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Education as a Source of Hope: An Examination of Teacher Beliefs and the Lack of Support for Children with Chronic Health Conditions

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This thesis, written under the direction of the candidate's thesis advisor and approved by the program chair, has been presented to and accepted by the Department of Education in partial fulfillment of the requirements for the degree of Master of Science in Education.

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**Education as a Source of Hope: An Examination of Teacher Beliefs and the Lack of
Support for Children with Chronic Health Conditions**

By

Marissa Schow

A culminating thesis submitted to the faculty of Dominican University of California in partial
fulfillment of the requirements for the degree of Master of Science in Education

Dominican University of California

San Rafael, CA

2023

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Abstract

As survival rates increase, more children with chronic health conditions are returning to K-12 classrooms after receiving medical treatments. Research has shown that many teachers believe that students with chronic health conditions should not have to worry about school while they are going through treatment (Irwin & Elam, 2011; Legislative Alliance for Students with Health Conditions, 2017). Research also suggests that many schools are violating the Every Student Succeeds Act of 2015 by withdrawing students from the district due to chronic absenteeism (Eaton, 2012; Wilkie, 2012). The purpose of this mixed methods study was to explore and examine the ways in which teachers and schools are supporting students with chronic health conditions, as well as the experiences of teachers who have witnessed inequities impacting these students. An initial survey was sent out to elementary school teachers from a local Bay Area school district, in order to examine the relationship between the beliefs of teachers and the level of support for students with chronic health conditions. Three hospital teachers were also interviewed from a Northern California hospital. Data was analyzed through an open coding process to identify themes and patterns. The findings from this study indicate that teachers benefit from shifting their perspectives from a parent centric way of thinking to student centric, in order to understand the benefits of continuing education during medical treatment. Findings also suggest the need for awareness about the normalizing aspects of education in a hospital setting. By identifying the obstacles that are preventing students with chronic health conditions from receiving the education they have a right to, teachers can better support these students during treatment and their re-entry back into the classroom.

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I would also like to thank my third-grade teacher, Mr. Saville. Words cannot express how thankful I am for your support during such a difficult time in my life. The belief you had in me helped me to get to where I am today. Thank you for making me laugh, smile, and find my voice. When you cast me as Oliver you helped to set me on a path towards learning how to use my big voice despite my small stature. You are the reason I am fighting for these kids.

Finally, I would like to thank my mom and brother who have been my constant support system throughout my life. Mom, you have fought for me since day one. You taught me to fight for what I believe in. You have always been there for me, and I am beyond grateful for everything you do to support me as I continue on my path forward. Dillon, thank you for being the first to walk when we were young. You were that push I needed to reach significant milestones and to find that strength I had lost during treatment. You are my best friend, and I am so lucky to be able to call you my brother. I would not be here without your support, Mom and Dillon. Thank you.

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Table of Contents

Abstract	iii
Acknowledgements	iv
List of Tables	vii
Chapter 1: Introduction	1
Statement of Purpose	2
Overview of the Research Design	2
Significance of the Study	3
Chapter 2: Literature Review	5
Misperceptions and Beliefs about Students with Chronic Health Conditions	6
Violations of Educational Laws and Policies	10
Definition of Disability	13
Conclusions	16
Chapter 3: Methods	19
Research Questions	19
Description and Rationale for Research Approach	20
Research Design	21
Data Analysis	25
Validity and Reliability	27
Chapter 4: Findings	29
Vignette #1: Rebecca	32
Vignette #2: Monica	34
Vignette #3: Jennifer	37
Conclusion	42
Chapter 5: Discussion	45

Implications of the Literature	46
Implications for Practice and Policy	48
Limitations of the Study	49
Directions for Future Research	50
Conclusion.....	50
References.....	52
Appendix A - Letter of Permission.....	55
Appendix B - Survey Questions	57
Appendix C - Interview Questions (Magnolia School District)	59
Appendix D - Interview Questions (The Griffin School)	61

List of Tables

Table 1 Survey Results	30
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Chapter 1: Introduction

Students should not have to worry about school while they are going through treatment for a chronic health condition. This belief seems to be the general consensus between parents and teachers alike. Despite being well-intentioned, these beliefs can have unfortunate consequences. When I was 15 months old, I was diagnosed with a benign Juvenile Pilocytic Astrocytoma (JPA) brainstem tumor. For the next seven years I was in and out of the hospital for surgeries, shunt replacements, and chemotherapy. These long and short hospital stays led to several interruptions in my education. By the time I entered 3rd grade I had almost no grasp of the concept of numbers. The private school I attended from preschool through second grade would not provide the help I needed unless I was physically in the classroom, leaving me to fall further and further behind whenever I had to undergo treatment. When I was able to attend school, my teachers would have me leave to get caught up during times when they were teaching new material to my fellow classmates.

It was not until my mom made the decision to move me and my brother to a public school that I was finally able to get the help that I needed. I qualified for special education under the category of traumatic brain injury; I had an incredible third grade teacher who understood the complexities of my situation; and I only missed class to get caught up when it was free time or another time in the class where I would not be missing anything new. I am now 27 years old, graduated from college cum laude, and am on my way to becoming a teacher myself. Unfortunately, not all students with chronic health conditions are as lucky as I was when it comes to getting the support they need to succeed in school. According to Bradley-Klug et al. (2010), 10-30% of students in the educational system are dealing with a chronic health condition. So why then are students still struggling to get the support they need to continue education

during treatment, or for those instances when they finally get the chance to return to the classroom?

Statement of Purpose

There is a considerable amount of research noting the inequalities students with chronic health conditions experience, as well as the variety of ways schools are violating federal laws and policies that were created to protect students with disabilities. However, there is much less conversation about why these school districts are not being held accountable for not supporting the education of students with chronic health conditions. The purpose of this research project was to explore and examine the ways in which teachers and schools are supporting students with chronic health conditions, either during treatment or once they have returned to the classroom. The hope was for a positive outcome that would identify ways in which schools can better support these students; these strategies are based on lived experiences by hospital teachers.

Overview of the Research Design

Participants for this research study were recruited from elementary schools within the Magnolia School District, a local northern California school district serving 2,640 students ranging in grades from kindergarten through 8th grade (CA Department of Education). After receiving permission from the principals of each elementary school, an initial survey was sent out to teachers. Each teacher that participated in the survey was also given the option to participate in a follow-up interview. These elementary schools were purposefully selected because of the district's comprehensive list of resources related to how the school can best support students with health conditions such as asthma, diabetes, and other serious illnesses. The purpose of recruiting teachers from elementary schools was to understand teachers' beliefs about

students with chronic health conditions. A total of five elementary school teachers completed the survey, and one teacher agreed to a follow-up interview.

Hospital teachers from the Griffin School, a local Bay Area hospital-based school, were recruited to understand the inequities towards students with chronic health conditions. Three teachers participated in an hour-long interview that consisted of open-ended questions about students with chronic health conditions and their perspectives of what they were observing on their end. The Griffin School was selected because of its offering of a school re-entry program for students returning to the classroom.

This study aimed to answer three central questions: (1) What policies and laws protect students with disabilities, especially students with chronic health conditions? How are these upheld or not? (2) What can the school and hospital schools do to support these students? (3) What changes are needed at schools to support this population of students? The initial survey and interviews with the elementary school teacher and hospital teachers were used to collect quantitative and qualitative data, in order to answer these three central questions.

Significance of the Study

Based on personal experience and findings from the literature, general education teachers and schools may be violating local and national laws and policies that were created to protect students with disabilities. A majority of schools, however, do not think students with chronic health conditions qualify for special education or as having a disability, which is leading to many students to navigate school without appropriate support. Additionally, teachers may not be emotionally or mentally prepared to confidently support these students. Three central themes came about after conducting research for this project: the importance of school, inequities towards students with chronic health conditions, and changes for the future. The main focus of

this study was the perspectives of the hospital teachers, something missing in a majority of the literature on this topic. As the researcher, I chose to focus on these perspectives, because hospital teachers have a unique relationship with these students; they are more than just teachers.

Analysis of interview transcripts and researcher notes led to findings showing that schools and teachers must shift their perspectives from parent centric ways of thinking to a student centric one, in order to see the benefits of continuing education during medical treatment. All three teachers also stressed the importance of bringing more awareness to the normalizing aspects of education in a hospital, and chronic health conditions in general, all of which is needed to better support students with chronic health conditions. My hope is that these findings will increase educational equity for free and appropriate public education for a population of students who are consistently being overlooked, but who ultimately need emotional and academic support.

Chapter 2: Literature Review

As survival rates increase, more children with chronic health conditions are having the opportunity to return to the classroom. Unfortunately, due to a lack of communication between the students, medical personnel, and schools, many of these children are academically left behind. Many teachers wonder if the student is still their responsibility while they are in the hospital undergoing treatment for their condition. Current laws and policies, such as the Individuals with Disabilities Education Act of 2001 (IDEA), do not provide a clear definition as to whether a student with a chronic health condition qualifies for special education or a 504 Plan. As a result, these students' academic needs may be overlooked during treatment, which may lead to students experiencing feelings of isolation, as well as being excluded, especially when a school makes the decision to withdraw them due to absenteeism. This scenario of withdrawing chronically ill students is, however, in violation of the Every Student Succeeds Act (replacing the No Child Left Behind Act of 2001), signed into law by President Obama in December of 2015; “This bipartisan measure reauthorizes the 50-year-old Elementary and Secondary Education Act (ESEA), the nation’s national education law and longstanding commitment to equal opportunity for all students” (U.S. Department of Education).

This research project explores: the importance of educational inclusion for students with a chronic health condition, federal laws and policies that were created to protect students with disabilities, and actions taken by schools that ultimately violate these laws, which leads to educational inequities. In the first section of this literature review, I will explain how misconceptions and beliefs about students with chronic health conditions are contributing to a lack of support from teachers and other school personnel. Then, I will discuss the historical background of educational laws and policies in the United States and provide examples of how

schools violated these laws and policies within the last 10 years. The last section of this literature review will explore the term “disability” as defined by the Individuals with Disabilities Act of 2004 and Section 504 of the Rehabilitation Act of 1973 and discuss how this growing population of students with chronic health conditions is not qualifying as having a disability, and therefore not receiving the support they need to return to the classroom.

Misperceptions and Beliefs about Students with Chronic Health Conditions

When a teacher discovers that one of their students has been recently diagnosed with a chronic health condition, they may begin to experience a number of emotions, ranging from uneasiness to sympathy. A chronic health condition is defined as having severe symptoms that last for three or more months and require several forms of treatment (Akin-Little et al., 2008). Due to the intensive course of treatment required to treat the condition, many students with chronic health conditions miss a good portion of school. With an increase in medical advances though comes an increase in the number of students returning to the classroom. Teachers must be prepared to support these returning students; it is important to note that “the demands placed on educators to provide an environment that supports both the learning and medical needs of these children can be overwhelming, especially when ‘little information is available to help them deal with the often complex and difficult issues that may arise’” (Bradley-Klug et al., 2010, p. 263). These authors also point out that 10-30% of students in the educational system are dealing with a chronic health condition (Bradley-Klug, et al., 2010). The roles of the schools and teachers are crucial in a student’s recovery. However, misconceptions and negative perceptions are contributing to a lack of support for students with chronic health conditions (Elam & Irwin, 2011).

The Role of School in a Student's Recovery

When a student with a chronic health condition is given the opportunity to continue with school, they are given the message that they will recover and be able to return to their previous life (Eaton, 2012). Studies have shown that “about 10.3 million children and adolescents in the United States have chronic medical conditions or illnesses, which involve limitations in cognitive, physical, or psychosocial development” (Akin-Little, 2008, p. 217). Schools not only provide students with a place for social and emotional guidance, they also give them the opportunity to learn about the structure of their world and people outside of their family (Eaton, 2012). Schools are a place to experiment and explore with the knowledge that there will always be someone there to turn to. According to Bradley-Klug et al. (2010), “to date, few studies have examined current collaboration practices between medical and school providers” (p. 265). When a school makes the decision to cut off contact with the student with a chronic health condition and their family, they are taking away this continued connection that is so integral in a child's life. In fact, Barakat (2018) explains that “maintaining pre-illness academic achievement and participation in school-related activities is an important goal for youth with cancer and has been related to enhanced quality of life” (p. 1). A continued connection to school life is important for all young students and especially those students with chronic illnesses who must be absent for extended periods of time. In addition to improving quality of life, returning to school or continuing their education during treatment allows students with chronic health conditions to have a sense of normalcy (Hay et al., 2015). It is clear that schools play an important role in these students' recovery process.

The Role of the Teacher

Teachers play an important part in any child's life. They are one of the first people to teach children how the world around them works, other than their parents or other family members. Irwin and Elam (2011) state that educators are accountable for ensuring "quality of life experience" (p. 67). For young children, "many must also cope with social and academic challenges at school and thus may benefit from teacher assistance in improving their interpersonal functioning or academic performance" (Akin-Little et al., 2008, p. 217). However, when a teacher discovers that one of their students has been diagnosed with a chronic health condition, they "may feel that they do not have the knowledge or lack the confidence to help them" (Akin-Little et al., 2008, p. 217). These teachers play an important role in that they are the bridge between life in the hospital and life outside of the hospital.

Bronfenbrenner's Socio-Ecological Theory highlights the key role teachers play in the psychological development of students (Runions et al., 2019). This theory describes the system of relationships in a child's life, such as their family, teachers, peers, and community. According to Relajo and Pilao (2018), "changes of conflict in any one layer will ripple throughout other layers. To study a child's development then, we must look not only at the child and [their] immediate environment, but also at the interaction of the larger environment as well" (p. 19). Bronfenbrenner's theory later paved the way for the creation of an ecological framework for curriculum development - "the framework was structured to identify and teach the routines, activities, and skills that students needed to learn and support their full participation in home, school, work, and community settings" (Crockett, Hunt, & McDonnell, 2012, p. 139). With Bronfenbrenner's theory in mind, the teacher can also have a significant impact on the way

fellow classmates see a student with a chronic health condition, which in turn can dissuade bullying and further stigmatization from peers (Runions et al., 2019).

Impact on Students with Chronic Health Conditions

Despite clear evidence of the importance of a continued presence of schools and teachers in a student with chronic health condition's life, many of these students are being left behind. Studies show (Wilkie, 2012) that the longer a student is absent, the more likely they are to receive decreased support from their school. For example, "at diagnosis and during treatment, absenteeism due to therapy regimens and their associated side-effects can lead to increased social difficulties and feelings of disconnection, inhibiting the child's ability to learn and engage in their education" (Bryan et al., 2021, p. 2). In addition to long lengths of time of being absent from school, differing suggestions from school districts are leading to more barriers, in regards to what procedures need to be followed to support a student with a chronic health condition (Eaton, 2012). When it comes to supporting a student with a chronic health condition who is absent due to their condition, teachers are unsure of whether they should "be the teacher" or provide emotional support (Wilkie, 2012). This idea is reinforced by the ambiguities surrounding the teacher's legal responsibilities while the student is absent due to treatment. Teachers have also reported that they "feel mean" (Wilkie, 2012) giving students with chronic health conditions schoolwork while they are undergoing treatment. Hay, Nabors, Sullivan, and Zygmund (2015) state that these beliefs are also accompanied by feelings of not being academically and emotionally trained to support a student with a chronic health condition, and therefore teachers are unsure of how to develop an academic plan that addresses the student's needs. These teacher beliefs may negatively impact the student, which could result in students feeling isolated and excluded. Clearly, schools and teachers play an important role in supporting students with

chronic health conditions. In this project, I hope to gain a deeper understanding about educators' beliefs about how students with chronic health conditions could be supported.

Violations of Educational Laws and Policies

Inclusion is an important part of any educational setting; the National Center in Educational Restructuring and Inclusion (NCERI) defined inclusion as “providing to all students, including those with severe disabilities, equitable opportunities to receive effective educational services, with supplementary aids and support services as needed, in age-appropriate general education classes in their neighborhood schools, toward the outcome of preparing all students for productive lives as full members of the society” (Francisco, Hartman, & Wang, 2020, p. 1). Larwin and Smith (2021) define inclusion as students having “an inherent right to be part of a classroom learning community with their peers who do not have disabilities” (p. 5). For the purposes of this review, I will be using The National Center in Educational Restructuring and Inclusion's definition of inclusion. Studies suggest that several barriers continue to prevent students with chronic health conditions from getting the support they need in regards to state and district policies, as well as laws and policies that protect a child's right to a free and appropriate public education (Legislative Alliance for Students with Health Conditions, 2017). For this project, inclusion in schools means also ensuring students with chronic health conditions have “equitable opportunities to receive effective educational services” (Francisco, et al., 2020, p. 1).

Historical Background of Education Laws and Policies

In order to better understand barriers to inclusion for these students, we must first take a closer look at the history of the laws and policies enacted to protect students with disabilities. According to Larwin and Smith (2021), Henry Bernard and Horace Mann played an integral role in the establishment of schools that would support students with disabilities, which up until that

point, there were none. In fact, “until the 19th Century, there is no substantial evidence that individuals with disabilities received any type of formal education” (Larwin & Smith, 2021, p. 1). It was not until the 20th Century that more legal cases began to arise in regards to including students with disabilities in the general education classroom. The first of these cases was *Brown v. the Board of Education* - “This court ruling set the tone for the elimination of segregation. Although geared toward segregation of students of color, the ruling had implications for the segregation of students with disabilities as well” (Larwin & Smith, 2021, p. 3). Other important legal cases and policies include the Panel on Mental Retardation in 1962, *Pennsylvania Association of Retarded Children (PARC) v. the Commonwealth of Pennsylvania* of 1971, and P.L. 94-142, also known as The Education for All Handicapped Children Act, established in 1975, all of which helped to guarantee a student’s right to a free and public education (Larwin & Smith, 2021).

The Education for All Handicapped Children Act was renamed and reauthorized in 1990, with the most recent reauthorization occurring in 2004 (U.S. Department of Education). The revised Individuals with Disabilities Education Act was created to ensure access to education for all students (Legislative Alliance for Students with Health Conditions, 2017) and defined “special education as instruction that is designed specifically to respond to the learning needs of an individual with disabilities regardless of environment, whether in a classroom, home, or hospital” (Francisco, Hartman, & Wang, 2020, p. 1). Alternatively, if a student does not require special education services, they could be eligible for support through Section 504 of the Rehabilitation Act of 1973, which would allow the student to fully participate in a general education classroom (Hopkins & Hughes, 2015). According to Gilchrest et al. (2005), “Section 504 of the Rehabilitation Act sought to protect the rights of disabled individuals through what

appeared to be clear and straightforward language” (p. 48). Three years before the reauthorization of the Individuals with Disabilities Education Act, the No Child Left Behind Act of 2001 was enacted into law. The No Child Left Behind Act of 2001 was originally created to establish standards for best practice in schools and to ensure that all students had access to this education (Irwin & Elam, 2011). Fourteen years later, President Obama signed into law a new version of the No Child Left Behind Act, called the Every Student Succeeds Act of 2015, that ensured an education to all students regardless of race, income, zip code, disability, home language, or background (Chu, 2019).

Violations

Unfortunately, all of these laws and policies have not ensured a free and appropriate public education for students with chronic health conditions. Elam and Irwin (2011) state that despite numerous violations, there is a lack of literature documenting such violations. Research shows (Irwin & Elam, 2011) that schools are withdrawing students with chronic health conditions from their districts, in order to avoid negative repercussions on the school’s performance (Legislative Alliance for Students with Health Conditions, 2017). This trend of students with chronic health conditions being denied their right to a free and public education is not just occurring in the United States; it is happening globally. In the United Kingdom, “there is a lack of awareness that young children also attend education settings. Consequently, lack of specific, statutory guidance may mean that young children in early childhood settings are discriminated against because there is no legal requirement to support their medical needs” (Musgrave & Levy, 2020, p. 163). In Australia, “no consideration has yet been given to this group as a *cohort* of students, with the important educational perspective so far remaining absent” (White, 2015, p. 1295).

A number of sources discuss the various ways schools are violating these laws and policies, especially here in the United States. Much of the literature also explains the social and emotional impact of these violations. Hay, Nabors, Sullivan, and Zygmund (2015) state that withdrawing students who are chronically ill can have an impact on their quality of life by making them feel isolated and exiled. Threats of retention can also cause significant socio-emotional and behavioral consequences leading to a number of students with chronic health conditions to drop out of school (Irwin & Elam, 2011). In fact, some states will only provide support to those students who are absent for more than three months or those with a documented disability (Eaton, 2012). Irwin and Elam (2011) write, “school districts do not withdraw students with learning disabilities as a result of their disabling condition, therefore it should be unacceptable to withdraw children suffering from an illness” (p. 71). Another way that schools are violating these federal laws and policies is through the use of homebound instructional services. According to Lustig (2018), “students in homebound placements are typically only served for a few hours per week by a teacher that is usually licensed and certified in only one subject, if at all (paraprofessionals may often act in the role of a homebound teacher as long as they are under the guidance, but not direct supervision, of a licensed teacher)” (p. 261). In addition to the above violations, many schools are forced to interpret existing laws and policies that do not adequately outline what educational plans need to be developed for students with chronic health conditions (Hay et al., 2015). The definition of a “disability” is just one part of these existing laws and policies that each school district is left to interpret.

Definition of Disability

The Merriam-Webster dictionary defines *disability* as “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person’s ability to engage in

certain tasks or actions or participate in typical daily activities and interactions” (Merriam-Webster, 2022). The Americans with Disabilities Act (ADA) defines *disability* as “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” (U.S. Department of Justice Civil Rights Division). In the educational setting, the Individuals with Disabilities Education Act of 2004 and Section 504 of the Rehabilitation Act of 1973 provide support to students with disabilities in the least restrictive environment (Hay et al., 2015). Unfortunately, research suggests (Hay et al., 2015) that students with chronic health conditions do not clearly fit these definitions of what constitutes a disability under these federal laws.

In the United States, approximately 32 million or up to 43% of students have a chronic health condition, with 58% of these students routinely missing school and 10% missing more than 25% of the school year (Legislative Alliance for Students with Health Conditions, 2017). In 2015, pediatric cancer was one of the “leading cause[s] of death by disease in children from infancy to age 15 in the United States” (Hay et al., 2015, p. 2). Medical advances have made it possible for children to live longer. Approximately 388,500 children are surviving childhood cancer, with 83.5% of these children living more than 5 years after their initial diagnosis (Losinski & Ennis, 2018). 66% of these survivors experience some sort of chronic health condition related to their cancer or course of treatment. These chronic health conditions include neuropsychological deficits, psychological distress, and chronic pain (Losinski & Ennis, 2018). With these statistics in mind, students with chronic health conditions should qualify as having a disability according to the Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act.

Definition According to the Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act provides teachers and other school personnel with 13 categories that help them to know if a child qualifies for special education or not. These 13 categories include specific learning disability (SLD) such as Dyslexia, Other Health Impairment, Autism spectrum disorder (ASD), emotional disturbance, speech or language impairment, visual impairment, deafness, hearing impairment, deaf-blindness, orthopedic impairment, intellectual disability, traumatic brain injury, and multiple disabilities. Students with chronic health conditions who qualify for special education typically do so under the category of “other health impairment” (Hay et al., 2015). The category of “other health impairment” is defined as having “limited strength, vitality, or alertness due to chronic or acute health problems” that must adversely affect the student’s ability to succeed in class (Hay et al., 2015, p. 3). Any student that qualifies as having a disability under these 13 categories will then begin the process of having an Individualized Education Program created for their specific needs.

Definition According to Section 504 of the Rehabilitation Act

For those students who do not qualify for special education, there are still support systems available to them. Students who are not eligible for special education, but still require additional support to succeed in class due to a condition that affects one or more of their daily life activities would then qualify for a 504 Plan. Unlike the Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act is considered more of a civil rights law for students who do not fit under any of the 13 categories (Hay et al., 2015). “Under Section 504, a chronic illness can be categorized as a disability, consequently providing individuals with chronic illness protection from discrimination” (Irwin & Elam, 2011, p. 71). Section 504 also states that any school-age child with a disability, which is defined as any physical or mental

impairment that affects one or more major life activities, has the right to a free and appropriate public education (Irwin & Elam, 2011).

Ambiguities with the Definition of a Disability

Despite the presence of various support systems offered through the Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act, many students with chronic health conditions are not qualifying as having a disability. Many students with chronic health conditions do not end up qualifying for special education under the category of “other health impairment,” because of an increase in school absences, even if the absences are a result of their treatment (Legislative Alliance for Students with Health Conditions, 2017). Hay et al (2015) also state that the Individuals with Disabilities Education Act’s category of “other health impairment” is restrictive and not comprehensive. Loopholes and gray areas in these laws are allowing school districts to limit support services for students with chronic health conditions (Legislative Alliance for Students with Health Conditions, 2017).

Conclusions

There is a considerable amount of research noting the inequalities students with chronic health conditions experience, as well as the variety of ways schools are violating federal laws and policies that were created to protect students with disabilities. Research also suggests that the positive benefits of allowing a student to continue their education has been traced back to the 1920s at Stanford University Hospital (Eaton, 2012). Acknowledgement of loopholes and gray areas (Legislative Alliance for Students with Chronic Health Conditions, 2017) shines a light on the need to hold schools accountable for the part they play in denying a student with a chronic health condition their right to a free and appropriate public education.

Overall Strengths of the Literature

The root of many of the inequalities experienced by students with chronic health conditions stem from ambiguities around the term “disability.” A number of articles detail this restrictive nature of legislation’s definition of a disability. Information found in the research regarding the various ways schools are violating federal laws and policies also has the strength of illustrating the inequalities this population of students face when returning to the classroom during or after treatment. Lastly, another strength of the literature reviewed for this project is the statistical evidence of the increase in survival rates for students with chronic health conditions.

Overall Weaknesses of the Literature

Some studies suggest that students with chronic health conditions do not have any problems qualifying for special education. In fact, Losinski and Ennis (2018) argue that strategies and accommodations that support students with other disabilities are available to students with chronic health conditions as well. Some studies also suggest that it is the responsibility of the district, state, and federal educational policymakers to clarify what types of support students with chronic health conditions require. Meanwhile, Eaton (2012) argues that it is the hospital teacher’s responsibility to assist students and families with the re-entry process. According to Eaton, it is the responsibility of the hospital teacher to inform families of education laws, and that without them, it may be months before a student’s family becomes aware of the resources available to them. This weakness, however, is leading to ambiguities about roles and responsibilities when it comes to supporting students with chronic health conditions, leading to a whole host of finger pointing from all sides of the situation. All of this continues to be an ongoing problem today.

Gap in the Literature

While numerous studies focus on the violations and ambiguities of educational laws and policies protecting students with disabilities, there is much less conversation about why these school districts are not being held accountable for not supporting the education of students with chronic health conditions. Given that this is an ongoing issue throughout the United States and in other parts of the world, it is clear that there is a necessity for further discussion about the role of education in a student's treatment and well-being.

Purpose of Research

The purpose of this research project is to explore and examine the ways in which teachers and schools have supported students with chronic health conditions. The experiences of teachers who have witnessed inequities towards students with chronic health conditions will also be examined. The hope is for a positive outcome of this research, and that it will identify ways in which schools can better support students with chronic health conditions based on lived experiences of teachers.

Chapter 3: Methods

A number of research studies critically analyze the violations and ambiguities of educational laws and policies protecting students with disabilities. However, there is little information in the academic literature about why schools are not being held accountable for violating these laws and policies that were created to protect this population of students. More data is needed to better understand why these school districts are not being held accountable for not supporting children with chronic health conditions, and ultimately denying them their right to a free and appropriate public education. According to authors Irwin and Elam (2011), “although these violations are numerous, the atrocity of these offenses is not documented in the literature” (p. 70). These violations include withdrawal, retention, and segregation through homebound instruction (Irwin & Elam, 2011).

The research methods for this study were designed to capture the perspectives of elementary school teachers and hospital teachers, pertaining to support systems in school settings for students with chronic health conditions. In this study, the personal viewpoints of elementary school teachers and hospital-based teachers were the primary source of data, with an initial survey used to guide investigation throughout the research process.

Research Questions

This study focused on responses from elementary school teachers and hospital-based teachers to a series of questions, first presented as an initial survey and then followed by a series of individual interviews in order to obtain both quantitative and qualitative data. The questions for the survey and interviews were formed based on the following central questions:

- What policies and laws protect students with disabilities, especially students with chronic health conditions? How are these upheld or not?

- What can the school and hospital do to support these students?
- What changes are needed at schools to support this population of students?

These central questions were used to investigate how policy and law violations are affecting students with chronic health conditions and their right to a free and appropriate public education, to understand ambiguities with the term “disability” that are making it difficult for these students to get the support they need in school, and to identify ways hospitals can provide a supportive bridge between hospital-based schools and the student’s school. A deeper understanding of this topic could potentially lead to the creation of a new policy or other support systems that better serve the needs of students with chronic health conditions as they make the transition back to the classroom.

Description and Rationale for Research Approach

The philosophical worldview represented in my research is a transformative view. A transformative worldview focuses on providing a voice to marginalized communities and seeking out ways to empower this population by researching the changes that need to be made (Creswell, 2018). This study supports a transformative view because it looks critically at the beliefs held by teachers through the use of open-ended questions from the perspectives of elementary school teachers, whose realities have been shaped by social and disability values of past educators. My study also uses Freire’s critical pedagogy as a framework to explore the ways teachers are upholding myths regarding students with chronic health conditions. One such myth that continues to be prevalent among educators, is the belief that students with chronic health conditions should not have to worry about their education while undergoing treatment for their condition. “When well-meaning adults discourage children from their focus on school, they are often missing the child’s connection between school and health, quality of life, and recovery”

(Eaton, 2012, p. 271). By focusing on teacher perspectives, an action plan is developed in order to bring about changes to the current oppression of this marginalized community (Creswell, 2018). Further marginalization and victimization is being avoided by looking in-depth at the history of the identified myths, how these myths are continuing to affect these students today, and putting an action plan into place based on the knowledge gathered.

This study uses a mixed methods design to obtain information about the support from schools for students with chronic health conditions. A mixed methods approach involves both qualitative and quantitative research and is used to provide additional insight into a particular piece of qualitative or quantitative data (Creswell, 2018). Before exploring the perspectives of individual teachers, it is important to look at the beliefs acknowledged in the literature. This mixed methods approach allows for initial quantitative results that can be used to better understand the shared beliefs by teachers of students with chronic health conditions. Research has shown that teachers believe that students with chronic health conditions should not have to worry about school while they are going through treatment (Eaton, 2012; Wilkie, 2012). Initial quantitative research will be able to provide insight into where these beliefs might be coming from as it relates to schools today. Further qualitative research will allow for a more personalized perspective on the issue at hand by both district elementary school teachers and hospital-based teachers. The main objective in using a mixed methods approach is to answer the questions: “what is happening and what should be happening?”

Research Design

This is a mixed methods research study. Data was collected through an initial survey of elementary school teachers from a local school district (quantitative data), follow-up interviews

with a select group of teachers, and interviews with teachers from a hospital-based school (qualitative data).

Research Site

The elementary schools where the initial survey was shared are part of a school district in northern California, which I will refer to as Magnolia School District (a pseudonym to ensure confidentiality for all participants). Elementary teachers from this school district were also interviewed during the research process. The hospital-based school where another portion of research was conducted serves pediatric patients in a hospital in northern California, which I will refer to as The Griffin School. To maintain confidentiality, pseudonyms are used for the schools and teachers. The Magnolia School District serves 2,640 individuals ranging in grades from kindergarten to 8th grade. The elementary schools within this school district serve 0.5% African American students, 0.3% American Indian or Alaska Native students, 4.3% Asian students, 0.4% Filipino students, 8.5% Hispanic or Latinx students, 0.1% Pacific Islander students, and 74.5% Caucasian students (CA Department of Education). There are approximately 315 students within the school district receiving special education, ranging from kindergarten through 8th grade (CA Department of Education). This school district was purposefully selected because of the district's comprehensive list of resources related to how the schools can best support students with health conditions such as asthma, diabetes, and other serious illnesses. The hospital-based school was selected because of its offering of a school re-entry program for students returning to the classroom.

Participants and Sampling Procedures

Principals of the elementary schools were contacted via email that included a letter of permission. After receiving approval for the proposed survey, the principals shared the survey

link with teachers. An initial survey was sent out to elementary school teachers within the Magnolia School district (see Appendix B for survey questions), at which point teachers were given the option to participate in an individual 30-minute follow-up interview (see Appendix C for interview questions). I then contacted volunteers to arrange an interview date. At the Griffin School, I announced a request for volunteers to participate in an interview and distributed the interview questions (see Appendix D for interview questions). All hospital teachers participating in an individual interview were asked to sign a consent form before proceeding with the interview process. Informed consent forms were signed by all elementary school teachers participating in interviews, and an informed consent was included with the survey before participants proceeded with answering the questions.

Methods for Data Collection

Data collection began with a survey of elementary schools within the Magnolia School District. The primary purpose of this survey was to empirically evaluate the beliefs held by teachers who may or may not have students with chronic health conditions in their classroom (see Appendix B for the survey questions). This cross-sectional survey was used to examine the relationship between the beliefs of teachers and the lack of support for students with chronic health conditions as identified in the research. An emailed survey was the main form of data collection for the survey portion of the research. This method was chosen because of its quick and easy data results, as well as its accessibility by teachers who all have access to email. An emailed survey also answered some of the research questions that could be used to determine where to make any possible changes in the next part of the interview process.

In order to understand the elementary school teachers' perspectives of the support systems in schools for students with chronic health conditions, I conducted a 30-minute

interview with volunteer elementary school teachers who also participated in the survey process. These interviews consisted of open-ended questions about their beliefs about students with chronic health conditions, and any possible current support systems at their school to help these students (see Appendix C for interview questions). I asked questions such as, “What support systems are put in place at your school to support these students?” and “Would you consider a student with a chronic health condition as having a disability, and if so, why?” The goal of these interviews was to assess particular beliefs found during the survey process. These interview questions also helped to answer the research question, “What is leading to these violations of policies and laws protecting students with disabilities?” Each interview was recorded on my iPhone that is password protected. Notes were taken during and after the interview. Names and any other identifying information, such as phone numbers and personal references, were not included in order to protect the confidentiality of the participants.

Interviews with hospital-based school teachers were conducted that consisted of open-ended questions about students with chronic health conditions and each teacher’s perspective of what they are observing on their end (see Appendix D for interview questions). During these interviews, I asked questions such as, “What inequalities have you witnessed, if any, towards children with chronic health conditions?” and “What changes need to be or can be implemented to support these children?” The goal of these interviews was to gain insight into the hospital side of the research problem and to hear a hospital’s perspective about what changes could be made to better support these students. These particular interview questions also helped to answer the research question, “What other changes need to be implemented to support this population of students?” Interviews were also recorded on my password protected iPhone. Names and other identifying information were also not included.

Data Analysis

I collected data through a mixed methods research design. I began by gathering data through a survey sent out to elementary school teachers within a local school district. Upon receiving 5 completed surveys, I started by looking at the overall trends across numerical data, followed by a closer look at individual surveys in order to identify any potential correlations between years of experience, and current or past experience with having a student with a chronic health condition in the classroom. Participants were given the option to take part in a follow-up individual interview. Data from this process was collected through open-ended questions. Each interview was recorded using my phone. Throughout the interview I wrote key phrases having to do with specific ways schools are supporting students with chronic health conditions. After the completion of each interview, I wrote analytic memos, making note of whether or not each teacher's specific school site had support systems in place. I then categorized the participant's number of years of teaching with positive or negative opinions about current support systems for students with chronic health conditions. A separate part of my research involved collecting and analyzing data from open-ended interviews with teachers from a local hospital-based school. While conducting these three interviews, I wrote key phrases having to do with positive or negative experiences with communicating with school districts. Analytic memos were also written after each interview. Each interview was categorized as being a positive or negative experience. The idea was that there should be a pattern in both categories.

Throughout the data collection process, I used all three of Maxwell's (2013) strategies for data analysis: writing analytic memos after each interview, categorizing strategies, including coding and thematic analysis, and connecting strategies. Writing analytic memos after the completion of each interview allowed me to make notes about the facial cues and physical and/or

emotional reactions to each individual interview question. According to Maxwell, “memos can perform other functions not related to data analysis, such as reflection on your goals, methods, theory, or your prior experiences and your relationships with participants” (Maxwell, 2013, p. 105). These analytic memos also gave me the opportunity to compare and contrast surprising or unexpected reactions, especially with the individual follow-up interview I had with an elementary school teacher.

Before I began the interview process, I created a list of words and phrases I expected to hear during each interview. These organizational categories, also known as codes, are “broad areas or issues that you want to investigate, or that serve as useful ways of ordering your data” (Maxwell, 2013, p. 107). These expected codes included: support, inclusion, communication, responsibility, disability, frustration, hope, future, and continued education. These codes were used to form a mini-hypothesis based on the review of literature, as well as my own experience. Once each interview was complete, I explored the transcribed interview several times in order to get a general sense of the data. I began coding by using open coding, a process that involved reading through the data several times and identifying emerging codes that were not on my list of expected codes. This process was followed by focused coding which involved narrowing down and creating a final list of codes by comparing my two lists to see if any unexpected or surprising codes were present. Peer coding was also used during the open coding process as another form of validity check. Using my final list of codes, I was then able to identify three categories: importance of school, inequities towards students with chronic health conditions, and changes for the future. Each code was then sorted into each final theme or category.

Finally, I used connecting strategies to look for similarities and differences between the narratives of the hospital-based teachers and those of the elementary school teacher. In

explaining the difference between categorizing and connecting strategies, Maxwell writes, “A research question that asks about the way events in a specific content are connected cannot be answered by an exclusively categorizing analytic strategy. Conversely, a question about similarities and differences across settings or individuals cannot be answered by an exclusively connecting strategy” (Maxwell, 2013, p. 115). The connecting strategies part of my data analysis involved creating a data analysis matrix that combined communication with a student’s school with beliefs about students with chronic health conditions (communication with positive and no communication with negative). This data analysis matrix helped me to locate similar key words and phrases to keep track of throughout the interview and analysis process.

Validity and Reliability

As a former student with a chronic health condition, who had a negative experience with receiving support while undergoing treatment, reactivity is important to take into account throughout the research process. My personal experience may also have an impact on the data collection because of my emotional investment in seeing positive changes come about from this research. I am aware of these biases and have therefore implemented a number of strategies to increase the validity of the research.

A mixed method research design was used to ensure validity and reliability. This method was chosen as a way to obtain perspectives from both sides of the issue. Quantitative data was collected through an initial survey that was sent out to elementary school teachers to get a sense of what beliefs were currently being held by teachers. The qualitative data was collected through the process of individual follow-up interviews with volunteer elementary school teachers. In addition to these teachers, hospital-based school teachers were also interviewed as a form of qualitative data collection. By using these three different methods of data collection, I was able

to analyze the data and look for common themes among each data source. According to Maxwell, “This strategy reduces the risk of chance associations and of systematic biases due to a specific method, and allows a better assessment of the generality of the explanations that one develops” (Maxwell, 2013, p. 128).

I also utilized rich data in order to increase validity. This was done through the use of verbatim transcripts of interviews. Using rich data to increase validity means obtaining “data that are detailed and varied enough that they provide a full and revealing picture of what is going on” (Maxwell, 2013, p. 126). Before starting the data analysis process, I continued to increase validity by soliciting feedback from participants about the data and conclusions collected during the interview process (Maxwell, 2013). During the data analysis process, I made sure to address any discrepant evidence, such as unanswered questions from the survey, and negative cases in order to ensure that my own bias did not have an impact on the validity of the research. Addressing any discrepant evidence and negative cases made it possible to “assess whether it [was] more plausible to retain or modify the conclusion, being aware of all of the pressures to ignore data that [did] not fit [my] conclusions” (Maxwell, 2013, p. 127).

Chapter 4: Findings

This mixed method research sought to answer the following questions: (1) What policies and laws protect students with disabilities, especially students with chronic health conditions? How are these policies upheld or not? (2) What can the school and hospital schools do to support these students? (3) What changes are needed at schools to support this population of students? To begin addressing these questions, data was collected through surveys with elementary school teachers and interviews with hospital teachers and an elementary school teacher.

Three hospital teachers were interviewed. Their stories shed light on what it is like being a hospital teacher, the importance of continuing school during hospitalization, and the inequities they have observed for students with chronic health conditions. Analysis of interview transcripts and researcher notes led to findings showing that schools and teachers must shift their perspectives from a parent centric way of thinking to student centric, in order to see the benefits of continuing education during medical treatment. All three teachers also stressed the importance of bringing more awareness to the normalizing aspects of education in a hospital, and chronic health conditions in general, all of which is needed to better support students with chronic health conditions.

Findings from Initial Elementary School Teacher Survey

After receiving permission from the principals within the Magnolia School District, an initial survey was sent out to three elementary schools; this survey sought to understand teacher beliefs and attitudes towards students with chronic health conditions, as well as their knowledge about programs their school offered to support the re-entry process. A total of five elementary school teachers responded to the survey. See Table 1 below for survey results.

Table 1 Survey Results

Survey Question	Yes	No	Prefer Not to Answer
Have you had a student in your class with a chronic health condition?	60%	40%	0%
Should students undergoing treatment for a chronic health condition have to worry about school while they are in the hospital?	0%	100%	0%
Should schools continue to communicate with families and students during treatment?	80%	20%	0%
Should schools and hospitals be in regular communication about a student with a chronic health condition?	40%	60%	0%
Should students with chronic health conditions be seen as having a disability?	20%	40%	40%
	Yes	No	I Don't Know
Does your school have out of school programs or other programs to support students with health conditions?	40%	20%	40%
	The Hospital	The School	Other
Is it the school's or the hospital's responsibility to continue to educate a student while they are undergoing treatment?	0%	20%	80%

All teachers who participated in the survey had been teaching between 8-32 years, either within the same district or multiple districts. The survey revealed that 60% of these teachers had either had or currently have a student with a chronic health condition in their classroom. All five teachers responded that students should not have to worry about school while they are in the

hospital. Finally, when asked if a chronic health condition qualifies as a “disability,” one teacher wrote the following in an optional open-ended comment box:

The question about chronic health conditions being a disability is vague. A student who is unable to attend regular classes due to chronic health issues should have the right to an education and should have modifications and accommodations to meet their needs. If this falls under disabilities as a qualification for these services then I guess yes it is a disability.

Each teacher was given the option of participating in a follow-up interview to discuss more about having a student with a chronic health condition. Out of the five teachers who responded to the survey, only one teacher volunteered to participate.

Findings from Hospital Teacher Interviews

A second part of the research involved interviewing hospital teachers from the Griffin School, a hospital-based school in Northern California that serves pediatric patients ranging in age from 4 to 22. A request for participants was sent out to all of the teachers at the school. Three teachers volunteered to participate in an interview to discuss what they were experiencing as hospital school teachers. Each teacher had a unique story to tell, with one commonality being that they had no idea the job had existed when they first were approached to teach at the hospital school.

The following vignettes detail each teacher’s personal story about how they came to be a hospital school teacher, and the situations they experienced while working at the Griffin School. In addition to each teacher’s personal story about how they became hospital teachers, the vignettes also share their perspectives and opinions about the importance of school, the inequities towards students with chronic health conditions, and potential changes for the future.

Vignette #1: Rebecca

Rebecca began working at the Griffin School 12 years ago. While volunteering in her daughter's kindergarten class, the teacher came up to her and told her that she would make a really good teacher. So she made the decision to return to school to get her teaching credentials. While getting her credentials, she started out by volunteering at a local elementary school where she assumed she would stay. As chance would have it though, a fellow colleague ended up changing their mind about student teaching at the Griffin School. The director at the time reached out to her and asked if she would be willing to take the now vacant spot. The rest is history. After working at the Griffin School for 12 years, Rebecca loves being a hospital teacher because she can act as a resource for patients and families, advocate for the children, educate families about options for support, and develop lasting relationships with her patients. To Rebecca, the job is both challenging and rewarding, and ultimately, she feels like she is making a difference in the lives of those she works with.

Importance of School

When asked about the importance of continuing school while in the hospital, Rebecca stressed the many benefits of continuing education. According to Rebecca, school is important because it provides students with a normalizing experience. As she pointed out, patients just “want to be a kid again.” She also discussed the benefits of surrounding the student with a positive and encouraging community:

I get to do things like have doctors write letters on [the student's] behalf talking about, you know, why it would be great if they could go to college. So I have...we have many people who I work with, who get involved when we're trying to get a student, you know, into college.

Everyone at the Griffin School wants to provide patients with as many normalizing experiences as possible. Rebecca shared that at the Griffin School, they have local museums and aquariums

do Zoom visits, which gives the students the feeling of going on a field trip. They also host various events such as prom and Halloween parties.

Inequities Towards Students with Chronic Health Conditions

Assumptions and Beliefs. When asked about the inequities she has witnessed towards students with chronic health conditions, Rebecca pointed out that many schools and teachers have certain beliefs about these students. One of these beliefs is that these students are not going to be able to go college, and therefore teachers end up “giving up” on the student. During the interview, Rebecca recounted a time when she witnessed this firsthand:

And there was actually a school counselor who told me and [the student’s] mom during a meeting with the counselor that [the student] should just take his exit exam and not worry about completing high school.

She and the mom both agreed, though, that the student was perfectly capable of doing the work, despite being a year behind. In the end, the student graduated from high school and went on to attend college.

Visible vs. Invisible Symptoms. Rebecca also acknowledged the problem of visible vs. invisible symptoms, meaning that some pediatric patients come back to school with physical changes, while others return with changes that are either easier to hide or are occurring internally:

We also see a lot of inequity around schools not understanding how sick a kid really is. If you have a student who’s had a cancer diagnosis, a lot of times they won’t have hair. And so it’s obvious to notice they’re sick, but if you have a student who has something like seizures, just be looking at them, you don’t know that they’re sick, or that they have a medical condition.

According to Rebecca, when situations like this occur, the student ends up being placed in a special day class because the school does not know how to help the child. In the 12 years that Rebecca has been a hospital teacher, she has come to the realization that schools are not treating

all kids the same, and therefore not allowing them to have the same access to education because of the assumptions some educators have made about that student.

Unenrolling Students from their Districts. One inequity that Rebecca expressed extreme frustration with was how schools were unenrolling students who had to be in the hospital for a longer period of time:

So much so that we had a lot of kids, when they were here long term, their schools would take them off of their enrollment status. So they would no longer enroll. And they would give their space away within the school they are going to to another student.

Witnessing this ongoing inequity eventually led Rebecca and a group of hospital teachers to propose a bill that would make it so that kids could still be going to school, and ultimately go back to their regular classroom. And if a student did not survive, the school would give them an honorary diploma.

Changes for the Future

While discussing potential changes for the future, Rebecca expressed a need for more community involvement, training for teachers specifically for working with students with chronic health conditions, more awareness of chronic health conditions, and a better way of managing resources for families. She explained, “So I think that there are resources out there to make sure that everybody’s on the same page. They’re just not managed in a way that everybody even knows they exist.” According to Rebecca, there are resources and support systems out there, but if no one tells you that they are indeed out there, then you will have a harder time getting the support your child needs.

Vignette #2: Monica

Monica made the decision to become a hospital teacher 19 years ago while obtaining her credentials to become a Child Life Specialist. Before entering the program, Monica already

possessed her teaching credentials. Shortly after starting her program to become a Child Life Specialist, a supervisor from the Griffin School contacted her graduate school to see if they knew of anyone who had their teaching credentials. In the end, Monica was hired as a part-time hospital teacher while she completed her Master's program. Like her fellow colleagues, she had no idea that the job existed. Nearly 19 years later, she loves that she is able to develop such intimate relationships with her students at the Griffin School. She explains that being a hospital teacher means that you are always having to be creative and flexible. Monica also expressed that she sees herself as someone who helps to build a support system, advocates for the student, and shows compassion and empathy towards her patients and their families.

The Importance of School

For Monica, continuing education while in the hospital is important for a child's mental health. Continuing education during hospitalization can be beneficial for multiple reasons, including helping students feel like they are still part of their school community:

I think it's so like, validating, and you know, that I'm still part of like, a school community, and I want to stay up with my work and my friends with what they're doing. I think it's super important, and especially like, just for your mental health, to feel connected to, you know, what's normal for you.

Monica also pointed out that continuing education gives the student the opportunity to go back to being a kid.

I can't stress that normalcy piece of school, and feeling a part of that school community and your friends and socializing. You know, that's all part of growing up and life and kids want to get back to that.

As a hospital school teacher, Monica loves incorporating games and other kinds of learning activities, such as crafts or things that are based on the child's interests. Working with oncology pediatric patients, Monica finds herself constantly personalizing her curriculum in a way that will

interest and motivate the student. Above all, Monica's main goal as hospital teacher is to give her students a sense of normalcy:

And this environment is not normal, and isn't where kids should be. But while they're here, you know, we try to normalize through school, I think, especially for school aged kids is super, super important.

Despite acknowledging the importance of continuing school, Monica also understands that sometimes continuing as normal may not be appropriate. Every kid is there for a different reason and everyone is going to have their own perspective of whether or not they want to continue their education. It is important to be understanding and empathetic, something Monica feels is missing in some schools.

Inequities Towards Students with Chronic Health Conditions

Unreasonable Expectations. In the 19 years that Monica has been working as a hospital teacher, she has witnessed schools having high expectations for their students who are in the hospital. While most teachers seem to be understanding, she has also come across teachers who expect their hospitalized students to complete the same amount of work that their fellow classmates do, and in the same amount of time:

Sometimes schools are super understanding and accommodating. And then like I said, other times, you know, they can be not so understanding and doing what's best for the kids and the families.

In response to circumstances where teachers are not being understanding and flexible, Monica poses the question, "Haven't you ever been sick?" For Monica, even if someone has not been in the hospital it is still important to be understanding and flexible.

Communication. When asked about communication between students and teachers, Monica seemed sad to admit that communication did seem to dwindle the longer the student was in the hospital. She was also quick to respond in an exasperated tone about whether or not schools provided families with information about resources available to them. According to

Monica, schools are not talking to families about the resources available to them and are therefore being “left in the dark.” She shared a recent experience she had where the mom of one of her patients did not know the difference between independent study and home hospital instruction. She also explained, “Sometimes kids will go for months and months without getting a teacher that comes to the home.”

Changes for The Future

Monica’s main hope for the future was a desire to see that schools are more forthcoming about the services they provide for students who need support. She also noted the positive outcomes of the COVID pandemic, especially increased accessibility through technology; for example, more students are now receiving school assignments via Google Classroom or other online platforms.

Vignette #3: Jennifer

Jennifer began her career as a general education teacher for a second-grade classroom. In 2015, Jennifer decided that it was time for a change. She loved being in a classroom and teaching but was becoming concerned that being a classroom teacher was not sustainable. That is when she stumbled upon the position of a hospital teacher. She had no idea Child Life existed, let alone teaching in a hospital-school setting. She applied for the job and never looked back. She has been teaching at the Griffin School for three years now and has learned so many important life lessons because of it, such as appreciating the little things in life. For Jennifer, being a hospital teacher is being more than just a teacher. She explained that this role requires a lot of flexibility, perspective, empathy, collaboration, creativity, and a willingness to help. She also loves that she can help her students to set and achieve goals. In the three years that Jennifer has been a hospital teacher, she has also learned the importance of being more patient centric rather

than adult centric (which is also known as adultism). Author John Bell defines “adultism” as “behaviors and attitudes based on the assumption that adults are better than young people, and entitled to act upon young people without their agreement. This mistreatment is reinforced by social institutions, laws, customs, and attitudes.” (John Bell, 2011).

The Importance of School

Like her fellow colleagues, Jennifer views education and school as a normalizing experience, as well as a source of hope. She recounts one story about working with a patient to meet the deadline for graduation:

We were like grinding, like trying to get the deadline so they can walk for graduation, because there’s such a credit deficit. And I was like, kind of negotiating, like, Can we do this? Can we do that? Well, you know, what can we do? And her and I were grinding, and she made it and she walked, and it was really triumphant. And it was a beautiful moment.

As a hospital teacher, Jennifer is able to build more intimate relationships with her students, and when she is able to help them set a goal and achieve it, it leaves her beaming with pride.

According to Jennifer, education is also important because it allows her students to have some feeling of control when everything around them is out of their control. She explains:

Like you can’t say, No, I don’t want you to take my vitals, No, I don’t want my meds today. No, I don’t want to do this treatment. They can’t do that. But with school, they have the option and autonomy to do that.

Control is important not only for the patients, but also for the family as a whole. Every family has their own unique daily routine, and when a child is diagnosed with a chronic health condition and requires treatment, that routine is disrupted, which can be scary for everyone involved.

School helps to normalize the situation and bring back some feelings of control.

Jennifer also points out that education can still happen during treatment. As a hospital teacher, she tries to work with schools to get their hospital experience to count towards credit:

I always tell the families and the kids, and the schools too like, how can we get their hospital experience to count for credits, because we're getting a huge education here. When you have to learn how to manage your meds, when you have to learn how to advocate for yourself, and speak to adults that you don't know, when you have to have this body autonomy and awareness, and language to describe conditions and vocabulary and medical jargon that your peers at your age don't know half of what it is, you what I mean?

This is just one of the reasons why Jennifer gets so frustrated with teachers when they tell the students not to worry about school during treatment. As she explained it, school is everywhere and you are always learning.

Inequities Towards Students with Chronic Health Conditions

Adulthood. One of the first inequities Jennifer pointed out was how adults are the ones making the decisions for the kids, thinking they know what is best for them. In fact, school in general is very adult-centered in her opinion. This was especially apparent during my interview with an elementary school teacher. Throughout the interview, the teacher would continually talk about what was best for the parents, rather than the needs of the student. For example, in one part of the interview she said, "And so I don't feel that schools should step in and make decisions for what's best for parents during this time." All of this relates to the issue of teachers telling their students not to worry about school while they are in the hospital; As Jennifer, a hospital teacher, shared:

You need to center that, you know, get well, be well. But then what? You return to school? And then what, you know what I mean? And then you missed, you know, five units on this content. How do you catch up?

As mentioned earlier in this chapter, 100% of teachers who responded to the survey believed that students should not have to worry about school while they are in the hospital. Being told not to worry about school can then have further consequences. According to Jennifer, when a student is not meeting the same metrics as their fellow classmates, they begin to feel like they do not belong or are less than, which can then lead to further feelings of isolation and depression.

Visible vs. Invisible Symptoms. Jennifer also discussed the problem with visible vs. invisible symptoms. There are students that come back with physical changes, such as being in a wheelchair, using crutches, hair loss, and swollenness from surgeries or other treatments. Then there are those students who come back and look healthy on the outside but are still grappling with having a compromised immune system. It is these students who end up getting push back from schools. Teachers and schools begin to question them. How severe is it? Is it really that bad? What do you mean you can't get out of bed? "If they don't have a doctor's appointment, or they weren't admitted, that's not a real absence" says Jennifer (with a disapproving look on her face). These students may appear healthy, but they may also still be struggling with debilitating migraines or having a catheter underneath their shirt, for example.

Lack of Support. Another issue that Jennifer has witnessed is a lack of support from schools, especially when it comes to providing students with chronic health conditions an aide. These students who require an aide may have trouble with getting from one place to another or reaching around to get something from their backpack. When resources are not available, parents then may not feel comfortable with sending their kid to school. According to Jennifer, "So then they have to stay home. So then they're isolated, so then they fall behind. So then they fall into depression." As Jennifer eloquently put it, when resources are not available you end being forced to navigate "a messed up system that's just messed up."

Changes for The Future

What changes need to be or can be implemented to support these children? Jennifer looks at me. With a look of confidence and seriousness in her voice she says, "abolish the system." To Jennifer, there is only one solution:

We need to abolish the system and build it up again. Rather than, you know, making changes to a broken system, right, with like, you know, just some tape and bubble gum, patching things together.

She comments that she is more a radical thinker, and that in order to fix things we must first break them down and start over. She also thinks we need more compassion:

I think so much of it has to do with compassion, and patience, and humanity, because sort of like this capitalistic system that we live in and this hierarchy of health care, just keeps pushing the needle forward at any, by any means necessary. You just have to keep pushing forward, keep pushing forward, at the detriment of our health and well-being.

When it comes to changes that she could see happening now, Jennifer shared that she would like to see more understanding from schools, as well as allowing more time to grieve. She elaborates: “But really just kind of making space like to grieve, because nobody plans to be sick, nobody plans that.” Everyone is mourning. Kids are mourning the life they thought they were going to have, the routine that kept them grounded, and not being able to participate in things that they wanted to, such as typical activities kids their age get to do. Jennifer points out that if schools can do this, it will be extremely beneficial to these students in more ways than one:

And I think if we can increase our capacity to address that type of grief, and really kind of get to the mental health part of things and center that, then the physical is going to follow also the physical healing and which in turn is going to allow our capacity to participate in school in whatever capacity that we can.

Jennifer finishes by explaining why schools should allow for more time to grieve; she says a lot of students feel like they have to keep pushing through, which in turn leads to less time to fully grieve the things that were lost. Jennifer explains, “That makes trying to have a normal education really hard. Because you’re always fighting to keep moving forward, but maybe you don’t need to move forward.” Maybe the ultimate goal is just getting back to that place where you can enjoy those moments with your family again.

Conclusion

While numerous studies focus on the violations and ambiguities of educational laws and policies protecting students with disabilities, there is much less conversation about the importance of continuing education during treatment and potential changes for the future. This study sought to explore the ongoing issue with educating students with chronic health conditions through the eyes of hospital teachers. Each teacher's story shed light on the inequities they are witnessing firsthand and what changes could be made to fix these problems, based on their own experiences of working with students with chronic health conditions.

The first research question asked, *What policies and laws protect students with disabilities, especially students with chronic health conditions? How are these upheld or not?* All three hospital teachers acknowledged the importance of continuing education during hospitalization. While each teacher did not specifically speak about the individual laws and policies that exist to protect students with disabilities, the inequities that were discussed did illustrate a denial of education from schools, whether it was in the best interest of the student or not. All three participants shared frustrations with a lack of support and communication between patients, families, and schools, and how all of this was leading to feelings of isolation. Two teachers also discussed the discrimination of students with "invisible" symptoms. A school's inability to comprehend or understand the wearing effects of these "invisible" symptoms is making it so that parents do not feel comfortable sending their child back to school. Each teacher expressed a desire to see resources made more accessible to families so that the child is getting the education they have a right to.

The second research question asked, *What can the school and hospital schools do to support these students?* As hospital teachers, they all agreed that it is important to go from a

parent centric way of thinking to a patient centric approach. Each teacher talked about the strategies they use to educate the students they see. These strategies included being creative, using a student's interests to build curriculum, and bringing in games or puzzles. Hospitals can also best support these students by being flexible and supportive. Some days a student might not have the energy to do school, while other days it is a welcomed distraction. When it came to what schools can do to support these students, all three teachers said more understanding and compassion. Empathy can make a huge difference in the long run, especially when a student is healing both mentally and physically.

The third research question asked, *What changes are needed at schools to support this population of students?* Each participant had their own opinions on what changes they would like to see for the future based on their own experiences. Rebecca and Monica both agreed that there was a need for a better way of managing resources for students and their families when it comes to continuing education in the hospital and returning to the classroom. For Jennifer, the more radical thinker, her solution was simply to “abolish the system.” While this is easier said than done, she explained that sometimes it is better to build something back up rather than temporarily fixing the problem. In terms of changes that could be made now, the two main ones seemed to be better accessibility to resources and increased awareness and understanding.

The findings of this study show that there is more to be done to help support students with chronic health conditions, and one of our best resources is hospital teachers. Hospital teachers have a unique perspective, since they are the ones working closely with patients to help them with continuing their education during treatment. They are also able to develop intimate relationships with these students and they want to see their students succeed. They understand the importance of not giving up on a child simply because they were diagnosed with a condition

that interferes with their ability to live a “normal” life. These teachers do not see their students as victims. These teachers understand that it is not fair that these children are having to deal with something that will forever change their lives, but “no one plans to be sick.” No one plans to be diagnosed with a chronic health condition. The teachers involved in this study want schools to understand that education equals hope.

Chapter 5: Discussion

This project showed several consistencies between the findings from the study and those from the literature review. One significant consistency included the conclusion that school is a normalizing experience for students with chronic health conditions. All three hospital teachers stressed the important normalizing aspect of education, and how continuing education during treatment allows a student to “be a kid again.” This is consistent with the findings from the literature review; Barakat (2018) states that “maintaining pre-illness academic achievement and participation in school-related activities is an important goal for youth with cancer and has been related to enhanced quality of life” (p. 1). Findings from the literature review also concluded that returning to school or continuing education during treatment allows students to have a sense of normalcy (Hay et al., 2015). The conversations with the three hospital teachers added to these findings from the literature review, by providing examples of activities and events that were being offered to children within the hospital setting.

Another similarity found in the research and the literature review was that a lack of support from schools leads to increased social difficulties and feelings of disconnection, depression, and isolation. Findings from the literature review revealed that “absenteeism due to therapy regimens and their associated side-effects can lead to increased social difficulties and feelings of disconnection, inhibiting the child’s ability to learn and engage in their education” (Bryan et al, 2021, p. 2). This is consistent with an observation made by one of the hospital teachers. During her interview, hospital teacher Jennifer pointed out that when a student is not meeting the same metrics as their fellow classmates, they begin to feel like they do not belong or are less than, which can then lead to further feelings of isolation or depression. In addition to these findings, Jennifer also noted that a lack of support from schools leads parents to not feeling

comfortable with sending their children to school, which then leads to the student falling further behind and then ultimately feeling more isolated and depressed.

Lastly, findings from both the literature review and research study indicated that assumptions and beliefs have an influence on the ways teachers and schools are supporting students with chronic health conditions. Conversations with the hospital teachers revealed that there is a tendency for schools to “give up” on the student. This is consistent with findings from the literature review. According to Hay, Nabors, Sullivan, and Zygmund (2015), teachers do not feel academically or emotionally trained to support a student with a chronic health condition, and therefore are unsure of how to develop an academic plan that addresses the students’ needs. These beliefs may in turn negatively impact the student when it comes to receiving the support they need to succeed in school. The literature also revealed that teachers “feel mean” (Wilkie, 2012) giving students with chronic health conditions schoolwork while they are in the hospital undergoing treatment. This belief, combined with not feeling academically or emotionally prepared, is one of the main reasons teachers are hesitant to support a student with a chronic health condition in a way that is the most beneficial for that particular student.

Implications of the Literature

Findings from the literature review overlapped several times with the findings from the research. Before conducting research, the aim of this study was to fill in the gap of why schools were not being held accountable for not supporting the education of students with chronic health conditions. While the research was not able to completely fill in this gap in knowledge, it did provide some answers as to what plausible changes could be made in the future.

This project uncovered the issue of “adulthood” as it relates to continuing education while a student is undergoing treatment. This is especially true when it comes to teachers believing that

a student should not have to worry about school while they are undergoing treatment. According to hospital teacher Jennifer, school in general is very adult-centered. But when a teacher makes that decision that a student does not need to worry about school while in the hospital, that leads to further consequences. When a teacher tells a student to focus on their health and not worry about school the student falls further behind. Then when the time comes for the student to return to class they are faced with a “long road of catching up.” As Jennifer points out in her interview, how do you catch up when you have missed so much, and the main reason for this being the case is because the teacher did not want the student to have to worry about school? The problem of adultism needs to be added to the conversation; for example, more perspectives from the students themselves can be incorporated, especially as it relates to their views on continuing education while in the hospital.

Another significant finding was the need for shifting from a parent centric perspective to a patient or student centric one. This issue first became apparent during an interview with an elementary school teacher, who noted that she did not “feel that schools should step in and make decisions for what’s best for parents during this time.” According to hospital teacher Jennifer, this is a common occurrence when students and families are approached about what steps to take in regards to continuing the student’s education in the hospital. During her interview, hospital teacher Monica shared a recent experience she had with a parent, who was beyond shocked at the idea of her daughter doing school while she was there for spinal surgery. This issue continues to persist due to the fact that children are seen as minors and therefore do not have the capability to make decisions for themselves, especially when it comes to serious situations such as treatment for a chronic health condition. This is a perception that society has ingrained in us, hence the sayings “mother knows best” or “father knows best.” According to Jennifer, adults are the ones

making the decisions for the kids, in the hospital and in school, thinking they are the ones who know what is best for them. Looking back at the findings from the literature review, a majority of research articles discussed the importance of continuing education during treatment, but did not take into account the amount of influence parents and other adults have on the access these students have to their education.

Implications for Practice and Policy

Findings from literature review and those from the research for this project can offer teachers the opportunity to better understand how to support students with chronic health conditions. Teachers can also use these findings to better inform themselves about the different ways to support these students, if and when they enter their classroom. All teachers will most likely have at least one student in their classroom with a chronic health condition at some point in their career. Literature and research findings from this project offer a new way of helping teachers to identify the various types of chronic health conditions that exist, and that having a chronic health condition does not simply mean “cancer,” another assumption that was discovered while conducting an interview with an elementary school teacher.

In order to shift from an adult centric perspective to a student centric one, these findings, as they relate to changing existing educational policy, highlight the importance of student voices from an underrepresented perspective. It also shines a light on the importance of the voices of hospital teachers, who have a unique relationship with this population of students. However, a larger sample size from more hospital schools and a survey of more general education teachers is needed in order to warrant state-wide and country-wide changes to relevant policies and laws. There cannot be any change without first pinpointing one small sample or example of a

systematic issue though. This study shows the direct voices of those teachers who are doing the work, and can create authentic solutions from the implementers themselves-the teachers.

Lastly, these findings are directly related to the goal of increasing educational equity for free and appropriate public education for a population of students who need support. Shedding light on how to provide more equitable access to continued education for students with chronic health conditions can also prompt a closer look at how to improve access for all students.

Findings from the literature review and research point out that there is a need for someone or a group of people to act as an in-between (or bridge) for schools and hospitals. Hospital teachers, for example, are one group of individuals who could be considered representatives of the student's home district. School counselors are another group who could be the point of continuing connection and aid in transitioning away from and back to school. Overall, it is the needs of the student that must be put at the forefront in order to solve this ongoing problem.

Limitations of the Study

Several limitations were identified after the completion of this study. First, only three hospital teachers were interviewed in this study. More perspectives are needed to provide a more in-depth look into what inequities are occurring towards students with chronic health conditions. If given another year to conduct research for this study, it would be beneficial for me to speak with more hospital teachers from outside of the Bay Area. Since only five elementary school teachers completed the survey, it would also help to strengthen the study by compiling a larger list of schools to survey. Second, one hospital teacher also worked closely on the creation of a bill that would help to support these students, which could mean that she already had a fairly biased perspective on the issue. In regards to the research site that was chosen for this study, the hospital teachers interviewed were from a large research and teaching hospital that serves a more

diverse population, compared to the school district surveyed which serves a predominantly wealthy white population. Finally, while writing about the finding of the study the main focus was to tell the stories of the hospital teachers based on the research questions. As the researcher, I tried not to reveal too much of my own personal history while speaking to the hospital teachers. I did share my story with them towards the end of the interview, which prompted two of the teachers to share some additional information about what they were seeing as it related to my story. Therefore, my bias and positionality, as the researcher, may have had some influence in regards to what parts of the interview I chose to include.

Directions for Future Research

The question of why schools are not being held accountable still needs to be investigated. The findings from this study did, however, uncover a need for the addition of student voices, especially when it comes to what changes need to be implemented that would be the most beneficial to the students themselves. Future researchers could talk to students inside and outside of the hospital and initiate a discussion about what school means to them. These perspectives would provide a more authentic voice as to why this problem matters in relation to equitable access to education.

Conclusion

Having experienced a similar situation to the ones discussed in this study almost 20 years ago, I was intrigued to see how access to continued education had changed over the years. Unfortunately, research indicated that this was still an ongoing problem for this population of students. The overall intellectual purpose of this study was to better understand the inequities occurring towards students with chronic health conditions, and why they are continuing to happen today. The overall practical purpose of this study, on the other hand, was to initiate a

discussion about what changes can be made to better support students with chronic health conditions, either now or in the near future. In order to initiate this discussion, it was important to first understand the inequities that exist, by hearing from hospital teachers who are witnessing them firsthand. These interviews brought to light the importance of moving from a parent centric perspective to a patient or student centric one. These conversations also raised awareness of the issue of “adultism,” and how many teachers believe it is the parent’s decision as to whether their child continues their education during treatment. All three teachers discussed possible practical solutions to this current issue, which could be used to propose changes to current local policies, or even prompt the creation of a new policy that would protect this specific population of students. Despite the fact that there are numerous research articles from the past 10 years, this is an issue that has not been discussed at length by schools and policymakers. My hope is that this study will prompt further research and discussion. Most importantly though, this research project has also brought awareness of the role of hospital teachers and the important part they play in a student’s education while they are undergoing treatment. All teachers who make a difference in a child's life, such as my third-grade teacher, deserve more recognition and I would like to help make that possible.

References

- Aruda, M. M., Kelly, M., & Newinsky, K. (2011). Unmet needs of children with special health care needs in a specialized day school setting. *The Journal of School Nursing*, 27(3), 209–218. <https://doi.org/10.1177/1059840510391670>
- Bell, J. (2011, April 11). *Understanding adultism*. National Youth Rights Association. Retrieved March 27, 2023, from <https://www.youthrights.org/understanding-adultism/>
- Bradley-Klug, K. L., Sundman, A. N., Nadeau, J., Cunningham, J., & Ogg, J. (2010). Communication and collaboration with schools: Pediatricians' perspectives. *Journal of Applied School Psychology*, 26(4), 263–281. <https://doi.org/10.1080/15377903.2010.518583>
- Bryan, G., Kelly, P., Chesters, H., Franklin, J., Griffiths, H., Langton, L., Langton, L., Wakefield, C. E., & Gibson, F. (2021). Access to and experience of education for children and adolescents with cancer: A scoping review protocol. *Systematic Reviews*, 10(1). <https://doi.org/10.1186/s13643-021-01723-4>
- California Department of Education. (n.d.). Retrieved December 1, 2022, from <https://www.cde.ca.gov/>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE Publications, Inc.
- Eaton, S. (2012). Addressing the effects of missing school for children with medical needs. *Pediatric Nursing*, 38(5), 271–277. <https://pubmed.ncbi.nlm.nih.gov/23189779>
- Every student succeeds act (ESSA)*. U.S. Department of Education. (n.d.). Retrieved December 4, 2022, from <https://www.ed.gov/essa?src=rn>
- Francisco, M. P., Hartman, M., & Wang, Y. (2020). Inclusion and special education. *Education Sciences*, 10(9), 1–17. <https://doi.org/10.3390/educsci10090238>
- Guide to disability rights laws*. ADA.gov. (n.d.). Retrieved December 4, 2022, from <https://www.ada.gov/resources/disability-rights-guide/#:~:text=An%20individual%20with%20a%20disability%20is%20defined%20by%20the%20ADA,as%20having%20such%20an%20impairment.>
- Hay, G. H., Nabors, M. L., Sullivan, A., & Zygmund, A. (2015). Students with pediatric cancer: A prescription for school success. *Physical Disabilities: Education and Related Services*, 34(2), 1–13. <https://doi.org/10.14434/pders.v34i2.19643>

- Hocking, M. C., Paltin, I., Belasco, C., & Barakat, L. P. (2018). Parent perspectives on the educational barriers and unmet needs of children with cancer. *Children's Health Care, 47*(3), 261–274. <https://doi.org/10.1080/02739615.2017.1337516>
- Hopkins, A. F., & Hughes, M. (2016). Individualized health care plans: supporting children with chronic conditions in the classroom. *Young Exceptional Children, 19*(2), 33-44. <https://doi.org/10.1177/1096250614566538>
- Hunt, P., McDonnell, J., & Crockett, M. A. (2012). Reconciling an ecological curricular framework focusing on quality of life outcomes with the development and instruction of standards-based academic goals. *Research and Practice for Persons with Severe Disabilities, 37*(3), 139–152. <https://doi.org/10.2511/027494812804153471>
- Irwin, M. K., & Elam, M. (2011). Are we leaving children with chronic illness behind? *Physical Disabilities: Education and Related Services, 30*(2), 67–80.
- Legislative Alliance for Students with Health Conditions. (2017). School success for children experiencing chronic illness: National recommendations for addressing global barriers. *Physical Disabilities: Education and Related Services, 36*(2), 8–15. <https://doi.org/10.14434/pders.v36i2.24106>
- Liasidou, A. (2014). Inclusive education and critical pedagogy at the intersections of disability, race, gender and class. *Journal for Critical Education Policy Studies, 10*(1), 168–184.
- Losinski, M., & Ennis, R. P. (2018). Teaching students with childhood cancer: It's more than just the disease. *TEACHING Exceptional Children, 50*(5), 292–300. <https://doi.org/10.1177/0040059918765433>
- Lustig, B. C. (2018). Home as the least restrictive environment for students with medical disabilities. *Journal of School Leadership, 28*(2), 259–286. <https://doi.org/10.1177/105268461802800205>
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed.). SAGE Publications, Inc.
- Merriam-Webster. (n.d.). *Disability definition & meaning*. Merriam-Webster. Retrieved December 1, 2022, from <https://www.merriam-webster.com/dictionary/disability>
- Musgrave, J., & Levy, R. (2019). Including children with chronic health conditions in early childhood education and care settings. *Journal of Early Childhood Research, 18*(2), 159–173. <https://doi.org/10.1177/1476718x19875776>

- Nabors, L. A., Little, S. G., Akin-Little, A., & Iobst, E. A. (2008). Teacher knowledge of and confidence in meeting the needs of children with chronic medical conditions: Pediatric psychology's contribution to education. *Psychology in the Schools, 45*(3), 217–226. <https://doi.org/10.1002/pits.20292>
- Peters, S., Hopkins, L., & Barnett, T. (2016). Education for children with a chronic health condition: An evidence-informed approach to policy and practice decision making. *British Journal of Special Education, 43*(2), 142–158. <https://doi.org/10.1111/1467-8578.12130>
- Pohlman, K., Schwab, N., Moses, M., Gilchrest, C., & Schwab, N. C. (2005). Section 504 of the Rehabilitation Act: Determining Eligibility and implications for school districts. *The Journal of School Nursing, 21*(1), 48–58. <https://doi.org/10.1177/10598405050210011001>
- Relajo, D., & Pilao, S. J. (2018). Case study of inclusive education programme: Basis for proactive and Life Skills Inclusive Education. *Journal on School Educational Technology, 13*(3), 19–26. <https://doi.org/10.26634/jsch.13.3.13952>
- Runions, K. C., Vithiatharan, R., Hancock, K., Lin, A., Brennan-Jones, C. G., Gray, C., & Payne, D. (2019). Chronic health conditions, mental health and the school: A narrative review. *Health Education Journal, 79*(4), 471–483. <https://doi.org/10.1177/0017896919890898>
- Smith, E., & Larwin, K. H. (2021). Will they be welcomed in? The impact of K-12 teachers' and principals' perceptions of inclusion of students with disabilities. *Journal of Organizational & Educational Leadership, 6*(3), 1–34. <https://doi.org/https://digitalcommons.gardner-webb.edu/joel/vol6/iss3/1>
- U.S. Department of Education. (n.d.). *A history of the individuals with disabilities education act*. Individuals with Disabilities Education Act. Retrieved December 2, 2022, from <https://sites.ed.gov/idea/IDEA-History>
- White, J. (2015). Students with chronic health conditions, the law and education: A salutary lesson from Australia. *International Journal of Inclusive Education, 19*(12), 1294–1306. <https://doi.org/10.1080/13603116.2015.1057242>
- Wilkie, K. J. (2012). 'Absence makes the heart grow fonder': Students with chronic illness seeking academic continuity through interaction with their teachers at school. *Australasian Journal of Special Education, 36*(1), 1–20. <https://doi.org/10.1017/jse.2012.4>

Appendix A - Letter of Permission



Jan 26, 2023

Marissa Schow
50 Acacia Ave.
San Rafael, CA 94901

Dear Marissa,

On behalf of the Dominican University of California Institutional Review Board for the Protection of Human Participants, I am pleased to approve your proposal entitled *Education as a Source of Hope: An Examination of Teacher Beliefs and the Lack of Support for Students with Chronic Health Conditions* (IRBPHP Initial IRB Application #[11068]).

In your final report or paper please indicate that your project was approved by the IRBPHP and indicate the identification number.

I wish you well in your very interesting research effort.

Sincerely,

Michaela George, Ph.D.
Chair, IRBPHP
Cc: Katie Lewis

Institutional Review Board for the Protection of Human Participants

Office of Academic Affairs · 50 Acacia Avenue, San Rafael, California 94901-2298 · 415-257-1310 www.dominican.edu

Appendix B - Survey Questions

Questions will be emailed to teachers via SurveyLegend. The questions below will be included in the survey.

Survey Questions:

1. Have you had a student in your class with a chronic health condition?
2. In your opinion, should students undergoing treatment for a chronic health condition have to worry about school while they are in the hospital?
3. In your opinion, should schools continue to communicate with families and students during treatment for a chronic health condition?
4. Does your school have out of school programs or other programs to support students with chronic health conditions?
5. In your opinion, should schools and hospitals be in regular communication about a student with a chronic health condition?
6. In your opinion, should students with chronic health conditions be seen as having a disability?
7. In your opinion, is it the school's or the hospital's responsibility to continue to educate a student while they are undergoing treatment?
8. Is there anything else you would like to share regarding support for students with chronic health conditions?
9. If you're interested in participating in a follow-up interview please include your name and email address below.

Appendix C - Interview Questions (Magnolia School District)

The questions below will be used during individual interviews with teachers from the Magnolia School District. Questions will focus on what teachers have seen when it comes to support for students with chronic health conditions. Questions will also focus on what it is or was like to work with a student with a chronic health condition, depending on if a teacher has or has had a student with a chronic health condition.

Individual Interview Questions:

1. How long have you been a teacher in the Magnolia School District?
2. Have you or someone you know had a student with a chronic health condition in the classroom?
3. If yes: what specific practices were put in place to support this student?
4. If no: You have a student who has been recently diagnosed with pediatric cancer. The student is going to be absent for long periods of time as they undergo treatment. What would you do in this situation?
5. What support systems are put in place at your school to support these students?
6. What changes would you like to see at your school, if any?
7. Do you believe it is important to continue to communicate with students and families while a student is undergoing treatment for their condition, and if so, why? And what would that ongoing communication look like?
8. Would you consider a student with a chronic health condition as having a disability, and if so, why?

Appendix D - Interview Questions (The Griffin School)

The questions below will be used during individual interviews with teachers from the Griffin School. Questions will focus on what teachers have seen when it comes to support for students with chronic health conditions. Teachers will also be asked about any inequities they have witnessed from the perspective of the hospital-based school.

Individual Interview Questions:

1. How long have you been a teacher at the Griffin School?
2. What inspired you to become a teacher for a hospital-based school?
3. What is it like to work with children who are undergoing treatment for a chronic health condition in a school setting?
4. What are your thoughts about children continuing their education while in the hospital?
5. What inequalities have you witnessed, if any, toward children with chronic health conditions?
6. How might this school work closely with a student's school district to better support students with chronic health conditions?
7. What changes need to be or can be implemented to support these children?