it’s the assigned time to go to the bathroom. It there is an elevator key, making sure that the child can have the elevator key so that they can

> go from floor to floor without having to use the steps.

Other emphasized concern of parents was centered on student absence, whether it be for illness or scheduled or unscheduled doctors' appointments. What accommodations would be made and/or would there be additional assistance available.

Interview Question #5: What supports do you offer?

Responses of the HPs varied in this area and was primarily based on the need of the student. For instance, HP 1 spoke of a resource of an educational consultant that is offered to students who receive services through the cancer center. The consultant conducts a comprehensive set of neurocognitive testing.

> It looks at the social emotional realms as well as intelligence testing and academic achievement. So, once he has completed his testing…he writes a very lengthy report. It's usually about 40 pages, so it's a very detailed report. Then he will have what is called a readout, where I attend with the parents and him. And he goes over all of this information. And he explains it to the parents and I take those notes so that I can then pass that on to the appropriate person at the school …this is another part of what this position offers, is just facilitating that relationship between the educational consultant and the school.

> HP 3 emphasized
>
> the concept of team work as a foundational aspect of the process:
>
> A lot of support. I mean I work continuously with the counselor and I work with the social worker so we work as a team. So therefore, we all know what's going on and I include the family care specialist because she is also a part of that team and the secretary. So, it's a big support team,

> so, we make sure because if the secretary is getting a phone call she knows to let me know that the mom is on the phone and the call gets transferred to me. So, we all work as a team and we are looking at where our pieces of what we can do as a team fit to support that family.

HP 2 spoke of the services offered to students by two teachers who are on staff at the medical facility:

> We have two teachers that work here that really help facilitate the school Piece. So, that's kind of the main part that those teachers work to integrate The kids back in the school. And they work with the teachers to get them on Homebound, if they are eligible for homebound services and make sure they're getting their homework if they're missing, so our teachers can help them with their school work while they're here.

HP 4 spoke did not indicate that there were any special resources available, but spoke to the effect that support is offered in the form of assistance regarding any concerns that are brought to their attention.

Interview Question #6: What reoccurring issues present themselves as students attempt to transition?

Feedback to this question yielded different responses. HP1 spoke of several students reporting that they are having processing and memory issues and the inability to focus. This is one of the may side effects of chemo that has routinely been described as chemo brain. HP2 made the brief comment that medical complications prevent students for participating in daily life activities is a recurring complaint. HP3 commented that students were concerned about the confidentiality of their condition. "The biggest problem they have is they don't want their friends to know that they have diabetes, so therefore, they're not always compliant with the treatment…so that means that I may have to go down to get them." HP4 recounted the concerns of students who have hidden chronic illness, being expected to perform the same as healthy students. Because they do not appear ill, accommodations may not be honored.

Interview Question #7: When personnel from the school system contacts you – what type of information are they seeking?

Feedback from HPs were evenly split. Half of the HPs commented that inquiries from personnel were primarily centered on expectations. They were interested in what to expect and how to effectively accommodate each student to remain in compliance. HP1 stated:

> They definitely like to have a clear idea of what to expect. They want to know the phase of treatment, because a lot of your kids are receiving treatments in phases…and they also want to know what should they look out for, like fever and things…I feel like they are very largely supportive, that they want to make sure that they are taking care of this person, but I think they are just a little scare at times.

The other HPs agreed that information frequently sought was centered on the student's condition. The intent was to have the student return to school at least part of the day if at all possible. HP2 said, "They are mainly just asking what their medical condition is and what limitations are they having."

Interview Question #8: Based on your experience is there a primary age group that has more/less challenges transitioning back to school?

Half of the HPs believed that high school students had a more challenging time transitioning back to school for various reasons that include the social, appearance, and workload challenges that elementary students may not have awareness of.

HP1 explained:

> I feel like those high school kids, their social life is such a huge part of their life right now. And to be isolated from their friends because they're here (hospital) all the time, they are missing out on things…going back to school bald and appearances are so important in high school…usually the workload is pretty challenging at that point and they can be a little bit stressed….so I feel like they have some added layers of challenge.

HP 4 felt that elementary students dealt with more challenges. However, in contrast, HP 2 believed that challenges were not contingent on the age or grade level, but the chronic illness that the student was faced with. "I wouldn't say anything about a specific age, it really depends on what the medical conditions is, how willing the family is able to help motivate them to keep their studies up."

Interview Question #9: What perceptions do you think students with chronic illness face?

Over half of the HPs comments were relative to perceptions being based on the appearance of the student. HP 2 felt that students were targets for being bullied, because they looked different, did not have hair, were thin, and needed assistance getting to and from class. According to HP 3 the way the student appears has a major impact on perception. "depending on what the disease is, it could be body image because it can affect the way they look. They don't look like other kids in the building." Again, HP 4 lamented the sentiment that appearance reinforces perception of others when it was stated, “I think they face the perception if they don’t look sick that they’re faking. I think they face the perception of…you really can do this.”

In contrast to comments made by the others, HP 1 hoped that students with chronic illness are perceived as being “strong brave warriors. And I think in many ways they are. We hear that a lot, that people just admire the strength they have to get through these situations.”

Interview Question #10: Have you participated in any focus groups on the issue – tell me about your experience?

Half of the HPs had not participated in a focus group at all. The other half participated in a focus group that was healthcare related, however, it was not specifically related to chronic illness. They were focused on issues that could lead to health concerns, such as traumatic trauma and other healthcare concerns.

Interview Question #11: What should parents do to ensure that transitioning the child back to school does not exacerbate their condition?

The common theme amongst all the responses was communication and listening/adhering to physician orders. Communication was expressed as the most crucial aspect of minimizing stress in the transition process. HP 1 stated:

> I think we just need to communicate clearly with the schools as much as we can predict what to expect, and to make sure that they understand how their accommodations can help impact the student. I mean, we don’t want, for example, a child who is maybe less likely to complain at school, to not be feeling well and, you know we want those teachers to kind of pick up on things. So, I think just

> communicating what their child's personality is and then what they likely might see making sure that school understands that.

HP 4 believed that communication was the key factor:

> Communicate as much as possible with the administration, with the healthcare professionals. Engage the doctors and hospitals, to support them in their transition back and just be very clear and available as well as once the child starts to feel better. Continue to call the schools, continue to stay connected and know what your rights are.

The other issue of importance was listening and following physician orders. HP 2 was blunt:

> Listen to the doctors. The doctor knows the family, knows the patients medical needs and how they could potentially take on school during this time. So, I think they should definitely rely on the doctor…I would say not to rush anything, but sometimes it's nice to have the child go back to school because they get to feel normal.

Interview Question #12: As a health professional, what do you recommend that parents avoid?

Communication avoidance was the central theme of most responses. HPs stressed the importance of providing feedback as well as keeping the lines of communication with educational staff fluid and accurate. On occasion, students may appear to be in a bad mood, due to circumstance attributed to issues at home. Parents may avoid communicating or making school staff aware of those issues that are considered private to the student. As such, it is difficult to effectively resolve issues that may present themselves at school, when vital information is withheld. HP 3 explained “I think they need to be honest with the staff and to let us know how they are feeling, because a lot of times they may have guilt.” HP 4 stated they should “avoid not communicating with the administrators or the health professionals that you are dealing with.” HP 1’s comment was in alignment with the others, “avoiding the lack of communication. I want them to communicate with the schools so they can have the full support of the school. So, avoid not sharing information with the schools.”

Interview Question #13: What barriers do you face?

There was not a recurring theme for this question, responses were varied. For instance, HP 1 simply stated that the support system was excellent and there were no barriers. While HP 2 felt that there was not enough time to coordinate all of the seasonal projects due to the workload. HP 3 stated that “parents aren’t always cooperative unfortunately. Especially with my diabetes students. Sometimes they are not very cooperative and they don’t bring supplies and I don’t know how I can treat if I don’t have supplies.” Finally, HP 4 indicated money is the barrier to providing resources needed to meet student needs.

Interview Question #14: What does an effective transition plan include?

HP 1 and 2 felt that it was important that an annual meeting be held to develop a plan. That all team members understand the plan, homebound services be outlined, and a 504 Plan be completed, if necessary. HP 3 discussed the concept of buy-in; felt it was necessary that the parent and the student buy into the plan or it would not be successful. HP 4 stated that “it includes the diagnosis, it includes what the anticipated needs are, it includes what the follow-up is going to look like…communication, ongoing communication and effectiveness."

Interview Question #15: What supports do health professionals provide and how are they communicated?

The recurring theme with regard to supports provided was communication and facilitation. All HPs unanimously agreed that communication and facilitation were the most valuable support provided. They provide detailed information to parents and students on process, procedure, direction, and coordination of the communication process to include; acting as a liaison, making contacts, and completing paperwork. Information regarding resources is provided both verbal and/or written form.

Interview Question #16: What is the process for following up – or do you wait to hear from parents?

The recurrent theme is follow-up is parent driven. HP 1, 2, and 4 indicated that follow-up was contingent on the needs of the student, once the parent initiates contact and request assistance. HP 3 in contrast, explained that a call to each parent is initiated to follow-up on the condition and outcome from the initial meeting. The intent is to engage the student and educate the parent.

Interview Question #17: What do you recommend that schools do to accommodate the transition of the student with a chronic illness?

Reaction to this question was varied. HP 1 believed that it was important for educational institutions to listen to the recommendations from the physician. It was also felt that being proactive in following up with the student could alleviate potential problems. HP 2 focus was being sensitive and understanding that each child situation and/or illness would be different. HP 3 felt that it was crucial to follow the established process. To ensure that there is “continuity that’s going on…we all have to follow the same process.” HP 4 believed that awareness was important and that any department that provides resources to students with chronic illness be informed, “Everybody is aware, I think awareness is important.”

Summary

In Chapter Four, interview transcripts were summarized. Commonalities were outlined and noted, and when appropriate, direct quotes from interview responses were used to support transcript summaries. In instances of dissention, interview responses were shared to describe the circumstances surrounding the perception of the interviewee and note areas of differences for the perceptions of the participants.

Chapter Four also included emerging themes from data collected. The themes were supported with noted commonalities among the study participant responses and are further discussed in chapter five. Qualitative studies rely on emerging themes from the data to determine research conclusions (Creswell, 2013). In addition, recommendations for future research on this topic are discussed, as well as a final summary containing an overview of the major components of this study.

Chapter Five: Discussion

This chapter provides a discussion of results from the study of Parental and Health Professional Transitional School Strategies for Chronically Ill Students. The chapter discusses the conclusions reached as a result of interviewing nine parents, four health professionals, and conducting focus groups with participants from the St. Louis Metropolitan area. The data collected through one-on-one interviews was valuable, as it provided clarification to additional areas that should be explored. Although one-on-one interviews are helpful, they do not provide enough rich data or dialog necessary to solidify findings and/or recommendations. It should be noted that initial one-on-one interviews are a stepping-stone and helpful in preparation of the focus group. Data from the focus group provided addition detail, perspective, and more confidence in reporting findings. In addition, interacting with parents who had children with different chronic illnesses, health professionals who interacted with those children, hearing and discussing their experiences provided clarity to the major findings to be discussed. Example being, after parents and health professionals shared personal experiences, one comment would elicit additional input from other participants, and they would continue to exchange an array of opinions, real life experiences and true momentum was gained. Completion of data collection was achieved through the focus group, with the outcome of rich data being retrieved. The study's intention was to examine the experiences, perceptions, assessments of transitional school strategies and compare them with health professionals' resource availability and recommendations. A qualitative study provided information of parents and Health Professional and their portrayal of transitional school strategies for Chronically Ill Students.

Results provided an in-depth view of perceptions of the transition process. The conclusions are grouped by major findings: 1) Lack of communication with the major parties and/or the breakdown of communication among the major parties. 2) A care team is needed to be functional and effective that includes peer entities, hospital, school, family and community. 3) Better informed entities; health professionals need to do a better job in conjunction with parents/guardians in getting medical and health information to teachers and other educators. The experience of the chronically ill student and the care has unique, but universal features.

The purpose of the study was to ascertain and provide effective and adaptable transitional strategies for the unique needs of the chronically ill student. This chapter will discuss limitations and recommendations for transitional strategies for Chronically Ill Students.

Research question one: In what ways do parents and health professionals perceive the quality of transitional school strategies available to them for Chronically Ill students?

The data revealed contrasting opinions. Several of the participants provided positive feedback regarding their experiences with the educational system, once informed of a current or ongoing medical condition or issue. Satisfaction is expressed in terms of response time upon notification of a student with a chronic illness. Due to the unexpected and surprising diagnosis of a student’s illness, the parents were facing a situation of the “unknown;” therefore, they did not have any concrete expectation from the school, and were pleasantly surprised with the immediacy of response, to the need of the child and family. General positive feedback was attributed to luck. Luck in terms that the school had gained valuable knowledge and experience, while providing education to previous students dealing with a chronic illness. It was felt that other students with similar situations, through trial and tribulations had prepared the school system to effectively deal with new and potential cases of chronic illness.

Empathy was another positive reaction from the perspective of the parent. Positive expressions that the school was receptive and attempted to accommodate the needs of the student while providing quality educational services. Quality of responses were reflective of actions that involved instituting an individualized, humanistic approach to meeting the need of the student. Open, two-way communication was used to identify, access, train, and institute classroom protocol utilized by healthy students when the student with the chronic illness was healthy enough to attend class. Actions, such as consistent hand washing, sanitizing of general use items, and frequent hydration breaks were necessary and openly accepted and respected. It also served as a method of teaching healthy students how to demonstrate compassion towards others when they are faced with an unwanted life event.

In contrast to the positive experiences, factors attributed to the perceived quality of transitional school strategies for Chronically Ill Students. Data revealed that there were feelings of disappointment, as well. Participants expressed the sentiment that reception and reactions of the school to their child’s condition was disappointing. Results yielded concrete examples that school personnel were receptive, but there was no real understanding, and instances of receiving a berouged of paperwork to complete without any directions or orientation. Participant 8 believed the school was good initially, but felt as time passed, the teachers did not read or follow protocol, because it was just too much to do. A parent emphasized that school staff were clueless; however, they talked as if they were going to support the student, but as time passed it became clear that they did not know what they were doing or the correct protocol to follow. Data also revealed that Health Professionals shared similar concerns, of students receiving appropriate accommodations as they transitioned back to school. The accommodation piece is key to student achievement. It eliminates feelings of frustration, being defeated, and ultimately the students' emotional and/or physical withdrawing in terms of focus, when appropriate accommodations are provided, followed by adequate education.

Research question two: What supports have parents received from parental and/or family groups that have assisted in transitioning Chronically Ill students back to school?

Data revealed that the most effective supporter in the transition process, yielded titles of a variety of individuals who were in contact with the child or acted as an advocate. The majority of the titles included school personnel, be it Homebound, Special Education, General Education, or the Vision Teacher. It was expected that individuals within the school setting, who routinely interacted with a student with a chronic illness and thereby being aware of the student's condition, would act as an advocate to ensure the needs of the student were met, and ultimately be recognized as a supporter. The recurring theme of all responses were that family, friends, and the cancer community provided lifesaving support needed when caring for a child with a chronic illness. It was not only expressed as lifesaving, but family was the driving force for encouragement, emotional support and meeting transportation needs for numerous doctors' appointments.

Caring for a child with a chronic illness is extremely difficult without the added stress of keeping pace with educational requirements and responsibilities. When families are faced with this type of dilemma a solid support system who can assist with daily tasks of providing the necessities of the student, to include physical, emotional and in some cases financial support, can mean the difference between night and day. The network/unit is necessary for the family to sustain forward moving progress. As the old Adage states, it takes a village to raise a child.

Research question three: What are the perceptions of each parent and health professional regarding the challenges that Chronically Ill students face in the school setting?

It is an expectation that any student who has a chronic illness will encounter some difficulty as they transition to the school setting. However, the type and the severity of the challenge can vary from student-to-student contingent of the type of illness. Data from the interview and focus group revealed that perceptions of the parent and health professional were in alignment in a few specific areas.

The perspective of great concern was the social-emotional aspect and challenges associated with isolation in the school setting. The concern was that the student was socially disconnected from their peers; therefore, they had little-to-no social life. The perception was not that it was intentional, it was just that the chronically ill students were constantly dealing with illness and did not have time to develop connections or bonds with their peers. It was also shared that students found it difficult to comprehend and understand many of the social issues that their peers complained of. They were dealing with day-to- day stressors of life-or-death issues, and their peers were concerned with trivial issues associated with their appearance or social fads. Students with chronic illness routinely lamented that they just want the existence and life of their healthy peers.

Data also revealed that chronically ill students' inability to control the impact of their heath on any given day was another factor that created hardship for students who were transitioning back to school. More often than not, they were pushing through the discomfort and pain of the illness, as well the side effects of medication from treatments. From the focus group and interview, it was shared with the researcher that students faced the physical challenge of not being able to keep up with same-aged peers on the playground or navigating through a multilevel school building within the allotted passing time. This only exacerbated the level of frustration that the student was feeling, which not only negatively fueled the social emotional piece, but ultimately impacted the student physically, due to additional anxiety and stress when they were already exhausted. Many students are unfortunately placed in a position of waiting to be helped and/or become a spectator to many activities, as they are physically unable to participate.

School absenteeism was another reoccurring challenge that chronically ill students understandably cannot avoid, as indicated during the interview process. As revealed in the focus group, the Health Professionals agreed that a chronic illness is a long-term condition that does not have a quick or easy cure. It is a lifelong condition that routinely effects the patient's ability to care for themselves or greatly limits their daily function. One hundred percent of the participants indicated that their child had missed a significant amount of time from school, due to their illness. Some instances were continuous blocks of time, and some were consistently sporadic amounts of time missed. One parent lost track of the time the student missed, as it was so significant. And in an extreme case, one parent reported the student had missed over a year of school as a result of their illness, side effects, and appointments.

Research question four: What are the differences and similarities between parental and health professions transitional school strategies for the Chronically Ill student?

Surprisingly, data revealed that there was unanimous agreement in terms of similarities for both parental and health professional strategies to transition students back to school. Communication was the key factor. Participants believed that someone within the school system should contact the family as a follow-up, to check for understanding of options available and to ensure that the educational, emotional, and physical needs of the student were being met throughout the transition process. Another participant added that the communication piece required documentation to ensure that all items discussed and outlined can be revisited and reviewed throughout the school year for compliance. Other participants were in agreement that a person in the position of a "Child Advocate or Child Life Specialist," who would spearhead and case manage each student would be helpful; thereby, ensuring that the vital piece of two-way communication, collaboration, and outcomes are achieved.

Review of feedback from Healthcare Professionals indicated that they were in agreement that there were more similarities than differences in regard to transitional strategies. They all believed that the most valuable support is communication and facilitation. According to the health professionals, use of effective communication strategies in-person, verbal or in writing would provide detailed information to students on process, procedure, direction, and coordination of services. As such, the health professional in conjunction with school personnel would act as a liaison, make connections/contact and assist with completion of paperwork.

The differences in opinion were in reference to who would assume the lead role in the process on communicating and facilitation of information to the various entities. The participants suggested someone within the school setting be responsible and the health professionals did not comment either way. However, they were agreement that someone should assume the role as the lead.

Limitations

This study was conducted in one state, within a metropolitan area, by one researcher. Having a larger sample in a different demographic area may have possibly provided a different representation and outcome. It is possible that securing a larger number of participants may have provided the researcher with additional data and lived experiences that varied from those involved in the sampling studied.

Recommendations

The literature review in Chapter Two focused on several studies that examined children with chronic illness, support systems, and strategies to effectively transition those students back to school. This dissertation discovered connections with the literature review. The following section will discuss the connections between what was learned during the interviews and focus group, what was reviewed during the literature review. Conclusions were drawn for each research question. A discussion of the key findings is provided below for the factors and characteristics of the research, as well as recommendations.

Research question one: In what ways do parents and health professionals perceive the quality of transitional school strategies available to them for Chronically Ill students?

The data revealed varying perceptions from participants and health professionals. There were participants who expressed satisfaction with the manner in which they were treated during the transition process. It was believed, that at that particular moment the needs of the child were being met. Therefore, the perception of the process was positive. It is more advantageous if the perception of the transition process was universally perceived (regardless of the school district) as positive, thereby ensuring the needs of the student were met. However, because key factors to achieve a positive outcome involve a team approach, there are occurrences when key stakeholders functioned independent of each other, because there was not clear understanding of established procedure or protocol; ultimately, resulting in failure to wholistically meet the need of the student or the expectations of the parent. Literature along with research agreed that effective transition strategies rely on careful planning of the multidisciplinary team that should include the parent, medical and school personnel (Shaw & McCabe, 2008). Most students with chronic illness will not need specific special education placement; however, they will require coordinated school interventions to maximize attendance and facilitate educational and social growth (Sexson & Madan-Swain, 1995). In reviewing the responses, neither parent, nor health professional, indicated or disclosed that a formal multidisciplinary team consisting of members from both the school entity and the supervising healthcare professional gathered to discuss or implement a comprehensive plan to meet the educational needs of the student.

Research question two: What supports have parents received from parental and/or family groups that have assisted in transitioning Chronically Ill students back to school?

The recurring theme of all responses were that family, friends, and community provided lifesaving support needed when caring for a child with a chronic illness. It was expressed as the driving force for encouragement, emotional support, and meeting transportation needs for numerous doctors' appointments. Ties to literature revealed a three phased approach to transition that outlined needed support from several entities. Madan-Swain, Katz, & LaGory (2004) noted phases that overlapped the sentiments of the recurring theme of family, friends and community. Phase one involved initiation of community supports (homebound and peer education), phase two involved hospital-school communication and phase three involved hospital, school, family follow-up communication.

The responsibilities and requirements of caring for a child with a chronic illness is difficult enough, without the added stress of keeping pace with educational requirements. When families are faced with this type of dilemma, a solid support system who can assist with daily tasks of providing the necessities of the student to include physical, emotional, and in some cases financial support, can mean the difference between night and day. The network/unit is necessary for the family to sustain forward moving progress.

Research question three: What are the perceptions of each parent and health professional regarding the challenges that Chronically Ill students face in the school setting.

Chronically Ill students face numerous challenges daily, as they attempt to function, navigate, and participate in routine life activities. Symptoms and effects of their illness and treatment regimen cause chronic absenteeism. There was a connection to literature and comments during interviews regarding absenteeism. The literature, along with research, agreed that chronic absenteeism is unavoidable, and is a routine factor of students with chronic illness. Kaffenberger (2006), noted that approximately half of all children diagnosed with chronic illness were absent from school more frequently, sometimes for extended periods of time, and therefore may require educational adaptations. This was confirmed in the study by the participants and health professionals. A parent expressed social disconnection from peers, as being a challenge. However, it was not intentional on the part of the students' peers. It was attributed to frequent absenteeism and the inability of the student to develop bonds and connections to others. Another common theme from research was the challenge of the "expectation" that the ill student would be able to physically and academically keep pace with healthy peers, when they were able to attend school. The perception is, if a student is well enough to attend school, then they should be able to function normally. Unbeknownst to their general peer population, students with chronic illness make exhausting attempts at keeping the signs of illness out of sight and under control for the purpose of being perceived as normal. Wiener & Srauss (1997), viewed normalization as enabling individuals with a chronic condition to resume their pre-illness roles and responsibilities, such as finding ways to live, or pretending to live a normal life while coping with symptoms and minimizing the disability. The expectation of being and/or consistently acting normal while living with a chronic illness is physically challenging, and emotionally draining. This is the daily reality of a student with a chronic illness.

Another notable issue expressed during the research was the perception that chronically ill students do not receive the same level of academic attention as their healthy peers. Some participants expressed disappointment that their child did not receive the full extent of academic resources, as staff felt that the needs of the ill student was too much trouble, and that they were ill prepared and lacked necessary training to effectively deal with the needs of the ill student. In the literature review, Kliebenstein and Broome (2000), noted that school personnel are not well informed about the illnesses experienced by many children in the classroom, and usually received little-or-no training to deal with the issues of the student.

Research question four: What are the differences and similarities between parental and health professions transitional school strategies for the Chronically Ill student?

The intent of both parent and health professional is to create, provide and implement a care plan that is comprehensive in nature, minimizing stressors to chronically ill students for successful transition back to school. The primary similarity of transitional strategies from both groups were expressed in terms of communication. Review of feedback indicated that any form of communication (letter, email, text, phone call), was useful for the purpose of coordinating resources that would benefit the student. It was perceived as taking proactive measures to ensure that the student was treated equitably in spite of their illness, limitations, or circumstance. One parent expressed appreciation of having several medical professionals working as a team, providing crucial information for the care of the child, meant that all areas were covered. Health professionals were in agreement that a team approach of collaboration and continuous communication was necessary for an effective, seamless transition to school. Connection with the literature, along with research agreed that communication amongst a multidisciplinary team is crucial. Shaw and McCabe (2008) noted that multidisciplinary teams should continuously evaluate and communicate student transition progress. As such, any unusual or sudden changes in attendance, academic performance, or social adjustment can be addressed quickly. There were not any noted comparable differences stated during the interview or focus group. Research indicated that the driving force was the need for current, forward moving feedback amongst both the parental group and healthcare professionals in this study.

Future Research

The scope of this study examined parent experiences, perceptions, and assessments of transitional school strategies to compare them with health professionals resource availability. Consequently, students with chronic illness impacts those who routinely interact with the student. For instance, the teacher is directly affected due to consistent interaction with the student, on good and not so good days. There is little research that exists on how sustained interaction with an ill student affects the teacher and their performance and time management, when the student exhibits academic or medical needs, as well as the mental and motivational impact of teaching an ill student. What are the psychosocial struggles of the teacher and how can schools better prepare them to teach the student, while minimizing the psychological and emotional drain? Another research consideration is the perception of the chronically ill students (gender based) in high school, with regard to transition. What would they have preferred in the process, which of their needs do they feel were or were not met, and how can they be involved in advocating for themselves? Lastly, the research should focus on students from either public or private schools.

Conclusion

As the incidence of students with chronic illness continues to rise, they will continue to have special educational needs that must be addressed. This includes their need to be accepted by peers, how they respond to the behavior of others, various medical condition restrictions, and the complexity of the communication stream among key players.

The parent, health professional, and the educator must make a concerted effort to establish a structured multidisciplinary team. The role of each team member is to strategically assist in adjusting school demands, address academic progress, and social emotional needs. This can be effectively addressed by development of written protocol that each member is annually trained to understand, as consistent implementation is essential. Finally, collaboration, communication, and corporation among each multidisciplinary member is crucial as they are responsible for integration of services, program implementation and intervention monitoring. The burden of figuring out what to do for students with chronic illness should not be placed on the doorstep of struggling families. Educational and health entities need to proactively support parents, so they can ensure the best educational school experience for students who live with (survive) a chronic illness. It is hoped that the results of this study can be used to assist future researchers, parents, healthcare providers, and employees of the education system in supporting the unique needs of students with chronic illness.

On a final note, parents expressed their appreciation for involvement in the study, as they had never been asked the questions outlined in the research and were grateful for the opportunity to share their experiences, provide recommendations and contribute to the field of study on transitional strategies for chronically ill students.

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Appendix A

Informed Consent of Participation in Research Activities

Lindenwood University - School of Education

"A Qualitative Study of Parental and Health Professional Strategies to Transition Chronically Ill Students Back into School"

Principal Investigator: Iris Robinson

Participant______________________ Contact Info:_________________________

1. You are invited to participate in a research study conducted by Iris Robinson under the guidance of Dr. Robyne Elder. The purpose of this research is to investigate
the strategies to transition chronically ill students back into school.

2. In order to participate you must be a **parent** of a child 18 years or younger identified as having a chronic illness, disease or condition, and be receiving services to transition back to school. Your participation is completely voluntary and your responses will be anonymous.

3. Your participation will involve
   - Completing an, interview, participation in a focus group and signing a consent form.
   - Agree to interview and participate in a focus group at a mutually agreeable location.
   - Agree to allow audio recording of the interview and focus group questions.
   - Answer questions about **parental** transitional strategies and experience of re-entry of a chronically ill child back to school.

4. The amount of time involved in your voluntary participation will be:
   - Interview – One hour
   - Focus group – 90 minutes

   Approximately 8-12 subjects will be involved in this part of the research study.

5. There is no anticipated risk associated with this research. There are no direct benefits for participating in this study. However, your participation will contribute to the knowledge about transitional strategies for chronically ill students and help to improve the process for future students.

6. Your participation is voluntary and you may choose not to participate in this research study or to withdraw your consent at any time. You may choose not to answer any questions that you do not want to answer. You will NOT be penalized in any way should you choose not to participate or to withdraw.

7. We will do everything we can to protect your privacy. As part of this effort, your identity will not be revealed in any publication or presentation that may result from this study and the information collected will remain in the possession of the investigator in a safe location.

8. If you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator, Iris Robinson at (314) 302-1414 or the Supervising Faculty, Dr. Robyne Elder at (636) 9449-4332. You may also ask questions of or state concerns regarding your participation to the Lindenwood Institutional Review Board (IRB) through contacting Dr. Marilyn Abbott, Provost at mabbott@lindenwood.edu or 636-949-4912.

I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy for my records (on request). I consent to my participation in the research described above.

___________________________ ______________________________

Participant Signature Printed Name

______________________________ ______________________________

Signature of Principal Investigator Printed Name

Appendix B

Informed Consent of Participation in Research Activities

Lindenwood University - School of Education

"A Qualitative Study of Parental and Health Professional Strategies to Transition Chronically Ill Students Back into School"

Principal Investigator: Iris Robinson

Participant____________________________ Contact Info.__________________________

1. You are invited to participate in a research study conducted by Iris Robinson under the guidance of Dr. Robyne Elder. The purpose of this research is to investigate
   the strategies to transition chronically ill students back into school.

2. In order to participate you must be a **<u>health professional</u>** providing service to a child identified as having a chronic illness, disease or condition. Your participation is completely voluntary and your responses will be anonymous.

3. Your participation will involve
   - Completing an interview, participation in a focus group, and signing a consent form.
   - Agree to interview and participate in a focus group at a mutually agreeable location.
   - Agree to allow audio recording of the interview questions.
   - Answer questions about **<u>health professional</u>** transitional strategies and experience of re-entry of a chronically ill child back to school.

4. The amount of time involved in your voluntary participation will be:
   - Interview – One hour
   - Focus group – 90 minutes

   Approximately **4-6** subjects will be involved in this part of the research study.

5. There is no anticipated risk associated with this research. There are no direct benefits for participating in this study. However, your participation will contribute to the knowledge about transitional strategies for chronically ill students and help to improve the process for future students.

6. Your participation is voluntary and you may choose not to participate in this research study or to withdraw your consent at any time. You may choose not to answer any questions that you do not want to answer. You will NOT be penalized in any way should you choose not to participate or to withdraw.

7. We will do everything we can to protect your privacy. As part of this effort, your identity will not be revealed in any publication or presentation that may result from this study and the information collected will remain in the possession of the investigator in a safe location.

8. If you have any questions or concerns regarding this study, or if any problems arise, you may call the Investigator, Iris Robinson (314) 302-1414 or the Supervising Faculty, Dr. Robyne Elder (636) 949-4332. You may also ask questions of or state concerns regarding your participation to the Lindenwood Institutional Review Board (IRB) through contacting Dr. Marilyn Abbott, Provost at mabbott@lindenwood.edu or 636-949-4912.

I have read this consent form and have been given the opportunity to ask questions. I will also be given a copy for my records (on request). I consent to my participation in the research described above.

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Participant Signature Printed Name

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Signature of Principal Investigator Printed Name

Appendix C

Interview Questions - **Parents**

"A Qualitative Study of Parental and Health Professional Strategies to Transition Chronically Ill Students Back into School"

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1. What is your child's illness and age?
2. What school district does your child attend?
3. Do you consider his/her illness chronic?
4. When was your child diagnosed and did you seek a second opinion?
5. How long has your child been dealing with their chronic illness?
6. What was you and your child's reaction to the diagnosis?
7. At what point did your child start to be absent from school?
8. Overall, how much time has your child missed due to their illness?
9. Has your child been able to return to school?
10. When the school was informed of your child's illness what did they do?
11. Explain what role and/or support services the school offered to you while your child was absent?
12. Where the options available clearly communicated?
13. What did you think about the transitional strategy?
14. Was the approach or service explained with regard to transitioning your child back into school?
15. Was there a team approach t transition your child back into school? If so, who was involved and what support did they offer?

16. What was it about the strategy that was effective and why?
17. Did anyone follow up with you?
18. Was there a formal system in place?
19. Due to the nature of your child's illness, have you participated in any support groups?
20. If so, what was your experience?
21. How has it helped you?
22. What are your perceptions regarding the challenges that chronically Ill students face in the school setting?

23. What actions/steps did you find necessary to take to transition your child back into school?
24. Did you express your concerns with the school and what actions/resolutions were offered?
25. As your child transitioned back to school, what were some of the social issues/challenges they expressed?

26. What barriers did you have to face?
27. What are the most difficult parts of balancing school and the illness?
28. Did the process of the transition have an impact on your child's condition?
29. Did your child's school have any programs for students with chronic illness?
30. Did you do any research on transition strategies and your options as a parent?
31. Is there anything in the transition process that is missing or should be added?
32. How has your family and friend support system helped with the transitioning your child back to school?

33. Who was the most effective supporter in your child's transition process?
34. Any additional comments?

Appendix D

<u>Interview Questions – **Health Professional**</u>

"A Qualitative Study of Parental and Health Professional Strategies to Transition Chronically Ill Students Back into School"

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1. How do you define chronic Illness?
2. How long have you provided services t students with chronic illness?
3. What percentage of students are able to return to school?
4. What are the expressed concerns of the parents, as they transition their child back into school?
5. What supports do you offer?
6. What reoccurring issues present themselves as students attempt to transition?
7. When personnel from the school system contacts you – what type of information are they seeking?

8. Based on your experience is there a primary age group that has more/less challenges transitioning back to school?

9. What perceptions do you think students with chronic illness face?
10. Have you participated in any focus groups on the issue – tell me about your experience?
11. What should parents do to ensure that transitioning the child back to school does not exacerbate their condition?

12. As a health professional, what do you recommend that parents avoid?
13. What barriers do you face?
14. What does an effective transition plan include?
15. What supports do health professionals provide and how are they communicated?
16. What is the process for following up – or do you wait to hear from parents?
17. What do you recommend that schools do to accommodate the transition of the student with a chronic illness?

Appendix E

Scrip for Visits to Scheduled Meetings and Events to Invite Parents and Health Professionals of Chronically Ill Students.

My name is Iris Robinson, and I am doctoral student in the Lindenwood Educational Leadership Program. I am conducting my dissertation research investigating Parental and Health Professionals Strategies to Transition Chronically Ill Students Back into School. My focus is on Chronically Ill Students as a result of my own personal experience with my daughter who was diagnosed with a muscle cell tissue cancer “Rhabdomyosarcoma,”

My interest is in the expressed experience, perceptions, and strategies that were utilized to transition the student back into school and the impact on the child.

Your participation would involve completing an interview, which should take no longer than an hour, and participation in a focus group about your experiences, which should take no longer than 90 minutes. There are no risks associated with this study and the information you provide will remain confidential and you will remain anonymous. Your participation is voluntary and there is no penalty for withdrawing participation at any time. My contact information is listed on the sheet I am handing out. Please call me if you are willing to participate in the study.

Thank you for your time and consideration, it is my hope that my study will add to the current body of knowledge and assist others who may be find themselves in a similar situation in the future.

Appendix F

Interview Questions – **Focus Group**

"A Qualitative Study of Parental and Health Professional Strategies to Transition Chronically Ill Students Back into School"

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1. Do you think/believe that your challenge or experience with transitioning your child is the same or different than others and why?

2. What are some of the similarities and differences in your experiences?

3. Was communication a problem?

4. Do you believe that empathy was a problem within the transition process?

5. The type of chronic illness varies among participants here, do you believe that a universal transitional strategy will be effective for any type of illness or should they be based on the condition?

*Focus group questions will be dependent on responses from interviews. I intend to frame
questions based on feedback received.

Appendix G:

Differences Between 504 Plans and IEPs

	IEP	504 Plan
Basic Description	A blueprint or plan for a child's special education experience at school.	A blueprint or plan for how a child will have access to learning at school.
What It Does	Provides individualized special education and related services to meet the unique needs of the child. These services are provided at no cost to parents.	Provides services and changes to the learning environment to meet the needs of the child as adequately as other students. As with IEPs, a 504 plan is provided at no cost to parents.
What Law Applies	The Individuals with Disabilities Education Act (IDEA) This is a federal special education law for children with disabilities.	Section 504 of the Rehabilitation Act of 1973 This is a federal civil rights law to stop discrimination against people with disabilities.

Who Is Eligible	To get an IEP, there are two requirements: 1. A child has one or more of the 13 specific disabilities listed in IDEA. Learning and attention issues may qualify. 2. The disability must affect the child's educational performance and/or ability to learn and benefit from the general education curriculum, leading to the need for specialized instruction.	To get a 504 plan, there are two requirements: 1. A child has any disability, which can include many learning or attention issues. 2. The disability must interfere with the child's ability to learn in a general education classroom. Section 504 has a broader definition of a disability than IDEA. (It says a disability must substantially limit one or more basic life activities, such as learning.) That's why a child who doesn't qualify for an IEP might still be able to get a 504 plan.

Independent Educational Evaluation	Parents can ask the school district to pay for an independent educational evaluation(IEE) by an outside expert. The district doesn’t have to agree. Parents can always pay for an outside evaluation themselves, but the district may not give it much weight.	Doesn’t allow parents to ask for an IEE. As with an IEP evaluation, parents can always pay for an outside evaluation themselves.

Who Creates the Program/Plan	There are strict legal requirements about who participates. An IEP is created by an IEP team that must include: • The child's parent • At least one of the child's general education teachers • At least one special education teacher • School psychologist or other specialist who can interpret evaluation results • A district representative with authority over special education services With a few exceptions, the entire team must be present for IEP meetings.	The rules about who's on the 504 team are less specific than they are for an IEP. A 504 plan is created by a team of people who are familiar with the child and who understand the evaluation data and special services options. This might include: • The child's parent • General and special education teachers • The school principal

What's in the Program/Plan	The IEP sets learning goals for a child and describes the services the school will give her. It's a written document. Here are some of the most important things the IEP must include: - The child's present levels of academic and functional performance—how she is currently doing in school - Annual education goals for the child and how the school will track her progress - The services the child will get—this may include special education, related, supplementary and extended school year services	There is no standard 504 plan. Unlike an IEP, a 504 plan doesn't *have* to be a written document. A 504 plan generally includes the following: - Specific accommodations, supports or services for the child - Names of who will provide each service - Name of the person responsible for ensuring the plan is implemented

	• The timing of services—when they start, how often they occur and how long they last • Any accommodations—changes to the child's learning environment Any modifications—changes to what the child is expected to learn or know • How the child will participate in standardized tests • How the child will be included in general education classes and school activities	

Parent Notice	When the school wants to change a child's services or placement, it has to tell parents in writing *before* the change. This is called prior written notice. Notice is also required for any IEP meetings and evaluations. Parents also have "stay put" rights to keep services in place while there's a dispute.	The school must notify parents about evaluation or a "significant change" in placement. Notice doesn't have to be in writing, but most schools do so anyway.
Parent Consent	A parent must consent in writing for the school to evaluate a child. Parents must also consent in writing before the school can provide services in an IEP.	A parent's consent is required for the school district to evaluate a child.

How Often It's Reviewed and Revised	The IEP team must review the IEP at least once a year. The student must be reevaluated every three years to determine whether services are still needed.	The rules vary by state. Generally, a 504 plan is reviewed each year and a reevaluation is done every three years or when needed.
How to Resolve Disputes	IDEA gives parents several specific ways to resolve disputes (usually in this order): • Mediation • Due process complaint • Resolution session • Civil lawsuit • State complaint • Lawsuit	Section 504 gives parents several options for resolving disagreements with the school: • Mediation • Alternative dispute resolution • Impartial hearing • Complaint to the Office of Civil Rights (OCR) • Lawsuit

Funding/Costs	Students receive these services at no charge. States receive additional funding for eligible students.	Students receive these services at no charge. States do not receive extra funding for eligible students. But the federal government can take funding away from programs (including schools) that don’t comply. IDEA funds can’t be used to serve students with 504 plans.

(Understood.org, 2015’ retrieved from https://www.understood.org/en/school-learning/special-services/504-plan/the-difference-between-ieps-and-504-plans)