EDUCATING CHRONICALLY ILL STUDENTS THROUGH THE LENS OF THE
CLASSROOM TEACHER: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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Abstract

Today’s public school teachers face the challenge of educating chronically ill students on a more regular basis. Previous research has focused on the preparedness of teachers, issues regarding re-entry and excessive absenteeism, as well as social and emotional obstacles to student achievement. Absent in the literature is the voice of the classroom teacher and the impact of this phenomenon on them. In better understanding the experience of the classroom teacher, schools can more effectively address the needs of chronically ill students. Utilizing Interpretative Phenomenological Analysis methodology through the theoretical framework lens of Self-Efficacy, this study provided insight into how teachers make sense of their experience in educating a chronically ill student. Data analysis of interview transcripts revealed four emergent themes including Teacher Perspective, Social Considerations, Emotional Considerations and Academic Considerations. Evident in the study is the inconsistency in training and communication that exists from school to school. Implications for future study include narrowing the definition of chronically ill and performing a study that is disease specific, creating a study of one student in one school through the lens of multiple teachers, and to extend the research to elementary school teachers to understand the experience of the classroom teacher with a different student population. Recommendations for practice include having specific professional development about chronic illness, identifying a liaison to serve as a point person between school and family, establishing re-entry meetings to ease transitions, and coordination of regular meetings for stakeholders to address the student’s academic, social and emotional needs, and providing emotional support for teachers of chronically ill students.

Key words: student chronic illness, self-efficacy theory, school re-entry, teacher professional development and interpretative phenomenological analysis
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Dedication

This work is dedicated to my family who has sacrificed so much to support me throughout this process. My wife, Jennifer, who patiently helped our kids with their homework and projects, shuttled them to and from practices and rehearsals, and managed just about everything else in our household, while I locked myself in my office to read, write and study. My daughter, Mollie, who graciously sacrificed time with her dad because she understood that I needed to do my homework, just like her. My son, Connor, who has served as the inspiration for this study and amazed me over the past ten plus years, with his ability to fight disease and inspire others. I love and thank you all for your support and for demonstrating that life is a team sport!
# Table of Contents

Abstract.................................................................................................................................2

Acknowledgement..................................................................................................................3

Dedication...............................................................................................................................4

Table of Contents..................................................................................................................5

List of Tables.........................................................................................................................8

Chapter One: Statement of the Problem..............................................................................9
  Significance of the Problem..................................................................................................11
  Positionality Statement........................................................................................................17
  Research Questions..............................................................................................................19
  Theoretical Framework........................................................................................................20

Chapter Two: Literature Review.........................................................................................23
  Organization.........................................................................................................................23
  Chronic Illness Defined.......................................................................................................24
  Legal Obligation of Public Schools....................................................................................25
  Obstacles to Academic Achievement................................................................................28
  Teacher Perceptions............................................................................................................28
  Re-entry...............................................................................................................................31
  Attendance.........................................................................................................................33
  Social and Emotional Development of Students...............................................................34
  Assistive Technology for Chronically Ill Students............................................................36
  Hospital Schools...............................................................................................................37
  Conclusion.........................................................................................................................38
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Areas of Vulnerability and Limitations</td>
<td>97</td>
</tr>
<tr>
<td>Implications for Future Study</td>
<td>99</td>
</tr>
<tr>
<td>Implications and Recommendations for Practice</td>
<td>100</td>
</tr>
<tr>
<td>Conclusion</td>
<td>105</td>
</tr>
<tr>
<td>References</td>
<td>107</td>
</tr>
<tr>
<td>Appendices</td>
<td>114</td>
</tr>
<tr>
<td>Appendix A (Superintendent Consent Letter)</td>
<td>114</td>
</tr>
<tr>
<td>Appendix B (Call for Participants)</td>
<td>115</td>
</tr>
<tr>
<td>Appendix C (Participant Consent Form)</td>
<td>116</td>
</tr>
<tr>
<td>Appendix D (Interview Questions)</td>
<td>118</td>
</tr>
<tr>
<td>Appendix E (Non-Disclosure Agreement)</td>
<td>120</td>
</tr>
</tbody>
</table>
List of Tables

Table 4.1   Demographics of Study Participants..................................................58
Table 4.2   Student Demographics.................................................................60
Table 4.3   Steps in Reviewing Qualitative Data.............................................64
Table 4.4   Thematic Codes and Occurrences in Data......................................65
Table 4.5   Organizational Chart of Code System............................................66
Table 5.1   Recommendations Connected to Literature and Theoretical Framework...102
Chapter One: Statement of the Problem

Some chronically ill children face the quizzical stares of strangers each day. This is their reality. These children are forced to accept that they may not look like their peers and have different needs and abilities. Attending school for these children should bring normalcy to their lives. It should be a place where they are welcomed, nurtured and educated like everyone else. Unfortunately, this is not happening. Schools are not equipped to educate chronically ill students in the same manner as their peers (Clay, Cortina, Harper, Cocco, & Drotar, 2004). These students receive an education that does not employ best instructional practices and is not designed to fully support their needs (Irwin & Elam, 2011). As chronically ill students enter high school, the struggle for independence and social acceptance are additional pressures they must face. If this problem persists, public schools will continue to systemically deprive chronically ill children from a quality education and perpetuate discriminatory practices.

Chronically ill students must balance hospital visits, physical limitations, and medication side effects, with the academic rigor of school. As difficult as this may be, chronically ill students depend on school for social and emotional development as much as academic achievement. As suggested by Sexson & Madan-Swain (1995), “School attendance for the child who has developed a chronic health problem may be as critical for social survival as medical treatment is for the physical survival” (p. 361).

Previous research about the educational experience of students who are chronically ill has focused on lack of teacher preparation to teach chronically ill students (Olson et al., 2004), scant teacher knowledge about the effects of chronic illness (Clay et al., 2004), the social and emotional demands of chronically ill students (Lynch et al., 1992), and programs that attempt to
ease transitions between home, hospital and school (Sexson & Madan-Swain, 1995; Prevatt et al., 2000). A common thread throughout the research is the inability of school districts to adequately educate chronically ill students.

In addition to the academic program of the chronically ill student, barriers exist that impact the social and emotional development of the student. As identified by Shiu (2004), chronically ill children feel disconnected to peers when returning to school. Sexson and Madan-Swain (1995) suggest that chronically ill children are concerned about being teased upon return to school because they may look different, due to side effects of medication and therapies. Erikson (1963) suggests that adolescence is a critical time in the development of children because this is the period when they develop their own sense of identity. He continues by stating that adolescents have a strong need to belong to a group. As this is critical to the social and emotional development of the chronically ill student, schools need to be prepared to support the needs of their chronically ill students by recognizing teaching practices that are effective and ensuring teacher preparedness to educate all students.

By using qualitative approaches to examine the classroom experience of teachers of chronically ill students, one can better understand the phenomenon of educating chronically ill students through an educator’s lens. This perspective is critical as teachers have multiple opportunities to interact with chronically ill students academically, as well as the ability to assess their interactions socially. Additionally, individuals will be able to identify practices that are well intended, but not grounded in educational research. This knowledge will provide teachers, parents and school administrator’s important information to make program decisions that can positively address the needs of future students with chronic illness.
Significance of the Problem

The advancement of science and medicine has increased the survival rate of children with access to care. As a result of improved medical outcomes, school districts face the challenge of educating students with chronic illness on a regular basis (Sexson & Madan Swain, 1993). The complex needs of the chronically ill student require the coordination of families, healthcare professionals, and school personnel to ensure appropriate programming based on the individual student’s needs.

Students with chronic illness are legally entitled to the same educational opportunities as their peers. Protected by Individuals with Disabilities Education Act of 2004 (IDEA), many students with chronic illness will qualify for an Individualized Education Program (IEP) to ensure special education services are provided to afford students access to the curriculum. For students with chronic illness who do not meet special education requirements, Section 504, of the 1973 Rehabilitation Act and Title II of the American with Disabilities Act may protect their rights. A 504 plan ensures that the needs of students with disabilities are met as adequately as the needs of non-disabled students for all entities that receive federal funds. Title II prohibits discrimination of people with disabilities regardless of whether they receive federal funds. This legislation requires public schools to provide a free appropriate public education (FAPE) for students with disabilities.

A full inclusion model is practiced by most public schools with a goal of providing students with disabilities the same educational experience as like peers, regardless of the disability of the student (Shanker, 1993). Full inclusion in the public school classroom will lead to a greater diversity of students within a school, some with significant needs. As such, there is
an impact on the operation of full inclusion schools, as new administrative policies are required with a greater expectation of teachers. A closer look at IDEA regulations provides a better understanding of the needs of the child with disabilities. IDEA defines a child with a disability as one:

1. With mental retardation, hearing impairments, speech or language impairments, visual impairments, serious emotional disturbances, orthopedic impairments, autism, traumatic brain injury (TBI), other health impairments or specific learning disabilities.

2. Who needs special education and related services because of his/her disability or disabilities (Grice, 2002 p. 7).

There also exists an additional classification under IDEA for children who would be considered Other Health Impaired (OHI). The requirements for these children are defined as:

1. Having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli that results in limited alertness with respect to the educational environment that:
   a. Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, cancer, nephritis, rheumatic fever, and sickle cell anemia; and adversely effects a child’s educational performance (Grice, 2002, p. 8).

According to federal law, a child must meet three conditions to qualify and include:

1. Child must suffer from a chronic or acute health condition,
2. The health condition must cause limited alertness to the educational environment due to limited strength vitality, or alertness or heightened alertness to the surrounding environment, and

3. The child’s educational performance must be adversely affected by the disability (Grice, 2002, p. 8).

Full inclusion model for schools is defined as:

1. A term used by educators to describe a philosophical approach to the education of children with disabilities. This philosophical paradigm maintains that a child with disabilities – even severe disabilities such as profound mental retardation – should be placed in a regular classroom for most or all of the school day (Shanker, 1993; Grice, 2002).

The shift in federal law to include chronically ill and medically fragile students into the classroom has had a significant impact on teachers. Duties beyond educating students are now an expectation of teachers and can include providing medical assistance to a student such as catheterizing, suctioning, diapering and other procedures that do not require a physician.

According to Blakeney (1995), chronically ill children are living longer and medically able to return to school sooner, however, schools have not changed the way they handle these students. Blakeney suggests that schools separate the physical/medical needs of the child from the academic needs, and in so doing, have created a fragmented program for students. Blakeney identifies five principles that are key to a successful reintegration:

1. Preparation by the school begins as soon as possible
2. Planning the educational program for the student needs to include the student and family in the decision making.

3. Each program is individualized to a student's individual needs.

4. Students are encouraged to return to school as soon as possible after discharge/treatment.

5. Medical professionals remain available for consultation with the school.

There is additional research assessing the educational program of chronically ill students, as well as their transition back to school after diagnosis. This research identifies gaps in knowledge concerning teacher preparation to educate the chronically ill student, as well as teacher perceptions about teaching the chronically ill student (Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004). Additionally, various reentry program models have been implemented by school districts but no empirical data supports the efficacy of any specific program. Identified components of various re-entry programs to facilitate transition have been compiled in studies but not achieved by school districts (Kliebenstein & Broome, 2000; Ashton, 2004).

Kathleen Thies (1999) identifies that schools are mandated by federal law to address the needs of all students and suggests that a proactive approach by the school be implemented to support the chronically ill student as quickly as possible. Thies (1999) notes the impact of absenteeism on both the academic and social development of the chronically ill student and identifies the cumulative effect this can have on the child potentially impacting future success. According to Thies, chronic illness heightens anxiety and fatigue and increases absenteeism. To address this, Thies makes five recommendations:
1. The population of chronically ill school aged children is increasing and educational organizations need to collaborate with healthcare agencies, families and other providers of the children to assist the chronically ill child.

2. Schools need to make sure that students with chronic illness are identified correctly within the educational system.

3. All educational personnel must work together in order to assure that the children are recognized and create an approach that works for the student, parents and healthcare providers within the system.

4. Children who miss school as a result of chronic illness must still have equal access to a full and complete education.

5. Educational organizations must begin to think outside the box as they create new ways of working with chronically ill students and their support groups (p. 395).

One way schools are addressing the needs of chronically ill students is through the use of emerging technologies that make curriculum accessible for students and can connect students to schools when they are unable to be there. According to the Massachusetts Department of Elementary and Secondary Education (DESE) Access to Learning Guide, school districts must consider what technologies are available that can best support students. Accordingly, the Massachusetts DESE has provided a guideline that classifies assistive technologies as either low tech, mid tech or high tech. According to Cook and Hussey (2002), no categorization of technologies is static and as the field advances, more options will be available. Some public schools are readily embracing technology to support students who are unable to attend school.
One such technology is VGo, a robotic telepresence with a video screen that enables a homebound student to be seen and heard within a classroom when he/she is unable to attend school. This technology is equally important for the social and emotional connection to peers as it is for the academic connection for the student. Other technologies that schools are incorporating include webcams, and Skype. This technology makes school reintegration easier because it provides a connection between the student and school.

As stated earlier, one of the most important concerns for parents, educators and healthcare professionals is the emotional adjustment of chronically ill students to school and their ability to cope with the pressures of being different. As noted by Sexson and Madan Swain (1995), chronically ill children can have high anxiety related to any physical changes caused by illness as well as limitations in their program or ability to attend school events. This anxiety may also be a result of falling behind academically from excessive absence. The authors warn of school phobia and separation anxiety as real impediments to the social and emotional success of students at school (1995). An equally important concern for students with chronic illness is the perception of other students that can act as an impediment to social adjustment (Chekryn, Deegan, & Reid, 1987). The acceptance of peer groups and the ability to build relationships in school is critical for the development of a student’s self-esteem and an indicator in the overall success of a student.

Understanding the experience of classroom teachers who educate chronically ill students can yield important information. For example, it would provide invaluable insight to future teachers and school administrators about the experience of teaching a chronically ill student through an authentic lens. It could provide data that would impact professional development opportunities for teachers and identify needs within a school or district to better support the
classroom teacher. Additionally, insight from the classroom teacher could provide a new lens for school personnel and service providers to understand the classroom experience of the chronically ill student. This ultimately could lead to new supports that would benefit the chronically ill student academically, socially and emotionally.

**Positionality Statement**

As noted by Carlton Parsons (2005), positionality is a concept that looks at the convergence of race, class, gender and other socially constructed identifiers. I believe that chronically ill students are children within other socially constructed identifiers because they can be categorized by their medical, physical, or emotional needs. In studying this topic I am keenly aware of my personal bias as the parent of a chronically ill child. My experience working with healthcare professionals has framed my perspective about the complex needs of these students.

As the parent of a son who received a bone marrow transplant to treat mixed lineage leukemia (MLL) at age six, and a bilateral lung transplant to combat chronic graft vs. host disease (GVH) at age fifteen, I understand the impact on a family when a child is admitted to the hospital for weeks and months at a time. I have firsthand knowledge of how challenging it is to manage the multitude of doctors who are responsible for the wellness of a chronically ill child, each with a different medical specialty and level of priority. Prolonged care is necessary for chronically ill children and scheduling checkups and therapeutic appointments are important for the child. These appointments frequently happen at the expense of attendance in school, which impacts continuity in instruction and learning. In addition to lengthy hospital stays and frequent visits, I have seen the side effects of medicinal protocols that can alter appearance, stamina and appetite. I have counseled school administrators and teachers about potential long-term learning
disabilities that may develop as a result of radiation my son received prior to his bone marrow transplant.

Finally, I have seen the emotional and social impact that chronic illness has had on my child. His life experience is dramatically different from his peers and social interactions have been limited due to his significant medical needs. I fully recognize that this has made me more empathetic to students in need. My role as dad over the past nine years has dramatically influenced my outlook on life and has enabled me to prioritize health and happiness above all.

In my role as a school administrator in my son’s district, I also have the unique experience of being the principal, and now assistant superintendent, partly responsible for making decisions about his educational plan. Working with colleagues, I have been able to modify his schedule, coordinate tutoring services, and purchase assistive technologies that have helped my son transition in and out of school for the past nine years. I recognize that my position within the district has afforded my son opportunities that other children do not have. Facilitating communication with teachers about academic and social needs or the school nurse about health needs was easy for me as a supervisor in the district.

As an educated white male in a position of authority, I understand the privilege I have and the impact this has had for my son. This privilege has motivated me to study the educational programming of chronically ill children because I feel a professional and moral obligation to help other children who face similar obstacles to learning. I am passionate about my work and believe that all chronically ill children should have a liaison in the school to inform families of available resources and to facilitate learning and social acceptance. My working knowledge of special education laws and educational programming created a distinct advantage for my son.
when compared to other chronically ill children. According to Briscoe (2005), researchers inevitably utilize a lens that is shaped by their own experiences. I cannot identify anything that is more personal or emotional to me than the overall wellness of my son. It will be challenging to ensure my bias does not impact my work and I will need to be reflective throughout the process.

The overarching purpose of this study is to understand the experience of classroom teachers who educate chronically ill students. The intent of the research is to understand how the academic, social and emotional needs of chronically ill students are perceived and met by classroom teachers.

**Research Questions**

Students with chronic illness have complex needs and require the coordination of multiple stakeholders in creating an educational program that supports their academic, social and emotional development. The central question will serve as an anchor from which all research is tied. The sub-questions will provide specific insight into the classroom relationship and experience as perceived by the teacher.

**Central Research Question**

• What is the experience of teachers who educate a chronically ill student in a public high school?

**Sub-questions**

• How do teachers view their ability to educate a chronically ill student?

• How do teachers perceive the training to educate a chronically ill student when compared to the actual experience?
• How do teachers describe the emotional impact of educating a chronically ill student?

Theoretical Framework

To better understand the classroom experience of teachers of chronically ill students, this study will use Bandura’s (1977) self-efficacy theory as the theoretical framework. This section will first provide a brief overview of the framework, followed by the application of the framework to teachers and their motivation. Finally, this section will conclude with an explanation of how this framework relates to the problem of practice, guides the literature review, and influences the research design.

Self-Efficacy Theory Defined

Self-efficacy theory is an appropriate theory to better understand the experience of classroom teachers who educate chronically ill students. This theory is rooted in the work of Bandura’s (1977) larger social learning theory. Specifically, self-efficacy theory focuses on the perceived capability of an individual. Bandura suggests that, “self efficacy is defined as people’s belief about their capabilities to produce designated levels of performance that exercise influence over events that effect their lives (Bandura, 1994, p. 1).” Bandura suggests that there are several types of self-efficacy and that no one definition is all encompassing. Additionally, Bandura believes that a strong sense of self-efficacy can help individuals approach tasks that are difficult.

The root of self-efficacy theory comes from the larger social context theory, which suggests that individuals have choice about their decisions and actions. Bandura identifies several factors that influence the level of self-efficacy an individual will have. He identifies these factors as the triadic reciprocal causation (Bandura, 1997). Specifically, Bandura suggests that the interrelationship between an individual’s past and current behaviors, cognitive factors and
motivation level, and environment, impact how an individual perceives his/her capability to achieve a desired goal.

**Self-Efficacy Theory in the Classroom**

An individual’s belief about their ability to complete a task makes up that individuals level of self-efficacy. According to Bandura (1977), self-efficacy beliefs impact the level of effort and motivation an individual has to succeed in light of obstacles. With a higher level of self-efficacy, an individual is likely to exert more effort and motivation to succeed, even if a task is difficult. With a lower level of self-efficacy, the less likely an individual is to exert effort and motivation particularly when a task is difficult.

In the classroom, this theory is applicable to teachers when looking at an individual’s ability to educate students and improve learning outcomes. Looking at Bandura’s (1977) triadic reciprocal causation belief, the classroom teacher’s self-efficacy level is determined by their previous and current classroom experiences, their previous training and educational background, and the current composition of their class. These external factors will influence the belief of the classroom teacher in their own ability to educate all students in the class.

**Influence on Study**

Self-efficacy theory appropriately fits the goal and design of this study. To better understand the experience of classroom teachers who educate chronically ill students, it is critical to understand the perceptions and experiences of the teacher. As suggested by Bandura (1977), multiple factors influence a teacher’s belief about their own ability to educate students effectively.
In the case of the chronically ill student, additional contextual factors come into play that will directly impact the teacher’s level of self-efficacy. The first factor is the training and experiential knowledge of the teacher in educating a student with a chronic illness. Understanding the impact of medicine and therapies on the physical ability of the student will most certainly impact classroom performance. Another factor that will impact the classroom teacher is the level of autonomy in adjusting curriculum and expectations to best meet the needs of the chronically ill student. Finally, a significant factor that could impact the teacher’s level of self-efficacy is their emotional connection to the student and the desire to support and protect the emotional and social development of the chronically ill student.
Chapter Two: Literature Review

Organization

The advancement of science and medicine has increased the survival rate and outcomes for children with disease. Federal legislation protects the rights of chronically ill students and mandates access to public education and full inclusion in schools. Students who are chronically ill or medically fragile face the challenge of reintegration into school after treatment, as well as obstacles to academic, social and emotional success for several reasons. School districts address the needs of students on a case-by-case basis with varying degrees of success. An additional issue impacting the success of chronically ill students is the preparation and expectation of the classroom teacher about educating chronically ill students as well as the evolving roles and responsibilities for the teacher to provide medical care. The advancement of technology has proved beneficial for some homebound students and has helped ease the transition back to school and closed some instructional gaps for chronically ill students.

This literature review will look at current research focused on the education of chronically ill children from multiple perspectives including teacher, family and district. Research studies have utilized multiple definitions of chronically ill to frame their work. The first section of this review will introduce common definitions that appear in research studies. The next section will look at legislation that protects the rights of chronically ill students and guarantees access to public education. This review will then identify various obstacles to success for chronically ill students in school including teacher preparation and expectations, re-entry after diagnosis and extended absence, and attendance. This review will then identify literature that focuses on the social and emotional development of the chronically ill student, as well as the impact on the family when a child is diagnosed with a chronic disease. Finally, this literature
review will look at options available to chronically ill students when attending school is not a safe possibility.

To best understand the experience of classroom teachers who educate chronically ill students, it is important to identify the role of external constraints and practices that influence teacher behavior and decision-making. Legal obligations, student attendance and local re-entry practices affect the experience of educating chronically ill students. Additionally, the climate and culture of both the school and community will also impact the social and emotional development of the student, which in turn, effects the teachers experience in educating a chronically ill student. Each section of this literature review will frame current knowledge as identified in peer-reviewed studies. This literature review will conclude with a summation of the information as well as the influence of this information on the proposed research study moving forward.

**Chronic Illness Defined**

In looking at the research on chronically ill children, most authors provide a working definition at the outset to establish parameters for their work. The definitions have a common theme of an illness that spans a period of time. The definitions do not all identify hospitalization as a requirement for inclusion. The following definitions have appeared in the research.

According to Thompson and Gustafson (1996), chronic illness is a condition that lasts for a considerable period of time. Chronic illness may require hospitalization for more than one month and generally persists for more than three months in a year. Brown and DuPaul (1999) suggest that chronic illnesses includes diseases that may be fatal or result in compromised mental, cognitive, and/or physical functioning. The authors suggest that periods of hospitalization may result from the disease. Cameron and Gregor (1987) define chronic illness as
a deviation from the normal as a result of “lived experience, involving permanent deviation from the normal, caused by unalterable pathological changes (p. 672).” Shaw, Glaser, Stern, Sferdenschki, and McCabe (2010), suggest that chronic illnesses are long standing and recurring medical conditions that have a continuous effect on an individual’s life.

In addition to establishing parameters in defining chronic illness, most research studies provide specific examples of diseases that are either included or meet the criteria of chronic illness. As identified by Brown, Daly, and Rickel (2007), chronic diseases vary in stability and predictability. Some chronic diseases included in the research include cancer, sickle cell anemia, epilepsy, diabetes, congenital heart disease, cystic fibrosis, chronic renal failure and asthma.

**Legal Obligation of Public Schools**

Educating chronically ill students is a legal obligation of the public school system. Most chronically ill students are classified by one of two legislative acts that protect their individual rights and entitle them to a quality public education. School districts are keenly aware of the laws that govern and protect the rights of all students. As such, most districts have programs and teachers that are specially trained to educate students who qualify for an Individualized Education Program (IEP) or a 504 plan, as outlined in the 1973 Rehabilitation Act. Another potential piece of legislation that protects the rights of chronically ill students is the American with Disabilities Act of 1990.

Prior to the enactment of legislation, the needs of most students with disabilities were not met. These students were not afforded or entitled to public education and were usually excluded from learning. It was the responsibility of the family to find the placement for their child so that individual services and needs could be met. These needs became the financial obligation of the
family with no support from the local school district or federal government (Heaton et al., 2005, Katsiaynnis & Yell, 2000, Kirk et al., 2005).

The Individual with Disabilities Education Act (IDEA), which was passed in 1997 and reaffirmed in 2004 and 2011, is a federal law that governs the educational services provided by public school districts to all disabled students. A free and appropriate education (FAPE) is the central priority of the law (Zirkel, 2007). The range of services includes early intervention, inclusionary practices and therapeutic supports for students identified as disabled. Special education and student services are guaranteed under the Individual with Disabilities Education Act specifically in the section entitled “Other Health Impairment.” The law states:

Limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that – (i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactive disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia; and (ii) Adversely affects a child’s educational performance (IDEA Final Regulations-34 C.F.R. & 300.7 (b) (9).

Section 504 of the 1973 Rehabilitation Act additionally protects chronically ill students, who do not qualify for special education services under IDEA. This federal law states that no person with a disability shall be excluded, denied access or discriminated against by any entity that receives financial funding, including public schools (29 U.S.C. 794 (a) 1973). Therefore, students with a 504 plan are entitled to the same educational opportunities as their peers and it
remains the obligation of the school system to ensure it. Though there is no specific funding to support 504 plans, school systems still are obligated to provide the necessary supports for chronically ill children that have a 504 plan.

The rights of the chronically ill child have been supported in the courts as well. The United States Supreme Court (Cedar Rapids Community School District v. Garret F., 1999), ruled in favor of parents, whose son required health care services during the school day, and believed it was the obligation of the school system to pay for these services. This decision was aligned with a previous federal court ruling, (Timothy W. v. Rochester School District, 1989), in which the court ruled in favor of the parents. This determination held the school district responsible for the cost of all educational programming for handicap children regardless of the severity of the disability.

At the intersection of IDEA and Section 504 for the public schools is the American with Disabilities Act (ADA) of 1990. This law identifies two primary purposes, a national law that eliminates discrimination against people with disabilities and a national law that establishes enforceable standards to address institutions that discriminate against people with disabilities. The American with Disabilities Act in public schools supports both an IEP and a 504 Plan and has helped increase access to facilities and resources for students.

Educating chronically ill students has evolved over time and the role of the school has shifted in light of federal legislation that protects the rights of students with disabilities. Prior to the IDEA and the 1973 Rehabilitation Act, students who were chronically ill were educated at home, usually by parents (Kirk et al., 2005). The advancement of science and medical treatments has led to improved outcomes for children with various chronic illnesses (Sexson & Madan-
Swain, 1993; Thies, 1999; Clay et al., 2004). Therefore, more students with chronic illness are being educated within public schools (Nabors & Lehmkuhl, 2004). In order to most effectively provide this education, research suggests that there are obstacles that school districts need to overcome (Irwin & Elam, 2011).

**Obstacles to Academic Achievement**

**Teacher Perceptions**

On the front line educating chronically ill students is the classroom teacher. Responsible for planning, teaching and assessment, the classroom teacher is a pivotal player in the literature as the overall educational program of the chronically ill child is studied. A closer look at the research identifies factors that impact the classroom teacher’s perception about educating chronically ill students and how these factors impact the actions of the teacher. According to Chesler and Barbarin (1986), a fine line exists for the teacher when balancing how to be helpful to students and families. Teachers are anxious about both the physical and academic needs of their students and need strategies to best support learning in their classroom. In order to understand current practices employed in school districts, it is important to look at the literature to understand the perception of teachers.

An issue that impacts the quality of education afforded chronically ill students is the preparation and perception of the classroom teacher. A pivotal study by Olson, Seidler, Goodman, Gaelic and Nordgren (2004) addressed these issues. The focus of this study was preparedness of teachers to educate chronically ill students. This research highlighted the fact that more than half of the 384 teacher participants in this study identified the need for more training and education to better serve the needs of the chronically ill student. Additionally, this
study showed that the educator’s perception of teaching chronically ill students was mostly positive. There still existed, however, a group of teachers that were concerned about personal liability and the amount of time it would take to educate chronically ill students. This research supports earlier work by Lynch et al. (1993) that identifies half of the teacher participants in a study feeling ill prepared to teach chronically ill students due to a lack of training. This literature identifies gaps in professional development and teacher preparation with regard to educating chronically ill students.

Utilizing a quantitative study, Clay, Cortina, Harper and Cocco (2004), surveyed 476 teachers in ten counties in a Midwestern state to assess their knowledge about chronic illness, and the preparation they had received to educate students with a chronic illness. The results indicated that 98.7% of the staff could identify a child in their school suffering from chronic illness. Further, the study indicated that 60% of the respondents had received no training to educate these students. This lack of teacher training supported previous research in the field by Esperat et al., (1999), Kliebenstein & Broome (2000), and McCarthy et al. (1996). Additionally, the survey revealed that over half of the respondents did not feel obligated to deal with issues of the chronically ill students. Additional research literature identifies the uncertainty of teachers in handling the complex needs of chronically ill students as troublesome (Esperat et al., 1999, Kliebenstein & Broome, 2000). It is expected that every teacher will have a child with medical needs in their classroom at some point of their career (Clay, 2004), therefore, there is a real need for preparation programs and professional development for teachers to improve educational opportunities for students with chronic illness.

Another issue that impacts the educational program for chronically ill students is the level of knowledge of the classroom teacher about a student’s illness. As evidenced in a study by
Moore et al. (2009), educators would appreciate more information from health care providers to better understand the complex needs of chronically ill students. Moore suggests that this information could prove beneficial to improving the learning experience for chronically ill students. This study supports previous research that identifies the teacher’s lack of understanding about the potential cognitive impact of the chronically ill student. For some diseases, cognitive issues develop over time, as a child undergoes treatment (Brown, Sawyer, Antoniou, Toogood, & Rice, 1999). As suggested by Worchell-Prevatt (1998), it may be beneficial for the chronically ill student if information regarding their diagnosis was disseminated to the teacher and the student. Providing information in a controlled manner may help to ease anxiety of both the students in the class and the teacher. Given the various illnesses and the effects on individual students, providing teachers with a clear expectation of potential issues would benefit chronically ill students.

An additional obstacle in educating chronically ill students occurs when classroom teachers are unable to establish clear academic expectations that are attainable. In many cases, the individual needs of the learner are adversely impacted by a lack of knowledge of the classroom teacher. Ashton and Bailey (2004) suggest that inaccurate information on the part of the teacher resulted in goals that were unrealistic and unattainable. The academic needs of the chronically ill student are diverse and research shows that some classroom teachers tend to be either empathetic or indifferent. These polarizing perceptions create an environment that does not adequately support academic achievement (Mukherjee et al., 2000). In a study by Sexson and Madan-Swain (1995), the authors determine that teachers are uncomfortable teaching chronically ill students because teachers are unfamiliar with the medical condition of each student.
Sexson and Madan Swain (1995) suggest that teachers lowered expectations for chronically ill students because of their own preconceived notion about illness. Classroom teachers have limited knowledge about disease and when students struggle, the teacher attributes the problems of the student to the disease and does not provide the necessary intervention and support (Sexson & Madan-Swain, 1993). Additionally, the authors suggest that teachers sometimes have unrealistic expectations of the students that can also lead to frustration for both parties. Sexson and Madan-Swain (1995) suggest that teachers can be overly empathetic and not challenge the student or may act in an overprotective manner which impacts academic performance in the classroom.

**Re-entry**

The type and acuity of disease impacts children differently. Whereas researchers incorporate multiple diseases under the umbrella of chronic illness, the amount of time and therapy required to treat each disease varies. Common in all definitions is the understanding that time out of school will be required for students who are considered chronically ill. The literature suggests that re-entry to school after diagnosis or extended absence impacts both the academic and social and emotional development of the chronically ill student.

According to Sexson and Madan-Swain (1993), chronically ill students face many obstacles when returning to school after an extended absence caused by illness. Missing school proved to be problematic for academic and social reasons, causing issues with self-esteem (Theis, 1999). According to Bloch (1986), 40% of chronically ill students had issues upon returning to school. This research also demonstrated the importance of a re-entry plan as it cited the impact that school attendance, peer relationships and academic achievement had on helping chronically ill students cope with their disease. This is aligned with previous research by Sexson
and Madan-Swain (1993) and Prevatt, Heffer and Lowe (2000), which stated that a successful re-entry correlates to a positive educational outcome. Gartin and Murdock (2009) suggested that school re-entry is most successful when teachers understand the difficulties faced by chronically ill children, including treatment regimens, potential side effects, and the illness in general. This knowledge enabled teachers to adjust expectations and provide the necessary supports and interventions for the chronically ill student.

No mandated protocol for re-entry exists for chronically ill students. Various approaches have been attempted to ease school transitions for chronically ill students. The literature suggests that a team approach is the best model in looking at school re-entry or reintegration (Power, 2003; Harris, 2009). In many schools, the information about a student with chronic illness is shared in a workshop with staff, and the information is specific to a particular student (Prevatt, 2000). Currently, plans to educate students with chronic illness are devised based on what works for parents and students. More deliberate planning needs to occur to ensure appropriate communication between stakeholders exists, and to ensure that realistic expectations in the classroom are set for the student (Irwin & Elam, 2011).

Bruce, Newcombe and Chapman (2012) performed a study that piloted a liaison program for nine children evenly dispersed between elementary, middle and high school. The students had similar oncologic diagnoses and were assigned a liaison that would work with the school, family and student, to ensure communication about the disease, treatment and potential side effects was ongoing. Additionally, the liaison worked with the student to develop academic and social supports as needed. Utilizing a qualitative study, the authors were able to show that improved communication led to decreased absenteeism, less fragmentation in programming, and a better understanding of the student’s needs at school and home (2012). Teacher’s particularly
appreciated having an understanding of the impact of the diagnosis on the student with regard to their academic abilities. Teachers also appreciated the liaison keeping the parents informed about realistic expectations for their child in school (2012).

Though further research is needed, current research suggests positive outcomes for defined re-entry programs. It is logical to assume that successful models and programs would have characteristics that would succeed in many school districts.

**Attendance**

Students suffering from chronic illness experience shifts in chronicity of disease. These shifts impact the wellness of the child and may cause absence from school. Additionally, periods of treatment and therapy will require time in the hospital or at doctor’s appointments, which also impacts attendance. The inability to consistently be in school poses academic, social and emotional obstacles for the chronically ill student.

A primary concern for teachers is the inconsistent attendance of the chronically ill student. Looking at surveys of school attendance, it is evident that students with chronic illness are absent more frequently than their peers (Sexson & Madan-Swain, 1993, 1995). Cook (1985) suggests absenteeism can be impacted by factors including, the child’s response to the chronicity of the illness, the child’s physical capabilities, and the educational level of the caregivers. Typically, when a student returns from absence, the practice is to have them complete work to catch up to the rest of the class. In so doing, educators are compounding the problem of absenteeism, as students are segregated from the class and inevitably miss the current lesson.

Another attendance issue of concern for teachers is the disconnect that exists between the classroom and periods of homebound instruction for the chronically ill student. Too frequently,
school districts utilize arbitrary formulas to determine the amount of instructional time a student with a chronic illness will receive when they are unable to attend school (Irwin & Elam, 2011). This practice creates educational gaps for the student and compromises the course of study experienced by peers. The attempt to satisfy the needs of the chronically ill student when they have missed significant time in school through homebound tutoring is insufficient (Sexson & Madan-Swain, 1995). Compounding the problem of homebound instruction is the rarity of the tutor being able to satisfy highly qualified teacher status, as defined by No Child Left Behind (Irwin & Elam, 2011).

**Social and Emotional Development of Students**

The overall success and wellness of a student is assessed using multiple factors including academic achievement and social and emotional development. For chronically ill students, attending school is important for this development. The literature supports the need for chronically ill students to attend school as regularly as possible.

According to Erikson (1963), adolescence is the period of time when children develop a sense of identity and strive for independence. During this stage of development, the individual wants to belong to society and is beginning to think about future relationships and a career. Adolescents strive to fit in and develop relationships with peers, while seeking sameness in appearance and actions (Erickson, 1963). Adolescents begin to think for themselves and strive to be less dependent upon parents in this stage. In addition to experiencing independence in thought, adolescents begin to change physically and begin to develop their own self-identity (Larson, Richards, Moneta, Holmbeck, & Duckett, 1996).
For the chronically ill student, adolescent development is complicated when emotional issues related to the disease are introduced. Specifically, chronically ill students need to manage feelings of denial, blame, rebellion, acceptance, and death (Bessell, 2001; Shiu, 2004; Worchel-Prevatt et al., 1998). Another issue impacting the social and emotional development of chronically ill children is specific to the level of independence that can be achieved. Chronically ill adolescents are more dependent on parents and family to assist with physical needs as a result of disease (Erikson, 1963).

Research shows that chronically ill students value relationships (Dockett, 2004). The affects of disease, however, impede opportunities for socialization as a result of medical restrictions and lost time at school (Berlin, Davies, Jastrowski, Hains, Parton, & Alemzadeh, 2006). According to a study by Shiu (2004), almost half of the chronically ill students that participated identified that they felt socially disconnected, different from peers and were anxious about returning to school after an extended absence. In a study by Sexson and Madan-Swain (1995), chronically ill students expressed concern about being teased by peers. Chronically ill students want to be accepted by peers and perceived as normal, however, these students are self conscious about physical differences as a result of illness and insecurity (McEwan et al., 2004). In a study by Eklund and Sivberg (2003), research showed that chronically ill students chose not to disclose their disease in an attempt to be perceived as normal by peers.

Being able to attend school is critical to the social and emotional development of a chronically ill child. Katz (1989) suggests that the health care team discuss re-entry to school upon diagnosis with children, because it is a significant part of the overall healthcare plan for the child. Additionally, the notion of returning to school also has a significant symbolic message that the child is well. The school may, in fact, be the only place where a chronically ill student can
feel like a child and not like a patient (Davis, 1989). There are important learning opportunities in school that a chronically ill student cannot experience at home or online, including socializing with peers, developing independence within the school and being in control of decisions in a classroom (Davis, 1989; Blakeney, 1994). The need for an effective transition program for the chronically ill student is evident throughout the literature.

**Assistive Technology for Chronically Ill Students**

As identified by Lee and Templeton (2008), the use of assistive technology is on the rise due to the legal obligation of schools to educate all students coupled with the advancement of technology services and devices. Many diverse options are available to school districts to educate students dependent upon the specific needs of the student. Lee and Templeton (2008) suggest that caregivers and schools need to collaborate to determine the most appropriate form of assistive technology for each student given that student’s ability and need. One factor that hinders the growth for greater inclusion of assistive technology is the cost prohibitive nature of some of the equipment, coupled with the lack of knowledge of the end user. Lee and Templeton (2008) believe that user-friendly equipment that can be easily accessed will provide greater benefits to more students. Additionally, the authors believe that guidelines should be developed for all school districts to ensure consistent interpretation of laws so that all students can have equal access to the assistive technology that they may require.

In a study by Puckett (2004), it was evident that teachers need to be trained about how to use assistive technology because it increased the teacher’s awareness about the capabilities of the technology, thus improving student outcomes. Edyburn (2004) believes that expert training is required for students and staff for the implementation of assistive technology. Edyburn states that
an evaluation of progress is needed to determine the efficacy of implementation of the assistive
technology. Moeller and Jeffers (1996) state that assistive technology can most definitely help
teaching and learning, however, they suggest that assistive technology can be optimized when
careful planning and design are practiced. The growth of assistive technology will only continue
and the impact that it may have for students is evident. Consistent interpretation of mandates
and accessibility for all students is both a fiscal and operational challenge.

Hospital Schools

For some chronically ill students, a public school setting is not achievable. Children who
have been diagnosed with serious illness or who have just undergone major surgery may still
require close immediate follow up in the hospital. For some students, proximity is an issue and
short-term enrollment in a local public school is not practical. In a study by Doering (2008), the
author identified potential threats to students in a public school setting including the fact that
many children who face serious illness have compromised immune systems where a common
cold could be potentially life threatening. Doering (2008) continues and notes that physical
limitations, risk for infection and required follow up appointments with specialists make
attendance in a traditional school setting impossible. Research has established that chronically ill
students who require medical attention face a significant risk of low achievement, minimal
academic accomplishment, and a lack of necessary educational services (Lubker, Bateman, &
Vizoso, 2005).

Hospital schools provide a necessary resource for students. Though it seems
contradictory to think about educating a child who is facing a life threatening disease or surgery,
research suggests education is important for the emotional well being of the child. According to
Harp (2001), hospital schools provide a sense of normalcy to an abnormal situation. As echoed by Lemke (2004) who stated that school services provided by hospital schools are an important factor contributing to the recovery of school aged children. The normalcy of school is a component in the health care plan for a child who is ill. As identified by Doering (2008), the support of teachers in hospital schools is second only to parents, and provides the student with a message of hope and recovery.

In a study by Fritts (2004), the researcher utilized a blended case study to highlight the impact that the diagnosis of cancer had on her family and his teachers. The research identified the importance of educating teachers about the impact of chronic illness and outlined factors to consider when creating assessment and intervention strategies. This research also addressed the effects of cancer on both her now deceased son and the professionals responsible for educating him. This study also identified the absence of research of the lived experience of the teacher and their perception of the experience of educating chronically ill students.

**Conclusion**

Given the research identified in the literature, it is clear that more work needs to be done to ensure equitable educational experiences are afforded students with chronic illness (Irwin & Elam, 2011). Much of this work needs to focus on the expressed concern of the classroom teachers about their preparedness to educate the chronically ill students (Clay et al., 2004). Legislation defends and supports the rights of the chronically ill child, however, a breakdown exists in the actual practice of educating chronically ill students. As identified by Irwin and Elam (2011), chronically ill students are receiving educational services from providers who do not employ best instructional practices and may not meet the requirements of a highly qualified
teacher when it comes to homebound instruction. Finally, the literature suggests the need for a successful re-entry to school so that the chronically ill child can be successful socially and emotionally (Sexson & Madan-Swain, 1993).

Understanding the experience of educating a chronically ill student from the perspective of the classroom teacher is crucial to improving outcomes for students. Authentic perspectives from teachers can improve teacher voice in creating a school professional development plan and creating targeted professional development training programs that will directly benefit students. This study will yield information that will benefit teachers and chronically ill students moving forward, by providing insight into the classroom experience through an academic, social and emotional lens.
Chapter Three: Qualitative Research

The goal of this study is to investigate the experience of classroom teachers who are responsible for educating students with chronic illness. A review of the literature indicates that quantitative research highlights concerns of classroom teachers about preparedness to educate chronically ill students specific to training and understanding the medical needs of the students. The research also highlights obstacles that impact the academic, social and emotional success for chronically ill students in the class. The focus of this study will provide a voice to the classroom teacher to describe their perspective of this phenomenon. The following overarching questions will drive the study.

Central Research Question

• What is the experience of teachers who educate a chronically ill student in a public high school?

Sub-questions

• How do teachers view their ability to educate a chronically ill student?

• How do teachers perceive the training to educate a chronically ill student when compared to the actual experience?

• How do teachers describe the emotional impact of educating a chronically ill student?

Research Methodology

This study employed a qualitative research approach to better understand the experience of the classroom teacher who has taught a chronically ill student. By allowing the perspectives and “voice” of the individual regarding this experience, a qualitative research method will
provide a different perspective than the quantitative research done in the field. According to Creswell (2012), qualitative research is appropriate when the goal of the researcher is to study a group or individuals who have experience with a particular phenomenon. Additionally, qualitative studies are appropriate when a deeper understanding of an experience or phenomenon can only come about in talking with people and providing opportunities for participants to tell their story (Creswell, 2012). Maxwell (2005) states that the strength of qualitative research is the inductive approach utilized by the researcher. The focus on words and not numbers sheds light on social and human problems (Maxwell, 2005). Through these stories and experiences, the researcher is able to better understand complex details that are unique to experiences and are shaped by circumstances.

As the focus of this study is the experience of the classroom teacher who educates chronically ill students, more specifically, how the teacher makes sense of their experience, an interpretative phenomenological analysis is fitting. According to Smith, Flowers and Larkin (2009), an interpretative phenomenological analysis allows the experience of the individual to emerge. Utilizing semi-structured interviews with open-ended questions, teachers were able to describe their experience educating a chronically ill student. Enabling teachers to tell their stories allowed the researcher to identify emergent themes about the experience of chronically ill students (van Manen, 1990). This authentic perspective provided an important lens about the experience of educating a chronically ill student.

**Research Paradigm**

In looking at this problem of practice, it was important to approach this study through a constructivist / interpretivist lens. As identified by Creswell (2007), the Constructivism-
Interpretivism paradigm involves the researcher and the participant collaborating to explore or understand a social or human problem. In looking at the experience of educating chronically ill students it was important to understand various perspectives and priorities as well as consider external factors that impact this experience for the classroom teacher. As such, this constructivist paradigm was most applicable as it provides a lens to better understand the issue, rather than attempting to answer or prove a hypothesis. According to Burrell and Morgan (1979), the interpretive paradigm seeks explanation through the lived experiences of the individual. Additionally, understanding the impact of external factors is in line with Ponterotto’s (2005) definition of constructivism that suggests that social and historical factors may impact research findings.

**Research Tradition**

**Phenomenology**

Phenomenological inquiry is an inductive and descriptive approach to understanding the lived experiences of individuals (Moustakas, 1994). Phenomenology focuses on the essence of an experience that goes beyond initial appearances and beliefs. Central to phenomenological study is the need for the researcher to describe the essence of an experience so that a reflective analysis of the experience is possible (Creswell, 2012). Different theorists have various philosophical assumptions and beliefs about phenomenology, which suggests there is no one uniform interpretation and methodological approach to a phenomenological study.

**Interpretative Phenomenological Analysis (IPA)**

The methodology utilized in this study was Interpretative Phenomenological Analysis (IPA). This methodology is rooted in traditional phenomenological inquiry and is focused on
how individuals make sense of both their personal and social world (Smith, Flowers & Larkin, 2009). IPA distinguishes itself from typical phenomenology in that it focuses on peoples’ ways of thinking, their actions and their motivations (Smith et al., 2009). IPA is interpretative in nature as it acknowledges that there is no clear way to access an individual’s world and focuses on exploring individual experiences as they are lived. The detailed examination of the lived experience of the participant is critical to an IPA study as it is the individual’s interpretation of events and not the events themselves that define experience (Smith et al., 2009).

**Hermeneutics**

This interpretative aspect of phenomenology can be traced back to the early work of Martin Heidegger (1889-1976), who introduced hermeneutics to phenomenology. Heidegger was a student of Edmund Husserl (1859-1938), who is considered by most to be the founding father of phenomenology. Husserl differed from Heidegger in that he believed in a more scientific approach to phenomenology called transcendental phenomenology, which focuses on a rigorous and undivided attention of things as they appear. Heidegger, however, introduces hermeneutics to phenomenology as a way to interpret the experiences. Heidegger suggests that the researcher brings their own perceptions and biases to research and that it is necessary for the researcher to bracket these experiences, so they do not influence the research. By bracketing experiences, the researcher can make new meaning based solely on lived experiences as they occur. IPA research, therefore, introduces the concept of the “double hermeneutic” or two-way interpretation of experience. The first interpretation is the participant making sense of a lived experience and the second interpretation is the researcher making sense of the participant’s recount of the lived experience.
Research Design

Participants

The goal of this study was to better understand the experience for teachers of students who are chronically ill. The focus was on six public high school teachers in Massachusetts. A purposeful sample of six teachers participated in this study and all participants have first hand experience involving the educational program of a chronically ill student. According to Smith and Osborn (2003) utilizing a purposeful sample is consistent with the aim of an interpretative phenomenological analysis research project. To establish clear parameters, chronically ill students were defined as students that have a disease that may be fatal or result in compromised mental, cognitive, and or physical functioning and may result in periods of hospitalization (Brown and DuPaul, 1999).

For the purpose of this study, the researcher identified six high school teachers who were assigned high school aged students who met the above definition for chronically ill. Potential participants received a phone call that provided an overview of the study and the anticipated scope of their participation. During this phone call, participants were advised about an Informed Consent Form (Appendix C) that explained in detail why this teacher had been chosen to participate and what the study involved. The intake phone call also enabled the researcher to gather some background information about each participant and establish an interview date, time and location. The first interview was semi structured and conducted in a comfortable, familiar environment for all participants. This sample size provided an authentic perspective of the experience of teaching chronically ill students from multiple perspectives.
Recruitment and Access

The researcher worked with local school superintendents who share affiliation in a regional superintendent’s association, to identify potential participants for the study. The researcher identified the purpose and scope of the study with the superintendent to gain support and access (Appendix A). The researcher then worked with the superintendent to identify a building administrator within the local high school who distributed the “Call for Participants” (Appendix B) to potential study participants who met the outlined qualifications.

The researcher provided copies of assent / consent forms, IRB protocols as well as a descriptive narrative about the scope and purpose of the study to each superintendent. The researcher met with the high school administrator, as determined by the local superintendent, to provide an overview of the study as well as the “Call for Participants” announcement, and answer any question that the building administrator had specific to the study and potential participants. The administrator then disseminated the materials to potential candidates, who then contacted the researcher directly via telephone to remove the administrator from the process, and to learn more about the study.

Upon agreement to participate in the study, the researcher worked with the teachers to coordinate interview dates, times and locations. Upon completion of the study, the researcher provided an incentive for each participant in the form of a $15 Amazon or Target gift card.

Protection of Human Subjects and Ethical Considerations

As required by the Northeastern University Institutional Review Board, the researcher complied with all regulations and practices to protect the physical, emotional and social well being of all participants (Fraenkel and Wallen, 2009). Additionally, the researcher ensured that
individual’s names who are both directly and indirectly associated with this study remain confidential and that appropriate pseudonyms were used so as not to identify subjects and places. The researcher has successfully completed the National Institutes of Health (NIH) web-based training course entitled “Protecting Human Research Participants” as required by the Northeastern University College of Professional Studies.

The participants in this study were selected purposefully. Participants were advised during each step of the process that they reserve the right to drop out of the study at any point. Additionally, all participants signed an approved consent form and were aware of the scope and commitment to the study, prior to participation. Finally, no research participants were included from the local public school district in which the researcher currently works. The purpose of this was to avoid impacting the data in any way, as the researcher is both an administrator and father of a chronically ill student.

**Data Collection**

The researcher was the primary instrument in the collection of data for this qualitative study (Creswell, 2012). Semi structured interviews were conducted in a familiar setting for the participants to relieve anxiety. The researcher conducted three interviews with each participant and structured the interviews so that the questions scaffold from informal to formal. As identified by Rubin and Rubin (2012), interview questions need to be framed in a manner that will not restrict the participant’s response. To protect against this, the researcher conducted a mock interview with a teacher in his home district who did not participate in the study. This exercise yielded important information about the depth, accuracy and scope of questions and provided an opportunity for revision. Utilizing a responsive interview style (Rubin & Rubin, 2012), the
researcher was able to adjust questions to gain a more complete description of the experience of educating chronically ill students. In this semi-structured format, the researcher was able to reflect upon the responses and seek further information and clarity when necessary (Frankel et al., 2012). The authors advise that the ability of the researcher to expand on topics is important, but they caution that it could impact the consistency between concepts.

The first interview was scheduled to be approximately 60 minutes long. The interview questions built upon the background information that was provided during the intake call. The researcher then asked structural and operational questions about the experience of educating a chronically ill student. These questions focused on the chronically ill student in the teacher’s class and yielded information about class dynamics, academic achievement, attendance, social interactions and anything that was different for the teacher with respect to educating this student. The researcher then asked questions that required the participant to be more reflective in nature. These questions provided a deeper understanding of the experience of the classroom teacher who is responsible for educating a chronically ill student. A sample list of questions is included in the Appendix section (Appendix D).

The face-to-face interview was digitally recorded and professionally transcribed. The researcher took notes as well during the interviews to create follow up questions, points of clarification and to document anything that may need to be revisited. The information was kept confidential and available only to the researcher and Doctoral Advisor.

The second interview occurred via telephone approximately one week later and was approximately 30 minutes in length. This interview began with questions to make the participant feel comfortable. The goal of this second interview was to provide member checking of the
previous transcripts as well as clarification to the first interview. The researcher shared the results of the first interview and allowed the participant to expand upon or clarify any information. Additionally, the researcher shared preliminary themes that emerged and asked for further detail or information about the experience.

**Data Storage and Management**

The researcher hired a professional company to transcribe all interviews. The primary researcher and Doctoral Advisor were the only people with access to this information, which was in a locked file cabinet or on a personal computer that is password protected. Any additional notes or artifacts were also kept in a locked file cabinet in the home of the researcher.

The researcher purchased a subscription to MAXQDA for data analysis purposes. This software program was loaded onto the researchers laptop and transcripts were uploaded to the program by the researcher. The laptop is password protected and was locked in the file cabinet each night after use.

**Data Analysis**

The data analysis process for the IPA study involved a thorough review of both individual interview transcripts and across interviews that produced common themes that describe a perceived experience of each participant with regard to a particular phenomenon. Specific to this study, the participants were public high school teachers and the phenomenon was the practice of educating chronically ill students.

IPA methodology requires the researcher to closely describe and understand the experiences of the participants through their words (Smith et al., 2009). To do this, a structured
and consistent analysis of the data was needed so that themes could emerge. As identified by Creswell (2012), the organization of information is critical to data analysis. As such, the researcher utilized MAXQDA as a tool to upload transcripts before beginning the analysis for coding.

The initial process began with a deep dive into each interview transcript individually. The first step in reviewing the data involved multiple reads of the transcript to understand the data from multiple perspectives (Smith et al., 2009) and noting the perception of the experience. After creating initial codes, the researcher began to categorize text according to themes. This thematic approach to analysis enabled the researcher to move from multiple non-specific themes to emergent themes within a singular transcript. This process was repeated for each individual transcript until a cross analysis of all transcripts was completed. Researchers need to be careful to bracket information accordingly so that each transcript is analyzed as new information and is not coded to fit with previously identified themes (Smith et al., 2009). This process enabled the researcher to identify how the participants make meaning of educating chronically ill students, as well as provide a voice to each participant.

**Trustworthiness and Verification**

Establishing trust with research study participants was paramount to this study and is important in establishing the value of a study (Lincoln & Guba, 1985). To effectively validate the study, the researcher employed multiple strategies including prolonged engagement, member checking, and rich thick description.

**Prolonged Engagement.** Prolonged engagement is when the researcher spends significant time in the field and is able to understand the phenomenon wholly. Specifically,
prolonged engagement requires that the research understand the culture, the social impact and affects of a particular phenomenon. Specific to this study, this researcher has worked in a Massachusetts public high school for the past seventeen years and has been responsible for evaluating teachers for the past thirteen years. Additionally, the life experience of this researcher, as the parent of a chronically ill child for the past ten years has provided experiential knowledge that meets the expectations of prolonged engagement. The professional and personal experience of the researcher will provide validity to the study, as the researcher will be able to detect any anomalies in data. As identified by Lincoln and Guba (1985), a focus on depth over scope will be possible for this study.

**Member Checking.** Upon completion of the research, the participant spoke with the researcher to review data and preliminary themes to ensure accuracy and logical interpretation. According to Lincoln and Guba (1985), this is a critical technique to establish credibility in a qualitative study. Participants had the opportunity to review their information and make corrections to both errors and misinterpretations.

**Rich, Thick Description.** The researcher included a detailed narrative that enabled readers to determine transferability of the information (Creswell, 2013). In order to reduce researcher bias, the researcher outlined his positionality to all research participants at the beginning of the study. Bracketing this information at the outset promoted trustworthiness and reduced any internal threat to validity.

**Limitations.** This study provided a limited view of the experience of educating chronically ill students. The teacher participants were from a similar demographic and the experience studied is limited to six public school teachers in Massachusetts. Trustworthiness and
honesty of the subjects interviewed cannot be controlled, as the interviewer disclosed that he is the parent of a medically fragile child, which may influence participant response.

Another limitation to this study was the chronicity or acuity of disease of each chronically ill student. The accommodations necessary for the student and the impact on the student’s performance and attendance impacted the individual experience of each classroom teacher. The supports available within school districts vary and, as such, impacted the experience of the classroom teacher as well. Available technology and staffing patterns varied between schools as well as the amount of support afforded the classroom teacher. These limitations affected the experience of the classroom teacher.

Additionally, participants in this study were sought with the assistance of local building administrators. Working with these administrators introduced a new level of bias, as the administrators may have been more apt to solicit teachers that involved themselves in the school community, or teachers that are generally positive or have had a positive experience with a chronically ill student.

Conclusion

There is significant research that identifies factors and obstacles to the academic, social and emotional success of chronically ill students. Lost in the research is the individual voice of the classroom teacher. The life and professional experience of this researcher coupled with the referenced work in this study focuses on the relationship between the teacher and student and the achievement of the student. This researcher suggests that providing a voice to the classroom teacher, in a reflective manner, provides insight into the complex relationship of the teacher and student and a teacher’s perspective of educating a chronically ill child. This information can
drive professional development and school practices and create a better overall educational experience for chronically ill students.
Chapter Four: Summary of Findings

The goal of this interpretative phenomenological analysis study was to better understand the perspective of classroom teachers who are responsible for educating chronically ill students. A growing population in public schools as a result of improved medical protocols and advances in science (Sexson & Madan-Swain, 1993); the chronically ill student has distinct needs that warrant an authentic perspective. This growing student population is frequently identified in public school districts by either an individualized education plan (IEP), a 504 plan or a local district health plan. A qualitative approach was appropriate as it allowed for teachers to describe the experience of educating a chronically ill student (Smith, Flowers & Larkin, 2009). Further, an interpretative phenomenological approach specifically enabled teachers to describe how the experience impacted them. As suggested by Smith et al. (2009), a participant’s way of thinking, actions and motivations are unique to IPA and the researcher was able to understand this perspective as a result of in depth conversations over the course of three interviews.

Central throughout the study was the goal to understand the potential impact of educating a chronically ill student academically, socially and emotionally. Utilizing a defined region in Massachusetts, the study was able to examine the experience of public high school teachers who have educated a chronically ill student within the past eighteen months. The definition of chronically ill students targeted students who had an illness for at least three months that impacted their attendance in school. Three high schools were selected for participation and two teachers who worked with the same chronically ill student from each school were interviewed. Each teacher had experienced educating a chronically ill student within the past eighteen months. Understanding that each student’s needs were different, and that each school had different expectations and requirements, this study shed light on the experience of educating a chronically ill student from the perspective of the classroom teacher and emergent themes were prevalent.
Research Questions

Students with chronic illness have complex needs and require the coordination of multiple stakeholders in creating an educational program that supports their academic, social and emotional development. The central question will serve as an anchor from which all research is tied. The sub-questions will provide specific insight into the classroom relationship and experience as perceived by the teacher.

Central Research Question

• What is the experience of teachers who educate a chronically ill student in a public high school?

Sub-questions

• How do teachers view their ability to educate a chronically ill student?

• How do teachers perceive the training to educate a chronically ill student when compared to the actual experience?

• How do teachers describe the emotional impact of educating a chronically ill student?

Data Collection and Results

Recruitment of Participants and Interview Protocol

The researcher targeted a geographic region to recruit potential participants for the study. This was accomplished by identifying a regional special education collaborative in Massachusetts, and targeting member school districts as potential recruiting grounds. This particular collaborative included nine public high schools, of which eight were kindergarten through grade twelve districts and one school was a regional vocational high school. Upon
identification of the region, the researcher solicited participation through a recruitment letter to
the local superintendent of schools requesting permission to contact the local high school
administration to discuss the study (Appendix B). Of the nine schools, one was disqualified
because it is the local district in which the researcher is employed. Five of the remaining eight
districts responded positively with the superintendent giving permission to contact the local high
school principal.

The researcher then emailed four of the five principals to request an in person meeting to
discuss the study and potential recruitment of teachers for participation. One principal chose to
meet individually with the researcher and subsequently granted permission. This principal agreed
to share the Call for Participants with teachers based on the qualifying criteria. The next principal
requested that the high school adjustment counselor attend the meeting to help identify potential
candidates, as the adjustment counselor was best informed about students who would potentially
be identified as chronically ill. This principal also agreed to share the Call for Participants to all
qualified teachers based on the established criteria. The third principal was joined in the meeting
by a high school dean. This principal was new to the high school and did not have the historical
knowledge of students. The dean was assigned the responsibility of distributing the call for
participants to potential teachers of chronically ill students. The final high school meeting was
with the principal and an assistant principal. The principal and assistant principal collaborated
with the recruitment of potential staff and both distributed the call for participants to teachers
who met the outlined criteria.

The researcher received emails as directed in the call for participants from seven potential
candidates from four different schools. The researcher began with three schools that had two
responses from potential participants. Upon receipt of the email, the researcher arranged a phone
call to discuss the focus of the study and to ensure that each participant met the established parameters in the call for participants. The phone call also enabled the researcher to collect some biographical information about each potential candidate. Of the four original schools that were contacted, multiple teachers from only three of the schools responded. The researcher was then able to coordinate a meeting with the six potential participants during a mutually convenient time.

The study involved a total of six participants, two from three different high schools. Participants are assigned a pseudonym (Jane, Sara, Lisa, Jack, Bob, and Mike) according to their gender. The high schools were assigned pseudonyms and will be identified as Northern High School, Central High School and Southern High School in this study. Northern High School is a rural high school, while Central and Southern High School are both suburban high schools.

Description of Participants

Jane. Jane is a veteran English Language Arts Teacher who has worked at Northern High School for the past four years, and has been a teacher for the past ten years. Jane became a teacher because of an opportunity that was presented to her. She had a passion for curriculum and English Language Arts content, but admits that teaching was not a calling for her. She needed a job and health insurance and an opportunity arose. A busy mother of three children, teaching worked for Jane’s schedule and filled a void that came as a result of another employment opportunity expiring.

Jack. Jack is a veteran art teacher who has worked at Northern High School for the past five years. Jack has been teaching a total of ten years and became a teacher after exploring options in the professional industry of graphic arts and photography. Jack had been teaching
adult education courses and learned of a specific outreach program from a local college that connected him with inner city high school students. Jack enjoyed the opportunity to share his excitement about art and how he pursued a career in the field.

**Sara.** Sara is a veteran English Language Arts Teacher who has spent her entire teaching career of ten years at Central High School. Sara has extensive graduate work that includes two master degrees and is nearing completion of her doctorate degree in divinity. Sara became a teacher after working for five years in residence life at a local college. While there, Sara came across a program that incorporated teaching religion to public school students, and it drove her to seek certification to teach. Sara eventually settled on English as her certification track and is particularly interested in working with students as they transition from high school to college.

**Lisa.** Lisa is a young mathematics teacher who has taught for five years, including four at Central High School, which is her alma mater. She is an active participant in the school community and coaches three sports at Central High School. Lisa became a teacher because she had such a positive experience with educators during her tenure as a student at Central High School. Additionally, Lisa comes from a family of educators and feels a responsibility to give back to her community.

**Bob.** Bob is a special education teacher at Southern High School and has been in this school for seven of the twelve years he has taught. Bob comes from a family of teachers and felt a calling to the profession at a very young age. His personal academic experience was challenging as he struggled in school. Bob was committed to earning a degree and getting in to education to be able to help students who, like him, struggle in school. Bob is the lead teacher in the alternative program at Southern High School and is dedicated to his students and work.
Mike. Mike is a special education teacher at Southern High School who carries a caseload of twenty special education students, in addition to teaching small pullout sections of math and science. Dually certified, Mike originally intended on teaching English, however he learned through his college coursework that he was drawn to helping teachers with strategies to reach all learners. Mike is a highly committed professional who remains current in his practice by attending workshops and enjoys connecting with students through after school activities.

General Demographics. As a group, the participants represented a broad demographic. Three of the participants were male and three of the participants were female. The participants ranged in age from mid-20s to mid 40s. The teaching experience of the participants ranged from five years to fifteen years. Four of the participants are parents. Five of the participants have earned a Masters degree and one participant was currently enrolled in a Masters program. Three of the participants identified a family member as suffering from chronic illness. None of the participants have received any specific training or education focused on educating chronically ill students.

In total, seven potential candidates responded to the Call for Participants. The six that were selected were chosen in an effort to provide more than one lens into a specific school. Specifically, three schools had two teachers respond and one school had one teacher respond. The researcher selected multiple participants from the three schools to give a better sense of the experience of teachers within a particular school.
Table 4.1

Demographics of Study Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Subject</th>
<th>Years in Teaching</th>
<th>Highest Level of Education</th>
<th>Relationship to person with Chronic Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jane</td>
<td>ELA</td>
<td>7</td>
<td>Masters</td>
<td>Son</td>
</tr>
<tr>
<td>Jack</td>
<td>Art</td>
<td>10</td>
<td>Masters</td>
<td>None</td>
</tr>
<tr>
<td>Sara</td>
<td>ELA</td>
<td>10</td>
<td>Masters (2)</td>
<td>None</td>
</tr>
<tr>
<td>Lisa</td>
<td>Math</td>
<td>5</td>
<td>Masters</td>
<td>Cousin</td>
</tr>
<tr>
<td>Bob</td>
<td>Sp. Ed.</td>
<td>12</td>
<td>Bachelors</td>
<td>Grandmother</td>
</tr>
<tr>
<td>Mike</td>
<td>Sp. Ed. (Pullout Science)</td>
<td>12</td>
<td>Masters</td>
<td>None</td>
</tr>
</tbody>
</table>

Participant Confidentiality

As outlined in the call for participants, the researcher clearly articulated the goal to keep information confidential. All interviews were professionally transcribed through an online transcription service named rev.com. The researcher required the company to include a non-disclosure agreement (Appendix E), as described to each participant. Additionally, the participants were encouraged to use pronouns or pseudonyms throughout the interview process, and the researcher has assigned pseudonyms to each school to protect confidentiality. After the transcription of the audio files was complete, the researcher deleted the original files. Prior to deletion, audio files were kept on a personal laptop computer that was locked and password protected. In addition to the audio files, all hand written notes, documents and drafts related to
the study were kept in a locked location and will be destroyed after three years per federal regulations. The researcher will also refrain from using an identifying language, names or locations in the written summary of this study.

**Student Confidentiality**

The goal of this study is to understand the perspective of public high school teachers who are responsible for educating chronically ill students, therefore, the researcher was careful with information, so as not to identify any students. When meeting with the high school administrative teams, the researcher requested from the outset that potential students who met the established parameters of chronically ill for this study, not be mentioned by name. Additionally, the researcher assured each participant during the phone interview that the name of the chronically ill student was not important and should not be mentioned during the interview process. Finally, when meeting with school personnel to gather demographic information, the researcher asked questions and kept notes so that no identifying documents would be shared or made public.

Table 4.2

*Student Demographics*

<table>
<thead>
<tr>
<th>School</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern High School</td>
<td>Bulimia</td>
</tr>
<tr>
<td>Central High School</td>
<td>Cancer</td>
</tr>
<tr>
<td>Southern High School</td>
<td>Pompeii Disease</td>
</tr>
</tbody>
</table>
Interview Techniques

Prior to any interviews taking place with participants, the researcher piloted the questions with a local teacher in his current school district who has educated chronically ill students. This practice round of questioning enabled the researcher to modify some of the questions so they were more clearly articulated. Additionally, practicing the interview questions prior to the actual research allowed the researcher the opportunity to refine interviewing skills and listen intently. This experience proved invaluable, as the questions were appropriately refined for participants in the study. Specifically, two original interview questions were framed to solicit a response that addressed the academic, social, and emotional needs of the student separately. This proved difficult for the participant, as there was overlap in the response. Additionally, the participant acknowledged that she felt that she was “forcing” answers to be compliant. Therefore, the researcher decided to frame questions that allowed the participant to choose a direction that would be more open-ended, authentic and valuable.

Upon receipt of correspondence soliciting more information, the researcher was able to call potential participants and discuss the purpose of the study, gather demographic information and clearly define expectations of participants, as well as answer any questions. This first contact was helpful in putting the participants at ease because they knew what to expect during the interview.

The first in person interview occurred in a meeting space within each participant’s school. The high school principal in each case had arranged a location and chose a space that was welcoming and comfortable. Each of the participants was excited to participate in the study and was quick to volunteer when presented the Call for Participants from an administrator. The interviews were collegial and informative and dialogue was natural and relaxed as the
participants were able to speak about a subject that they were passionate about, their own teaching experience. Another reason the interviews went well is because the participants were in control of time. They chose the ideal time that would work for them, when they would not be rushed and could focus on the interview.

Generally speaking, the researcher was able to utilize the semi-structured questions seamlessly as participants easily responded to the question and frequently expanded about their perspective and flowed naturally to the next topic. Occasional redirection was necessary for one participant, and none of the interviews needed to be cut short. The number of questions proved manageable for the participants and the time allotted worked well. As identified by Smith et al. (2012), the researcher encouraged participants to expand upon their answers and share stories or personal experiences. Central to an interpretative phenomenological study, this perspective of story telling and sense making about an experience provides substance to the interview and allows for a more authentic analysis of themes (Smith et al., 2009).

The next step in the interview process consisted of member checking. Utilizing an agreed upon email address, the researcher emailed the professional transcripts and coding information directly to the individual participant. This provided the participant the opportunity to review the interview and become familiar with the overarching themes and codes. After one week, the researcher called each participant to discuss initial reaction to the transcript and to gather additional information. This phone call also provided the opportunity for the researcher to give choice to each participant about which gift card they would prefer, either Amazon or Target. Finally, it enabled the researcher to again thank the teachers for their participation in the study.
Coding

Upon completion of the first interview, the researcher uploaded audio files to rev.com for transcription. Once received, transcripts and spreadsheets from the original phone interview with participants were uploaded to the software program MAXQDA that enabled the researcher to access all pertinent data for analysis in one window. The researcher also uploaded the interview questions to be able to cross reference responses and look for emergent themes.

Phenomenological inquiry is an inductive and descriptive approach to understanding the lived experiences of individuals (Moustakas, 1994). Phenomenology focuses on the essence of an experience that goes beyond initial appearances and beliefs. Central to phenomenological study is the need for the researcher to describe the essence of an experience so that a reflective analysis of the experience is possible (Creswell, 2012). Appropriate for this study through an Interpretative Phenomenological Analysis (IPA), the researcher focused on how individuals made sense of both their personal and social world (Smith, Flowers & Larkin, 2009). IPA distinguishes itself from typical phenomenology in that it focuses on peoples’ ways of thinking, their actions and their motivations (Smith et al., 2009). IPA is interpretative in nature as it acknowledges that there is no clear way to access an individual’s world and focuses on exploring individual experiences as they are lived. The detailed examination of the lived experience of the participant is critical to an IPA study as it is the individual’s interpretation of events and not the events themselves that define experience (Smith et al., 2009). The researcher therefore followed the steps outlined by Smith et al. (2009) in reviewing the data.
Table 4.3. Steps in Reviewing Qualitative Data

<table>
<thead>
<tr>
<th>Sequential Order</th>
<th>Action Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Reading and re-reading</td>
</tr>
<tr>
<td>Step 2</td>
<td>Initial noting</td>
</tr>
<tr>
<td>Step 3</td>
<td>Developing emergent themes</td>
</tr>
<tr>
<td>Step 4</td>
<td>Searching for connections across emergent themes</td>
</tr>
<tr>
<td>Step 5</td>
<td>Moving to the next case</td>
</tr>
<tr>
<td>Step 6</td>
<td>Looking for patterns across cases</td>
</tr>
</tbody>
</table>

The researcher reviewed the transcript and phone interview log from each participant as separate and distinct responses. After reading each transcript twice and reflecting upon the demographic information provided by the participant, the researcher utilized MAXQDA to establish broad based emergent themes as the initial step in first cycle coding. The themes that emerged from the data include Teacher Perspective, Social Considerations, Emotional Considerations and Academic Considerations. Table 4.3 details the thematic codes as well as the number of responses that fit appropriately into each code. For some responses, multiple themes were appropriate as the response categorically represented more than one code. After completion of first cycle coding, the researcher moved to second cycle coding as suggested by Saldaña (2013). Utilizing a pattern coding approach, the researcher was then able to create and populate sub codes within the overarching thematic codes. This approach enabled the researcher to identify commonalities and trends in responses.
After establishing four overarching themes, the researcher more closely analyzed the information and codes and sub-codes within each theme. The Teacher Perspective theme had a total of 380 occurrences. These occurrences fell into the sub-codes Empathy and Compassion (92 occurrences), Individual Beliefs, Opinions and Concerns (122 occurrences), Difficulty of Job (83 occurrences), and Preparedness to Educate Chronically Ill Students (83 occurrences). The Social Considerations theme had a total of 219 occurrences. These occurrences fell into the sub-codes Interactions/Collaboration with Parents (79 occurrences), Interactions/Collaboration with Peers (41 occurrences), Interaction/Collaboration with Staff (50 occurrences), and Struggles Faced by Chronically Ill Student (49 occurrences). The Emotional Considerations theme had a total of 133 occurrences. These occurrences fell into the sub-codes Personal Connection to Student (117 occurrences), Managing Peer Reaction and Needs (10 occurrences), and Emotional Impact on Colleagues (6 occurrences). The Academic Considerations theme had a total of 287 occurrences. These occurrences fell into the sub-codes Responsibilities of the Classroom Teacher (102 occurrences), Modification of Academic Program (98 occurrences), Achievement (69 occurrences), and Impact on End Result (18 occurrences).

<table>
<thead>
<tr>
<th>Emergent Themes</th>
<th>Number of codes identified in data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teacher Perspective</td>
<td>380</td>
</tr>
<tr>
<td>Social Considerations</td>
<td>219</td>
</tr>
<tr>
<td>Emotional Considerations</td>
<td>133</td>
</tr>
<tr>
<td>Academic Considerations</td>
<td>287</td>
</tr>
</tbody>
</table>
### Table 4.5

*Organizational Chart of Code System*

<table>
<thead>
<tr>
<th>Thematic Code</th>
<th>Sub Code</th>
<th>Number of Instances</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Teacher Perspective</strong></td>
<td>Empathy / Compassion</td>
<td>92</td>
</tr>
<tr>
<td></td>
<td>Individual Beliefs, Opinions and Concerns</td>
<td>122</td>
</tr>
<tr>
<td></td>
<td>Difficulty of Job</td>
<td>83</td>
</tr>
<tr>
<td></td>
<td>Preparedness to Educate CI students</td>
<td>83</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>380</strong></td>
</tr>
<tr>
<td><strong>Social Considerations</strong></td>
<td>Interactions / Collaboration with Parents</td>
<td>79</td>
</tr>
<tr>
<td></td>
<td>Interactions / Collaboration with Peers</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>Interactions / Collaboration with Staff</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Struggles faced by CI student</td>
<td>49</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>219</strong></td>
</tr>
<tr>
<td><strong>Emotional Considerations</strong></td>
<td>Personal Connection to Student</td>
<td>117</td>
</tr>
<tr>
<td></td>
<td>Managing Peer Reaction and Needs</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Emotional Impact on Colleagues</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>133</strong></td>
</tr>
<tr>
<td><strong>Academic Considerations</strong></td>
<td>Responsibilities of the Classroom Teacher</td>
<td>102</td>
</tr>
<tr>
<td></td>
<td>Modification of Academic Program</td>
<td>98</td>
</tr>
<tr>
<td></td>
<td>Achievement</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>Impact on End Result</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>287</strong></td>
</tr>
</tbody>
</table>
Data Analysis

The themes and sub-codes identified in Table 4.4 are a result of the iterative process of analyzing data and allowing themes to emerge. The results of this study are based upon the description of the experience of each participant as well as observations by the researcher. Each of these themes and sub-codes will be described in greater detail throughout the remainder of Chapter Four.

Theme One – Teacher Perspective

The teacher perspective theme specifically identifies the personal experiences of educating a chronically ill student, as described by the participants. Shaped by their own moral compass, training, and belief system, this perspective provided voice to the experiential knowledge of the participants and the impact this knowledge had on the experience of educating a chronically ill student. The sub-codes within this theme include empathy/compassion, individual beliefs, opinions and concerns, difficulty of job, and preparedness to educate chronically ill students. As the participants drew upon their own experiences throughout the interviews, an overarching theme related to the impact of these experiences became evident.

The first sub-code within the teacher perspective theme was empathy / compassion, and participants were able to describe specific events and tell stories about their experiences and perspectives. Though the level of empathy varied, each teacher expressed a level of concern for his or her chronically ill student. Jane shared an example of her compassion when she was asked about advice that she would offer teachers who are assigned chronically ill students.

Teach this child. Not even teach this child. Care for this child as you would your own child, or as you would hope that another teacher would your own child. Put your child in
that seat in the room and then think about what you’re doing in your content area…your expectations….your pacing.

The amount of empathy and compassion that teachers have for their students extends beyond the school day. Bob expressed his concern about bringing his work home with him and thinking about the needs of his student each night. As evidenced by his response, Bob has a high level of empathy for this student and is deeply impacted by this experience.

I can’t look at him now and not know that this kid’s life, the future holds something that could be pretty dark….when I make a mistake with this student, I say “Jesus Christ, I mean, this kid, it’s possible that he’s not going to be here in the future and what that anxiety must be like for him.”….I have to be a teacher. It’s not Home Depot. I can’t say go over there on your own. I really need to take this kid through the experience.

Lisa described what it was like to learn that one of her students was diagnosed with a chronic illness. Her response highlights a high level of compassion that was consistent across the participants. This response also depicts how helpless some of the participants felt in being able to meet the needs of their students. She described, “I was nervous. I was scared for her. I had her brother in a different section….I just automatically thought about what I could do to help them to make things better…I don’t know.”

The next sub-code specifically identified the experiential knowledge and belief system of the participants. Categorized as individual beliefs, opinions and concerns, responses in this code support the overarching theme of teacher perspective because they provide a different voice to each teacher, shaped by his or her own story and experience. Individual beliefs, opinions and
concern codes were assigned to parts of the transcript that influenced the actions of the teacher in the classroom. Sara who is struggling to balance everything in her life shared an example of this.

Getting it all done. I have a new baby, I have a four year old, I’m in a grad program and I have a lot of grading to do….My order of important things in my life goes family, students and then my doctorate.

Understanding the impact of individual beliefs, opinions and concerns was important as it also provided insight into how some teachers felt about educating chronically ill students. Jack offered a specific example of this when he was describing how the experience impacted his belief system. He shares a story about an old girlfriend who also suffered from bulimia and says, “One way that it affected my philosophy is that you can’t save people…I used to think that if I can just encourage her enough…I can change her patterns….that wasn’t the case.”

Another common concern that was shared by the participants was the difficulty of their job. As the participants described their experience, a level of frustration was evident about the impact of external factors on their ability to educate all students as best as they can. Whether the factor was a colleague or an expectation, the teachers identified these external factors as being prohibitive to supporting the chronically ill student. Jane provides a great story to highlight this.

The mother became a huge issue because she wanted the girl to eat lunch with me everyday. She wanted me to act like a clinician because part of her recovery plan was that she would have supervised meals….so she was accountable. The mother was like my daughter will eat lunch with this teacher everyday and my principal was like….this is not happening…..so she was eating lunch with her guidance counselor….that didn’t really work either….so it’s an issue.
Specific to the academic needs of the chronically ill student, Mike shares a story about his co-teaching experience that caused him stress.

Co-teaching with science is kind of a struggle because the teacher is very, “Got to prepare these kids for the MCAS, got to do this, got to do that.” She’s less willing to modify things….that’s my challenge right now is working with some teachers is harder than working with others.

The final sub-code in teacher perspective, that highlights the impact of experiential knowledge in educating a chronically ill student, is categorized as preparedness to educate a chronically ill student. One of the specific interview questions asked about prior training and coursework to address the needs of chronically ill students, and each participant identified the need for more training in this area. One consideration is how to address the number of potential illnesses on a broad based level. Jane provides a response that suggests the magnitude of the issue.

I don’t know how effective it would be….how do you teach empathy? You read about experiences, you have experiences, you survive experiences, you become a more empathetic person, but if you only read about them and learn about them, that’s just the first step, really in thirty steps. I don’t even know if PD would make a difference.

Another perspective is offered by Sara that addresses preparedness to educate a chronically ill student on a more personal level. She states, “Had I been called upon to be that shoulder to cry on, I do not know that I would have known the right things to say….I don’t know what I would have done well and what I would have done poorly?”
The teacher perspective theme emerged as participants described their stories and their experience in educating a chronically ill student. This theme captured the beliefs, fears and frustration of the participants.

**Theme Two – Social Considerations**

The next theme that emerged from the interviews was the multiple social considerations that impact the experience of educating a chronically ill student. As participants discussed their relationships with their students and colleagues, as well as their interactions with parents, the social well being of the chronically ill student was a recurring theme. The need to communicate effectively with various stakeholders was evident as the participants shared stories about strategies used to support the chronically ill student. The specific sub-codes that led to the evolution of this theme include interactions/collaboration with parents, interactions/collaboration with peers, interactions/collaboration with other staff, and struggles faced by chronically ill student.

The participants had varied levels of interactions with the parents. For one of the students, parent interaction was readily available as her dad was a teacher in the school. For another student, interactions were frequent as the student was primarily in a substantially separate program with one teacher for multiple subjects. For the last student, all communication was via email and was difficult because the expectations of the parents were greater than what the teachers were able to accommodate. Participants generally appreciated frequent communication with parents as evidenced by Lisa’s response.

Her parents were terrific, and it was always nice to, even when you’re going over tutoring, to start off with a normal day to day conversation with the parents.
Entertainment Weekly type stuff to get them to remember that you are human at the end of the day….because her father was in the building, it was easy to check in.

Being able to communicate in a frequent and timely manner with parents was also a benefit for Bob who shares this story when asked if he had a lot of contact with families.

Yeah. Sometimes daily. If the student is having a really hard time, I’m on the phone with the parent….I had to know what this kid is dealing with….the mother let me know that it was a serious condition. After doing some reading, I felt comfortable enough to say to mom could this be fatal in the end? She was like yeah, it could be.

Another consideration that was addressed by the participants was the need to support the chronically ill student socially and to manage students around them. The participants provided a range of responses that addressed their interactions with peers. As evidenced in the responses, the type of social support was really specific to the condition of the child. For one student, the school rallied around the diagnosis of cancer. For another student, the condition of bulimia and an immediate withdrawal from the school required a different type of social support. For the last student, the disease impacted his motor function and limited his ability to interact socially; therefore, a different level of social support was needed. Each student’s story is different and can best be seen through the description of his or her teachers.

Sara describes the support of the school and community to help a student diagnosed with cancer.

I run the community service club and we had a fundraiser for her. I got a hair salon in town to donate their space and their time…we called it a cutathon. People came in and paid a price and the hair salon donated all of the money to the student to help pay her
medical expenses. So we were able to give 100% of the proceeds to the family, which again made the students feel like they were making a contribution. A number of girls chopped off their hair and donated to Locks of Love. There was a lot of fun stuff going on. She was able to come that day with her family and was able to be at the event and express her gratitude.

For another student who was diagnosed with bulimia, the reaction of the school community was very different. The interaction and collaboration with peers for this student can be heard in a story shared by Jane.

She came back into my class and it wasn’t good. She didn’t talk to any of the kids. She did all of her work and she would talk to me. When she was done her work, she was reading. There was no dead time for her. She couldn’t have it because she didn’t want to deal with anybody.

For the third student who was diagnosed with Pompeii Disease, the social support necessary for successful interaction with peers was quite different. Two participants identify the impact of being in a substantially separate program as an obstacle to overcome. Both participants share stories of strategies they employed to assist this chronically ill student in succeeding socially. Mike describes it best with the following statement.

This kid was downstairs all day and I felt that he needed to come out of that program for one block a day. I suggested that why don’t we try my small group science class…that went well. Academically he wasn’t always doing all of the work because it was a little harder….but at least he was getting exposed to the information and working with kids that he wasn’t necessarily working with downstairs in the other program.
The participants also discussed the frequency of interactions/collaboration with other staff in the building and some described the importance of this collaboration for the success of the student. Jane described a positive relationship with the guidance department in her school and how it was reassuring to know that other professionals were equally concerned for her student.

It became really noticeable and she got quieter and quieter…I called her guidance counselor, who’s awesome…and he said “I’m on it.”….he called me back a couple of days later and told me that she had an eating disorder….I was glad to know that it was on his radar.

For some participants, sharing information in the school could have been more thorough. Specifically, Bob was hoping for more information regarding a specific disease from his school nurse, but it never came. Bob describes the additional time and research he did on his own to better prepare himself to address the needs of his student. When asked about advice he would offer administrators and other professionals in the building, Bob articulates his concern about the lack of shared knowledge about the disease.

Let the teacher know the things that are at stake, the severity, the symptoms, how to help the student cope with some of the things that are happening.

Finally, many of the participants described some of the social obstacles faced by their chronically ill student upon return to school. This is captured by the sub-code struggles faced by chronically ill student, and provides insight into the teacher’s experience of managing the social needs of the chronically ill student. Mike shares a story of dealing with his student who struggled with the reality of his disease that impacted his social success.
He always carried any drama that he had going on in his life into the classroom. Those concerns always had to be addressed first otherwise we’d never get to academic concerns….we had to get the student to a state of mind where he would feel comfortable to do work.

The situation was quite different for Jane, who describes the social regression of her student who returns to school after her treatment at a residential program for people with eating disorders.

There were thirty kids in the class, so that’s a lot of time working with a partner or working in groups. She’s uncomfortable. She was embarrassed.

Each participant was able to describe the social impact of educating a chronically ill student through multiple lenses. For the chronically ill student, the participants described relationships with peers and the struggles faced by the students. For the participants, they described their relationships with other stakeholders and colleagues. Each participant was able to share a story about educating a chronically ill student from multiple perspectives.

**Theme Three – Emotional Considerations**

The next theme that emerged from the interviews was the emotional impact of educating a chronically ill student. The participants shared stories of the impact that this experience had on them as a result of their personal connection to the student. Three sub-codes emerged in the transcript analysis that described the emotional impact of educating a chronically ill student. The sub-codes were personal connection to the student, managing peer reaction and needs, and emotional impact on colleagues. Common among all participants was the personal connection to the student. Lisa describes one of her tutoring sessions with her student who is battling cancer.
Emotionally it was taxing because there were days when I would go over and help her, and I could tell she had, had a bad day…it was emotionally taxing when you see her struggling and there’s nothing you can do to, well, when it feels like there’s nothing you can do.

For Bob, the relationship with his student was emotionally challenging due to the complex needs of his student.

I really like him. He’s a good kid. He’s a smart kid. He’s a very unique kid. When you find yourself in that frustration with him, you look back and go Jesus Christ, this kid. I mean, his future could be pretty bleak.

Jack describes his connection to his student as one that evolved over the subject matter he teaches. Finding common ground with this student and being the resident expert in something that was important to her, enabled Jack to develop a personal connection to her.

When she submitted this last project, I did actually write to her. I knew what the issue was….I’m looking at this piece and I’m really moved by it. I know you’re hurting right now but when you come back to school please drop by and see me….I’m looking forward to seeing you back.

As the participants describe their personal connection to the students, many identified this relationship as a primary reason for becoming a teacher. Each participant was able to tell a specific story about their connection with their chronically ill student and the emotional impact this had on them.
The two other sub-codes were not common across participants and were mentioned specifically by two teachers from the same school. Managing peer reaction and needs and emotional impact on colleagues were responses from participants who had a student diagnosed with cancer in the same building where her father taught. This complex situation impacted two of the participants differently than the other participants. The nature of the disease and the emotional impact in this school was described in greater depth than the emotional impact in the other two schools. As such, it suggests another layer of emotion that must be managed when preparing to educate a chronically ill student. Cancer is a well-known disease that carries an intense level of uncertainty for people. A fear of the unknown for peers and colleagues as well as managing other students in the school who may have had this teacher for class, intensified the experience for these participants.

**Theme Four – Academic Considerations**

The final theme emerged from the data as each participant described how their instructional practices and academic expectations for the chronically ill student changed as a result of diagnosis. Participants shared stories and described the practices they employed to best prepare their chronically ill student academically. Communication about expectations was different in each school, and the participants had varying levels of autonomy to modify curriculum or programming. Their stories describe multiple concerns for the classroom teacher who is responsible for educating a chronically ill student. Four sub-codes emerged from the transcripts that relate to an overarching theme of academic considerations. The four sub-codes include responsibilities of the classroom teacher, modification of academic program, achievement, and impact on end result.
The responsibilities of the classroom teacher code represents the number of mandates and requirements faced by public school teachers daily. This code was assigned to text where the teacher described the complexity of their job in managing students as well as the requirements of their job with respect to mandates and legislation. Additionally, this code was assigned to responses that addressed the local expectation of teachers to provide a rigorous and aligned curriculum. Lisa provides an example of this when asked about programming.

I was still able to meet the standards that were designed for the class. I didn’t take out anything that would be pivotal to moving on the next class.

Mike provided a direct answer when asked to describe the experience of educating a chronically ill student.

Professionally, it’s my job and we can’t exclude those students. We have to do our best to make sure they’re included in everything.

Another recurring point that was raised by the participants was specific to the amount and type of modification to academic programming for chronically ill students. Each participant discussed how he or she modified the program and it was evident that a clear message or quantifiable amount was never communicated. As such, the participants in the study each made decisions about what material to modify or drop entirely for their student. These decisions were made with compassion in mind, as evidenced in the responses. Jane describes the conversation with her student about program modification.

I said to her, “do what you want to do. I don’t care.” I said those words, “I don’t care” and I completely backed off. My expectations were none. Be well and get better. Be happy. That’s it.
Unlike Jane, Jack did not have the option to modify coursework, as his course was an elective and a decision was made by the student’s parents and administration to medically withdraw her from the course. Jack had little input in this decision.

She was just pulled. I mean that’s the thing, you know it was that kind of a big cliff jump decision.

Sara made a curricular decision to protect her chronically ill student. In light of the uncertainty of therapy for cancer, Sara decided to change one of the novels to protect the emotional well being of her student. Sara was more concerned that her student understands the structure of the novel as opposed to the content. Sara shows her compassion as she describes this experience.

My priority was 100% her health, and her emotional health too. I cut one of the books because it was just not, it was about death, so. I got into teaching because I love working with kids and students. My other experience is hospice care and things like that are a priority for me. I want to help kids get through stuff like this.

As readily as the teachers modified curriculum, there was still an overarching concern about student achievement. The participants describe stories of parents with high expectations and students who want to return to normalcy and achieve great things. The participants tell stories and describe the balance between compassion and having high expectations. Responses that focused on the end product or academic expectations were coded as achievement. These codes also support the overarching theme of academic considerations.

Jane describes a difficult relationship with the mother of her student who had not clearly communicated her expectations with the teachers. As curriculum modifications were made, Jane
had to deal with an intense parent who wanted her daughter to be prepared to compete academically with other students who were not having troubles and missing school. Jane describes the high level of academic competition within her school and community. She expresses her concern for students being pushed too hard to achieve. Eventually, the relationship between Jane and her student’s mother was fractured. Jane tells the following story about her communication with the educational liaison at the residential treatment facility that supports her concern about parents pushing students to achieve.

I said to the liaison that she got through the most rigorous part of the course. I can certainly help her catch up when she gets back. I’m not going to worry about it. Well the mother had other ideas. She emailed me and was like “I insist that you send the assignments. (Student) wants to do assignments!”…Then in her 1000 word essay…the girl beautifully satirizes the role of the daughter that gets pushed, pushed, pushed.

Mike discusses his struggle with balancing student achievement and teacher expectations. Specifically, Mike was concerned about the modification of curriculum and believes that he could have covered more material and gone deeper into his subject matter. When asked if he was confident that he could meet the needs of his chronically ill student, Mike states.

I was pretty confident that I addressed the student’s social and emotional needs at an excellent level. I’m pretty confident I helped the student achieve his academic levels but it would have been nice if I could have pushed him more academically….we were dealing with so much socially/emotionally.

The final sub-code addresses the ability of the teacher to keep the chronically ill student academically aligned to the program. Essentially, this code addresses what the teacher hope to
achieve at the outset of this experience, provide the necessary academic support for the chronically ill student so that they are able to return to a comparable academic level as their peers, despite their disease. When asked about the final achievement in her class, Lisa describes how she met the needs for her student after modifying the curriculum.

I got a really nice letter from her when she graduated thanking me for everything. She got a good grade in my class and was able to stay on the honors track after that.

Each participant was able to describe their experience educating a chronically ill student in terms of academic programming, expectations and outcomes. Participants shared stories of the experience that highlight the autonomy that teachers have within their classroom. Communication between stakeholders was varied and as a result, led to some tension for some participants and parents. Ultimately, the teachers provided an academic program that balanced the social and emotional needs of the students with outcomes that matched anticipated expectations.

Summary

This study focused on the experience of classroom teachers responsible for educating chronically ill students in three Massachusetts public high schools. Two English teachers, one mathematics teacher, one art teacher and two special education teachers provided insight about their classroom experience with a chronically ill student. Chapter four highlights emergent themes from the study that evolved from a two cycle coding process. After coding individual transcripts, the researcher was able to compare across participant responses to identify four overarching themes. The stories allowed the voice of each participant to emerge and can be seen in the sub-codes that were categorized as: empathy/compassion, individual beliefs about,
opinions and concerns, difficulty of job, preparedness to educate chronically ill students, interactions/collaboration with parents, interactions/collaboration with peers, interactions/collaboration with other staff, struggles faced by chronically ill students, personal connection to student, managing peer reaction and needs, emotional impact on colleagues, responsibilities of the classroom teacher, modification of academic program, achievement, and impact on end result. These sub-codes enabled the researcher to organize the responses into four themes including Teacher Perspective, Social Considerations, Emotional Considerations and Academic Considerations.
Chapter Five: Discussion of Findings and Implications for Practice

Public schools are legally responsible for providing a free and appropriate education for all students regardless of their individual need or ability (Zirkel, 2007). A growing population that needs to be understood is the chronically ill student. As advances in science and medicine are made, children once categorized as terminal are living longer (Sexson & Madan Swain, 1993). As a result, their complex medical needs impact their ability to develop academically, socially and emotionally with their peers (Irwin & Elam, 2011). The goal of this study was to understand the experience of educating a chronically ill student from the perspective of the classroom teacher and to explore how they make sense of this experience. The following research questions guided the study and allowed the researcher to understand individual experiences and perceptions in how teachers support the chronically ill student.

Central Research Question

• What is the experience of teachers who educate a chronically ill student in a public high school?

Sub-questions

• How do teachers view their ability to educate a chronically ill student?

• How do teachers perceive the training to educate a chronically ill student when compared to the actual experience?

• How do teachers describe the emotional impact of educating a chronically ill student?
Underpinning the findings of this study is Bandura’s (1977) theoretical framework of self-efficacy theory. This theory focuses on the level of motivation an individual has to overcome an obstacle, given their experiential knowledge and individual level of confidence. An interpretative phenomenological lens into this group of teachers provided insight into strategies being employed in various districts as well as the efficacy of these strategies, as perceived by the classroom teacher. The goal of this chapter is to examine the findings of the study more closely through the lens of previous research and the theoretical framework of self-efficacy, as well as explore potential implications to current practice and future research.

**Overview of Findings**

As a result of this study, the researcher identified several findings consistent with each high school teacher who participated in this study.

1. Each teacher prioritized student wellness over academic program. This is evidenced as each participant identified the need to modify classroom expectations and academic coursework for the chronically ill student with whom they worked.

2. The emotional relationship between student and teacher is evident as each of the six participants discussed how they cared for their students and each shared a personal story about their relationship. This level of empathy for the student increased teacher motivation to help the student achieve.

3. Each participant identified the need for further preparation to best be able to educate chronically ill students. As identified in their responses, participants acknowledged that specific training and a comprehensive understanding of the illness should be conveyed to them at the onset.
4. Collaboration between stakeholders in the school was identified by all study participants, as an important piece in addressing the academic and emotional needs of the chronically ill student. Communication about wellness, academic, and social/emotional needs enabled teachers to modify programming to best meet expectations for students.

**Discussion of Research Findings**

The organization of this section will link the findings from the study to previous research from the field. Each finding will then include specific examples linking the experience of the participant to the literature and finding.

**Wellness over Academics**

Each teacher prioritized student wellness over academic program. This is evidenced as each participant identified the need to modify classroom expectations and academic coursework for the chronically ill student with whom they worked.

The academic program for the chronically ill student is difficult to manage. Ashton and Bailey (2004) suggest that teachers have inaccurate information about disease that leads to unrealistic or unattainable goals. Sexson and Madan Swain (1993) contend that teachers lower expectations for students based on their own preconceived notions about illness. They also believe that teachers can be overly empathetic and overprotective, thereby creating lowered academic expectations.

Specific to the academic program, the participants all identified a change in programming for the chronically ill student as a result of diagnosis. None of the participants were told directly
to modify coursework or curriculum, yet most did. Three of the teachers modified the quantity of work and required alternate assignments that addressed the core curriculum. Specifically, the number of readings or assignments was reduced and major themes were minimally addressed. Two of the participants stated that sections of the curriculum were dropped and could be addressed at a later time. One participant stated how his class was dropped entirely and was told that the student could earn this elective credit later on when they were well. These examples support the literature in that teachers have preconceived notions that impact decision-making around academic expectations.

Further, the emotional development of students during their high school years is critical and managing a chronic illness compounds the task. As identified by Shiu (2004), chronically ill students feel socially disconnected and anxious upon returning to school after extended absence. The chronically ill student must also manage internal feelings of denial, blame, acceptance and death (Bessell, 2001; Shiu, 2004) as they develop their sense of identity.

As evidenced in the transcripts, the participants readily discussed the emotional well being of their students. Prioritizing these needs over academic needs, the participants attempted to support the student on an emotional level as best they could, though there were clearly varying levels of comfort from teacher to teacher.

**Relationship to Student**

The emotional relationship between student and teacher is evident as each of the six participants discussed how they cared for their students and each shared a personal story about their relationship. This level of empathy for the student increased teacher motivation to help the student succeed.
A significant factor identified in the literature and supported in the data focuses on the relationship between the teacher and student. As suggested by Chesler and Barbarin (1986), there is a fine line that teachers must balance when it comes to being helpful to students and families. As evidenced in the interviews, each teacher participant expressed empathy and compassion for the student who was suffering from disease. Several participants discussed the personal impact this experience had on them as a professional.

Cook (1985) believes that the school setting is the only place a chronically ill child can feel like a student and not a patient. The data support these statements as each participant identified the social impact of the disease within their class and the school as a whole. Further, the teacher participants shared personal stories of how each school attempted to accommodate the social needs of the chronically ill student with varying degrees of success.

**Teacher Preparation**

Each participant identified the need for further preparation to best be able to educate chronically ill students. As identified in their responses, participants acknowledged that specific training and a comprehensive understanding of the illness should be conveyed to them at the onset.

According to Olson et al. (2004), teacher preparation is an area of concern for the classroom teacher. This research supports the earlier work of Lynch et al. (1993), which specifically identifies the lack of preparation afforded teachers who educate chronically ill students. This sentiment was evidenced in the study as all six participants stated that they had received no formal training about the disease that their student was fighting. This is seen in the
research and is an area of concern moving forward as Clay et al. (2004) suggests that all teachers will have a child with medical needs in their classroom at some point during their career.

Four of the participants also voiced a concern over supporting the emotional needs of the student because they felt ill prepared to do so, while two of the participants believed they were successful. The first teacher approached the experience as if the chronically ill student were her own child. This teacher actually had a daughter who was in the same class as the chronically ill student, so it was easy for her to relate to this student. She acknowledged that her focus was to treat this child as she would want her daughter treated and her high level of empathy was evident throughout the interviews. The second teacher approached the situation as a mentor for the chronically ill student. As an alternative classroom teacher, this individual was confident in his ability to understand external factors that impact his students. This teacher also exhibited a high level of empathy and compassion for the student. The concern of the other four teachers was evident and was clearly articulated in the interviews, and their apprehension was a result of a perceived lack of training and a concern about their level of responsibility to manage the emotional well being of the student.

Collaboration Between Stakeholders

Collaboration between stakeholders in the school was identified by all study participants, as an important piece in addressing the academic and emotional needs of the chronically ill student. Communication about wellness, academic, and social / emotional needs enabled teachers to modify programming to best meet expectations for students.

This is consistent with research by Chesler and Barbarin (1986) that highlights the desire of the teacher to support the student without clearly established expectations agreed upon by all
stakeholders. As suggested by Irwin and Elam (2011), well-intended plans by local administrators can be minimally successful. Prevatt et al. (2000) and Irwin and Elam (2011) identify practices of schools with respect to sharing information that are also problematic for the chronically ill student. Additionally, Irwin and Elam (2011) suggest that schools use arbitrary formulas to determine the amount of instructional time a student needs in tutoring services or programming. Specifically, these scholars identify ineffective communication strategies between stakeholders as problematic for the chronically ill student.

As evidenced in the study, the teacher participants all identified a key stakeholder group with whom they had no contact. Specifically, two of the participants stated that they had no contact with the parents of the chronically ill student. Five out of six participants identified that they had no contact with the school nurse about effects of the disease or potential impact of medical protocols on learning. All six participants stated that they received information about the wellness of the student secondhand, usually from the school’s guidance counselor. The inability to clearly communicate with all stakeholders was a point of frustration for the participants because they were unsure of expectations. Fully understanding the needs of the chronically ill student, as well as those who support him or her, will improve transitions in and out of school and will improve social outcomes for the student (Power, 2003; Harris, 2009).

Research Findings and Teacher Self-Efficacy

An overarching goal of the three research sub questions was to understand how teachers reflect upon their ability to educate chronically ill students and make sense of their experience. During the interview, the participants were provided a brief definition of self-efficacy according to Bandura (1977). They were asked to think about this definition prior to responding to a series of questions aligned to the study sub questions. Specifically, teacher participants were informed
that self-efficacy is the motivation of the individual to overcome a perceived obstacle. This section will describe the self-efficacy level of each participant as they described it and then provide a broader statement about the group, specific to self-efficacy theory.

In looking at the central research question, “What is the experience of teachers who educate a chronically ill student in a public high school?”, in light of the theoretical framework of self-efficacy, it is important to understand the impact of the previous findings and participant responses. Specifically, Bandura’s (1977) triadic reciprocal causation suggests an interrelationship between an individual’s past and current behaviors, cognitive factors and motivation level, and environment that impact the perceived capability to overcome an obstacle. Accordingly, it can be stated that the higher the level of self-efficacy, the more likely an individual is to exert more effort and motivation, particularly when a task is difficult. To better understand the level of self-efficacy of the participants in this study, it is appropriate to identify their individual responses to interview question number 11 (Appendix D) that states, “How confident were you that you could meet the academic, social and emotional needs of the chronically ill student?”

Jane

This mother of three children is empathetic to the needs of chronically ill students. Her own experience as the parent of a chronically ill child impacts her ability and motivation to provide for students. As evidenced in several responses, Jane shows compassion for her student and frequently identifies herself as the mother of a child who was actually in the class with the chronically ill child. Jane modified coursework and was particularly concerned with stress being placed upon the student by her mother who was requesting additional work while the student was
in a treatment center to address her eating disorder. Though Jane did not feel equipped to handle the emotional needs of the student, Jane worked in an environment that supported the social needs of both the staff and student. The intersection of Jane’s life experiences and her work environment positively influenced her ability to address the needs of the chronically ill student. Though she lacked formal training and would have liked more disease specific insight, Jane acted in a motherly way and was confident that she was a positive influence for this student.

**Jack**

Jack is a compassionate teacher who was a stable presence in the student’s life. Jack kept routines in place and did not have an opportunity to modify the academic program, as the student was withdrawn from his class to attend treatment. Jack understood that his class was an elective and that the core subject areas would be the focus for the chronically ill student. His life experience and his first girlfriend who had a similar chronic illness to his student shape Jack’s perspective about this specific chronic illness. Jack is well versed in the needs of student with this particular illness in part due to his previous research and experiences. This life experience influenced Jack’s belief on how supportive and helpful he could be for his student. Jack realized his limitations and believed that the student needed professional help and support, which he did not feel confident in providing.

**Sara**

Sara is a busy professional who has clearly established the priorities in her life family, work and then her own doctoral coursework. Sara’s life experiences have influenced her perspective on life and her own capacity to work with children. Her background with the church and her experience with hospice care shape her compassion and empathy for those in need.
looking at her level of self-efficacy, Sara has a great deal of experience and comfort working with those in need. As such, she is confident in her ability to meet the needs of her students academically and socially. Her experience has also influenced her perspective about the appropriateness of the classroom teacher meeting the emotional needs of a student.

**Lisa**

Lisa is a young professional who wears multiple hats in her role as educator. Lisa acknowledged that her co-curricular experience as a coach for multiple seasons has created connections to students that cannot be made in the classroom. Many of her student athletes seek Lisa out during the school day for a check in. The support that these students need beyond the field has influenced Lisa’s compassion and empathy for students in need. Lisa readily avails herself to her players and this has carried over into the classroom for all of her students. Lisa was also responsible for tutoring this chronically ill student while she was away from school. As such, Lisa went to the student’s house and saw her at some of her most vulnerable times. Though the student wanted to continue with the academic purpose of the visit, Lisa acknowledges that the social connection to the student and the ability to laugh were impactful for her. Lisa has described the experience of educating a chronically ill student as a “growing” experience for her professionally.

**Bob**

Bob is a veteran special educator who is committed to developing his alternative program and helping students with needs. Whether the needs are physical or emotional, Bob’s life experience has influenced his perspective. Bob identified that he was a student with emotional needs in school and that he struggled with bouts of depression. It was his own research into his
family history that identified a familial history with depression. His level of empathy and compassion for students is high and Bob readily references the times he has had to step back and look at the bigger picture emotionally and socially for his students. Bob’s life experience and ability to be successful with his work have influenced his belief in his own ability to help reach all of his students, regardless of their level of individual need.

**Mike**

Mike is a veteran special education teacher who is committed to his work. His level of compassion is influenced by his pride in his role as a special education teacher. Serving as a liaison and case manager for twenty students, Mike enthusiastically shared stories about how he is a collaborative educator who prioritizes the needs of his students. Mike’s confidence in his ability to educate his chronically ill student is evidenced by his advocacy for the student. Mike approached administration to have the student come out of the alternative program and be placed in Mike’s small group science class for one period a day. Mike advocated for this experience because he believed that he could support the student and more importantly, he believed it would improve the emotional and social experience of school for the student.

The results from this study, when viewed through a self-efficacy lens, align with Bandura’s (1977) definition. The first commonality that was evident in the participant responses was the comfort each teacher expressed in being confident to deliver the necessary curriculum to the chronically ill student. This is understandable when using the triadic reciprocal causation of Bandura (1977), as all participants had attained or were in the process of attaining advanced degrees in education, work with children as a career choice, and are surrounded by students and other professionals committed to children each day. Accordingly, there would be a high level of
motivation to ensure access to curriculum for all students, including those chronically ill. The participants in the study all had a high level of self-efficacy with respect to the academic needs of the chronically ill student.

In looking at the social needs of the chronically ill student, it was evident that there was a decrease in the level of self-efficacy of the teacher participants. Two out of six participants felt ill prepared to address the social needs of the student. These participants addressed privacy rights of the student as well as a lack of training to address social needs as factors in their response. Both participants addressed the social needs of the chronically ill student to the best of their ability; however, their confidence in their knowledge and training undoubtedly impacted their effectiveness in meeting these social needs. The other four teacher participants were satisfied with their ability to address the social needs of the students. Two of the teachers shared stories about the fundraisers and benefits that were sponsored by the school to support the chronically ill student and her family. Both teachers were active participants in these social experiences and believe that these events benefitted the chronically ill student and helped her stay connected to the school and her friends. The final two participants discussed their involvement as quiet supporters of their chronically ill students. By making themselves available to the student, these participants believed their attention and support helped the chronically ill students adjust.

The most notable finding was the low level of confidence and self-efficacy expressed by the participants in meeting the emotional needs of the chronically ill student. Each participant expressed a level of empathy for the chronically ill student and the student’s family, however, only one participant felt confident in their training to effectively address the emotional needs of the chronically ill student. This teacher had specific training outside of education, as a hospice worker, and she credited this training as the primary factor why she felt confident. When looking
at the triadic reciprocal causation for the emotional needs of the chronically ill student, the teacher’s work in an environment that supports children, however, the training to work in this environment does not specifically address emotional support for most of the professionals. Though three of the participants have a family member who has or had a chronic illness, the relationship with students is different and two of the participants expressed a concern related to “boundaries” in relationships with students. As such, the level of self-efficacy to address the emotional needs of chronically ill students was the lowest for the participants.

**Credibility and Trustworthiness**

A qualitative study needs to be evaluated with appropriate criteria to ensure the concepts of validity and reliability (Smith, 2012). According to Golafshani (2003), qualitative research should focus on the credibility and trustworthiness of the study as opposed to validity and reliability, which are terms traditionally, used with quantitative research. Accordingly, this qualitative study followed the protocols of an IPA study as defined by Smith et al. (2012). The researcher followed established guidelines for interview, data collection, analysis and interpretation to best understand the perceived experience of public high school teachers in Massachusetts who are responsible for educating chronically ill students. The researcher then used member checking and follow up discussions to ensure accuracy of interpretation and authenticity of information. Specifically, the researcher coded the information after each interview and cross-referenced notes with transcripts to ensure accuracy. Finally, the researcher determined Yardley’s (2000) four principles for assessing quality in qualitative research would be appropriated for this study. These principles include sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance (Yardley, 2000).

**Sensitivity to Context**
This principle focuses on the level of sensitivity shown to the participants, the subject being studied, current research and all information and perspectives gained from participants. For this study, IPA protocols enabled the researcher to work closely with a small group of participants. Multiple discussions including a phone interview, an in person interview, and a follow up phone interview allowed the researcher and participant to build rapport. This rapport created a sense of trust between the researcher and participant and allowed for a high level of sensitivity with respect to information gathered. The researcher showed a high level of sensitivity to the data by quoting participants to provide an authentic perspective and lend voice to the teachers. Additionally, the researcher provided the transcripts and developed codes to each participant so that they could verify accurate interpretation. The sharing of information with each participant shows a high level of sensitivity to the data. Contextually, the researcher shows a high level of sensitivity to the subject by aligning findings and cross-referencing previous research.

Commitment and Rigor

This principle focuses on the commitment with respect to the processes and attentiveness given the collection of data and analysis, as well as the rigor or thoroughness of the study. The researcher showed commitment to the study by working closely with the participants to ensure they were comfortable with each step of the process. Additionally, the researcher provided some latitude during the interview to enable each participant to have a voice and describe his or her personal experience. The researcher showed a high level of rigor by following proper channels of approval within each district beginning with the superintendent, then the school principal before being contacted by potential participants. The researcher followed all IPA protocols, as defined by Smith et al. (2012), to ensure a high level of rigor. Finally, data analysis was a multi step
process that utilized Saldaña’s (2009) coding technique of two-cycle coding. The first step of two-cycle coding was to look for overarching themes that emerged from the transcript. These four themes then enabled the researcher to continue to the second step of two-cycle coding which required greater depth of analysis to identify sub codes within each overarching theme. This technique allowed themes to emerge from the data and demonstrated a high level of rigor.

**Transparency and Coherence**

This principle focuses on the level of clarity in the research process as well as the logic between the study, the findings and write up. The researcher attained a high level of transparency by clearly articulating each step in the research process, detailing steps taken to gain access to school districts as well as access to participants. With respect to the data, the researcher fully identified the procedural steps taken to gather and analyze data as outlined in Chapter 4. The researcher carefully worked towards coherence by meticulously outlining, writing and editing the information. Utilizing the theoretical framework of self-efficacy provided the researcher continuity to reflect upon the data and findings. Further, the study was highly coherent as the researcher was able to connect data to previous research.

**Impact and Importance**

This principle looks at the importance of the information gleaned from the study and the relevance of the information, specifically addressing whether the information is important and useful (Smith, 2012). The results from this study coincide with the literature and may be transferable to other teachers of students who would be considered chronically ill. These results are important as they address a need of teachers who work with a compromised and vulnerable population of students.
Areas of Vulnerability and Limitations

Although the researcher adhered closely to measures to promote a high level of credibility and trustworthiness in this study, areas of vulnerability and limitations emerged throughout the process. One of the primary areas of concern with this study was the transferability of the results of the study to the multiple factors impacting perspective. First, the definition of chronically ill needed to remain broad enough to be able to solicit participants who were responsible for educating this population of student. As such, the level of chronicity varied with each participant, as well as the amount of follow up care required by each student. Another issue regarding transferability was specific to the classroom teacher and his or her certification. The experience of a core subject teacher could be different than the experience of an elective subject teacher, and this was evident in one school, as the chronically ill student was simply removed from the class. Another issue of transferability is specific to the protocols and expectations of each school. School cultures have nuances, and the level of communication and access to resources varies from district to district, based on local priority.

Another potential area of vulnerability relates to privacy and confidentiality. In spite of a thorough explanation by the researcher of intent to protect privacy, teachers in general become hesitant discussing student medical needs. Several of the teacher participants were concerned about HIPPA regulations prior to the study and thought that sharing information was illegal. The researcher clearly articulated at the onset of the study that there was no desire to know any identifying information about the chronically ill student. Although this reassurance was made, it is impossible to know if teachers still withheld stories or modified statements in an effort to protect the identity of his or her student.
Finally, one area of vulnerability was the positionality of the researcher and the impact that this positionality had on the research and interpretation of data. The researcher chose to study public high school teachers who educate chronically ill students as a result of his life experience as the father of a chronically ill student. The researcher acknowledges positionality in Chapter 1, and makes every effort to limit bias by utilizing an interpretative paradigm, as well as self-reflecting throughout the study. Utilizing a critical friend throughout the writing process created an authentic and independent perspective that enabled the researcher to look critically at his work.

The goal of this study was to understand the experience of classroom teachers who educate chronically ill students. The life experience of the researcher impacts his understanding of how teachers make sense of their experience, as the stories and concerns of teachers were easily transferable to the researcher’s personal history as the parent of a chronically ill student who was highly involved in his son’s education. The experiential knowledge of the researcher impacted the level of empathy and compassion he has for the teachers and the difficult responsibilities they have in educating a chronically ill student.

**Implications for Future Study**

As research suggests, educating chronically ill students will be experienced by all teachers at some point in their career due to advances in both science and medicine (Clay et al., 2004). As a result of these advances, it would be beneficial to continue research surrounding chronically ill students and programs that are effective.

One specific study that would add to the scholarship on this topic would be to narrow the definition and scope of chronically ill. The broad based perspectives of teachers were transferable, however, a study of teachers who educate students with one specific illness may
yield results that would provide sound information for teachers who have a similarly diagnosed student. Additionally, by narrowing the definition of chronically ill students, a future study may yield more information about the impact of attendance on the emotional stress faced by classroom teachers with respect to the students well being and the academic requirements that need to be satisfied. Finally, a clearer definition of chronic illness could provide an authentic perspective about the impact of specific medications and therapies that impact student achievement.

Another potential study that would prove beneficial to the research would be a case study of one student and all of his or her teachers. As evidenced in this study, the subject area of the teacher impacted the academic program of the student. Additionally, all teacher participants in this study were willing volunteers. A future study that heard from teachers who were less willing to participate, or a teacher who taught a subject matter that was not prioritized by stakeholders, may offer a different perspective or “voice” to the topic of educating a chronically ill student.

Finally, a study that would add to the research about educating chronically ill students would be to shift the focus to elementary school teachers. One of the major themes that came through in the interviews was the personal connection of the teacher participants to the student. Extending this study to elementary school teachers would provide a different perspective. The amount of contact time and emotional support provided by an elementary school teacher is vastly different from a high school teacher and it would be interesting to note the level of empathy and compassion of this teacher population. This perspective would also provide another viewpoint about the preparedness of teachers to educate a chronically ill student emotionally and socially.

**Implications and Recommendations for Practice**
The results of this study have a direct impact on current practices in place in local public high schools. In thinking about educating chronically ill students, approaches are varied and may not meet the needs of chronically ill students. Specifically, teachers make independent decisions about curriculum modifications, they attempt to address the social and emotional needs of their chronically ill students with various levels of training and experience, and they have questions and concerns about the impact of disease and medicine that are not being addressed. In addition to potential future research, the results of this study validate the implementation of the following recommendations.

The first recommendation is to assess current professional development practices at local schools. Evident in the response of the participants was the lack of a clear plan to address the needs of chronically ill students. In thinking about the academic, social and emotional needs of the students, teacher participants identified a lack of preparation on their end, which in turn impacted their level of self-efficacy and confidence. Addressing the knowledge base of teachers who educate chronically ill students by providing professional development that educates teachers about the disease and the potential impacts, provides a sense of understanding which would better prepare the teachers to educate the whole student. As teachers responded to this during the interviews, three of them acknowledged that the professional development would have to be specific to the student and that any overarching professional development or protocol may not address the targeted needs of the student before them.

The second recommendation as a result of this study relates to the academic needs of the chronically ill student. Teachers need increased communication between stakeholders to better understand the academic expectations and goals of the chronically ill student. If all stakeholders are not aligned, academic programming is the sole responsibility of the teacher and may not meet
the needs of all. Collaboration between stakeholders needs to be consistent, as evidenced in this study as parents and teachers were not always on the same page. School liaison programs have proven successful and would be a way to ensure open communication between home schools. Additionally, a liaison program could also address the communication issue that occurs between professionals in the same school. Establishing a point person to support all stakeholders working with the chronically ill student may increase the overall achievement and development of the student academically, socially and emotionally. As evidenced in this study, a liaison could also prove to be an outstanding resource to support the classroom teacher, thereby increasing the level of self-efficacy of the teacher.

The assessment of current re-entry protocols is a third recommendation to ensure a seamless transition for a chronically ill student when they come back to school regularly, either from home or hospital care. As evidenced in this study, the classroom teachers noticed a social impact on the chronically ill student after diagnosis. This impacted the manner in which the teacher interacted with the student as well as the expectations of the teacher for the student during class. By establishing protocols that support the re-integration of the chronically ill student after diagnosis, schools are also supporting the emotional needs of their teachers who are highly empathetic to the needs of their chronically ill student.

The next recommendation would be to establish a team approach to educating a chronically ill student. A clear concern of the teacher participants was the level of communication that existed between stakeholders. Establishing a regular meeting time in schools that included the student and parents, administration, support services and teachers, would provide a dedicated time for dialogue about expectations and goals. This simple step would allow stakeholders to modify plans and implement changes academically, socially or
emotionally, in a manner that best supports the student. This step would also create an opportunity for questions to be answered, which in turn, would positively impact a teacher’s level of self-efficacy.

A final recommendation would be to provide the necessary support for staff members who are emotionally connected to the students by utilizing the regional crisis response team. One point that was evident in this study was the concern expressed by the teachers about how to best address the emotional needs of the students. The teachers then described how educating a chronically ill student impacted them personally and emotionally. Stories of teachers losing sleep and being worried at home about their chronically ill student supports the need for school districts to find an emotional outlet for the teacher. One recommendation would be to utilize the regional crisis management team to take a proactive approach with educators. This group is reactive by design to a school crisis or death. By proactively meeting with staff at the beginning of the school year, these crisis response counselors could provide support to teachers who are struggling with an emotional attachment to a student. These response teams are generally comprised of counselors who have specific training and live within proximity to the local district.

Table 5.1 summarizes these recommendations and ties them directly to the research that is available, as well as the theoretical framework of self-efficacy as defined by Bandura (1977).

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Connection to Literature</th>
<th>Self-Efficacy</th>
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<tbody>
<tr>
<td>Create targeted professional development for teachers of</td>
<td>As evidenced in several studies, teachers do not feel</td>
<td>The triadic reciprocal causation identifies cognitive</td>
</tr>
<tr>
<td>chronically ill students that educates teachers about the disease, side effects and needs of the student</td>
<td>prepared to educate chronically ill students because they have limited knowledge about disease and impact.</td>
<td>factors and life experience. If these are low to non-existent, teachers will have little confidence in their ability to educate chronically ill students.</td>
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<tr>
<td>Olson et al., 2004 Clay et al., 2004</td>
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<tr>
<th>Establish a school liaison that will be responsible for coordinating information and communication between stakeholders.</th>
<th>As evidenced in the literature, all too often well-intended administrators make plans for educating chronically ill students with little input. Creating a point person to ease communication between stakeholders will increase understanding and knowledge, and improve outcomes.</th>
<th>Improving the confidence and knowledge of the classroom teacher would increase the level of self-efficacy of the teacher. Addressing the “unknown” and having clear expectations would lead to greater confidence in ability to educate a chronically ill student.</th>
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<tr>
<th>Identify protocols for re-integrating students into school after extended absence from disease or therapy.</th>
<th>School re-entry or re-integration is critical for the social success of the chronically ill student. As high school aged students begin to develop independence, chronically ill students may need support from schools based on their battle with disease.</th>
<th>Addressing this issue will alleviate the amount of pressure a teacher feels to address and support all needs of the chronically ill student. By making the obstacle less daunting, a teacher’s level of self-efficacy may increase.</th>
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<tr>
<td>Sexson and Madan Swain (1993)</td>
<td></td>
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<tr>
<td>Prevatt et al. (2000)</td>
<td>Gartin and Murdock (2009)</td>
<td>The personal nature of a regular meeting will impact the level of motivation of the classroom teacher to support the chronically ill student. Additionally, by answering questions and empowering the classroom teacher with more knowledge and confidence, the level of a teacher’s self-efficacy will improve.</td>
</tr>
</tbody>
</table>

| Convene regular meetings of all stakeholders to address communication issues and establish clear expectations and goals | There is a level of uncertainty that exists for classroom teachers about how to appropriate handle the complex needs of chronically ill students. Esperat et al. (1999) Kliebenstein & Broome (2000) | The personal nature of a regular meeting will impact the level of motivation of the classroom teacher to support the chronically ill student. Additionally, by answering questions and empowering the classroom teacher with more knowledge and confidence, the level of a teacher’s self-efficacy will improve. |

| Proactively introduce the regional / local crisis response team to staff at the beginning of the year so that staff are aware of available emotional supports. | Educating a chronically ill student has an emotional impact on teachers. Fritts (2004) | Supporting the emotional needs of teachers will improve the relationship of the teacher with the student and increase the teacher’s confidence in supporting the student. |

**Conclusion**

The aim of this study was to better understand the experience of high school teachers who are responsible for educating chronically ill students. A better understanding of this experience could provide a voice to staff and offer greater insight into the classroom experience of chronically ill students.

This study supported previous research about the experience of educating chronically ill students and teacher participants were able to substantiate much of the scholarship in the literature review. Specifically, it was evident that teachers felt ill prepared to educate chronically ill students and lack the level of professional development to address this need. Also, teacher participants discussed the importance of communication between stakeholders and how a lack of
knowledge about both disease and expectations impacted their priorities for the chronically ill student in the classroom. Finally, teacher participants were able to discuss how educating a chronically ill student impacted them personally and provided anecdotal accounts of their own need for emotional support.

In light of the research findings, public high schools must work on supporting the professional and emotional needs of their teachers, as evidenced by the accounts within this study. Some of the essential experiences that teachers of chronically ill students shared will help readers understand the sensitive and critical relationship of teacher to student. In addition, teachers’ understanding of their ability to support this fragile student population is an important area of research. This study can potentially lead to further studies that investigate the perspective of classroom teachers responsible for educating chronically ill students.
References


Dockett, S. (2004). ‘Everyone was real happy to see me’: The importance of friendships in the return to school of children with chronic illness. *Australian Journal of...*
Early Childhood, 29(1), 27-32.


Retrieved from http://www.nasponline.org/resources/principals/

Chronic_Illness_Mar10_NASSP.pdf


Appendix A

Letter to Superintendent of Schools

School District Heading

Dear Superintendent,

As part of my doctoral studies at Northeastern University, I will conduct a research study that addresses an identified problem of practice in education and contributes to the field of study. I am writing to request permission to conduct an interview with a high school teacher in your district. This letter outlines my intentions and presents the context for the study.

The problem of practice that I seek to address is the complex issue of educating chronically ill students. Current research highlights the obstacles that impede success academically, socially and emotionally for this population of students, including a void in reintegration to school after extended absence or treatment. The need for coordination between stakeholders is evident, and the classroom teacher has a critical perspective that needs to be heard. The aim of this study is to better understand the teacher’s experience in educating chronically ill students.

Utilizing qualitative research practices, data will be collected through two in-person interviews and the responses will be professionally transcribed, coded and evaluated for emergent themes. An interpretative phenomenological analysis design for the study will yield an authentic lens of how teachers perceive their experience educating chronically ill students.

It is my contention that the research will provide insight into the classroom experience for teachers and provide voice to educators. Information from this study may create a transferable framework for professional development and administrative protocols that can be applied in a variety of school settings regardless of content or discipline. It is my hope that this study will make a positive contribution to the field of education and benefit both teachers and chronically ill students.

If you have any questions regarding this study, please contact me directly at (978) 877-9433 or via e-mail at flanagan.mic@husky.neu.edu, or my Doctoral Advisor, Dr. Carol Young at c.young@neu.edu or 508-587-2834. Thank you for your continued support. I look forward to hearing from you regarding this request for permission.

Sincerely,

Michael Flanagan
Appendix B

Call for Participants

A study is being conducted to better understand the experience of classroom teachers who educate chronically ill students.

In order to participate, individuals must be licensed Massachusetts public high school teachers who have taught a high school aged chronically ill student within the past eighteen months. In an effort to establish some working parameters, a chronically ill student is defined as a student who has been diagnosed with an illness that lasts for more than three months of a year, and may require hospitalization.

The study consists of a brief (5 – 10 minutes) phone interview to ensure qualifications are met to participate in the study and two in person interviews (45-60 minutes), which can be conducted at your convenience and at a location of your choice. Participants who complete the interviews will receive a $25 gift card to Amazon.com.

If you are eligible and willing to participate, or know someone who may be interested in participating, please email Flanagan.mic@husky.neu.edu or call (978) 877-9433 for more information.

Confidentiality of all parties is guaranteed. No identifying information will be published or shared with others.
Appendix C

Participant Consent Form

Northeastern University, Department of Education

**Name of Investigator(s):** Dr. Carol Young (Principal Investigator), Michael Flanagan (Student Researcher)

**Title of Project:** Educating Chronically Ill Students Through the Lens of the Classroom Teacher: An Interpretative Phenomenological Analysis

**Request to Participate in Research**
We would like to invite you to take part in a research project. The purpose of this research is to better understand the experience of classroom teachers who are responsible for educating students with chronic illness.

**You must be at least 18 years old to be in this research project.**

Your participation in this study is voluntary and you may choose to withdraw at any time. If you agree to participate, you will receive an intake phone call that will last approximately 5-10 minutes to provide background information. You will then participate in a semi-structured interview to answer approximately 15 questions. This interview will last approximately 60 minutes. You will then be asked to participate in a second interview to clarify information and validate accuracy of data, and this interview will last approximately 45 minutes.

**There are no foreseeable risks or discomforts to you for taking part in this study.**

**There are no direct benefits to you for participating in this study.** Your participation, however, may provide insight about strengths and gaps that currently exist in educating chronically ill students.

**Your part in this study will be handled in a confidential manner.** The Principal Investigator and Student Researcher will know that you participated in this study. Any reports or publications based on this research will use only group data and will not identify you or any individual as being part of this project.

**The decision to participate in this research is up to you.** You do not have to participate and you can refuse any question. Even if you begin the study, you may withdraw at any time.

You will receive a $15 gift card to Amazon.com or Target upon completion of the interview.
If you have any questions about this study, please feel free to contact Michael Flanagan (Tel: 978-877-9433, Email: Flanagan.mic@husky.neu.edu), the person mainly responsible for the research. You can also contact Dr. Carol Young (Northeastern University, Boston, MA, Email: C.young@neu.edu), the Principal Investigator.

If you have any questions about your rights in this research, you may contact Nan C. Regina, Director, Human Subject Research Protection, 960 Renaissance Park, Northeastern University, Boston, MA 02115. Tel: 617.373.4588, Email: irb@neu.edu. You may call anonymously if you wish.

You may keep this form for yourself.

Thank you,

Michael Flanagan

___________________________________________________  __________
Signature of Participant                               Date

___________________________________________________  __________
Signature of Student Researcher                        Date
Appendix D

Interview Questions

The following questions will guide the first semi-structured interview. Follow up and clarifying questions, based on the participant’s response, will be used for the second interview.

Participants Belief About Teaching

1. Why did you become a teacher?
2. How would you describe your role as a teacher?
3. What are some challenges you face each day?
4. What is the best part of your job?

Participants Experience with Chronically Ill Student

5. Please describe how you learned that one of your students was chronically ill?
   a. What thoughts and concerns did you have?
   b. How much input did you have about placement?

6. How were you able to meet the academic needs of the chronically ill student?
   a. Did you have any concern about the social or emotional needs of the student?
   b. If so, how did you address these needs?

7. How would you describe your communication with stakeholders of the chronically ill student?
   a. Parents
   b. School Support Staff
   c. Others
Participants Reflection Upon the Experience of Educating a Chronically Ill Student

8. Upon learning of the student’s diagnosis or that you were assigned a chronically ill student, describe the impact on your priorities / objectives for this student?
   a. Did they change significantly / moderately / not at all?
   b. Why do you feel this was the case?

9. How and where do you feel you were most effective as a teacher for this chronically ill student?
   a. Academically / Socially / Emotionally

10. How would you describe the experience of educating a chronically ill student professionally and emotionally?

Provide a working definition for Self Efficacy prior to asking this set of questions:

The goal of this study is to utilize Albert Bandura’s definition of Self Efficacy, which is a subset of his original Social Learning Theory (2011). Bandura suggests that Self Efficacy focuses on the perceived capability and motivation of individuals in light of difficult tasks or perceived obstacles.

11. How confident were you that you could meet the academic, social and emotional needs of the student?

12. How confident were you in your ability to adapt to the individual needs of the chronically ill student?

13. How confident were you with your preparation and prior knowledge of educating a chronically ill student?

14. Is there anything that you would like to add about your experience with chronically ill students personally or professionally?

15. What advice/suggestions do you have for teachers who are assigned chronically ill students.

16. What advice/suggestions do you have for administrators in charge of developing an educational plan for chronically ill students?
CLIENT NON-DISCLOSURE AGREEMENT

This CLIENT NON-DISCLOSURE AGREEMENT, effective as of the date last set forth below (this "Agreement"), between the undersigned actual or potential client ("Client") and Rev.com, Inc. ("Rev.com") is made to confirm the understanding and agreement of the parties hereto with respect to certain proprietary information being provided to Rev.com for the purpose of performing translation, transcription, video captions and other document related services (the "Rev.com Services"). In consideration for the mutual agreements contained herein and the other provisions of this Agreement, the parties hereto agree as follows:

1. Scope of Confidential Information

1.1. "Confidential Information" means, subject to the exceptions set forth in Section 1.2 hereof, any documents or other text supplied by Client to Rev.com for the purpose of performing the Rev.com Services.

1.2. Confidential Information does not include information that: (i) was available to Rev.com prior to disclosure of such information by Client and free of any confidentiality obligation in favor of Client known to Rev.com at the time of disclosure; (ii) is made available to Rev.com from a third party not known by Rev.com at the time of such availability to be subject to a confidentiality obligation in favor of Client; (iii) is made available to third parties by Client without restriction on the disclosure of such information; (iv) is or becomes available to the public other than as a result of disclosure by Rev.com prohibited by this Agreement; or (v) is developed independently by Rev.com or Rev.com’s directors, officers, members, partners, employees, consultants, contractors, agents, representatives or affiliated entities (collectively, "Associated Persons").

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2.2. Notwithstanding anything to the contrary herein, Rev.com is free to make, and this Agreement does not restrict, disclosure of any Confidential Information in a judicial, legislative or administrative investigation or proceeding or to a government or other regulatory agency; provided that, if permitted by law, Rev.com provides to Client prior notice of the intended disclosure and permits Client to intervene therein to protect its interests in the Confidential Information, and cooperate and assist Client in seeking to obtain such protection.

3. Certain Rights and Limitations

3.1. All Confidential Information will remain the property of Client.

3.2. This Agreement imposes no obligations on either party to purchase, sell, license, transfer or otherwise transact in any products, services or technology.

4. Termination

4.1. Upon Client’s written request, Rev.com agrees to use good faith efforts to return promptly to Client any Confidential Information that is in writing or recordable on tangible media, and to certify the return or destruction of all Confidential Information; provided that Rev.com may retain a summary description of Confidential Information for archival purposes.

4.2. The rights and obligations of the parties hereto contained in Sections 2 (Use and Disclosure of Confidential Information) (subject to Section 2.1), 3 (Certain Rights and Limitations), 4 (Termination), and 5 (Miscellaneous) will survive the return of any tangible embodiments of Confidential Information and any termination of this Agreement.

5. Miscellaneous

5.1. Client and Rev.com are independent contractors and will so represent themselves in all regards. Nothing in this Agreement will be construed to make either party the agent or legal representative of the other or to make the parties partners or joint venturers, and neither party may bind the other in any way. This Agreement will be governed by and construed in accordance with the laws of the State of California governing such agreements, without regard to conflicts-of-law principles. The sole and exclusive jurisdiction and venue for any litigation arising out of this Agreement shall be an appropriate federal or state court located in the State of California, and the parties agree not to raise, and waive, any objections or defenses based upon venue or forum non conveniens. This Agreement (together with any