

THESIS

LIVING WITH A CHRONIC PHYSICAL HEALTH CONDITION: THE ACADEMIC,  
SOCIAL, AND EMOTIONAL EXPERIENCES OF ADOLESCENTS

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## ABSTRACT

### LIVING WITH A CHRONIC PHYSICAL HEALTH CONDITION: THE ACADEMIC, SOCIAL, AND EMOTIONAL EXPERIENCES OF ADOLESCENTS

Interviews were conducted with 11 adolescents with chronic physical health conditions between the ages of 15 and 19. Participants also kept a journal of their daily experiences every day for one week. The purpose of the interviews and journals was to capture the academic, social, and emotional experiences of adolescents living with a chronic physical health condition.

Findings from the current research study supported the findings from previous research studies conducted with adolescents with a chronic physical health condition. Both the current research study and previous research studies found that adolescents with chronic physical health conditions experience physical restrictions and obstacles, social and emotional restrictions and obstacles, and educational implications due to their chronic physical health condition. In addition to supporting previous findings, the current research study found that positive emotions and strengths helped adolescents with a chronic physical health condition cope with the challenges they experienced.

Based on study results, implications for practice are provided for teachers, school counselors, career counselors, and other counselors when working with adolescents with chronic physical health conditions. Suggestions for further research are recommended, especially surrounding the use of the constructs of positive emotions, hope, and strengths to help adolescents with chronic physical health conditions cope with the challenges they experience.

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Most importantly, I want to say thank you to my 11 participants. Thank you for having the courage and strength to share your stories with me and with the world. Each one of you has

touched me and inspired me, and it was your stories that kept me going when it would have been much easier to give up.

## DEDICATION

This research is dedicated to all of those who live with a chronic physical health condition. My wish is that each of you can find the hope and strength needed to rise up and conquer the challenges you face each day and remember that you are never alone.

Keep dreaming, keep hoping, and keep fighting.

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## CHAPTER 1: INTRODUCTION

Meet Joe. He is a junior in high school. Joe likes school, participating in activities at school, and doing things with his friends. Sometimes it is hard for him to get out of bed and go to school in the morning because of pain. Joe also has to miss school frequently due to medical appointments, injuries, and pain. Some days it is hard to pay attention in class because of the pain. Taking notes can be difficult because Joe's hands do not always function properly. Joe likes hanging out with his friends, but they do not understand what his life is like. He wants to play basketball, football, and skateboard with his friends, but usually his body will not let him. Joe worries about the future. He wants to go to college, but he is concerned he will not be able to meet the academic rigors of college or be able to manage all of his healthcare needs by himself. Sometimes, he just wishes he was normal.

Joe is a hypothetical example of a teenager who has a chronic physical health condition. A chronic physical health condition is defined as “a health problem that lasts over three months, affects ... normal activities, and requires lots of hospitalizations and/or home health care and/or extensive medical care” (Boyse, Boujaoude, & Laundry, 2012, para. 2). Approximately 133 million people in the United States have a chronic physical health condition (Partnership for Solutions, 2004). It is estimated that 15% to 18% of these people are children and adolescents (Boyse et al., 2012). Having a chronic physical health condition affects all areas of life, but for adolescents with chronic physical health conditions, one of the areas impacted most is school and academics. According to a study conducted by the University of Michigan (2002), teens spend a large part of their week (32.5 hours) at school and experience a significant portion of their social interactions in the academic environment. It is likely that students with chronic physical health conditions confront various obstacles in their educational, social, and emotional experiences at

school. It is important for parents and teachers of children and adolescents with a chronic physical health condition to be aware of the challenges these children and adolescents face. Parents and teachers may need to be aware of different circumstances or methods of working with these adolescents in comparison to working with adolescents without a chronic physical health condition. In addition, parents and teachers need to understand potential ways of helping these teens with chronic illnesses.

### **Background**

Adolescents with chronic physical health conditions face a number of challenges in the school setting. These challenges are physical, social, and emotional. Physical challenges range from chronic pain (Erkolahti & Ilonen, 2005; Meldrum, Tsao, & Seltzer, 2009; Sexson & Madan-Swain, 1995; Taras & Potts-Datema, 2005) to fatigue and weakness (Erkolahti & Ilonen, 2005; Sexson & Madan-Swain, 1995). Social and emotional challenges include difficulty making friends (Miauton, Narring, & Michaud, 2003) and mental health issues such as anxiety, fear, and depression (Atkin & Ahmad, 2001; Eklund & Sivberg, 2003; Rhee, Wenzel, & Steeves, 2007). Students with chronic physical health conditions worry about issues such as how their pain will affect their future (Meldrum et al., 2009; Miauton et al., 2003), and being able to find a job (Miauton et al., 2009; Wolman, Resnick, Harris, & Blum, 1994). They also have anxiety due to missed schoolwork and school absences (Sexson & Madan-Swain, 1995).

When one examines these issues in the school setting, there are educational implications for students with chronic physical health conditions. The most common educational implication is school absence (Boice, 1998; Sexson & Madan-Swain, 1995; Taras et al., 2005; Taylor, Gibson, & Franck, 2008; Thies, 2005). These multiple absences combined with other factors, such as stress and medications, often lead to a variety of academic difficulties. Multiple absences

can cause students to fall behind in their school work, which can lead to failing grades, and poor academic performance (Sexson & Madan-Swain, 1995; Taylor et al., 2008; Thies, 2005).

The school experience of adolescents with chronic physical health conditions is also influenced by the attitude and actions of teachers and other school personnel. Generally, teachers have a limited knowledge of the specific chronic illness a student has or incorrect preconceived ideas about either the specific chronic illness or chronic diseases in general (Sexson & Madan-Swain, 1995). Sexson and Madan-Swain (2005) suggest that there are two approaches that teachers use with students with chronic physical health conditions. One approach is teachers are overly sympathetic towards the student. The result of this is that the student may not be adequately challenged. The other approach is teachers are unable to recognize the limitations a student may have as a result of their condition and thus may have unrealistic expectations of the student.

One way to help adolescents handle the many effects of a chronic physical health condition may be through the use of positive psychology. Positive psychology is a term that encompasses the study of positive emotions and positive character traits (Seligman, Steen, Park, & Peterson, 2005). It is “work that investigates the conditions and processes that foster happiness, optimal functioning, and mental wellness in people” (Norrish & Vella-Broderick, 2009, p. 270). Unfortunately, research on positive psychology in regard to adolescents appears to still be in the formative stage, with little to no research focusing on positive psychology and adolescents with chronic physical health conditions. However, positive psychology, specifically the constructs of hope and strengths, could have a tremendous benefit for adolescents with chronic physical health conditions. Snyder (2002) states, “higher hope consistently is related to better outcomes in academics, athletics, physical health, psychological adjustment, and

psychotherapy” (p. 249), which could be a great benefit to students with chronic physical health conditions. These adolescents could also potentially benefit from a refocus to look at their strengths instead of dwelling on the limitations of their chronic physical health condition. Bromley, Johnson, and Cohen (2006) found that strengths were able to protect adolescents against developing mental health problems, even if the person experienced two or more negative events in life.

### **Statement of the Problem**

There was limited research found relating to adolescents with chronic physical health conditions. Furthermore, of the literature located, a portion of it provided observations and suggestions, but did not indicate specific empirical studies that fully substantiated the information. This clearly indicates the need for further research in this area. Researchers have suggested that the research related to adolescents with chronic physical health conditions needs to be continued and expanded (Boice, 1998; Taras & Potts-Datema, 2005; Taylor et al., 2008). Researchers have also suggested that future research expand on educating teachers about students with chronic physical health conditions and the educational implications for school personnel. (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Nabors, Little, Akin-Little, & Iobst, 2008).

### **Researcher’s Perspective**

In January 2011, I was diagnosed with a chronic physical health condition. My diagnosis led to the end of my teaching career, which forced me to re-examine my life, and my plans for my future. It was this experience, and my passion for education and youth, that led me to the topic of researching adolescents with chronic physical health conditions and their academic, social, and emotional experiences in the schools. I have worked in schools for many years, both

in the elementary and secondary settings. I found my passion for teaching early in life and had the goal of becoming a teacher from a very early age. When I worked with middle school students, I found myself constantly working with students that were considered the “underdog.” The students I worked with had many challenges in life, from living in foster care, to disabilities, to living in poverty. It was one of the most touching moments of my career to receive a letter from a student at the end of the year, thanking me for helping him and caring about him. As I sat and read that letter, I knew that no matter where life took me, I wanted to be able to work with youth and try to make a difference in their lives. By pursuing this research, I can continue my passion for working with youth and hopefully make a difference, not only in their lives, but in the knowledge and perceptions of those who work with youth.

Although my diagnosis came as an adult and not before or during adolescence, I can relate to the physical, social, emotional, and academic challenges discussed here. There are days when I am distracted by pain and find it difficult to concentrate in my graduate courses. Some of my medications make me extremely tired, which also affects my concentration in class and ability to complete assignments. I have had to miss classes because of surgeries and then worry about missing class and making up the assignments. I also worry about the future and how my disease will affect my hopes and plans for my life.

Fortunately, I have been able to make new plans, discover new hopes for the future and that is what keeps me going on the days where I get overwhelmed with my condition. I am drawn to positive psychology because it has helped me focus on what I *can do*, rather than what I *cannot do*.

I chose to design a qualitative research study because I wanted to be able to give a voice to adolescents with chronic physical health conditions. This study utilized a basic interpretive

qualitative study design. In this type of design, “the researcher is interested in understanding how participants make meaning of a situation or phenomenon, and this meaning is mediated through the researcher as instrument” (Merriam, 2002, p. 6). By interviewing adolescents with a variety of chronic physical health conditions, I hoped to make meaning of how they experience life with a chronic physical health condition, including the challenges faced, and the way they use hope and their strengths in surmounting these challenges.

### **Purpose of the Study**

The purpose of this study was to explore and understand the academic, social, and emotional experiences of adolescents with chronic physical health conditions. In addition, this study examined how adolescents with chronic physical health conditions used their strengths and hopes to overcome or endure barriers to success in these areas. Although specific diseases have their own characteristics, the experience of living with a chronic illness can be shared among adolescents with chronic physical health conditions. Boice (1998) writes that the “chronic nature of a disease is more important than its specific characteristics” (p. 7). Therefore, by interviewing adolescents with different types of chronic physical health conditions, it was anticipated that meaning could be made of the study results for individuals with various types of chronic illnesses.

### **Research Questions**

There were two research questions that the present study explored:

1. What is the experience of an adolescent with a chronic physical health condition in the school setting?
2. What has helped the adolescent deal with having a chronic physical health condition?

## **Definition of Terms**

The following is a list of definitions of terms used in the present study:

*Chronic physical health condition*- This study will use the definition presented by Boyse, et al., (2012) which is “a health problem that lasts over three months, affects ... normal activities, and requires lots of hospitalizations and/or home health care and/or extensive medical care” (para. 2). Other terms that may be used interchangeably are chronic physical illness and chronic physical disease.

*Adolescent*- For this research study, an adolescent is a male or female between the chronological ages of 13 and 18. Other terms that may be used interchangeably are teen and teenager.

*Strength(s)* - McQuaide and Ehrenreich defined strengths as:

The capacity to cope with difficulties, to maintain functioning in the face of stress, to bounce back in the face of significant trauma, to use external challenges as a stimulus for growth, and to use social supports as a source of resilience (as cited in Rawana & Brownlee, 2009, p. 255).

*Hope*- Snyder (2002) defines hope as “the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways” (p. 249). Essentially, hope is the capability to think and see beyond what one thought was possible and figure out a way to get to that place.

## **Delimitations and Limitations of the Study**

There were various delimitations in this study. One delimitation was the participant’s age; the participant had to be between the ages of 13 and 18. Additionally, the participant must have been enrolled in school. Participants had to be able to meet in person for the interview or have access to Skype if too far away to meet in person. Participants also had to be able to write, type or speak into a recorder to complete the journal part of data collection.

One challenge of the study was that I, the researcher, have a chronic physical health condition and as a result, I was concerned about making assumptions based on my own experiences and not accurately portraying the experiences of the study participants. Another challenge is that, while an effort was made to find adolescents with a variety of chronic physical health conditions, the sample could not include a representative of every chronic physical health condition in the United States. To address these limitations, data was triangulated, and thick, rich description was used, as well as peer review.

## **CHAPTER 2: LITERATURE REVIEW**

### **Introduction**

When reviewing the available literature surrounding adolescents with chronic physical health conditions, several themes were identified across many different studies. For the purpose of the literature review, these themes were characterized by the different types of experiences of adolescents with chronic physical health conditions. The broad, overarching themes identified were: physical restrictions and obstacles, social and emotional restrictions and obstacles, and educational implications. In addition to these themes, I explored the constructs of hope and strength within the context of positive psychology as a potential benefit to adolescents living with chronic health conditions.

### **Physical Restrictions and Obstacles**

#### **Pain**

One of the major causes of physical restrictions in adolescents with chronic illnesses is pain (Erkolahti & Ilonen, 2005; Meldrum et al., 2009; Sexson & Madan-Swain, 1995). The most common type of pain is joint pain due to chronic musculoskeletal conditions (e.g. arthritis), but teens also suffer from stomach pain, headaches and pain from surgical or injection sites. Sexson and Madain-Swain (1995) reported that chronic pain distracts students from learning. Additionally, both Meldrum et al., (2009) and Sexson and Madain-Swain (1995) indicated that chronic pain is an obstacle to participating in physical activities, such as gym class.

Meldrum et al. (2009) conducted a study interviewing 53 children between the ages of 10 and 18 with a diagnosed chronic pain problem. The purpose of this research study was to gain further understanding of the impact of chronic or recurrent pain on children. Participants were interviewed prior to their first visit to a university pediatric clinic and then interviewed again 6 to

12 months later. One common theme reported by participants was that their pain was an obstacle to participating in activities, including school activities. The emotion identified by 49% of participants in relation to their pain was frustration. One participant stated “And it’s really, really hard for me to give up [school] because I’m an overachiever and expect a lot of myself. Now... I’m not able to do anything, which really bugs me” (Meldrum, 2009, p. 1023).

A study conducted by Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, and Schmucker (2005) looked at the effects of chronic pain on children and adolescents. The study was conducted in one elementary school and two secondary schools in Germany. Parents of children in grades first through fourth grade and children in fifth grade and higher were asked to complete a questionnaire. This questionnaire examined the characteristics and consequences of chronic pain. A total of 68.2% of participants reported restrictions in activities of daily living due to pain. The most prevalent types of pain reported were headache, abdominal pain, limb pain, and back pain. Results also indicated that the participants’ pain increased as they aged, which led to more restriction in daily living. These physical restrictions, frustrations, and other consequences of pain can obviously interfere with numerous life aspects, including academics.

### **Fatigue**

With chronic illness, another physical restriction that interferes with learning is fatigue. Students report a general feeling of malaise, fatigue and weakness (Erkolahti & Ilonen, 2005; Sexson & Madan-Swain, 1995). Furthermore, Dworkin (1989) suggested some medications students take to manage their condition(s) cause them to feel tired and may hinder school performance. The potential impact of medication on school performance is supported through a study by Eklund and Sivberg (2003) in which researchers interviewed 13 adolescents between the

ages of 13 and 19 who had a diagnosis of epilepsy. Participants in the study reported medication side effects such as feeling tired, difficulty concentrating, and memory impairment.

Fatigue may also cause students to miss school or spend a portion of the day in the nurse's office (Thies, 2005). Fatigue, weakness and general malaise can also cause difficulties in attention and concentration in the classroom, which may prevent students from fully participating in class activities, especially those involving physical exertion (Dworkin, 1989). This assertion is supported via Beaune, Forrest, and Keith (2004) who conducted a study involving six adolescents with Treacher Collins Syndrome. Participants were interviewed about their experiences living with this syndrome and the interviews were analyzed to find common themes within their experiences. The adolescents identified one way that they felt different from others was being physically unable to participate in sports or other physical activities.

As evidenced by the preceding sections, the physical aspects of chronic illness affect adolescents in several ways. In addition to physical restrictions and obstacles, adolescents with chronic physical health conditions also face social and emotional issues relating to their chronic illness.

### **Social and Emotional Restrictions and Obstacles**

#### **Friendships**

Much of an adolescent's world involves their friends, peers, and social situations. Adolescents with chronic physical health conditions can struggle with friends, peers, and social situations for multiple reasons. Teens with a chronic illness can have a difficult time making friends (Miauton et al., 2003). Miauton et al., (2003) studied adolescents with chronic physical health conditions in Switzerland. The study sample was 9,268 adolescents between the ages of 15 and 20 and included students with and without chronic physical health conditions.

Investigators reported that 33.6% of girls and 27.7% of boys with a chronic physical health condition reported rarely making friends. In addition, 28.8% of girls and 20.6% of boys reported worrying about their friends' behavior towards them.

Adolescents with chronic physical health conditions can also struggle with making friends because they feel different from their peers (Beaune et al., 2004; Meldrum et al., 2009). In the previously referenced qualitative study conducted by Beaune et al. (2004), the participants identified making friends as a challenge because peers were sometimes afraid to make friends with someone who was different. Participants also identified a struggle between feeling the same as everyone else while also being different from others. Furthermore, they identified having to participate in less or different activities than others because of their physical condition.

Teens with a chronic physical illness can also feel rejected by or isolated from peers (Boice, 1998; Meldrum et al., 2009; Sexson & Madan-Swain, 1995). In support of this is a qualitative study conducted by Hokkannen, Eriksson, Ahonen, and Salanterä (2004). In this study, researchers facilitated focus groups with 20 adolescents with cancer between the ages of 13 and 18. These teens were attending a cancer adjustment camp. The interviews were analyzed using inductive content analysis. One of the issues for these teens was making or keeping friends. Participants said that they felt isolated from peers when they were receiving treatment. Participants also said that they lost friends because of their illness.

Further supporting the assertion of peer rejection is a qualitative study using focus groups conducted by McEwan, Espie, Metcalfe, Brodie, and Wilson (2004). The participants were 22 adolescents between the ages of 12 and 18 who all had epilepsy. In the focus groups, 19 out of 22 participants reported having experienced social isolation and feeling left out because they

could not go and do things with friends. Eight of the participants told stories of actual peer rejection and 11 participants expressed fears of rejection from peers.

Social isolation was addressed during in depth interviews in a study conducted by Atkin and Ahmad (2001) with adolescents with sickle cell disease and thalassaemia major. There were 26 participants with sickle cell disease and 25 participants with thalassaemia major, ranging in age from 10 to 19 years old. Participants stated that missing school because of appointments or hospitalizations resulted in a sense of social isolation and disrupted their friendships.

The previously referenced qualitative study conducted by Meldrum et al. (2009) also identified a common theme of feeling a sense of isolation from peers and feeling different from peers. In reference to feeling isolated from peers because of having a chronic physical health condition, one participant stated, “It sort of feels like you’re the only person on earth who has it” (Meldrum et al., 2009, p.1023).

Some teens struggle to tell their friends that they have a chronic illness because they want to fit in and be normal (Taylor et al., 2008). Many teens have an illness that is invisible, leading them to have difficulties with friends because their friends do not understand their problems because their illness cannot be seen (Boice, 1998; Meldrum et al., 2009). The qualitative study conducted by Meldrum et al. (2009) examined the difficulties participants experienced with friends because of having an invisible illness. One participant stated, “They kind of forget and everyone just kind of goes on with their lives. And I’m still in pain” (Meldrum et al., 2009, p. 1023). Another participant said,

The people who don’t understand it, think that I’m faking it, they’re the people who go... “She’s over-exaggerating, she’s milking it.” It’s really not true and it really upsets me when I hear that, because I’m doing the best I can. (Meldrum et al., 2009, p.1023)

As is evidenced by the literature, adolescents with chronic physical health conditions struggle with making and keeping friends, as well as talking with friends and peers about their illness. Another struggle that adolescents with chronic physical health conditions face concerns their mental health.

### **Mental Health Issues**

Adolescents with chronic physical health conditions often deal with mental health issues such as depression, fear, and anxiety (Atkin & Ahmad, 2001; Eklund & Sivberg, 2003; Rhee, Wenzel, & Steeves, 2007). Teens fear that pain will affect their future and what the future holds (Meldrum et al., 2009; Miauton et al., 2003). They worry about being able to graduate from high school (Meldrum et al., 2009). They worry about being able to find a job (Meldrum et al., 2009; Miauton et al., 2009; Wolman, Resnick, Harris, & Blum, 1994) or worry about finding a job without discrimination (Taylor et al., 2008). The previously referenced qualitative study conducted by Meldrum et al. (2009) also identified a common theme of children's fears about how the pain from their chronic physical health condition will affect the future. Of those in the study, 53% of participants expressed this concern. One participant stated, "I'm scared I won't be able to graduate on time and stuff like that" (Meldrum et al., 2009, p. 1023). In reference to going to college or holding a job, one participant said, "You're not able to say, okay, I'm in a lot of pain and can't do anything" (Meldrum et al., 2009, p.1024).

Additional worries of teens with chronic physical health conditions include moving away from home and family (Taylor et al., 2008), and having children and passing on the illness (Boice, 1998). Kyngas and Barlow (1995) conducted a study with Finnish adolescents between the ages of 13 and 17, all of whom had a diagnosis of insulin dependent diabetes mellitus. Participants were interviewed about the personal meaning and perceived impact of having this

illness and identified a belief that having diabetes would adversely impact their ability to have children.

Some struggle with a fear of dying because of their illness (Wolman et al., 1994). In referring to a 1989 text by Krementz that chronicled the lives of 14 children and adolescents living with chronic physical health conditions, Boice (1998) suggested that adolescents with chronic physical health conditions have uncertainty about their life expectancy.

In addition to these worries and stresses, adolescents with chronic illnesses also struggle with a poor or negative body image (Boice, 1998; Miauton et al., 2003; Wolman et al., 1994). Wolman et al. (1994) conducted a study comparing psychological outcomes of students with and without chronic physical health conditions. The researchers administered a survey to 1683 students with a variety of chronic physical health conditions and 1650 adolescents without chronic physical health conditions in seventh to twelfth grade. The results of the study indicated that adolescents with a chronic physical health condition did less well than those adolescents without a chronic physical health condition on several psychological outcomes: “emotional well-being, worries and concerns, and body image” (Wolman et al., 1994, p. 203).

The research referenced here illustrates the effects of chronic illness on the emotional experience of adolescents with chronic physical health conditions. Adolescents with chronic physical health conditions deal with many mental health issues. In addition to social and emotional concerns, there are educational implications of chronic illness for adolescents.

## **Educational Implications**

### **School Absence**

Having a chronic physical health condition affects a student's educational performance and experience in several ways. The most common educational implication is school absence (Boice, 1998; Sexson & Madan-Swain, 1995; Taras & Potts-Datema, 2005; Taylor et al., 2008; Thies, 2005). These absences may be due to illness, fatigue, medical appointments, and treatments. According to Thies (2005), of students with chronic physical health conditions, 58% routinely miss school and 10% miss more than 25% of the year. These are not typically extended absences, but multiple brief absences lasting a few days at most (Sexson & Madan-Swain, 1995; Thies, 2005). In the previously referenced qualitative study conducted by Hokkanen et al. (2004), teens reported being absent from school frequently because of their treatments. Additionally, in the study conducted by Roth-Isigkeit et al. (2005) of the 749 participants, 48.8% reported school absence due to pain in the preceding three months.

### **Academic Performance**

These multiple absences combined with other factors, such as stress and medications, usually lead to a variety of academic difficulties. In an article written by Dr. Paul Dworkin (1989), he stated "epidemiologic surveys have suggested that from one quarter to one third of chronically ill students have problems with academic achievement" (p. 304). When students frequently miss school, they fall behind in their school work, and then have failing grades which can cause poor academic performance (Taylor et al., 2008; Thies, 2005). According to Martinez and Ercikan (2008), teens with chronic physical health conditions struggle in math and other areas that build on previously acquired knowledge and skills. Students may have missed some of the information and skills due to their multiple absences. According to the qualitative study by

Hokkanen et al. (2004) involving 20 adolescents with cancer, participants reported that they advanced more slowly in academics than their peers. They also reported particular academic difficulties in math and languages.

Some medications can cause learning and attention issues, which can affect a student's ability to retain information (Boice, 1998). Furthermore, the stress of dealing with a chronic physical health condition can cause attention and concentration issues in the classroom, which also leads to more academic difficulties for these students (Boice, 1998; Taras & Potts-Datema, 2005). Taken together, these barriers to academic skills development may lead students with chronic physical health conditions to have lower test scores on achievement tests than their unaffected peers (Fowler et al., 1985).

Fowler et al. (1985) conducted a study interviewing 270 families with children with various chronic physical health conditions. The investigators also looked at the participants' hospital records, a survey completed by the participants' physicians, and school records, which included national achievement test results, days absent, and a teacher survey. Results indicated that students with chronic physical health conditions did significantly less well in comparison to students without a chronic physical health condition on the national achievement test.

A study conducted by Martinez and Ercikan (2009) looked at the educational and psychological effects of chronic illness on 1512 children ages 10 to 15. The study was a retrospective analysis looking at data from the National Longitudinal Survey of Children and Youth. One area looked at was performance on a Mathematics Computation Exercise. Results showed that children with a chronic illness performed poorly on this exercise in comparison to peers without a chronic physical health condition. The researchers believed that this difference in performance could be related to increased school absences which caused students with chronic

physical health conditions to miss vital learning opportunities and mastery of important core skills needed to advance to more difficult skills.

Clearly, the available research shows that a chronic physical health condition can have a substantial academic impact for adolescents. Chronic illness leads to frequent school absence, which can cause students to fall behind in school work and miss important academic concepts. Students with a chronic physical health condition have also been shown to perform poorly in relation to healthy peers on standardized assessments. In addition to these areas, the attitudes and actions of school personnel can have a significant influence on the academic experience of adolescents with chronic physical health conditions.

### **School Personnel**

The school experience of an adolescent with a chronic physical health condition can be greatly affected by the school personnel. Past research suggests that many teachers and school personnel do not feel prepared to deal with the implications of students dealing with chronic illness in the schools, in regards to both the academic and social needs of students (Clay et al., 2004; Nabors et al., 2008). First, the school personnel may be unaware that a student has a chronic illness (Fowler et al., 1985; Sexson & Madan-Swain, 1995). Even if they are aware, teachers generally have a limited knowledge of the specific chronic illness a student has or the teacher has incorrect preconceived ideas about either the specific chronic illness, or about chronic diseases in general (Sexson & Madan-Swain, 1995). In the study by McEwan et al., (2003), participants reported one of the biggest issues with having epilepsy was the reaction of teachers. Nine participants felt that teachers did not know enough about epilepsy and they over-reacted to seizures.

There seems to be two ways that teachers approach students with chronic physical health conditions. One way is that the teacher is overly sympathetic towards the student and then may not adequately challenge the student and his/her capabilities. In the study by Beaune et al. (2004), which involved six participants with Treacher Collins Syndrome, one of the participants stated, “Usually some persons, like teachers, not giving me the challenge that I want [because of] ... pity. That I don’t understand.” The other way that teachers approach students with chronic physical health conditions is that the teacher is unable to recognize the limitations a student may have as a result of their condition and consequently the teacher has unrealistic expectations of the student (Sexson & Madan-Swain, 2005). Thies (2005) wrote that some teachers are afraid to address academic issues because they do not want to overtax the student and as a result students do not receive adequate academic or social support.

Clay et al. (2004) conducted a study surveying 480 teachers. The teachers were given a questionnaire to complete. This questionnaire assessed “school personnel’s training, knowledge of, and experience with children with chronic illness” (Clay et al., 2004, p. 231). Of the participants, 59.4% of teachers indicated receiving no preparation for dealing with children with a chronic illness. Over 50% of the teachers indicated that they did not feel it was their responsibility for dealing with students’ chronic health issues.

The study conducted by Fowler et al., (1985) that involved 270 families with children with various chronic physical health conditions, found that one in five teachers did not know that the student had a chronic physical health condition before receiving the survey to complete as a part of the study. That included teachers who had students with significant chronic physical health conditions such as epilepsy, asthma, and diabetes. This concerned researchers because

these conditions may require sudden, immediate medical attention at school, and it may be up to teachers to provide this medical attention.

Nabors et al. (2008) conducted a study surveying 247 teachers about their knowledge of chronic medical conditions and confidence in their ability to meet the academic and social needs of students with chronic medical conditions. The survey looked at 13 specific conditions. The results indicated that most teachers have some knowledge of the medical conditions, but few teachers indicated high levels of confidence in working with children with chronic medical conditions.

There are many educational implications for adolescents with chronic physical health conditions. Further research is needed to be able to design interventions to help students and design trainings to educate school personnel on ways they can help students with chronic physical health conditions. One possible way to help adolescents handle or overcome the issues that come with a chronic physical health condition is through a focus on the constructs of hope and strengths. Hope is defined by Snyder (2002) as “the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways” (p. 249). Hope is the capability to think and see beyond what one thought was possible and figure out a way to get to that place.

### **Positive Psychology**

Much of the research found surrounding adolescents with chronic physical health conditions focused on the negative aspects of dealing with a chronic disease. While it is true that there are many struggles, obstacles, and challenges to living with a chronic physical health condition, researchers and participants could benefit from looking beyond the negative in order to find a positive perspective. Research on positive psychology and adolescents appears to still

be in the formative stage, with very little research found focusing on positive psychology and adolescents with chronic physical health conditions. However, positive psychology could have a tremendous impact on adolescents with chronic physical health conditions.

Ryff and Keyes (1995) suggested six factors that contribute to psychological well-being: “autonomy; personal growth; self-acceptance; purpose in life; environmental mastery; and positive relations with others” (p. 721). As evidenced by the preceding discussion, adolescents with chronic physical health conditions struggle with more than one of these factors. For example, adolescents with chronic illnesses struggle with the idea of finding and keeping a job, which can impact their ability to find purpose in life through work. They also struggle with making and keeping friends. Not only must they accept themselves, but they also must accept their illness and its effect(s) on their lives. Hope and strengths are two positive psychology constructs that were explored in this study in an effort to examine them in relation to students with chronic physical health conditions.

## **Hope**

One major theme that was located in a few studies on chronic illness is the idea of hope. In writing about hope, it has been stated that “there is no greater virtue, no more powerful therapeutic tool, no better ally for the sick” (Scioli, Scioli, & Nyugen, 2011, p. 78). Results from a study by Snyder, Lopez, Shorey, Rand, and Feldman (2003) indicated that “a child’s hopeful thinking is positively associated with perceived competence and self-esteem, and negatively associated with symptoms of depression” (p. 124). Snyder (2002) stated, “higher hope consistently is related to better outcomes in academics, athletics, physical health, psychological adjustment, and psychotherapy” (p. 249).

A study conducted by Venning, Elliott, Whitford, and Honnor (2007) examined the impact of chronic illness on hope scores as reported by participants. There were 29 participants with chronic illnesses and 24 participants without chronic illnesses. The participants completed four measures: the Child Hope Scale (Snyder, Hoza, Pelham, Rapoff, Ware, Danovsky, et al., 1997), the Depression Anxiety Stress Scale (Antony, Bieling, Cox, Enns, & Swinson, 1998), the Generalized Self-Efficacy Scale (Jerusalem & Schwarzer, 1992), and the Systems of Belief Inventory (Snyder, Harris, Anderson, Holleran, Irving, Sigmon, et al., 1991). Positive social functioning was also assessed by the number of friends the child and parent reported, as well as the frequency of social interaction issues reported by the child. Results indicated that hope scores of children were “lower when they had a congenital chronic illness and lowest when they had an acquired chronic illness” (Venning et al., 2007, p. 716). The study also identified suggested predictors of hope for children with a chronic physical health condition. One predictor of hope identified was perceived self-efficacy. “Perceived self-efficacy is important to hopeful thinking when a child faces a chronic illness as it enables them to set goals, facilitates adherence to treatment schedules, and keeps them energized to achieve goals in difficult situations” (Venning et al., 2007, p. 721). Another predictor of hope was interaction difficulties. The greater number of interaction difficulties a child had resulted in a lower level of hope. The fewer interaction difficulties a child had, the higher the level of hope. The authors concluded their findings by stating, “attention may be best directed at the development of individually tailored rather than generic hope-based interventions to inspire hopeful thinking in these times” (p.725).

Dorset (2010) conducted a 10-year longitudinal study with a sample of 46 participants with a spinal cord injury. Interviews were conducted with participants when they left the hospital, and at 6, 12, 24, 36 months and 10 years after discharge from the hospital. Seventy

percent of participants in the study said that maintaining hope was a critical factor in coping, especially in the early stages of injury. Hope continued to be an important concept in coping with long-term consequences of the participants' injuries. One theme that was identified from the study was that "hope looked to a future life that could be satisfying to them" (Dorset, 2010, p. 95).

For students with chronic physical health conditions that struggle with issues such as self-esteem, anxiety, and depression, instruction and interventions about hope could help change their focus away from their problems and toward a positive outlook on life. Boyse, et al. (2012) offered this advice to parents of children with chronic physical health conditions:

Coping with a chronic illness can be discouraging and scary. It is incredibly important to stay hopeful. Don't ignore your worries or your negative feelings—they need to be recognized and addressed. But it's not helpful to dwell on them. If you try to find the positive side of things and keep your eye on the potential positive outcomes, you will be teaching your child a valuable lesson, and maintaining your ability to cope as well. (Be Hopeful section, para. 1)

## **Strengths**

Another area that appears to have been neglected in the research on adolescents with chronic physical health conditions is the idea of strengths, and how knowing about and using their strengths might impact their lives. Bromley, Johnson, and Cohen (2006) conducted a study to investigate the effects that personality strengths in adolescence could have on early adulthood. The study involved 688 mothers and their children in upstate New York. Participants were interviewed in 1983, from 1985 to 1986, and from 1991 to 1993. The study used the construct of ego resilience, which is a measure designed to look at "positive, adaptive, and healthy personality functioning" (Bromley et al., 2006, p. 316). They found that strengths, especially a high level of ego resilience, were able to protect adolescents against developing mental health problems, even if the person experienced two or more events in life that were negative. Bromley

et al. (2006) suggested that adolescents with a high number of strengths are less likely to struggle when faced with major life challenges and adversity.

Norrish and Vella-Broderick (2009) stated:

Importantly the goal of positive psychology is not to avoid negative emotions or personal distress, but to help individuals to use their strengths and recognize and feel that life is worthwhile so that when they encounter adversities in life, they can draw on these inner resources. (p. 276)

Through these explanations of positive psychology, hope and strengths, and discussion of their benefits, it is likely that adolescents with chronic physical health conditions could benefit.

These benefits include hope for the future and a better foundation for handling the daily difficulties of living with a chronic illness.

## **CHAPTER 3: METHODS**

### **Research Approach**

This study utilized a basic interpretive qualitative study design. In this type of design, “the researcher is interested in understanding how participants make meaning of a situation or phenomenon, and this meaning is mediated through the researcher as instrument” (Merriam, 2002, p. 6). In this approach, the researcher seeks to “discover and understand a phenomenon, a process, the perspectives of the people involved” (Merriam, 2002, p. 6). This strategy was used because it is inductive and the outcome is descriptive, which allowed me as the researcher to gain in depth understanding of how the participants made meaning of living with a chronic physical health condition. This approach was used to answer the following research questions.

1. What is the experience of an adolescent with a chronic physical health condition in the school setting?
2. What has helped the adolescent deal with having a chronic physical health condition?

### **Participants**

In order to gain multiple perspectives of adolescents living with a chronic physical illness, the researcher utilized a purposeful sample of 11 adolescents. The participants were selected based on two criteria: (1) the diagnosis of a chronic physical health condition and (2) being between the ages of 13 and 18. Participants were identified with the assistance of one or more gatekeepers. A gatekeeper is one who assists the researcher in identifying participants (Creswell, 2008). The gatekeepers in this study were doctors, nurses, and other health care providers. They were provided with information and flyers about the study from the researcher. The gatekeeper then passed the information on to patients who were interested in participating in the study and then the participant or parent/guardian of the participant contacted the researcher.

Although in the beginning of the current study, the researcher planned on finding many participants through these gatekeepers, the majority of participants ended up being located through snowball sampling. Participants referred those they knew and participants also read about the research through the researcher's online website. Once the researcher was contacted, the purpose of the study and details about participation in the study were explained. If the parent(s)/guardian(s) and adolescent agreed to participate in the study, an interview with the adolescent participant was scheduled.

### **Procedure**

For this study, data was collected in the forms of semi-structured interviews and participant journals. The interview took place either in the participant's home or via Skype for participants who lived too far away to interview in person. Prior to beginning the interview, the consent process was explained to the participant and the parent(s)/guardian(s) of the participant. The interview usually lasted between 20 and 30 minutes and was audio recorded. Breaks could have been taken any time during the interview and the interview could have been stopped at any time if the participant so requested. The parent/guardian could have stayed in the room for the interview if the participant or parent/guardian wanted. Only one parent chose to stay in the room for the entire interview. If the parent/guardian left the room, the door to the room was kept open and the parent stayed on the premises. Both the parent/guardian and the participant signed the consent form.

Each participant was assigned a number to keep his/her identity confidential. The list of participant numbers, along with the audio recordings and the journals, were kept in a locked drawer in the researcher's office. The only people with access to this drawer and the key were me as the primary researcher and my advisor. The consent forms will be retained for at least

three years and the interviews and journals from the study will be retained until the completion of the researcher's dissertation.

During the interview, the following questions were posed for the interviewee to respond to:

1. Tell me about your experience living with (insert illness) at school and how you have handled it.
2. What successes have you had?
3. What has helped you?
4. Is there anything about you personally that has been helpful in dealing with a chronic physical health condition?
5. Is there anything else you would like to tell me about?
6. Are there any barriers that having this illness has presented to your academic success?
7. How does having this illness affect you emotionally?
8. How does having this illness affect your relationships with friends?

In addition to participating in the interview, participants were asked to keep a journal for the week following the interview. The participant was supposed to use the journal to document what daily life with a chronic physical health condition entails, especially in relation to school and relationships with friends. The participants were asked to write in the journal at least once per day for one week. All 11 participants completed the interview and seven out of 11 participants completed journals.

### **Data Transcription and Analysis**

During the data analysis process, the researcher transcribed all interviews and journals. The researcher created Microsoft Word files for the journals and the interviews and these files were saved on a flash drive, to which only I as the primary researcher and my advisor had access. Constant comparative analysis was used to analyze the data (Boeije, 2002). This type of analysis

involved first comparing words and statements within a single interview and summarizing the core of the interview (open coding). Open coding is defined by Strauss and Corbin (1990) as “the process of breaking down, examining, comparing, conceptualizing, and categorizing data” (p. 61). Strauss and Corbin (1990) also stated:

Conceptualizing our data becomes the first step in analysis. By breaking down and conceptualizing, we mean taking apart an observation, a sentence, a paragraph, and giving each discrete incident, idea, or event, a name, something that stands for or represents a phenomenon. (p. 63)

There are two steps in the open coding process. The first step in open coding involves looking at and breaking apart the data in minute detail. Then the second step in open coding is grouping concepts together that seem to belong to the same phenomena and giving them a name. This is called categorizing (Strauss & Corbin, 1990).

After open coding, separate interviews were then compared with each other to hypothesize about patterns and types (axial coding) (Boeije, 2002). Axial coding is defined by Strauss and Corbin (1990) as “a set of procedures whereby data is put back together in new ways after open coding, by making connections between categories.” Thus, axial coding takes the data that was taken apart in open coding and puts it back together in a new way by making connections within the data categories (Strauss & Corbin, 1990).

### **Trustworthiness**

Several validation strategies were used to give credibility to the research and findings of this study. These strategies were triangulation, member checking, peer review, and rich, thick description. The data was triangulated with the interviews, interview notes, and participant journal entries (Creswell, 2008). Rich, thick description was achieved by presenting the participants’ voices and experiences in a detailed, honest, and accurate manner, including using direct quotes from the participants to support research themes (Creswell, 2008). Member

checking was conducted by having the participants review the transcript of his/her interview and drafts of the findings and interpretation to see if the themes that were created accurately represented the participant's experience (Creswell, 2008). Peer review was also used to provide an external check to the research process (Creswell, 2008). This was achieved through bi-weekly meetings with the co-investigator during the data analysis process to debrief researcher feelings and concerns brought about by the interviews and thus check for researcher bias and accuracy in interpreting the participants' experiences. These meetings also debriefed and verified the accuracy of the axial codes. Several meetings were also with a qualitative research methodologist to check for accuracy in the interpretation and data coding and analysis processes. In these meetings, the methodologist reviewed three interviews, checked the open codes, and confirmed their accuracy.

## **CHAPTER 4: RESULTS**

### **Summary of Study**

The purpose of this study was to explore and understand the academic, social, and emotional experiences of adolescents with chronic physical health conditions. In addition, this study examined if or how the adolescents with chronic physical health conditions in this study used strengths to overcome or endure barriers to success. This qualitative research study was designed as a basic interpretive qualitative study. Participants between the ages of 13 and 19 with chronic physical health conditions were interviewed once by me and asked to keep a journal for one week. The data that was collected was analyzed using constant comparative analysis (Boeije, 2002). This method of analysis uses open and axial coding. Several validation strategies, such as member checking and peer review, were in place to triangulate the data and give trustworthiness to the research and findings.

There were 11 participants for this study, ranging in age from 15 to 19. There were ten female participants and one male participant with various chronic physical health conditions. The breakdown of conditions was: three participants with Ehlers Danlos Syndrome (EDS); three participants with Crohn's disease/ulcerative colitis; one participant with solar urticaria; one participant with chronic neck pain; one participant with Wegener's Granulomatosis; and two participants with diabetes along with another condition, either Celiac disease or a form of muscular dystrophy. Participants lived in Colorado, Wyoming, Maryland, California, and Texas. Data concerning race, ethnicity, and socio-economic status were not collected.

Table 4.1  
Participant Information

Participant ID	Sex	Diagnosis	Age	Time Since Diagnosis
1	Female	Hypermobile Ehlers Danlos Syndrome	15	One year
2	Female	Crohns Disease	18	Three years
3	Female	Diabetes and Muscular Dystrophy	15	Ten and six years
4	Female	Crohns Disease	15	Two years
5	Male	Ulcerative Colitis	15	One year
6	Female	Chronic Neck Pain	15	One year
7	Female	Diabetes and Celiac Disease	19	Sixteen years
8	Female	Wegener's Granulomatosis	17	Two years
9	Female	Classical Ehlers Danlos Syndrome	16	Four years
10	Female	Vascular Ehlers Danlos Syndrome	18	One year
11	Female	Solar Urticaria	17	One year

### Data Analysis and Coding

Constant comparative analysis was used to analyze the collected data (Boeije, 2002). The first step in analyzing and coding the data was transcribing the participant interviews and participant journals. Once each interview and journal was transcribed, each transcription was read through multiple times and words and phrases that stood out as significant in regards to the research questions were highlighted. These words and phrases were separated from participant identification and were compiled into a comprehensive list. This list was then analyzed and the words and phrases were sorted into open codes or general categories that captured reoccurring ideas and themes. There were 33 open codes that were identified in this process and are displayed in Table 4.2.

Table 4.2  
Open Codes

Anger	Depression/Down	Discouraged/Hopeless	Worry/Anxiety
Grief	Pain	Impaired Mobility	Gastrointestinal Issues
Skin Issues	Issues Interacting with Others	Physical Issues Affecting School	Missing School
Accommodations/ Modifications	Losing Friends	Friends Do Not Understand	Avoidance/Isolation from Friends
Social Successes	School/Academic Successes	Personal Attributes	Medication
Hospitalization	Medical Tests	Supportive Family	Unsupportive Family
Coping for Physical Health	Coping for Mental Health	Interacting with Others with Health Issues	Diet
Fear	Medication Side Effects	Teachers	Doctors
Fatigue			

After the data was organized into open codes, it was further coded into axial codes. Nine axial codes were determined by studying the open codes, finding similarities and differences, making connections, and then grouping the open codes into broader themes or axial codes. The nine axial codes that were identified are displayed in Table 4.3.

Table 4.3  
Axial Codes

Emotional Experiences	Physical Experiences	School Experiences
Medical Experiences	Social Experiences	Family Experiences
Coping Strategies	Support and Accommodations	Personal Strengths and Successes

### Research Questions

Prior to collecting data, the researcher had two questions to be answered by the research. The research questions were:

1. What is the experience of an adolescent with a chronic physical health condition in the school setting?
2. What has helped the adolescent deal with having a chronic physical health condition?

The answers to these research questions were found within the axial codes in the following sections.

### **Themes**

To organize the information, the results of the study were separated by research question. The school experiences of adolescents with chronic physical health conditions encompass positive, neutral, and negative experiences that cannot necessarily be separated. To better manage the data and results, the answers to research question one were focused on the negative or neutral experiences reported by study participants and the answers to research question number two were focused on the positive experiences reported by study participants.

#### **Research Question One**

What is the experience of an adolescent with a chronic physical health condition in the school setting? Although many of the following experiences were not exclusive to the school experience, they all affected the school experience of adolescents living with a chronic physical health condition to varying degrees. The axial codes that were found to fall under this research question were: emotional experiences, physical experiences, school experiences, medical experiences, social experiences, and family experiences. These codes are represented in Figure 4.1.



Figure 4.1  
Axial Codes Under Research Question One

### **Emotional Experiences**

Study participants reported experiencing a variety of emotions in daily life. One of these emotions was anger. From participant eight, “At the beginning I was really resentful and angry.” Participant six said, “It makes me mad that I have to pay for it [physically] after when I want to go have fun.” Another emotion reported was grief. Participant eight said, “When you get diagnosed with a medical disease, it’s kind of like the grief process, like you go through many different cycles.” Participants also reported feeling depressed or down. “I get very depressed a lot,” explained participant ten.

Other emotions reported were feeling discouraged or hopeless, worried, anxious, and fearful. Participant six expressed, “I’m just afraid that it won’t ever get better”. Participant two

said, “It’s very scary when I get sick.” Participant one said, “I get really depressed, especially when I’m missing school. I get really stressed out and worried that things are just never going to get better.” She also said that having Ehlers Danlos Syndrome (EDS) causes her to worry about what kind of job she will be able to have in the future because of the possibility of missing work and not being able to handle a job that is physically demanding.

### **Physical Experiences**

As a result of their chronic physical health condition, participants experienced various physical issues such as pain (both acute and chronic pain), impaired mobility, gastrointestinal issues, skin issues, fatigue, and numerous physical side effects from medications. Participant ten shared her experience, “I tried to get out of bed and I fell, because I can’t walk. There’s days when you just can’t walk because your ankles or your feet or whatever, they just won’t work.” Participant eleven explained, “I’m allergic to the sun, which is technically the UVA rays... so I cannot go outside for extended periods of time, I can’t drive in a car without getting hives really bad, and wherever your skin is exposed and you do not have clothing covering it [you get hives].” Participant nine explained her fatigue, “I haven’t been getting out of bed more than a couple of hours a day, I had it up to four hours [out of bed] I can handle.”

Side effects from medication include a compromised immune system, nausea, puffy face, weight gain, and loss of appetite. Participant five said, “I had to be on prednisone a couple months ago and I took a bunch of prednisone pills [steroids] and I got really chunky in my face. I gained like 20, 25 pounds.” He also said “They gave me a new medicine that lowers my immune system, so I have to be really careful around people that are sick. I get sick really easily.” Participant four said. “I’m on [medication] so it knocks out my immune system so I get sick really easily.” She also explained that another side effect of her medication was that she “gets

really sick and I lose all my appetite and I get really nauseous and throw up. I get really tired because I'm not eating anything because I feel so sick." Participant 11 said, "I've been on steroids three times. The steroids work, but they make you kind of crazy. My face was very puffy and I gained like 35 pounds when I was on them."

### **Medical Experiences**

Participants had numerous medical experiences such as hospitalizations, enduring medical tests such as colonoscopies and computerized tomography (CT) scans, needing medication, following a specific diet required to manage their condition, and having specialists such as neurologists, cardiologists, and gastroenterologists, along with a primary care physician. Many participants required hospitalization and/or extensive, and sometimes invasive, medical testing over several months or years to get an accurate diagnosis. Participants 2, 3, 4, 5, 7, and 11 all required specific diets to manage their conditions. Dietary restrictions included following a gluten free diet and monitoring insulin and blood sugar levels and then making dietary choices based on those levels. Participant seven said:

I take quite a few blood tests a day, insulin shots, I take a lot of insulin shots or I'm on my pump. You look at food completely different with being gluten free and worrying about how things are going to affect your blood sugar.

Participant 11 said "I've discovered histamines are a big factor in allergies and eggs have a lot of histamines in them, so I stopped eating eggs about five weeks ago and the hives have stopped."

In terms of extensive medical treatment regimens, participant four explained that the current medication she is taking via intravenous (IV) infusion is no longer as effective as it is supposed to be and if it continues to be ineffective, she will need to change to a different medication. Participant two received medication infusions prior to finding other methods of

managing her condition, such as acupuncture, herbs, and diet. Participant eight described her experiences with medication to manage her condition:

At the beginning I did chemo at the hospital and I had a pic line so I would go into the hospital, they would do it for me and I would just be in and out in a day. And then after that I had to do subcutaneous shots in my stomach, which my mom started doing for me and eventually I learned how to do it on my own. And now I'm taking the pill form and I was on ten pills [of chemo] and I just reduced to nine pills of chemo every Saturday night... The medication obviously helps, because without that I'd be dead in about eight months if I stopped completely.

Participant 11 has struggled to find a medication to treat her condition. She said:

Over the summer, I did immunoglobulin transfusions, it's four needles that go in your legs and it's 70 cc's of umbilical cord fluid to try to balance out my blood cells. It didn't work, but it was worth a try. I've been trying to stay positive about all the different medicines. There's tons of different medicines out there to try. The problem is because I'm one of the youngest with solar urticaria, they don't know how it can affect me, so they only try it on older people mostly.

### **School Experiences**

Specifically regarding their experiences at school, participants reported having physical issues that affected them at school and missing multiple days or weeks of school. When asked to describe what life at school is like, participant six explained,

It's pretty hard because the pain is all day every day and school is really hard because looking down [at the desk] and just being in one place for a period of time is really hard and it makes it hurt a lot more. I miss school and it would be hard to catch back up, just because I have to figure out time when I will feel good enough to do the work.

Participant eight said, "On my chemo days it's hard to go to school and focus on things when I'm really nauseous. I miss a lot of days." Participant nine ended up taking an exam to graduate from high school. She said,

If I made it to class, I could not do any of the actual work because the fatigue got to me. I wound up having to make a choice between going to class or doing the work and I needed to do both for the school system to be happy.

Participant four reported missing school for one week every five weeks due to treatment side effects. She said, “Every five weeks I’ll stay home because my ribs and stomach will hurt.”

Participants also reported having difficulties with teachers or other school personnel and needing accommodations and/or modifications to be successful at school. Participant eight explained, “I have had quite a few teachers not let me use the restroom as much, which is hard for me. I have had to go talk to the administration office multiple times because of certain teachers.” Participant ten shared, “My teacher just thought I was being lazy, she had no idea that I was in so much pain.”

### **Social Experiences**

One area of difficulty reported across all participants was in their social experiences, especially concerning friends. Participants reported losing friends, avoiding friends, feeling isolated from friends, and friends not understanding life with a chronic illness. “At the beginning [of my illness] I lost all the friends I had,” reported participant eight. Participant one described her experience as, “I can’t do most of the stuff everyone else can in high school so it’s really tough being left out of a lot of things.” Participant three reported, “Normal kids have friends, but they don’t have the disability that I do. And so they’re more liked and talked to. And I’m talked to; it’s just not a lot.” A period in participant seven’s life was described as follows:

I really backed off of having friends and I became pretty isolated. I remember thinking how could I see my friends in the way that I was then, in being so sick and being so ashamed that I had gotten myself into such a dire position.

Participant nine said:

I think leaving school [due to the chronic physical health condition] affected my friendships because I no longer see them unless I make an effort to do so. And it [condition] does affect my relationships when I have to struggle through the fatigue just to meet them and it does affect my relationships because when I do meet them, if I stay too long, I start getting too foggy to think clearly.

Participants also reported issues with interacting with others. Participant three explained, “Some of them [kids at school] treat me like I can’t walk or I’m even stupid.” Participant ten said:

A lot of times you question whether you should even tell anybody. I’ve had issues with lots of people understanding. So, there’s always that element of judgment, should I share or shouldn’t I type of feeling. It takes a lot out of you to deal with people.

Participant eleven explained:

A lot of people question it or people don’t believe me. A lot of people want to play like it’s a game and want me to show them proof of what’s going to happen [if sunlight touches my skin] and kind of mess with me about it. Pretty much everybody.

## **Family Experiences**

Results were mixed in terms of participants’ relationships with their families; some participants reported family being supportive and some participants reported family being unsupportive. Participant seven reported having to move out of her house and in with a friend’s family during her senior year of high school because there was too much tension between her and her mother over the best way to manage her condition. Participant ten said this about her family:

I told some of my family when I was diagnosed and they laughed. A few kind of understood, but then after a while they said they didn’t want to be around me because they didn’t want to catch it. So, I had a pretty estranged relationship beforehand, and now we just don’t talk.

Participant eleven reported having both supportive and unsupportive family members. She said:

My mom has always been behind me on it and believed me when I told her that something’s wrong or I’m really not feeling good, there’s something more wrong than what we just think. And she’s always tried to help me, like when I was doing research about [my condition], she always tried to help me do it to. She’s always been right there behind me, helping me with doctor’s appointments and understands that I can’t go outside. My dad hasn’t really, [pause] he still hasn’t really accepted it. He kind of thinks I’m still faking it. Even though I’ve been diagnosed, he still wants me to push it at times.

I think at times he forgets that I have it, which is kind of hard and he picks on me about it. It's kind of upsetting.

## Research Question Two

What has helped the adolescent deal with having a chronic physical health condition?

The axial codes that were found to support this research question were: coping strategies, support and accommodations, and personal strengths and successes as shown in Figure 4.2.

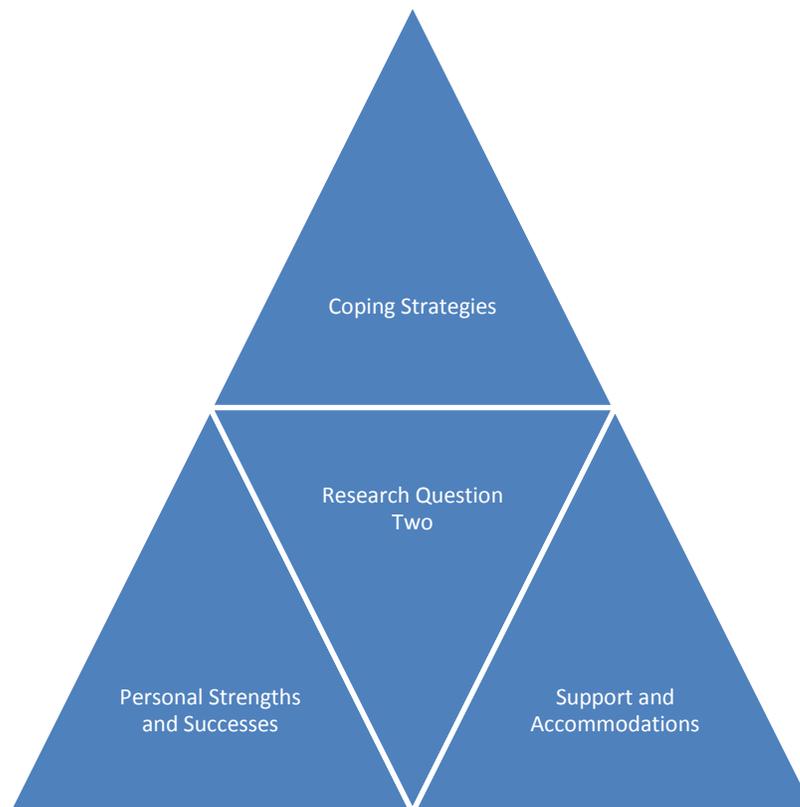


Figure 4.2  
Axial Codes Under Research Question Two

## Coping Strategies

Participants reported several different coping strategies to help them deal with having one or more chronic physical health conditions. These strategies were primarily coping strategies that helped with either mental or physical health. One theme was that participants coped by trying to

live a “normal” life. Participant five said that he coped by “just trying to be normal, act normal.” Participant seven said, “I never saw myself as different, even though there are like 17 things I have to do in the morning to get ready that normal kids don’t have to do.” Participant eleven said, “I always look for a different way, a way around it [my condition]. I fight with it a little bit. I know when to push myself, what I can and can’t do.” Participant eight said, “I try and live a normal life and I try and just do what everybody else does.”

Another theme that emerged across many participants was that one major way of coping was to interact with others with health issues, usually those with chronic physical health conditions. Participant number six said that hearing stories of how others with chronic physical health conditions coped helped her deal with her situation. Participant ten said, “It’s definitely difficult and you deal with a lot of things that are overwhelming, and so you end up getting a family of people with [the same condition] that are actually a lot closer to you than actual family.” Participant eleven said:

I’ve also found a group on [social media] that also have [the same condition], and talk to them about it and know that I’m not the only one with problems. So that helps a lot, talking with people who have the same exact condition.

Participant two wrote in her journal, “Is it bad that I love meeting people with problems? I find they are so much easier to get along with than the healthy kids.”

### **Support and Accommodations**

Support from friends, as well as accommodations and modifications at school, were reported to help participants cope with having a chronic physical health condition. Participant one reported:

My teachers last year really understood, they all sent me all my makeup work over email when I missed and when I got back they would help me catch up and they would stay after school with me and help me. I have a 504 plan at school so I have extra time

between classes if I need it, I have extra textbooks at home, so I don't have to carry them to and from school and I have an elevator key if I need it.

Participant three said, "I have scribes who help me take notes during class... They write it down, which makes stuff easier. My computer helps me at school." More than one participant reported taking online classes part of the time for school as a helpful and sometimes necessary accommodation.

Although many participants struggled with making and keeping friends, several participants reported receiving support from friends that made coping with a chronic illness easier. Participant nine wrote:

My friends are, IMO [in my opinion], pretty supportive. They're always cool if I want to leave early or if I need to sit down, and they never demand that I prove my illness to them like teachers and doctors and my father periodically do.

Participant six said, "Being with my friends helps me take my mind off of the pain," and participant one said, "Talking to my friends helps a lot."

### **Personal Strengths and Successes**

In spite of all of the previously mentioned difficulties, all participants reported successes in their lives as well as having positive personal attributes. Personal attributes described included openness, determination, having a sense of humor, and wanting to help others. Participant number eleven provided an example of determination. She had experienced unexplained symptoms for nine years and finally did her own research of her symptoms and tried to match them up with a diagnosis. She found a match, went to her doctor, presented her research and was finally able to get an explanation and diagnosis. She also said, "I've learned to ignore people and what they say about me, just laugh it off or make it into a joke." As far as helping others, both participants two, four, and eight were able to recognize symptoms in others and helped them get a diagnosis. Participant eight volunteered for a program at her school that helps freshmen with

the transition to high school. Despite all of her physical issues, participant one was able to stay in marching band and considered it an accomplishment to finish the tenth grade. Participant six said she considered it a success to have kept her grades up, even with missing a lot of school, and being in constant pain while at school and while doing homework. Success for participant two was helping to raise money and participate in a walk to benefit research for her disease. Participant five found success in other activities such as wakeboarding and joining the mountain biking team at school when his condition no longer allowed him to play baseball.

Having a positive attitude was repeatedly referred to by nearly all participants. Participant two commented, “I’ve known what it’s like to be devastated in my bedroom and I would lay on the floor because I couldn’t move because I was so sick. I just had to have a positive attitude through it all.” Participant four said, “I’m not like a negative person on it, I just stay positive.” Participant six said, “I try to stay as positive as possible.” Participant five reported being open and stated, “I don’t really keep things a secret. It’s helped me that I’m open about it.” Participant one said, “I just try to make the best of everything I can. It gets me through everything.” Participant ten made this statement, “Because of [condition], just everyday living is an accomplishment. It’s weird to say every day is an accomplishment, but that’s just how it goes.” Finally, participant eleven said, “Stay positive always. There’s always an answer out there somewhere, even if it hasn’t been discovered yet.”

### **Summary**

This qualitative research study was designed as a basic interpretive qualitative study. The purpose of this study was to explore and understand the academic, social, and emotional experiences of adolescents with chronic physical health conditions. In addition, this study examined if or how adolescents with chronic physical health conditions used strengths to

overcome or endure barriers to success. Several themes were found that illustrated the lived experiences of adolescents living with chronic physical health conditions within the following themes: emotional experiences, physical experiences, school experiences, medical experiences, social experiences, and family experiences. Ways that helped adolescents with chronic physical health conditions deal with daily life were: coping strategies, support and accommodations, and personal strengths and successes.

## CHAPTER 5: DISCUSSION

The purpose of this study was to explore and understand the academic, social, and emotional experiences of adolescents with chronic physical health conditions and examine if or how these adolescents used strengths and/or hope to overcome or endure barriers to success. By analyzing interviews with adolescents with different types of chronic physical health conditions, it was hoped to make meaning of the results of the study for individuals with many types of chronic physical illnesses and give these adolescents a voice in the research community. The research questions that were addressed in this study are in Table 5.1 and the interview questions are in Table 5.2.

Table 5.1  
Research Questions

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What is the experience of an adolescent with a chronic physical health condition in the school setting?

What has helped the adolescent deal with having a chronic physical health condition?

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Table 5.2  
Interview Questions

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Tell me about your experience living with your condition and how have you handled it?

What successes have you had in spite of your condition?

What has helped you?

Is there anything about you personally that has been helpful in dealing with a chronic physical health condition?

Are there any barriers that having this condition present to your academic success?

How does having this illness affect you emotionally?

How does having this illness affect your relationships with friends?

Is there anything else you would like to tell me about?

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### Participant Sample

The sample for this research study was composed of 11 participants, ten females and one male. The participants ranged in age from 15 to 19 and lived in Colorado, Wyoming, Maryland, Texas, and California. Participants had a variety of chronic physical health conditions, as

previously discussed. Nine participants had one chronic physical health condition and two participants had two chronic physical health conditions. One participant was born with both her conditions, one participant developed her conditions in early childhood, and nine participants were diagnosed with their conditions in their early teen years. It was initially thought that participants would be recruited through doctor's offices in Northern Colorado, but in actuality, only one participant was recruited this way. Other participants were recruited through snowball sampling and others contacted me through my personal blog.

This type of participant sample was relatively unique from other research done with adolescents with chronic physical health conditions because the participants had a variety of different chronic physical health conditions. Previous studies have focused on adolescents with one type of chronic physical health condition or two groups of adolescents with two different chronic physical health conditions (Atkin & Ahmad, 2001; Beaune, Forrest, & Keith, 2004; Eklund & Sivberg, 2003).

## **Discussion of Research Question Results**

### **Research Question One**

The first research question asked about the experiences of an adolescent with a chronic physical health condition in the school setting. Findings from the literature review indicated that adolescents with chronic physical health conditions struggle with frequent school absence (Boice, 1998; Hokannen et al., 2004; Roth-Isigkeit et al., 2005; Sexson & Madan-Swain, 1995; Taras & Potts-Datema, 2005; Taylor et al., 2008; Thies, 2005), difficulties with academic performance (Boice, 1998; Dworkin, 1989; Fowler et al., 1985; Martinez & Ercikan, 2008; Taras & Potts-Datema, 2005), and issues with school personnel (Beaune et al., 2004; Clay et al., 2004; Fowler et al., 1985; McEwan et al., 2003; Nabors et al., 2008; Sexson & Madan-Swain, 1995;

Thies, 2005). These findings from the literature review were supported by the results of the current research study.

Participants in the current research study reported having physical issues that affected their functioning and performance at school. These issues included both acute and chronic pain, medication or treatment side effects, and fatigue. Participants reported difficulties concentrating in class because of pain, nausea, or fatigue distracting them. These difficulties not only caused problems at school, but also at home when students tried to complete homework. If they could not get their homework done, then they were worried about getting behind, or teachers being upset with them, or getting a bad grade. These physical issues also caused them to miss school for multiple days and sometimes weeks. Missing school often led to students getting behind in school work and exams, affecting their grades, and causing a significant amount of stress and anxiety. For some participants, their physical condition became too debilitating for them to attend school, and so they took online classes for high school or found ways to graduate early (e.g. a state competency exam).

For some students with chronic health conditions, their condition or the medications taken to manage their conditions caused drastic changes to their appearance. These physical changes included extreme weight loss or gain, and changes to their face, such as the puffiness that results from taking steroids over an extended period of time. These changes to their physical appearance caused these adolescents to feel embarrassed to go to school and see their friends.

Participants also reported difficulties with teachers or other school personnel surrounding their chronic physical health conditions. Some had teachers that thought they were “lazy” or making excuses to not be in class. Participants also reported needing accommodations and/or modifications at school to be more successful. For some participants, these requests for

accommodations or modifications were well received and quickly implemented, whether that was receiving homework via email or receiving extra time from a teacher to help them catch up on their work. For other participants, these requests were ignored or never put in place, including the possibility of failing to develop and/or implement a 504 plan.

For adolescents with a chronic physical health condition physically attending school, it was impossible to separate their school experiences from their social experiences. Findings reported in the literature review showed that adolescents with chronic physical health conditions can struggle with making and/or keeping friends, feeling rejected or isolated from peers, and talking to friends about their chronic physical health condition (Atkin & Ahmad, 2011; Beaune et al., 2004; Boice, 1998; Hokkannen et al., 2004; McEwan et al., 2004; Meldrum et al., 2009; Miauton et al., 2003; Sexson & Madan-Swain, 1995). These issues were also reported by participants in the current research study. Participants reported losing friends after being diagnosed with a chronic physical health condition, as well as friends not understanding what it is like to live with a chronic physical health condition. Participants also reported feeling isolated from friends because of their condition and various effects of the condition on their lives. Furthermore, some participants reported difficulty talking about their condition to friends.

Emotional and/or mental health issues can affect adolescents with a chronic illness in various settings, including school. Findings from the literature review explained that adolescents with chronic physical health conditions cope with emotional issues such as depression, fear, and anxiety (Atkin & Ahmad, 2001; Eklund & Sivberg, 2003; Rhee et al., 2007), as well as worry or fear about issues related to the future such as graduation (Meldrum et al., 2009), finding a job (Meldrum et al., 2009; Miauton et al., 2003; Taylor et al., 2008; Wolman et al., 1994), and having children (Boice, 1998; Kyngas & Barlow, 1995). Participants from the current research

study reported experiencing emotional issues such as anger, discouragement, hopelessness, fear, depression, and grief. Some also worried about being able to successfully perform in a job in the future or had to change their career goals because they could no longer meet the physical requirements for that career.

Medical experiences can also influence the school experiences of an adolescent with a chronic physical health condition and were listed as one reason contributing to school absence (Hokkanen et al., 2004). The findings from the current research study supported that assertion. Participants reported missing school for medical procedures such as medical tests, treatments, and surgeries. Additionally, hospitalizations necessary for diagnosis and stabilization were also an occurrence that interfered with school attendance, as were side of effects of treatment regimens (such as chemotherapy) which made students too sick to attend school. Furthermore, specialists were sometimes needed which often meant traveling lengthy distances from home, thus also interfering with school attendance. These absences were difficult for participants to handle not only because of the reason(s) they missed school, but also because the missed schoolwork and exams turned into makeup work which became overwhelming and stressful.

### **Research Question Two**

The second research question asked about what had helped the adolescent deal with having a chronic physical health condition. The current research study attempted to address the concepts of hope and strengths with study participants, but did not want to impose ideas upon participants, so direct questions were not asked about hope and strengths. Most answers to this research question were received upon asking participants what helped them deal with having a chronic physical illness, what successes they have had in spite of their condition, and if there was anything about them personally that was helpful in dealing with their condition. When asked

these questions, study participants reported various coping strategies, support and accommodations, and personal strengths and successes that helped them deal with having a chronic physical health condition. The reported coping strategies as well as the reported personal strengths of study participants are reflective of the constructs of hope and strengths. For the purposes of the current research study, the definition of strengths by McQuaide and Ehrenreich was used, which defined strengths as:

The capacity to cope with difficulties, to maintain functioning in the face of stress, to bounce back in the face of significant trauma, to use external challenges as a stimulus for growth, and to use social supports as a source of resilience (as cited in Rawana & Brownlee, 2009, p. 255).

Snyder's (2002) definition of hope was used, which defines hope as "the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways" (p. 249). Essentially, hope is the capability to think and see beyond what one thought was possible and figure out a way to get to that place. Participants reported strengths such as a positive attitude as helping them cope with having a chronic physical health condition.

Participants also reported having successes, as well as goals and dreams for the future, which will be accomplished through having and maintaining hope, as defined previously.

Coping strategies reported by participants included trying to live a "normal" life and interacting with others with health issues, many times in the form of social media, and online or in-person support groups. Support was generally reported in terms of receiving emotional support from family and friends. Accommodations were in place to help the participant at school, such as having a 504 plan, scribes to help with note taking, extra time between classes, extra textbooks at home, and access to a computer for assignments and note taking. All participants reported experiencing what they considered successes in their lives. Participants also reported having positive personal attributes such as determination, a sense of humor, a positive attitude,

and being open about their condition with others. While none of these aspects were addressed specifically in the literature review, this study's findings related to hope and strengths support the need to further explore and encourage the coping strategies, recognition of successes, and positive personal attributes reported by the study participants.

### **Study Limitations**

The current research study was a qualitative research study, thus generalizability was not a goal. However, an effort was made to find participants with a variety of chronic physical health conditions. In spite of the different conditions, data saturation was still reached, which contributed to the trustworthiness of the study. It was known that data saturation was reached when the same or similar answers were repeatedly given during interviews.

Results could be limited as far as the male perspective is concerned since the majority of the study participants were female, with only one male participant. Socioeconomic status was not asked of the participants, so there is no record of that, but that could be something that might be helpful to ask in future research.

The final potential limitation of this study was researcher bias. As a person living with a chronic physical health condition, there was no way to separate that part of me when conducting and analyzing the data. While qualitative research approaches assume that this is typically the case, I still wanted to make sure that the voices and experiences of the participants were heard, rather than my own. Therefore, strategies such as peer review and member checking were utilized to mitigate the possibility of my personal experiences overly influencing data analysis.

### **Implications for Practice**

A purpose of this research study was to give adolescents with chronic physical health conditions a voice for their experiences. Additionally, these results can be used to inform the

practice of those involved in the lives of adolescents with chronic illnesses. The following practical implications of this research are discussed to inform the work of school administrators, teachers, and counselors.

### **School Administrators and Teachers**

Since both past research (Beaune et al., 2004; Clay et al., 2004; Fowler et al., 1985; McEwan et al., 2003; Nabors et al., 2008; Sexson & Madan-Swain, 1995; Thies, 2005) and the current study found issues with school personnel as contributing to difficulty at school for adolescents with chronic physical health conditions, this is an area that needs to be addressed. Furthermore, considering that approximately 133 million people in the United States have a chronic physical health condition and that number is estimated to increase to 157 million by the year 2020 (Partnership for Solutions, 2004), with 15% to 18% being children and adolescents (Boyse et al., 2012), it is critical that teachers are given training and assistance to help students with chronic physical health conditions experience academic success. Based on the findings from this study, there are two potential ways in which teachers can become a support and an ally for students with chronic physical health conditions.

One way is for all school personnel, especially teachers, to be provided with at least a brief training about ways to help students in their classes who are living with a chronic physical health condition. Study participants reported receiving benefit from teachers who know about resources and were willing to make accommodations to help them succeed. These accommodations ranged from emailing homework and assignments to the student, providing extra time with the student, and providing additional textbooks for the student to keep at home to alleviate the strain of carrying the books to and from school. Additionally, providing students with extra time during passing periods, or allowing them to travel to classes before or after

typical passing periods can help mitigate mobility issues as well as keep students from exacerbating pain levels by fighting through crowded hallways. Technological assistance, such as using computers to complete assignments rather than paper and pencil was also found to increase efficiency and alleviate pain, fatigue, or discomfort.

Past research studies indicate that teachers are not given training or resources to help students with chronic physical health conditions, and many staff members, other than special education teachers and school nurses, do not feel comfortable being asked to help these students (Fowler, et al., 1985; Nabors et al., 2008). This was also my own experience in a teacher training program and working in various schools. Teachers, school counselors, and other school personnel need to be given knowledge about 504 plans and accommodations and modifications that can be provided so that students with chronic physical conditions are still held to the same academic standards as other students, but are given the opportunity to be more successful in their efforts. Teachers also need to be connected to resources, such as assistive technology, as well as to alternative methods of students demonstrating knowledge and proficiency. Because of high stakes standardized testing, increasingly rigorous academic standards, larger class sizes, and tighter budgets, teachers can be under a significant amount of stress and have a shortage of time to ensure their students are meeting standards. If teachers are provided with resources and options without having to spend a significant amount of time researching and developing these options, they may be better able and more willing to put ideas in place to help students with chronic physical health conditions succeed. Future research could be focused on developing these types of trainings and the results of future research could also provide guidance for developing and implementing trainings in schools and school districts for school personnel.

A second way to help students with chronic physical health conditions succeed is for teachers, and all school personnel, to be aware of students in the school who have a diagnosis of a chronic physical health condition and potential complications of the condition. Findings from this study indicated that teachers that received this information and education were more accommodating and understanding. Parents can help facilitate this awareness by providing the school with information about the adolescent's specific chronic health condition. The American Academy of Pediatrics (2013) recommends that parents provide a written document for the school, outlining the following information: brief medical history, specific special needs, medication or procedures required during the school day, special dietary needs, transportation needs, possible problems, special precautions, doctor's name, and emergency plans and procedures. The American Academy of Pediatrics (2013) also offers this advice to parents of a child with a chronic health condition:

Don't be afraid to tell the school about your child's condition. Some parents worry about sharing this information, but the more informed teachers and other school staff are, the better prepared they will be to help your child. If the school staff doesn't have all the facts, they may make wrong assumptions about your child's behavior or performance. (Parent Responsibilities section, para.1)

### **School Counselors**

For some of the participants in the current study, their school counselor was an ally and a source of assistance. For others, their school counselor contributed to difficulties at school and was not viewed as helpful by the participants. School counselors can play an important role in minimizing the school issues experienced by adolescents with chronic physical health conditions. One important way that the school counselor can be helpful is to inform parents of students with chronic physical health conditions about 504 plans and students' rights under the law to accommodations and/or modifications such as extended time on tests, extra time between

classes, use of assistive technology, and modified assignments. Some participants in this study knew about and had 504 plans in place, but some participants had no idea what a 504 plan was or how to use one.

School counselors can also be a source of support for students with chronic illnesses, especially for those students that may have unsupportive family and/or have lost friends because of their condition. School counselors can check in on these students, facilitate ways they might be able to make friends, and serve as a safe person and provide a safe space for the student. Study participants reported feeling isolated and alone at school, so it could be beneficial for these students to have someone such as a school counselor who can provide a connection, support, and encouragement.

### **Career Counselors**

Previous research has shown that adolescents with chronic physical health conditions worry about future job possibilities and holding a job due to their condition and the limitations that may go along with their condition (Meldrum et al., 2009; Miauton et al., 2003; Taylor et al., 2008; Wolman et al., 1994). More than one participant in the current research study reported being concerned about having a job in the future or what sort of job they would be able to do. Others that did have career goals prior to their diagnosis experienced uncertainty, anger, fear, resentment, and worry after their diagnosis. Thus it appears that adolescents with a chronic physical health condition could benefit from meeting with a career counselor to assist them with exploring viable career options.

### **Other Counselors**

Multiple participants in the current research study reported that one of the ways they coped with having a chronic illness was being around others with a chronic physical health

condition. This was done through in-person support groups, online support groups, and social media groups with participants finding comfort and support from others who were also dealing with a chronic physical health condition. Based on this information, adolescents with chronic physical health conditions could benefit from group counseling for people with chronic physical health conditions run by a counselor.

### **Recommendations for Future Research**

This research study is unique in that not only were the struggles and difficulties of having a chronic physical health condition investigated, but also successes and what helped the adolescent cope with having a chronic physical health condition were illuminated. While there were a few studies found that looked at interventions for helping people cope with having a chronic physical health condition, none were found that conducted research specifically on interventions focused on fostering positive emotions, hope, and discovering and applying one's strengths to cope with having a chronic physical health condition as an adolescent. A review of interventions conducted by Sansom-Daly, Peate, Wakefield, Bryant, and Cohn (2012) found 25 studies that were conducted with an intervention aimed at adolescents and young adults with chronic illness. The types of interventions in these studies were: emotional/peer-support group interventions, educational/psychoeducational interventions, skills-based interventions for the adolescents and young adults with chronic health conditions, and skills-based interventions that included the parents/family of the adolescent and young adult with a chronic health condition.

### **Positive Emotions**

When asked what helped them deal with having a chronic physical health condition, study participants reported positive personal attributes such as determination, a sense of humor, a positive attitude, and being open about their condition with others. These findings suggest that

some adolescents with chronic health conditions have already identified positive emotions within themselves as a way of coping. Other adolescents with chronic physical health conditions could benefit from further research specifically around interventions to help adolescents with chronic physical health conditions develop and maintain a positive attitude or positive emotions.

Previous research conducted has supported the idea that positive emotions serve as an effective coping strategy and contribute to a longer and healthier life. Barbara Fredrickson (2004)

suggested that positive emotions:

produce optimal functioning, not just within the present, pleasant moment, but over the long-term as well. The bottom line message is that people should cultivate positive emotions in themselves and those around them, not just as end-states in themselves, but also as a means to achieving psychological growth and improved psychological and physical well-being over time. (p. 1367)

Introducing adolescents with chronic illness to Barbara Fredrickson's broaden and build theory could be one such intervention that is helpful in encouraging them to cultivate positive emotions and put those positive emotions to use as a coping strategy. Fredrickson (2004) suggested that if positive emotions can accumulate over time, they have the power to transform a person and "fuel human flourishing" (p. 1373).

## **Hope**

Although hope was not specifically mentioned by study participants, it is likely that hope is an essential positive emotion for all people, especially for those living with a chronic physical health condition. Scioli et al. (2011) stated about hope that "there is no greater virtue, no more powerful therapeutic tool, no better ally for the sick" (p.78). Snyder (2002) defined hope as "the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways" (p. 249). Essentially, hope is the capability to think and see beyond what one thought was possible and figure out a way to get to that place. This could be

extremely beneficial for adolescents with chronic physical health conditions because findings from this study indicated that often their thinking is focused on what they used to be able to do and cannot do anymore, instead of looking forward and thinking about what they can do. They often felt that their lives were not going to get any better and that everything they had worked for was gone. However, hope was also demonstrated with participants giving advice about working through resentment and fear, accepting life “as it is”, and not losing hope. These results support a finding by Dorsett (2010) that 73% of her study participants with a spinal cord injury “identified hope as an essential factor that helped them cope following their injury” (p. 83). Dorsett (2010) also recommended that more interventions around the facilitation and support of hope be researched and tested. Additionally, results from research conducted by Venning et al. (2007) suggested that “hope-based interventions need to be tailored to suit the individual and onset of illness” (p. 708). Finally, Snyder (2002) found that high levels of hope have been consistently linked with higher academic outcomes, better physical health, and better psychological health.

### **Strengths**

As stated in the previous section, several participants in the current research study reported many activities that they used to be able to do and were no longer able to do because of their condition. One way to encourage adolescents with a chronic physical health condition to think beyond what they cannot do and focus on what they can do would be to design interventions based on identifying and using strengths.

Rawana and Brownlee (2009) conducted a study using a strength-based assessment and intervention framework for clinical work. McQuaide and Ehrenreich defined strength as:

The capacity to cope with difficulties, to maintain functioning in the face of stress, to bounce back in the face of significant trauma, to use external challenges as a stimulus for growth, and to use social supports as a source of resilience (as cited in Rawana & Brownlee, 2009, p. 255).

Rawana and Brownlee (2009) stated, “We posit that when practitioners draw on a diversity of strengths in the intervention, children and families are further empowered as they perceive such strengths as assets that can be used for resolving difficulties” (p. 255). Supporting this idea, the findings from this study indicated that using character strengths such as determination, a sense of humor, a positive attitude, and being open about their condition with others were ways that participants coped with their condition.

In a review of the literature concerning psychological interventions for adolescents and young adults living with chronic illness, Sansom-Daly et al. (2012) stated, “this review points to the need for intervention development that teaches adaptive coping skills, [and] is grounded in theoretical frameworks” (p. 380). This suggests that the research about adolescents with chronic illness would strongly benefit from research focused on the effectiveness of an intervention designed to encourage hope, positive emotions, and identify strengths as coping skills within the context of living with a chronic physical health condition. Compas, Jaser, Dunn, and Rodriguez (2012) supported this idea saying, “A final important direction for future research is the development and evaluation of interventions to enhance children’s abilities to cope with the stress of chronic illness” (p. 473).

### **Summary**

The purpose of this study was to explore and understand the academic, social, and emotional experiences of adolescents with chronic physical health conditions. In addition, this study examined if and how adolescents with chronic physical health conditions used their strengths and hope to overcome or endure barriers to success in these areas. By using a qualitative research method, it was the intent of the researcher to share the voices, stories, and experiences of adolescents living with chronic physical health conditions. Major findings of the

current research study supported findings from previous research that found that adolescents with chronic physical health conditions contend with various difficult physical, social, and emotional experiences that impact them in the school setting. In addition to supporting previous findings, results from the current research study provided evidence to support the idea of the importance of hope, strengths, and positive emotions in helping adolescents with chronic physical health conditions. Results from the current research study suggest practical implications for those who work with adolescents with chronic physical illnesses. The practitioners addressed using the results from this study were teachers and administrators, school counselors, career counselors, and other counselors.

Using the current research study as a foundation, I plan to delve further into this research area and into the area of interventions to improve the lives of adolescents with chronic physical health conditions. Research focused on the development of successful and meaningful interventions to help adolescents with chronic illness cope with their condition could facilitate their movement beyond simply surviving life to thriving in life and thus follow the example of this participant who said, “I know what I want to do with my life. I have a don’t quit attitude and I’m never ever going to give up on my dreams.”

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## APPENDIX: RECRUITMENT AND CONSENT DOCUMENTS

### **LIVING WITH A CHRONIC HEALTH CONDITION:**

THE ACADEMIC, SOCIAL, AND EMOTIONAL EXPERIENCES OF ADOLESCENTS

#### **What are we studying?**

Adolescents will be asked to tell their story about living with a chronic health condition and the way that having a chronic health condition impacts academic, social and emotional experiences, as well as ways of dealing with or overcoming obstacles that come from having a chronic illness.

#### **How much time will this take?**

Participants will participate in one interview lasting between 1 and 2 hours and asked to write in a journal once a day for the week following the interview. Participants will also be asked to review the written transcript of the interview to verify accuracy. Your total time commitment should be no more than 5 hours.

#### **Who can participate? And where?**

Adolescents between **the ages of 13 and 18**, who have been diagnosed with a **chronic physical health condition**, can participate. Participants will be interviewed at home, in a private location at CSU, or via Skype if not available for an in-person interview.

#### **Are there any benefits?**

1. At your request, we will provide you with a written summary of study findings when the study is completed.
2. While there may be no direct benefit to you, you will be contributing to the greater understanding and knowledge about adolescents with chronic health conditions and ways to help.

#### **Who is doing this study?**

Julie C. Hill, graduate student and Jackie Peila-Shuster, Ph.D., Assistant Professor;  
School of Education

#### **Want to Find Out More?**

Contact Us!

Phone: 970-691-1816 or Email: [julie.hill@colostate.edu](mailto:julie.hill@colostate.edu)



## CONSENT FORM

CONSENT TO PARTICIPATE IN A RESEARCH STUDY AT

COLORADO STATE UNIVERSITY

We are asking you to be in a research study. Being in this study is voluntary. To make an informed judgment on whether or not you want to be part of this study, you should understand the risks and benefits of participating. This process is known as informed consent.

This consent form gives you detailed information about the research study. Please ask any questions you may have about the study or this form before signing it. We will give you a copy of the consent form to keep.

### **What is this study called?**

Living with a Chronic Health Condition: The Academic, Social, and Emotional Experiences of Adolescents

### **Who is doing this research project?**

Jackie Peila-Shuster, Ph.D.  
School of Education  
College of Applied Human Sciences  
Colorado State University (CSU)  
Email: [jackie.peila-shuster@colostate.edu](mailto:jackie.peila-shuster@colostate.edu)

Julie Christine Hill, graduate student  
School of Education  
College of Applied Human Sciences  
Colorado State University (CSU)  
Phone: (970) 691-1816 Email: [julie.hill@colostate.edu](mailto:julie.hill@colostate.edu)

### **What is the study purpose?**

The purpose of this study is to explore and understand the academic, social, and emotional experiences of adolescents with chronic physical health conditions. In addition, this study will examine how adolescents with chronic physical health conditions overcome or endure problems in these areas.

**Who will be in this study?**

Adolescents between the ages of 13 and 18 who have been diagnosed with a chronic physical health condition.

**What will the participant be asked to do?**

If you give consent to participate, you will participate in an interview with Julie Christine Hill. The interview questions will have to do with your experience of living with a chronic health condition and ways of managing effects of living with a chronic health condition. The interview will last between one and two hours. Additionally you will be asked to write your experiences in a journal at least once a day for the week following the interview. If you become tired, stressed, or otherwise unable to complete the interview, the interview will be ended. You do not need to answer any question you would rather not answer.

**Where will the study take place?**

The interview will be conducted either at your home, in a secure location at Colorado State University or via Skype for those who are too far away for an in person interview

**Will I be audio recorded?**

With your permission, the interview will be **audio recorded** so that the interview can be transcribed.

**Will I benefit from being in this study?**

There are no known personal benefits in participating in this study, but the information gained from this study may be important in planning and informing future research and ultimately interventions for adolescents with chronic health conditions and trainings for educators.

You may choose to receive a summary description of the entire study (please see checkboxes at the end of this form).

**Are there any risks?**

Through participating in this study, you will have no greater chance of getting hurt than you would in regular daily activities. Due to the topic of the research, you may experience emotional or mental discomfort while discussing your health condition and how it affects daily life. It is not possible to identify all of the potential risks in research procedures, but we have taken reasonable safeguards to minimize any known and potential, but unknown risks.

**Do I have to take part in this study?**

Participation in this research study is entirely voluntary. You may choose not to participate and you may stop your participation at any time. If you choose not to participate in the journal activity, then only the data collected from the interview will be included in the study. The time commitment for the journal activity is approximately 10 minutes per day, for one week, totaling approximately 70 minutes or 1 hour and 10 minutes.

**Who will see the research records?**

All information obtained in this research study will be kept confidential. All participant identities will be kept confidential by using a number. The data will be seen primarily by the graduate student, Julie Christine Hill's thesis committee, Jackie Peila-Shuster, Sharon K, Anderson, James Banning, and Lise Youngblade. We may also use data from the entire study group, which would not include identifying information from participants, for teaching university students, or professionals working with adolescents with chronic health conditions.

We will keep private all research records that identify you, to the extent allowed by the law. Your information will be combined with information from others taking part in the study. When we write about this study to share it with other researchers, you will not be named in the materials. We may publish the results of this study; however, we will keep your name and identifying information private. Additionally, there is the possibility that publications (book, articles) may be written and published telling the stories of the adolescent participants, but your story will only be used with your and your parents' permission as evidenced by a check box at the end of this form.

Specifically, a linked list, which will be created and used during the time data is being collected, will be used to connect data and participant names. A random number will be assigned to each participant. Once a number is assigned, only that number will be used for identification.

We will keep all materials, including audio recordings, transcriptions, and papers in a secure location for at least three years, after which time they will be destroyed. We will make every effort to prevent anyone who is not on the thesis committee from knowing that you gave us information, or what that information is. You should know, however, that there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court.

**What will it cost for me to participate?**

You will not have to pay money to be a part of this study; CSU will likewise, not pay you for your participation. Colorado State University is a Colorado government agency. Laws govern what the University can pay for. If you get hurt because of this study, the University may not be able to pay your doctor's

costs. You might have to pay them yourself. If you were to get hurt, you will have to take specific legal steps.

**What happens if I am injured because of this research?**

The Colorado Governmental Immunity Act determines and may limit Colorado State University's legal responsibility if an injury happens because of this study. Claims against the University must be filed within 180 days of the injury.

**Will I receive any compensation for taking part in this study?**

There is no compensation available for participating in this study.

**What if I have questions?**

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact Julie Christine Hill at (970) 691-1816 or [julie.hill@colostate.edu](mailto:julie.hill@colostate.edu).

If you have any questions about your rights as a volunteer in this research, contact Janell Barker, Human Research Administrator at 970-491-1655. We will give you a copy of this consent form to take with you. This form has been approved by the Institutional Review Board for the protection of human subjects on \_\_\_\_\_.

**What else do I need to know?**

Please use the boxes below to let us know your wishes regarding these options.

**Do you give permission for the audio recording of yourself to be included in the study?**

Yes       No

**If Yes, do you want a copy of the transcribed interview?** (You will be asked to address an envelope. We will not keep your address on file for general purposes.)

Yes       No

**Do you want a summary of the entire study?** (You will be asked to address an envelope. We will not keep your address on file for general purposes.)

Yes       No

**In addition for use in the study, do you give permission for the audio to be included in teaching (college students, researchers) for up to ten years? Participants who are under 18 years old will be contacted when he/she turns 18 to re-consent.**

Yes     No

May we contact you for future research or to follow up from this research study? ?

Participants who are under 18 years old will be contacted when he/she turns 18 to re-consent.

Yes     No

If comments or stories by you are used in publications, how would you like for us to refer to you?

No Name (Real or Fake)

Participant Number

Fake Name (must provide)

First Name

**Consent:** Your signature indicates that you have read this handout and willingly sign this consent form. Your signature also acknowledges that you have received, on the date signed, a copy of this document containing 5 pages.

\_\_\_\_\_

Signature of person agreeing to take part in the study

Date

\_\_\_\_\_

Printed name of person agreeing to take part in the study

\_\_\_\_\_

Name of person providing information to participant

Date

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Signature of Research Staff

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Date

PARENTAL SIGNATURE FOR MINOR

As parent or guardian I authorize \_\_\_\_\_ (print name) to become a participant for the described research. The nature and general purpose of the project have been satisfactorily explained to me by \_\_\_\_\_ and I am satisfied that proper precautions will be observed.

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Minor's date of birth

---

Parent/Guardian name (printed)

---

Parent/Guardian signature

---

Date