

Chronic illness and the college student experience:  
An anti-deficit achievement study of resilience in higher education

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The undersigned, appointed by the Associate Vice Chancellor of the Office of Research and Graduate Studies, have examined the dissertation entitled

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## Dedication

This dissertation is dedicated to Derek and Catherine. Derek Scheese for being my husband, best friend and active cheerleader through my graduate school process. Thank you for listening to my excitement and complaints through the learning and writing process.

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## Abstract

Data from the National Longitudinal Study of Adolescent Health indicates that students with chronic illness graduate college at half the rate of non-ill college students (18% vs. 32%) (Herts, Wallis & Maslow, 2014). Statistics such as this might explain much of the current discourse around college students with chronic illnesses centers on deficits and failure points (Devine, 2016; Agarwal, Moya, Yasui, & Seymour, 2015; Lombardi, Kowitt, & Staples, 2015; Oswald, Huber, & Bonza, 2015; Sniatecki, Perry, & Snell, 2015). Understanding challenges and barriers faced by these students is certainly important, however focusing on deficits has provided little insight into how the students who are staying succeed, which leads to the main research question of this dissertation: how do students with chronic illnesses use assets and resources to build resiliency as they navigate their educational path?

To challenge the idea of deficit modeling as the right fit for explaining the phenomena of college students and chronic illness on campus, I employed an anti-deficit achievement and resiliency framework in the current study. The resiliency framework in and of itself is an anti-deficit theory that focuses on how someone uses internal assets and external resources to navigate risk (Stoddard, Zimmerman, & Bauermeister, 2012). At the same time, I wanted a theory that framed the entire research experience, from questioning to analysis in an anti-deficit light. The anti-deficit achievement framework developed by Harper (2010), was originally applied to black males in STEM fields, but provided the perfect mindset and framing for resiliency theory to reside, as the theory's line of questioning and interest in the student's past was strengths focused.

The phenomenological approach was the best fit to explore the lived experiences of 13 college students with chronic illnesses in a large public university in the Midwest in this study. Participants were recruited through advertisements in the all-campus bulletin and through flyers around campus. Interviews of each participant were conducted at the beginning and end of the semester. During the course of the semester they also maintained journals to document their experience in real time. Once data was collected, themes were found among each participant and then across all participants in the study.

Several important findings came out of the current study. First, participant's reported using internal assets in combination with external resources to build resiliency to navigate risks associated with their chronic illness, but also educational risk. Internal asset findings included development of personality characteristics, such as positivity, personal agency, and faith in a higher power as well as an overarching adaptability that was realistic and self-aware. External resource findings indicated that family, significant others, friends and professors were a major source of support. Institutional resources were also identified as important, in particular the disability center and student health.

The findings resulted in rich knowledge of the participant's experience in higher education with a chronic illness. Findings resulted in significant recommendations for research, policy and practice, which are included in chapter 5. However, what is clear is that this population needs additional attention, and the best resource for understanding students with chronic illnesses are the students themselves. If higher education institutions and leaders intend to support their students at a high level that leads to satisfaction and matriculation, this population can no longer be ignored.

## **Chapter 1: Introduction- College Students with Chronic Illness**

A college professor at a large research based university recently received e-mails from a frustrated graduate student with chronic disease who was tired of administrative roadblocks at her particular school, and a distraught parent of a college student who was about to withdraw from another school because of her health. Both e-mails sought commiseration and advice, and both speak to the same issue: What happens when patients with chronic illness enter higher education (Edwards, 2014, p.1)?

This story illustrates some of the more common challenges facing students with chronic illness as they embark on their educational journey. With more and more children with chronic illness reaching adolescence (Maslow, Haydon, McKee & Halpern, 2012), this group is now seeking additional educational opportunities in higher education institutions; however, matriculation for college students with chronic illness is grim (Herts, Wallis & Maslow, 2014). As college students with chronic illness experience additional risk in their educational career outside of the non-ill student, it is important for educational leaders to understand how these students navigate their educational endeavors. Understanding their assets and resources will enable higher education institutions to help this population capitalize on their strengths to ultimately improve retention and graduation rates. This new strengths or anti-deficit based understanding will also enable higher education institutions to identify any structural barriers that exist for students with chronic illness and provide educational leaders an opportunity to remove those barriers. This study uses an anti-deficit achievement framework as the foundation to address how college students navigate their

educational path at one public land grant institution in the Midwest, despite having a chronic illness.

### **Statement of the Problem**

For the estimated 20.4 million college students who entered degree-granting institutions in 2016, there are many challenges to educational attainment such as increasing tuition, issues of social justice and inappropriate high school preparation (National Center for Education Statistics, 2016). College students with chronic illness also experience these challenges, but with the additional difficulty of managing the ups and downs of their illness.

Despite these challenges, “up to 90% of children with significant childhood onset illness are expected to survive to adulthood” (Maslow, et al., 2012); however, even with higher survival rates, a large majority of these children face issues of educational attainment as they mature. Data from the National Longitudinal Study of Adolescent Health indicates that students with chronic illness graduate college at half the rate of non-ill college students (18% vs. 32%) (Herts, Wallis & Maslow, 2014). As degree attainment is often linked to positive financial and social mobility outcomes, low matriculation rates for chronically ill college students can severely impact their future earning potential and social outcomes (Maslow, et al., 2012). To add to the challenge of supporting chronically ill students on higher education campuses, many student conditions are non-apparent, making it difficult to identify student need. Non-apparent conditions, and lack of disclosure of the condition by the student, may prevent higher education staff from even connecting students to much needed systems of support, compounding issues of matriculation.

Due to the low college completion rate of this group of students, researchers and practitioners may expect a substantial portion of scholarly work dedicated to exploring the

experience of students with chronic illness on college campuses, however quite the opposite is true. Due to the late appearance of the Individual with Disability Education Act (1990), college students with chronic illness did not appear on United States campuses en masse until the early 1990s leading to a large deficit of research on this group.

### **Purpose of the Study**

In this study I developed an anti-deficit resiliency narrative of how students with chronic illness use assets and resources to build resiliency as they move toward degree completion. This study collected qualitative data from semi-structured interviews and participant journals at a large public university in the Midwest. Interviews were conducted with undergraduate students at the beginning and end of the semester. Journals were also kept by the participants to record their experiences throughout the semester (Appendix C). Participants received weekly open-ended prompts throughout the semester to help them explore and reflect on their college going experience. Since all college students have the capacity for resiliency, I used these interviews and journals to determine the process these students use to become resilient as they navigated their illness within their higher education experience.

### **Research Question**

This research study considers the following question within an anti-deficit achievement framework:

How do college students use assets and resources to build resiliency, despite navigating a chronic illness?

**Chronic Illness, Anti-Deficit, Resiliency and Risk Defined**

In the literature chronic illness, chronic disease and chronic medical condition are terms used interchangeably. Chronic medical condition is used to refer to a human health condition or disease that lasts for more than three months (Charmaz & Rosenfeld, 2010). Chronic disease refers to the physiological response to the condition, while chronic illness refers to the person's experience of the condition or disease, including psychological and social outcomes (Charmaz & Rosenfeld, 2010). Even though these terms are often used interchangeably, this research study will continue to use the term chronic illness because it most aptly describes the wide range of physiological, psychological and social impacts associated with the condition.

To clearly define the population explored in this study, there are three definitions of chronic illness to consider. First, it is important to note much of the literature reviewed in this study looks at either the medical or educational definition of chronic illness. In the field of medicine for example, the Centers for Disease Control and Prevention (2016) definition of chronic illness states: "chronic illnesses are conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living" (2016, p.1). The Department of Education (2016) definition under the law is slightly broader and says "a chronic illness involves a recurring and long-term disability such as diabetes, heart disease, kidney and liver disease, high blood pressure, or ulcers" (p. 1). Other examples common in studies of chronic illness include: diabetes, fibromyalgia, multiple sclerosis and asthma. These conditions require routine management and may disrupt college trajectory. It is also vital to note that behavioral or learning disorders, physical disabilities, and addiction are not the focus of this

research, even though it is recognized that these conditions can occur concurrently (Centers for Disease Control and Prevention, 2016).

One of the challenges to the current definitions of chronic illness in the literature is their broad nature. While in some circumstances broadness allows for flexibility, in the case of recruiting research participants, a narrowing of the definition of chronic illness is necessary to recruit participants whose chronic illness is a risk factor to college completion. For example, some children with asthma may outgrow the condition as an adult (Li, 2017). If a person had a childhood illness, but no longer experienced the illness as an adult, they would not meet the prerequisite to be a participant in the study. When this dissertation discusses participants, the definition of chronic illness tightens to one based on the American Association of Diabetes Educators (AADE) diabetes self-management education core outcomes. The AADE diabetes self-management education core outcomes (2003) consist of the following: activity level, eating, monitoring, medication, problem solving, complications, and psychosocial adaptation (Table 1). Even though these outcomes are used primarily for those diagnosed with diabetes, these same factors can be applied to other populations with chronic illness, and have been used in previous research to identify this population (Ravert, Russell & O'Guin, 2017). All of the above outcomes focus on impacts to daily life. For this study to qualify as a participant, the chronic illness must have met at least three of the seven criteria listed in Table 1. Three criteria may seem arbitrary as a minimum, but it is flexible enough to encompass a wide variety of chronic illness at the level that students experience their condition. Table 1 gives a general description of each of the above-mentioned outcomes.

Table 1

Outcome	Description
Activity Level	The intensity of the exercise and duration of the physical activity is significantly influenced.
Eating	Due to the chronic condition, eating involves a complex set of behaviors including when to eat, what to eat, how much to eat and how many times a day.
Monitoring	Monitoring includes monitoring vitals, illness symptoms or reactions and being able to interpret the results.
Medication	Medication is taken for the illness or symptoms resulting from the illness, and includes a variety of management skills for administering the proper dose.
Problem Solving	Recognizing and responding to unanticipated situations related to the illness.
Complications	The person actively seeks out ways to understand and prevent complications related to the illness.
Psycho-Social Adaptation	The illness creates behavior changes, and sometimes barriers must be overcome to create these changes, such as monitoring psychological well-being and relationships.

(AADE, 2003)

The foundational mindset of this study is anti-deficit. Due the prevalence of deficit modeling of college students, it is important to make a brief comment on the anti-deficit concept. The Merriam-Webster online dictionary (2017) defines deficit as “as a lack or impairment in ability or functional capacity”. Anti-deficit acts as the antonym of deficit. Instead of looking at where there is a lack or impairment, anti-deficit looks at where there are abilities and functional capacities. If higher education institutions and administrators truly want to see students be successful, persist, graduate, and achieve employment or acceptance to advanced educational programs, it is only logical that research surrounding college students should take the latter perspective instead of the former.

Also, important to the study is to understand the definition of resiliency, as resiliency is the lens through which this study is developed. Although, some researchers look at

resiliency as an internal trait, others view resiliency as a process developed from a variety of external (resources available) and internal factors (assets the individual possesses; Masten, & Wright, 2009). For the purposes of this project, I use the latter approach as it fully encompasses the complexity of navigating risk. Officially, resiliency is defined in this study as the process by which a person navigates risk through the use of assets or internal factors, like self-esteem, and resources or external factors, such as parental support (Siebert, 2005). Further, the risk referred to in resiliency encompasses any situation, which could result in a loss or damage, causing adverse results (Stoddard, Zimmerman, & Bauermeister, 2012). Risk can be short term and acute or lingering and chronic (Fergus, & Zimmerman, 2005). In the case of college students with chronic illness, the illness itself acts as a risk to college completion in addition to the myriad of other risks to college completion faced by the college going body. Resiliency can be used to recognize the assets and resources used to navigate the commonly recognized risks inherent to the college going experience along in combination with the risk associated with having a chronic illness. Viewing resiliency as a process also recognizes that resiliency can be built over time, and is not a static trait of the haves and have nots (Fergus & Zimmerman, 2005).

### **Legislative Protections**

It is useful to note that protections for individuals with disabilities made a leap forward in 1990 with the Individuals with Disabilities Education Act (IDEA). In 1997, the added additional legislation that supported transition services past the secondary education level. The new form of education for students with disabilities under IDEA (1997) provided, in most cases, an inclusive education in mainstream classrooms. Students with disabilities

were also taught adaptive strategies and self-advocacy, which allowed them to compete with their non-disabled peers.

Additional legislative support of the civil rights of students with non-apparent disabilities was affirmed under section 504 of the Rehabilitation Act of 1973. Section 504 did several things for students with non-apparent disabilities. First, it prohibited colleges and universities from inquiring whether a student had a disability before admission. Second, this legislation required post-secondary education institutions to provide reasonable accommodations under the law for any student attending a school that received federal funding and were otherwise qualified to carry out essential requirements of the program.

The Americans with Disabilities Act, in 1990, did much to increase awareness of the availability of protections afforded to students with disabilities, even though it did not substantially change the law from section 504 of the Rehabilitation Act on college campuses (Mayerson, 1992). One new requirement for institutions of higher education is found under Title II of the ADA and requires colleges and universities to conduct additional accessibility self-evaluations not required under section 504. Private colleges are also held accountable under Title II of the ADA when the removal of barriers is accomplished without much difficulty or cost. An amendment to the ADA in 2008 broadened the definition of disability to include impairments such as “the functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions”. The 2008 ADA amendment was the first true attempt in legislation to explicitly cover a wide range of disability due to chronic illness. These amendments offered protections for students with chronic conditions and enabled them to successfully enter higher education institutions, and is really when research began on this population.

From a legal standpoint, it appears many of the appropriate protections are in place to ensure success for students with chronic illness on higher education campuses, but as the literature below demonstrates, there are still improvements needed for equity for this population to occur.

### **Studies that Have Addressed College Students with Chronic Illness**

The body of literature surrounding college students with chronic illness is limited, but what does exist is widely varied, deficit oriented, and lacks depth into the student's college going experience. This section discusses a general overview of chronic illness as a disability, deficit and barrier modeling for students with chronic illness, lack of support systems faced by these students, as well as risk taking in the population.

As mentioned in the section above, there is very little research on students with chronic illness prior to the creation of legislation in the 1990's which allowed students to successfully navigate the education pipeline. Due to these legislative changes, chronic illness sometimes finds itself in the disability studies literature under immunological disability. These studies often draw conclusions about the experience of those with disabilities broadly, even though it is typical to find only one or two participants who experience an immunological disability (Farmer, Allsopp, & Ferron, 2015; Lombardi, Kowitt & Staples, 2015). The limited number of participants who actually experience chronic illness calls into question whether findings can be broadly applied to the population.

When exploring the literature with a critical eye, one also finds a great deal of deficit modeling in the disability research field (Devine, 2016; Agarwal, Moya, Yasui, & Seymour, 2015; Lombardi, Kowitt, & Staples, 2015; Oswald, Huber, & Bonza, 2015; Sniatecki, Perry, & Snell, 2015). A few studies focused on strengths based programming (Farmer, Allsopp, &

Ferron, 2015), sense of belonging (Vaccaro, Daly-Cano, & Newman, 2015) and one study out of Canada looked at school related factors that led to graduation (Fichten et al., 2013). While some anti-deficit research is available, many of the studies in the disability/college student literature focused on learning disabilities or ADHD and used scales to measure internal and external attributes for success, instead of solid in-depth qualitative methods to explore how these students were using these attributes (Lombardi, Kowitt, & Staples, 2015; Oswald, Huber, & Bonza, 2015; Sniatecki, Perry, & Snell, 2015). The addition of one or two students with chronic illness into these studies almost seems an afterthought to demonstrate inclusiveness of a wide variety of disabilities, and does little to create in-depth knowledge of their lived experience. The disability literature tends to homogenize chronic illness with other disabilities, even though the nature of chronic illness varies drastically by individual.

Within the limited literature that addresses college students with chronic illness specifically, it is common to see the word “barrier” (Kranke et al., 2013; Goodwin & Morgan, 2012; Balfe, 2007; Olney, & Brockelman, 2005; Abraido-Lanza, Guier, & Colon, 1998). As such, much of the research on college students with chronic illness can be broadly categorized into several barriers to educational attainment. The first barrier found in the research is stigma. When it comes to students with chronic illness, the discourse centers on external and internal stigma (Goodwin & Morgan, 2012; Kranke et al., 2013). These negative reactions by others were found to have caused strong negative emotions, which impact self-esteem and prevent students from fully capitalizing on opportunities (Kranke et al., 2013).

Connected to the stigma of having a chronic illness on campus, other researchers identified negative self-concept and mental illness as being additional barriers to educational attainment (Haemmelmann & McClain, 2013; Abraido-Lanza, Guier, & Colon, 1998). Some

researchers even reported that the illness itself changed self-concept, and led students to feel as if did not belong on campus (Olney, & Brockelman, 2005). In relationship to self-concept, students with chronic illness were found to have greater incidence of anxiety and depression, leading to a refusal to return to school, and risky behaviors to cope (Barakat & Wodka, 2007; Sankey et al., 2006). Despite these mental health and negative self-concept indicators, college students with chronic illness have also revealed inadequate support systems in previous research (Olney & Brockelman, 2005; Garmezy, 1991).

Support systems for students with chronic illness are found to occur both inside and outside the institution. However, Royster and Marshall (2008) found that lack of understanding of the experience of students with chronic illness led to an inability of college personnel to offer appropriate support. Other studies show colleges are ill equipped to provide a solid support system (Irwin & Elam, 2011; Jung, 2002). The research regarding family support was often hit and miss and the amount of support offered often differed by gender (Olney & Brockelman, 2005; Garmezy, 1991). The literature offers mixed results on whether families were a substantial form of support. Some studies found families in significant distress when they experienced raising an adolescent with a chronic illness. (Quach & Barnett, 2015; Senger et al., 2015). Others found decreased parental productivity and loss of income (Plumb et al., 2015; Groenewald, 2014). Given these challenges within the family, one would assume that lack of family support would impact graduation. However, other studies found parental support did not impact academics overall. Maslow et al. (2012) found parental relationship quality did not impact college graduation rates, however Wodka and Barakat (2007) found high family support did lead to less overall anxiety in adolescents. Compounding the mixed results of family support in the literature, the literature revealed

only a minority of college students with chronic illness had a relationship with a primary care physician, student health or the disability center freshmen year (Herts, Wallis, & Maslow, 2014). The lack of adequate medical support was found to negatively impact the success for students with chronic illness on campus (Kranke et al., 2013).

Outside of these factors found when attending college, students with chronic illness were found to be disproportionately from lower SES backgrounds, with challenges in educational attainment and lower quality of life (Haas & Fosse, 2008). Financial and prior challenges with educational attainment compounds issues of matriculation for college students with chronic illness. According to a research study Sankey et al. (2006), a pause in an educational program due to health reasons led to a 21% drop out rate. The unpredictable withdrawals and pauses in the educational trajectory also have a strong financial impact for those, who on average already have more limited means. In addition to lower educational attainment, students with chronic illness were found to experience lower quality of life (Fedele et al., 2009; Adler et al., 2008). This led to challenges in connecting to campus, higher absenteeism, lower performance and higher dropout rates (Herts, Wallis & Maslow, 2014; Fedele et al., 2009).

Last, but not least, the literature explores the risk taking behaviors of chronically ill college students. The literature surround risk approaches this concept from two different perspectives: adverse risk behaviors and positive risk taking. Students with chronic illness were often found to take risks they knew would adversely affect their health in order to fit in with the “typical” college experience (Ravert, 2009; Balfe, 2007; Eaton et al., 2001). On the flip side, when it came to taking risks for an improved support system, students with chronic illness were found to be much less likely to make these positive steps (Kranke et al., 2013;

Goodwin & Morgan, 2012; Jung, 2002). Risk taking, or lack thereof, typically had to do with the students attempt to control the outward appearance of health and normality to their peers.

### **Gaps in the Literature**

When reviewing the research available regarding college students with chronic illness there is much to be desired, both in theory and method. First of all, college students with chronic illness as a whole are a very under researched and undertheorized group. Even though there is some literature available that addresses educational issues for those with chronic illness, there is next to no research for those experiencing chronic illness while in college within an anti-deficit framework. Lack of research in this area leaves a tremendous gap as the literature knowing where one fails does little to create understanding of one's ability to access resources and build assets.

What makes deficit modeling so challenging is that the constant focus on failure contributes to the mindset that these students are going to be challenging, they are going to struggle and use a disproportionate amount of resources, which costs time and money for educational leaders and practitioners. Deficit modeling also does not offer a true answer to persistence, as knowing what leads students to drop out does not provide the solution to what makes students stay.

Another major absence in the limited literature available is the failure to address the strengths of these students, who overcome more than the normal challenges even to arrive to college in the first place. Research and theory in this area leaves a blank picture in understanding why some students with chronic illness are successful in school and are able to attain positive educational outcomes. Understanding the internal and external factors that keep students on the path toward graduation provides useful insight to higher education

leaders and practitioners, who often attempt to replicate the experiences of success to achieve desired performance metrics. However, an incomplete picture of a student's strengths creates an environment where offering appropriate supports is challenging at best and wholly inadequate at worst. For example, if it is found that this population has strong parental support and that support encourages success, higher education leaders can encourage that support for all, creating ways that parents can engage more fully in the higher education experience. Lacking knowledge of a community's strengths also fails to recognize that the culture of college students with chronic illness has its own capital, which adds value and wealth of college campuses and society in general (Yosso, 2005).

Outside of deficiencies in modeling and building theoretical frameworks for college students with chronic illness, the research tends to take a more quantitative than qualitative focus. This is limiting in several ways. First, the literature acknowledges the difficulty of accessing this group, which makes developing an accurate quantitative picture difficult (Adler, et al, 2008; Herts, Wallis & Maslow, 2014; Jung, 2002; Kranke, Taylor & Floersch, 2013). Second, the experiences students with chronic illness face are complex and diverse (Kranke, et al., 2013; Herts, Wallis & Maslow, 2014). Exploring the life of a chronically ill person on campus by having them fill in a survey, measuring GPA, graduation or retention rates, is unlikely to lead educational leaders and practitioners to a deep understanding of their educational experiences.

A theoretical framework is needed to fully understand how college students navigate their college experience. However, the college student experience is complex, and adding a chronic illness creates additional complexities students must navigate. Through the course of

this research, a combination of two separate theories will be used to fully encompass this topic.

First, exploring this topic through the lens of resiliency theory proves to incorporate both the internal and external factors students use to deal with risk. As chronic illness tends to wain and wax in severity over a period of months or years, resiliency for these students is of great interest. Resiliency allows students with chronic illness to respond to challenges and setbacks, opens students to new ways of learning, makes them more receptive to assistance, and allows them to adapt and thrive in an environment that is constantly changing, because they are confident they will achieve their goal (Siebert, 2005). Looking at resiliency theory helps to develop an even deeper understanding of how individuals use assets and resources to navigate risk.

Second, as mentioned previously, the research available on students with chronic illness tends to be deficit focused. There is much focus on student failures, but little on strengths. This study challenges those notions among researchers and educators, and modifies the traditional deficit approach to studying this population with the anti-deficit achievement framework (Harper, 2010). The anti-deficit achievement framework is used as the underpinning of resiliency theory in this study. Originally developed to apply to Black men in STEM, Harper (2010) used this theory to explain how Black male achievers gained admission to their institution, overcame hurdles typical to their college going peers, and persisted through college to build a competitive portfolio allowing them access to jobs, internships and graduate schools. While this is not a story about Black men in STEM, students with chronic illness also face similar challenges of marginalization, transition, and identity reconciliation (Lynch, 2008); this theory helps shift the research mindset from one

focused on failure, to one of success. While this study did not focus in specifically on power dynamics at play related to race, like Harper's (2010) original work, and is a limitation discussed further in the study, findings did indicate students had to navigate a higher education world that was sometimes culturally unresponsive to their disability status, and this lack of responsiveness created additional risk factors.

### **Significance of the Study**

A report by the American Association of State Colleges and Universities (AASCU) on the *Top 10 Higher Education State Policy issues for 2017* reported that one of the primary issues facing higher education is institutional productivity and student success. States are increasingly looking at performance based funding (PBF) models to fund higher education in a post-recession environment (AASCU, 2017). Two of the key performance indicators of PBF are leaving with a degree and job placement. For those institutions that do not make strides in these metrics, they are almost guaranteed reduced support from the state. This impetus to obtain funding has pushed institutions into seeking ways to improve student outcomes. For those students who persist in their educational endeavors, this study will provide a clearer picture into how these students build resiliency and navigate having a chronic illness on campus. Exploring the resources and assets used by these students to build resiliency gives those with chronic illness a voice to name their experiences on campus. This new narrative will allow educational leaders and practitioners to build interventions and programming that plays to the strengths of the students. This has several benefits; a strengths based approach values the capacity, skills, knowledge and potential of individuals. A focus on strengths does not ignore challenges, but looks at how an individual's strengths can be used to navigate the challenge, and there is evidence that strength's based methods can

improve health, quality of life, well-being and retention (American Council on Education, 2012).

In addition to changing the perceptions about the individual and an institution's ability to offer appropriate support and remove barriers, degree completion for those with chronic illness have future impact on wealth accumulation and job placement, which is a second metric often associated with performance based funding. On average, those individuals who attain a degree earn significantly more income over their lifetime than those who do not have a degree, and in the cases of recession, are more likely to remain employed (Bureau of Labor Statistics, 2016). For this population, who already face higher living expenses and unemployment rates due to the illness (Center for Disease Control, 2003), degree completion becomes even more vital.

Not only does this study do much to enhance the experience of the individual with chronic illness on campus, there are positive institutional outcomes as well. Students with chronic illness come from diverse backgrounds and their experience can lead to institutional enrichment. Engaging and normalizing differences among the student body creates the opportunity for those who are marginalized and those who are privileged to learn from each other. It creates understanding and awareness, which leads to an appreciation of difference and an increase in diverse identities on campus (American Council on Education, 2012). The benefits of increasing diversity on a college campus include enriching the educational experience creating a rich intellectual and social environment, development of personal growth by challenging preconceived notions, improving communication and encouraging critical thinking and builds community (American Council on Education, 2012). All of these benefits are what institutions of higher education sometimes do, and often should, strive for

on a regular basis. What this study does not do is argue that barriers are not important to know exist for this population or that marginalization of these students is not important to recognize, however this study takes the view that mostly one-sided focus on deficits has done little to offers solutions to improving persistence, so a new understanding is necessary to create the positive changes higher education leaders desire for students with chronic conditions.

### **Definitions of key terminology used in this study**

*Anti-Deficit Achievement-* an approach originally developed by Shaun Harper (2010) to explore the experience of black males in STEM. This theory focuses away from deficits and onto persistence and successful navigation of the higher education pipeline, by reframing of common research questions.

*Chronic Illness-* a condition that is ongoing and meets at least three of the criteria in the AADE self-management education core outcomes (Table 1).

*External Resource-* resources in the external environment.

*Higher Education Institution-* post-secondary institution (e.g. college or university).

*Immunological Disability-* a disability impacting the immune system.

*Internal Asset-* traits or skills an individual possesses internally.

*Resiliency-* a process which a person uses to navigate risk. This process is developed from a complex interplay of external resources and internal assets.

*Risk-* any situation which could result in loss or damage, causing adverse results.

## **Chapter 2: Literature Review and Resiliency Theory**

Despite the growing need for research into how college students with chronic illness fair on higher education campuses, the research to address this topic is sparse. This may be in part due to a lack of legal obligation of colleges and universities to support college students with chronic illnesses. Until the 1990's there were no true federal mandates requiring higher education institutions to provide reasonable accommodations to those with chronic conditions. Once these changes were made, those with chronic illnesses started to trickle through the education pipeline. To begin this section, I offer an overview of legislation history that explains the literature or lack thereof later in the chapter.

### **Legislative Background Protecting Students with Chronic Illness in the United States**

Although chronic illness affects thousands of college students today, legislation meant to provide equal protection to this group under the law was, and currently is lumped under disability legislation. This context is an important one to note as it is one of the underlying reasons there is little to no research around this population prior to the 1990's. The United States initial focus on students with disabilities began in the late 1950's with the Training of Professional Personnel Act of 1959 (PL 86-158), which helped train those who worked to educate children with mental and developmental impairments. Other provisions in law that provided professional development to teachers working with students with disabilities were the Captioned Films Act of 1958 (PL 85-905), Teachers of the Deaf Act of 1961 (PL 87-276), the 1965 Elementary and Secondary Education Act (PL 89-10), State Schools Act (PL 89-313) and the Handicapped Children's Early Educational Assistance Act (PL 90-538) of 1968. While these acts moved forward the professional development of educators who worked with student with disabilities, it did little to provide students with

access to a quality public education. The lack of educational equity from legislative action was demonstrated by the fact that in 1970 the federal government estimated only 1 in 5 students with a disability received some sort of public education. States often responded to federal legislation by drafting their own legislation banning students with disabilities from the public school setting (Department of Education, 2007).

The first true guarantee of a free public education under the law came in 1975 with the passage of the Education for all Handicapped Children's Act (EHCA) (PL 94-142). The EHCA was really the turning point in high school completion for many students with chronic illness. The EHCA (1975) guaranteed a free, appropriate public education to every student with a disability in PK-12; this legislation created a pipeline of students who were able to graduate from high school and explore post-secondary education options. The EHCA faced multiple revisions over the next two decades and in 1990 was renamed the Individuals with Disabilities Education Act (IDEA). In 1997, the IDEA made a leap forward, with additional legislation that supported transition services past the secondary education level. These transition plans, often referred to as an IEP, identified specific procedures for those with disabilities to enter into appropriate employment or post-school activities, along with designated responsibility to persons near the student to assist in the transition. Even though institutions of higher education are not legislatively bound by the IDEA or IEP content, the IEP is often the starting point for Disability Services in providing students accommodations on campus. The new form of education for students with disabilities under IDEA (1997) provided, in most cases, an inclusive education in mainstream classrooms. Students with disabilities were also taught adaptive strategies and self-advocacy, which allowed them to compete with their non-disabled peers.

At approximately the same time as the development of the ECHA, the civil rights of students with non-apparent disabilities was affirmed under section 504 of the Rehabilitation Act of 1973. Section 504 did several things for students with non-apparent disabilities. First, it prohibited colleges and universities from inquiring whether a student had a disability before admission. Second, this legislation required post-secondary education institutions to provide reasonable accommodations under the law for any student attending a school that received federal funding and were otherwise qualified to carry out essential requirements of the program. Students who choose to advocate for accommodations, and can provide appropriate documentation are provided an opportunity to participate fully in the higher education experience, increasing their chance of degree completion.

The Americans with Disabilities Act, in 1990, did much to increase awareness of the availability of protections afforded to students with disabilities, even though it did not substantially change the law from section 504 of the Rehabilitation Act on college campuses (Mayerson, 1992). Both laws protect college students with disabilities from discrimination. The one new requirement for institutions of higher education is found under Title II of the ADA and requires colleges and universities to conduct additional accessibility self-evaluations not required under section 504. Private colleges are also held accountable under Title II of the ADA when the removal of barriers is accomplished without much difficulty or cost. An amendment to the ADA in 2008 broadened the definition of disability to include impairments such as “the functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions”. The 2008 ADA amendment was the first true attempt in legislation to explicitly cover a wide range of disability due to chronic illness. From a legal standpoint, it appears

many of the appropriate protections are in place to ensure success for students with chronic illness on higher education campuses, but as the literature below demonstrates, there are still improvements needed for equity for this population to occur.

These legislative differences created opportunity for disability researchers to include those with chronic conditions into research. Even though some disability literature includes a small population of the chronically ill, it is worthwhile to bring issues of chronic illness out of the disability literature. This is not to say that having a chronic illness is not a disability. Despite the debate among researchers in the disability studies arena whether chronic illness should be recognized as a disability (Wendell, 2001), this study recognizes that chronic illness is a form of immunological disability, or a deficiency in the immune system causing impairment. However, burying those with chronic illness into the broad spectrum of disabilities to draw conclusions fails to recognize several things. One, the more popular view of chronic illness looks at the condition of illness as one that needs to be cured or fixed (Wendell, 2001). This fixable nature viewpoint is problematic and creates the perception that chronic illnesses are of a temporary nature, with a single possible cure, as opposed to other types of disability. A society that looks at chronic illness as a need to be fixed contributes to deficit thinking about those with chronic illness, internalizing the message they need to be fixed and fails to recognize the strengths they possess. Second, the majority of those with chronic illness have an immunological disability that is frequently only diagnosed by medical professionals through a battery of tests (Holman & Lorig, 2000). Not only is chronic illness overwhelmingly non-apparent, but the symptoms of the illness are often cyclical, unpredictable in nature, and requires a more constant connection to medical teams (Wendell, 2001). That is not to say that those experiencing other types of disabilities do not have

similar lived experiences, but these experiences overwhelming effect those with chronic conditions, making their conditions unique, and one that is important to highlight and bring to the forefront of research, without including other types of disabilities prevalent on campus.

Those studies directly focusing on chronic illness in higher education are far and few between. The research on college students with chronic illness generally admits to a lack of focus on this group, even though one study of over 1200 undergraduates found that one third of college respondents reported some form of long-standing illness (Herts, Wallis & Maslow, 2014). The literature on college students with chronic illness can generally be categorized into two main categories: barriers to educational attainment, the deficit based approach, and anti-deficit approach of the resiliency of college students with chronic illness. Below is a snapshot of these themes in the literature.

### **Barriers to Educational Attainment**

The overview below provides a clear picture of the factors that hinder success for chronically ill students, leaving the question of what causes these students to be successful generally untouched. Despite these shortcomings, it is necessary to explore the deficit modeling of the current research in order to move scholarship in an anti-deficit achievement approach in future studies. The discussion of barriers in the research is divided into nine themes: stigma, negative self-concept, mental health issues, low socio-economic status (SES) backgrounds, low educational attainment, lack of quality health and disability services, an inadequate support system, lower quality of life and negative risk taking.

**Stigma.** Students with chronic illness often face stigmatization on college campuses that affect completion. Negative reactions can include avoidance, awkwardness, and stereotypes about competence or whether a person has a right to be on campus (Goodwin &

Morgan, 2012). Additionally, one study found that illness could exhibit strong negative emotions about ones' own mortality, which can cause a non-ill person to avoid interaction with a chronically ill student (Goodwin & Morgan, 2012). One assumption is students with chronic illness can easily disclose their condition and have no negative consequences. However, students with chronic illness, and especially those with non-apparent illness, were found to be embarrassed or stigmatized when they told faculty and students about their condition (Kranke, et al., 2013). Some in the study experienced negative interactions from faculty who were unreceptive or uncooperative, and who felt that providing reasonable accommodations would not be fair to other students. For students with chronic illnesses stigma is often not only external, but internally focused. Even when those in the college or university environment are supportive of the student with chronic illness, students can suffer from self-stigma.

Self-stigma could be considered an intrinsic stressor because individuals with disabilities have internalized rejection and public discrimination; it may limit functioning by impacting feelings of self-esteem, thus potentially reducing individual's willingness to capitalize on life opportunities (Kranke, et al., 2013, p. 36).

As this literature indicates, stigmatization of students with chronic illness can affect the motivation to seek help or even fully participate in the college experience, leading to potential non-completion. What is missing though in this body of literature are the narratives of those who found a supportive environment or were able to overcome stigmatization, as well as literature related to stigma associated from multiple marginalities (e.g. race and gender and chronic illness). This lack of exploration into stigma faced by students with

chronic conditions that hold other identity pieces that are often also stigmatized, leaves a gap in understanding the true complexity of the college student experience. What the current literature does do however is give the impression that this group of students are destined to be discriminated against, which does students with a chronic illness no favors.

**Negative Self-Concept.** Self-concept in higher education literature is a common topic. In general self-concept revolves around the self, how the person thinks about himself or herself and how they evaluate themselves and their worth. Even when the groundwork on self-concept is broad, the discourse on this issue for college students with chronic illness often finds the level of uncertainty common with illnesses negatively affects self-concept. Some have claimed that disability or disability in combination with gender, has a greater impact on self-concept than all other factors combined (Olney & Brockelman, 2005). One researcher reported that the chronic illness itself changed normal adolescent self-concept, requiring a number of psycho-social adaptive tasks outside the baseline for the college bound age group (Abraido-Lanza, Guier & Colon, 1998). As students with chronic illness often suffer from hidden conditions, they may also experience lower self-concept than those with highly visible disabilities (Olney & Brockelman, 2005). Negative self-concept is often connected to stigmas mentioned above. Young people with chronic conditions are not only worried about overt discrimination and rejection, but these negative reactions affect their overall view of themselves as individuals and their place on campus (Balfe, 2007). While understanding that some youth with chronic conditions experience negative self-concept is important, the current literature does little to resolve if any experience positive self-concept or explore the differences between those two groups. A comparison on what creates negative

and positive self-concept in college youth with a chronic illness would be a valuable resource for working with these students and directing future research endeavors.

**Mental Health Issues.** The literature also highlights that many students with chronic illness experience some sort of mental health condition, often in the form of depression and/or anxiety. Haemmelmann and McClain (2013), in their discussion of the illness intrusiveness model, developed the concept that illness-induced interference, in combination with the loss of participation in valued activities, affects one's psychological wellbeing and creates negative outcomes. Those authors found that low levels of personal control created learned helplessness in the individual. Likewise, Balfe (2007), Barakat and Wodka (2007), and Sankey, et al. (2006) found students with chronic illness faced moderate to severe anxiety creating a variety of responses, such as refusal to return to school, and turning to drinking in order to cope. Anxiety was a factor even in cases where family supports when transitioning to college were similar to their non-chronically ill peers (Barakat & Wodka, 2007). Ensuring that students with chronic illness have adequate access to mental health facilities is essential to success, as "self-efficacy, mastery and self-esteem are critical determinants of psychological well-being for people with chronic illness (Abraido-Lanza, Guier & Colon, 1998).

The above studies are able to make a valid connection between chronic illness and mental health issues, but mental health concerns on campus are not limited to this group alone as a recent survey found eight out of 10 college students reported experiencing some sort of mental health crisis while in college (Gil, 2015). The researchers did not make a strong argument that mental health issues affect this population more than the general

campus community, which means their research only adds to the general conversation of the mental health crisis on our campuses and does little to determine needs specific to this group.

**Low Socio-Economic Status Backgrounds.** Several researchers of college students with chronic illness explored the demographics of this population and found additional challenges for this group. Cox (2016), found that the gap in degree attainment between students with chronic illness from high-income families and low income families is widening. This should not be surprising as economic factors in the United States often create educational disparities. Lower SES students are often less able to afford the costs of college, face complicated guardian arrangements and housing, are less prepared by their public school system, and lack the social capital to navigate entrance requirements, and financial aid options (Cox, 2016). With all the challenges experienced by low SES families, it makes sense that students with chronic illness also experience these challenges. This is especially true as the research shows students with chronic illness are disproportionately from lower SES backgrounds (Haas & Fosse, 2008). Those who have a child or children with chronic illness also experience major financial outcomes from continual treatments and frequent hospitalizations associated with chronic illness. Haas and Fosse (2008), pointed out that:

The diminished educational outcomes of adolescents in poor health may simply reflect the fact that they come from disproportionately disadvantaged social backgrounds and that it is their socioeconomic disadvantage which is responsible for their poor health and their diminished educational attainment (p.2).

In this case, focusing on SES, which is beyond most college students' control, provides only small gains in studying students with chronic illness as data demonstrates the majority of students from low SES backgrounds matriculating despite the challenges of growing up in a

low SES family. A recent study of 1149 public and private nonprofit colleges and universities by The Education Trust found those students who received Pell grants, a common metric of low SES status, were found to on average graduate at rates only 5.7 points lower than that of the institution (2015).

**Low Educational Attainment.** A large chunk of the literature on barriers focuses on the low educational attainment of students with chronic illness. According to Haas and Fosse (2008), the research demonstrates a strong relationship between poor health and negative educational outcomes. In one study when student data was controlled for SES, it was found a one unit decrease in health led to a drop in on time high school graduation by 34%, and a drop in enrollment in post-secondary institutions by 30% (Haas & Fosse, 2008). Much of the challenge of completion seems to stem from the start-stop gap inherent to those experiencing negative effects of flares often associated with the illness itself. A recent study found that for participants who had to pause their educational program due to chronic illness flare-up, 79% returned to full time educational pursuits or employments, but the majority of those who returned took three or more months to do so (Sankey, et al., 2006). In the college environment, three months translates into an entire semester, which can have implications for academic progress and financial aid. When surveyed, most students found it difficult or very difficult to transition back, and 68% felt their illness significantly affected their educational or career trajectory (Sankey, et al., 2006). What the researchers do not describe in their study are the factors that caused students to return to school after the gap, which would provide educational leaders and scholars useful information to meet the needs of students who must pause their educational plan due to health complications. It is important to recognize the struggles of those with chronic illness to attain education as educational attainment can lead

to future employment opportunities and financial stability. Often though, there are other key supports missing from campus for college students with chronic illness that also compounds the issues of educational attainment.

**Lack of Quality Healthcare and Disability Services.** In the United States, much of the social approach to dealing with chronic illness is with the legal aspect of accessibility and accommodation, however the literature suggests colleges and universities do not do the best job at making students aware of those supports. However, it is important to note that until the last few decades, higher education institutions had no legal obligation to support students with chronic illnesses on campus. One of the major supports found to be missing in the lives of college students with chronic illness was a quality relationship with health and disability services while on campus. Herts, Wallis and Maslow (2014) found that approximately 15% of chronically ill students located a physician on or near campus within the first year of enrollment and only 17% had registered with disability support programs. Reasons for this could vary, but one major factor in lack of services was that students were unaware of the support services available nor did they fully understand the procedures for requesting accommodations (Kranke, et al., 2013). For students with chronic illness, having access to personnel who are trained to specifically assist with the epidemiology of the illness is often essential to their well-being. As mentioned previously, there is a logical connection between wellness and academic completion, so these resources are vital to college completion for any students with chronic illness.

**Inadequate Support System.** Primary care physicians and disability service staff are just one cog in a wheel of staff for students on college campuses. Much of the literature on students with college illness demonstrates that this group of students have inadequate support

compared to their non-ill peers. Part of inadequate support often stems from lack of understanding. Royster and Marshall (2008) found that programs for traditional aged college students often had staff and faculty who were not able to understand the unpredictable nature of chronic illness, and so were unable to fully understand the student's needs and offer appropriate support. The scramble of faculty and staff to try something often left students with chronic illness feeling plans to fit their unique needs were developed on the fly, creating an unequal playing field for success (Irwin & Elam, 2011). Another study argued that faculty and staff were somewhat jaded toward students with chronic illness, as they typically absorbed more than the average share of resources in the form of money, time and personnel (Jung, 2002). In addition, some student with chronic illness found policy surrounding accommodation seeking to be suspicious, and skeptical of those who did not fit the mold of disability as it is commonly imagined (Jung, 2002). In a time of reduced funding for many institutions, some may feel this is a legitimate argument, but this type of mentality may easily contribute to the non-completion of a student with chronic illness at institutions of higher education. Despite a body of quantitative research indicating lack of quality healthcare is a major concern for the success of students with chronic illness, the literature falls flat due to lack of exploration in how students are able to manage their illness successfully when pursuing a degree.

Outside of the institution, the literature shows mixed results for students with chronic illness. What is acknowledged is that time spent transitioning from high school to college is heavily influenced by social factors, and if social issues affect the self-esteem of the individual negatively, there is a lesser chance he or she will be able to cope and adapt (Haemmelmann & McClain, 2013). For this population, family is a major support system

(Garmezy, 1991). Overall, support from home was viewed as generally supportive by 68% of students in one study, but non-profit support groups showed no significant correlation in the success of navigating the individual's situation (Sankey, et al., 2006). Support for students with chronic illness also differed by gender. Interestingly, one study found that female participants identified a much smaller support group than men and the majority did not name one male figure in their lives as a primary means of support (Olney & Brockelman, 2005). Lack of a support system both on and off campus has broad implications to student success and in turn college completion, so attention to this area is reasonable. One would assume in an analysis of scholarly work examples of successful support systems would abound, however only De Paul University's now defunct Chronic Illness Initiative stood out as a successful experiment in supporting those with chronic illness (Royster & Marshall, 2008). However, as is the nature of higher education, sometimes even programs like DePaul's that provided successful interventions for students with chronic illness lose campus support and fail.

**Lower Quality of Life.** Another theme found in the research is that students experiencing chronic illness typically also experience lower health related quality of life (HRQoL). Quality of life is an important metric of overall well-being, which affects a person's ability to have a successful educational experience. Like other barrier topics, the discourse for the chronically ill focuses on the isolation of students instead of ways students have demonstrated improvements in quality of life over the course of their education. Several studies which looked at college students with a variety of illnesses found disease negatively affected disease-specific QoL and mental and physical health related QoL (Adler, et al., 2008; Fedele, et al., 2009). On the more extreme side, one study found college students with

chronic illness experienced sub-clinical symptoms of post-traumatic stress disorder (Barakat & Wodka, 2006). While many factors contribute to quality of life, part of the reasoning for lower HRQoL in students with chronic illness could be due to lack of control. Bishop (2005) found that students with chronic illnesses were often restricted from participation in normal life events due to symptoms of illness, treatment programs and physical limitations. This loss of control had a direct impact on educational attainment. For example one study of college students with chronic asthma found an increased risk of absenteeism and missed work, creating lower overall performance and higher dropout rates (Fedele, et al., 2009). Lower quality of life also had significant effect on connectedness to campus. Chronically ill freshmen were found to have higher levels of impaired HRQoL and loneliness, in fact only “7% of first year students knew more than one person with a chronic illness on campus, and 57% knew none. Fifty percent of chronically ill students had told fewer than five friends of their condition” (Herts, Wallis & Maslow, 2014, p. 477). The isolation of college students with lower HRQoL demonstrates a major impact to success and in some instances can lead to risk taking in an attempt to appear normal.

**Risk-Taking.** Risk taking occurs in two forms in the research: that of risky health practices in an attempt to appear normal in the college environment, and lack of risk taking in the form of non-disclosure of illness to others. While these two types of risk taking may appear separate, there is direct connection between risk taking to develop a persona of normality and lack of disclosure to maintain the appearance of normality. The literature on risk taking found that students with chronic illness primarily do so in public spaces (Eaton, et al., 2001). A health geographer found students with diabetes primarily took risks in student spaces such as bars, clubs and parties (Balfe, 2007). Students in these places undertook risky

drinking practices that could create negative health implications for their illness. The study found that these students engaged in risky practices despite medical advice, in an attempt to produce a desirable social identity; to be normal (Balfe, 2007). Another study on diabetes and alcohol management found that 36.6% of participants reported one or more consequence related to drinking, including injuring themselves, doing something they regretted or having memory lapses (Ravert, 2009). Overall, the Balfe (2007) and Ravert (2009) study showed that for college students with diabetes, participating in the risks of drinking to give the right type of physical capital outweighed the risks of health consequences. In addition, students were found to over control other forms of consumption in private, such as food to counteract the negative effects of their drinking in public settings. In total the research found control over the perception of a normal identity outweighed any negative health outcome (Balfe, 2007), although Ravert (2009) did find that for those who practiced health management strategies, there were less serious outcomes to student risk taking.

The other form of risk taking discussed for students with chronic illness in the literature is that of disclosure. In this case, students with chronic illness are often found to be risk adverse, but this aversion was also directly related to a need to control the appearance of normalcy. In several cases students found advantage to non-disclosure such as a better ability to manage social relationships, less risk of stereotyping and more privacy (Goodwin & Morgan, 2012; Kranke, et al., 2013; Jung, 2002). However, lack of disclosure sometimes had unintended consequences. A study on women with chronic illness found that those who chose not to identify limited their accommodations and often experienced social invisibility and isolation (Jung, 2002). Students who choose not disclose may be allowed to exist under the appearance of normality on college campuses, but at the same time their lack of

disclosure does not allow them to tell their story or represent themselves in a majority, non-ill culture. Instead educating their higher education institutions on the barriers and resiliency of chronically ill students on campus, they perpetuate the idea that they do not really belong.

### **Resiliency for College Students with Chronic Illness**

Unlike the majority of literature focusing on the deficits and barriers of students with chronic illness, there is also a small, but growing, body of literature focusing on resiliency and factors that lead to success. Resiliency theory provides an anti-deficit model that provides a backbone to help higher education professionals understand why some college students successfully graduate from college, despite the risk factors associated with chronic illness (Zimmerman, 2013). However, resiliency is a complex concept with many factors. Maslow, et al. (2012) explored mentors, parents, school and religion as factors and found no difference for adolescents with childhood onset chronic illness and those without illness. The study also reported school connectedness as the only positive factor associated with college graduation. Other high risk groups such as older adults (Seeman & Chen, 2002), Latina's (Abraido-Lanza, Guier & Colon, 1998) and low socio-economic status students of color (Morales, 2010) were found to have psycho-social factors that outweighed negative factors to their success.

Protective factors, are often associated with theories of resiliency, but whereas resiliency is the process of becoming resilient to risk, protective factors are the mitigators of risk. The literature identifies many protective factors for students at risk of failure. One project identified cultural protective factors such as familialism, family relationship, religion and spirituality and acceptance of insurmountable difficulties (Abraido-Lanza, Guier & Colon, 1998). However, another researcher found that these factors did not act as protections

to students with chronic illness (Maslow, et al., 2012). Other studies identified positive affect (Abraido-Lanza, Guier & Colon, 1998) and being future oriented as main protective factors that aided in resiliency and thriving. The challenge to the exploration of protective factors is these studies focus on the personal attributes of a person who is resilient, rather than the factors that promote resiliency.

More recently, researchers are connecting resiliency theory to promotive factors, which attribute resiliency to processes rather than attributes. These positive contextual, social and individual variables, known as promotive factors, interfere with or disrupt development of negative outcomes (Fergus & Zimmerman, 2005). According to Fergus and Zimmerman (2005) promotive factors in resiliency theory consist of assets and resources. Assets deal with internal promotive factors, like self-efficacy, whereas resources are the external promotive factors such as mentors and parental support. Resiliency theory has successfully explored promotive factors for a wide variety of risks faced by adolescents such as poverty (Garnezy, 1991), race (Morales, 2010), violence (Stoddard, Zimmerman & Bauermeister, 2012), substance abuse (Fergus & Zimmerman, 2005) and mental illness (Maslow, et al., 2013). Research that uses resiliency theory is useful in building practitioner knowledge, enabling higher education staff to more deeply understand how college students with chronic illnesses are able to successfully transition to a college campus, despite risk.

Based on research and barriers for students with chronic illness explored in the literature, it may seem logical for the focus to be on the deficits experienced or the effects of the illness after a flare or incident has occurred. The reality though is chronic illness is a lifelong cyclical process, so focusing on support at a moment in time, does students with chronic illness little good. To quote Livneh (2016), “adopting a future oriented, positively

valanced coping framework, rather than a past-oriented approach negates focusing not only on losses, but also on the future and its many opportunities for personal growth and improvement in one's quality of life" (p.76). An anti-deficit intersectional approach, through exploration of resiliency and promotive factors of students who experience chronic illness, would provide positive outcomes, shifting the research narrative to one focused on the asset that these students are to college and university campuses.

### **Current Theories of Research Surrounding Chronic Illness**

When exploring the literature, one finds little theory applied to those with chronic illness. Often the discussion centers narrowly on a specific illness (Adler, et al., 2008; Fedele, et al., 2009; Sankey, et al., 2006), which may or may not be applied broadly to the group. What theory that is available is often deficit focused (Barakat & Wodka, 2006; Balfe, 2007; Haas & Fosse, 2008; Goodwin & Morgan, 2012; Chambers, Bolton & Sukhai, 2013). A selection of commonly used theoretical frameworks for those with chronic illnesses is discussed below.

**Theories of Nursing.** Nursing theories are a set of concepts and assumptions developed out of nursing models and clinical practice. These theories are specifically developed for the practice of nursing and are meant to apply to practitioners. There are four key concepts common in nursing theory: the patient, the environment, health and the nursing role (Nicoll, 1997; Alligood, 2014). In addition to the four key concepts found in most nursing theories, generally these theories are divided into four different categories: needs, interactions, outcomes, and humanistic. These categories look at how nurses can meet basic needs for independence, how nurses interact with the patient and can be a change agent for adapting to ill health, helping patients grow (Nicoll, 1997; Alligood, 2014).

The middle range theory of self-care developed out of nursing theory to explain how the individual handles illness. Riegal, Jaarsma and Stromberg (2012) applied this theory to a broad spectrum of chronic illness as they recognized chronic illness requires a set of specific behavioral requirements to be successful. There are three main pillars to this theory, which are: self-care maintenance, monitoring and management. The strength of this theory is that it explores the processes of self-care the individual uses rather than the promotion of self-care by the health care professional. However, much of this theory relegates self-care success to following a prescribed course of treatment developed with a healthcare provider. So far the empirical evidence using this theory applies to home bound populations and the elderly (Räsänen, P., Backman, K., & Kyngäs, 2007), where self-care has a great impact on health and quality of life. In this approach the relationship between patient and provider is forefront and does not explore the roles of the myriad of internal and external factors that could lead to successfully living with a chronic illness.

**Theories of Adjustment.** Theories of adjustment are often difficult to apply as there is no general definition of adjustment. However, in the research on those with chronic illness, most often psycho-social and health related adjustment is devoted to this group (Abraido-Lanza, et al., 1998; Carver, Scheier, & Weintraub, 1989; Dennison, Moss-Morris & Chalder, 2009; de Ridder, et al., 2008). Psychiatric adjustment theories typically explore the presence or absence of psychopathologies as an indicator of positive or negative adjustment to chronic illness (Moss-Morris, 2013). The greatest benefit of applying theory in this way is that it boils down adjustment to a series of mental health disorders or symptoms. Yet it fails to consider adjustment may be influenced by other factors outside of mood. Assuming that mental health is solely responsible for adjustment or that chronic illness itself is the only

reason a person might develop a mental health disorder is misguided and may negatively impact treatment protocols.

Within the adjustment theoretical framework is the quality of life theory. The benefit of the quality of life (QOL) theory is that unlike most adaptation theory, QOL is multidimensional and acknowledges the social, individual and environmental interactions in those with chronic illness (Bishop, 2005). Additionally, QOL metrics allow researchers to identify positive and negative responses to illness, versus other theories which focus solely on the negative effects of adjustment. The downside to this approach is it is typically applied at the onset of a disability or illness. In the case of college students with chronic illness, most have been experiencing symptoms of the illness for years prior to entry into college. One main overall QOL metric has limited usefulness as those who report high overall QOL may be dissatisfied in multiple life domains (Bishop, 2005). This makes it difficult for a researcher to identify which domains may compensate or negate dissatisfaction in other domains.

The illness intrusiveness model is another psycho-social adaptation theory applied to those experiencing chronic illness (DeCoster, Killian & Roessler, 2013; Haemmelmann & McClain, 2013). The illness intrusiveness model was developed from the idea that illness induced interference compromises psychological well-being leading to negative emotional outcomes (Haemmelmann & McClain, 2013). Overall, the model posits the argument that when a person loses pleasure from every day and valued activities due to loss of control, significant adaptation and coping must occur. What is disappointing about this theory is that it assumes low levels of personal control result in learned helplessness that is difficult to change. Like most psycho-social adaptation theories, the illness intrusiveness model also

looks at positive adaptation as dominantly one related to mood, which does not fully encompass the experience of students with chronic illness on campus. One of the main areas that psycho-social adaptation theories do not address is the acquirement of knowledge about the illness, which is better addressed by learning theory.

**Learning Theory.** Over the past century there have been a myriad of learning theories developed to explain the process of absorbing, processing and retaining knowledge. Two sub areas of learning theory more commonly applied to those with chronic illness: self-directed and transformative learning. Self-directed learning theory looks at the process by which individuals take responsibility for their own learning by determining their needs, setting goals, identifying resources, implementing a plan and evaluating outcomes (Baumgartner, 2011). Several researchers argue that self-directed learning is a key means of coping with chronic illness. Rager (2004) and Holland (1992) found that self-directed learners overall felt more empowered and in control of their illness leading to positive outcomes. The challenge with self-directed learning theory is that not everyone has the skill set and educational background to be a self-directed learner. There are also many methods of learning and it is possible self-directed learning may not be a good match for every person experiencing chronic illness (Holland, 1992).

The second type of learning theory applied to chronic illness is transformative. The main difference between self-directed and transformative is that transformative learning is a change in self-concept of a person and their world. Meizrow (2000) is often considered one of the main theorists of transformative learning and identifies this type of learning as one that requires reflective discourse, complete and accurate information, objectivity and an inclusive environment. Courtenay, Merriam and Reeves (1998) found in their study of HIV/AIDS

patients that those who looked at their identity and role in life after their diagnosis developed new meaning about the importance of people and service to others. The challenge of this learning theory can be found directly in the assumptions. Learning is rarely rational, especially when related to health and well-being. It is even rarer to have complete and accurate information related to a diagnosis. This theory also fails to look fully at the historical and social context or the effects of gender, geography, SES or race on transformative learning.

**Intersectionality Theory.** Intersectionality was initially a concept developed by Kimberlé Crenshaw (1991) to bring to light the interaction of race and gender in violence against women of color. In her pivotal work she was able to explore the invisibility of many individuals within a broader group membership; one in which they are claimed because of one component of their identity, but at the same time, not represented due to another aspect of their identity. Intersectionality is regularly used to gain a deeper understanding of the complex ways society privileges and oppresses based on different parts of identity that are either privileged or marginalized (Crenshaw, 1991). Intersectionality is an important concept to study as data shows that chronic illness does not target the United States population equally, and that those communities experiencing chronic illness at higher or lower rates are based on other privileged or marginalized identities (Etherington, 2015).

Research and data have long shown that chronic illness hits populations of color harder than white population of similar SES status (Lynch, 2008). It is only recently though that the health field started to look at the implications of chronic illness acquisition when individuals occupy multiple disadvantaged identities. When adding an intersectional lens, the research shows that women, who also identify with marginalized racial and ethnic groups are

more likely to be diagnosed with a chronic illness (Etherington, 2015). Education, commonly thought of as a protective factor for chronic illness, is not as significant an impact factor for women of color, disregarding social class, meaning education is not the great equalizer for everyone (Etherington, 2015). However, social class in general is found to be a vulnerability for experiencing chronic illness, as it often prevents access to resources (Etherington, 2015). Studies have shown significant increases in chronic illness diagnosis among lower SES communities, and that those who are diagnosed show higher rates of maladjustment to their condition (Dispenza, Varney & Golubovic, 2017; Helgeson & Zajdel, 2017; Etherington, 2015). Sexual and gender minority communities are not exempt from chronic illness either. Sexual minority men and women, who are often in lower SES classes, report significantly higher rates of chronic illness than their heterosexual counterparts, and it is found that this group typically experiences chronic conditions at a much younger age than the general population (Dispenza, Varney & Golubovic, 2017). Racial minorities, who also share sexual and gender minority status, are even more likely to be diagnosed with a chronic illness (Dispenza, Varney & Golubovic, 2017).

The literature addresses several reasons why intersections of identity may increase diagnosis of chronic illness. One of the major factors discussed is residential segregation. Residential segregation, resulting from policy decisions of privileged groups and historical discrimination that redlined marginalized groups into small geographic areas, led to an intergenerational lack of access to healthcare and nutritional resources (Jones, 2013). For segregated, marginalized communities these health disparities start in utero and continue across the lifespan (Hogan et al., 2013).

Even when governments enact policies in an attempt to improve access to resources, they do little to impact the chronic stress from discrimination that is experienced on a daily basis for those with multiple marginalized identities (Helgeson & Zajdel, 2017).

Discrimination that exists in the everyday lives of marginalized populations also overlaps into the healthcare system. Studies have shown that for low SES men and women of color, adherence to prescribed forms of treatment or even future participation in the healthcare system is much lower (Hogan et al., 2017; Alexander, Hearld & Mittler, 2014; Rosenberg & Tsai, 2014). Much of this was due to prior negative experiences while utilizing the healthcare system or anticipated marginalization based on historical and societal contexts. These contexts are often cemented in legislation designed to privilege those with resources, and helps to explain why those with limited resources under-participate. This holds especially true in education, where legislation for students with chronic illness did little to nothing to provide an equitable educational experiences until the 1990s.

While intersectionality is commonly used as a theoretical framework, it can also be thought of as a tool of analysis that informs other theories, in particular those that help us understand how different sets of identities allow individuals to have certain rights or opportunities (Association for Women's Rights in Development, 2004). Intersectionality is used to gain a deeper understanding on the complex ways society privileges and oppresses based on different parts of identity that are either privileged or marginalized (Crenshaw, 1991). One of the main ways researchers have used intersectionality theory is to explain why certain populations are more impacted by chronic illness than others. In a study by Helgeson & Zajdel (2017), it was found that that factors affecting adjustment to a chronic illness diagnosis do not occur in a vacuum. The study pointed out that there are many contextual

factors at play that are based on intersections of sex, social class, race and ethnicity as well as vulnerabilities factors for individuals when they are in marginalized identity groups. Similar findings were found related to disease management for immigrant groups (Rosemberg & Tsai, 2014). Their results showed that being a woman, black, an immigrant, and from a low SES background connected to make it hard to manage chronic health conditions. These issues were compounded by job requirements that did little to support worker care.

Etherington (2015) found similar results in her work on intersectionality and healthcare. One of her main findings was that race and gender intersect and disproportionately impact women of color when it comes to chronic illness. These health disadvantages were found to continue to exist even under factors that are considered protective against chronic illness for white females. Jones (2013) used intersectionality as a lens to look at the disadvantages in health to groups impacted by race, gender and low SES status, but added residential segregation as an additional component. He found that residential segregation negatively impacted those in low SES communities, but even when metropolitan SES measures were controlled, individual SES factors were still significant in predicting a chronic condition (2013).

A second method of using intersectionality theory in the literature on chronic illness is to look at practitioner methods that may prevent participation in the healthcare system. One study looked at the experiences of LGBTQ communities with health care providers (Bolderston & Ralph, 2016). They found that age, disability, SES status, gender and ethnicity intersected to create systems of inequity in healthcare. This inequities, and outright discrimination, were found to severely limit continued participation in the healthcare system. Hogan et al. (2013) proposed using an intersectional model to look at healthcare participation of black women from low SES communities. Their results found that participant's wellness

behaviors were influenced by experiences of racism, gender, class and history. Dipenza, Vearney and Golubovic (2016) found similar results for sexual and gender minority patients who were experiencing chronic illness while accessing mental health services.

What ties many of the studies of intersectionality and chronic illness together are calls to action. All of the studies discussed above highlighted a need for further research into areas of intersectionality and chronic illness. The researchers also argued for policy changes and increased supports for identities that were historically marginalized. While these studies are extremely valuable, and a call to action to correct inequities is vital, the current research is limited. Theoretically it uses intersectionality to address the inequity in the healthcare system or the ability to manage the condition itself. This theory should be pulled out of the healthcare environment and used as a method to explore how those with chronic illness are able to participate in other environments that should be accessible to all, like education, housing, food, jobs, etc. Since it is obvious that intersections of identity have a significant impact on the chronically ill population at large, it only makes sense that intersectionality may impact college students on higher education campuses as well.

**Anti-Deficit Achievement Framework.** As discussed above, the conversation around students with chronic illness is mostly deficit based, focusing on the vulnerabilities or management of this population. While it is important to generally understand factors that create poor outcomes for a population, it does little to help researchers and practitioners understand what creates good outcomes for the group. Deficit modeling in schools is a long recurring problem since the inception of the public school system in the United States (Valencia, 2010). There are six characteristics of deficit modeling Valencia (2010) commonly found in the school setting:

- Victim blaming- school failure is linked to membership in a particular group
- Oppression- deficits between the haves and the have nots. This approach looks at deficits as an often irreconcilable difference.
- Pseudoscience - researchers approach their research in deeply biased ways and communicate their results to feed their agenda.
- Temporal changes- this area assumes some sort of genetic or socialized inferiority.
- Educability- predictive model of the ability to learn of marginalized groups.
- Heterodoxy- deficits are discovered based on the ideological climates of the time.

As seen from the above, deficit modeling of students does a disservice to students, as deficits are often steeped in biases and lack of recognition of the capital accumulation of the non-dominant culture. An anti-deficit achievement framework creates a shift in the thought process about students, and especially those with chronic illness. It orients researchers and practitioners to the positive factors of the population and allows them to focus on change strategies that are tailored to the student's strengths instead of one that focuses on fixing their weaknesses.

Originally, the anti-deficit achievement framework was used to explain how Black males in STEM were able to access higher education, persist and go on to successful careers or selective professional and graduate schools in a study called the National Black Male College Achievement Study (Harper, 2010). Harper's research recognized that understanding factors that created racial achievement gaps were important, but decided not to focus on the deficits of the black male college student experience in STEM and instead highlight institutional agents, policies, programs, and resources that help Black men achieve desired

educational outcomes at multiple institution types. In his own words, Harper (2010, p.66) describes the benefits of this new way of researching:

Instead of adding to the now exhaustive body of literature and conversations that highlight all the reasons why Black male participation, engagement, and attainment in higher education are so low, I used trajectory analyses to understand how the 219 Black male achievers managed to gain admission to their institutions, overcame hurdles that typically disadvantage their peers, and amass profiles and portfolios of experiences that rendered them competitive for internships, jobs, and admission to highly-selective graduate and professional schools.

While this framework was originally applied to black males in STEM, the approach can be broadened to apply to any marginalized student population, as it is a framework that shifts the way of thinking on how student groups are researched. In populations where the literature is abundant in failures, but that knowledge has done little to solve achievement gaps for the group on college campuses, this framework is particularly important. There are several key components of this framework that set it apart from the typical frameworks and make it a strong framework to use for any marginalized student population.

First, the research questions take a deliberate anti-deficit approach. For example, instead of looking at where students fail because of deficits, it looks at where students succeed, despite barriers, risks, biases, etc. Secondly, the framework looks at three points of time in the higher education pipeline: pre-college socialization and readiness, college achievement, and post-college persistence in the STEM field. During the pre-college socialization and readiness, the NBCMAS focused on the role relationships played in the students' college aspirations. During the college achievement phase, the study looked at how

students navigated identity conflicts, the social environment and thrived in environments that were sometimes racist and culturally unresponsive (Harper, 2010). Due to timing, this study will only explore the first two areas, but should this study be extended past the dissertation phase, post-college persistence in the student's field of choice would be an interesting area to explore. Implicit in this theory is the idea that to truly be able to improve student success there needs to be a mindset shift. The philosophical bent to the theory focuses on the wildly common sense idea that student success can be best identified by allowing those who have been successful to share their experience (Harper, 2010). In truth, inviting those college students with chronic illness to share their story and insight on their experience is the main purpose of this research. Even though the anti-deficit achievement framework has never been applied to this population, its previous applicability with other marginalized populations makes this framework the perfect match to setting the right frame of mind when investigating college students with chronic illness, who also have identities that intersect with other marginalized or privileged groups.

**Resiliency Theory.** Resiliency theory has several practical benefits over other theories and works in conjunction with the anti-deficit achievement framework. While the anti-deficit achievement framework can be thought as a mindset to ground one's research, resiliency theory take the anti-deficit approach and explains the process students use to become resilient and overcome risk. At its foundation, resiliency theory creates understanding of why some youth grow up to be high functioning adults despite exposure to risk. Risk exposure often leads to poor outcomes such as behavioral disorders, mental illness and poor health conditions. Resiliency focuses on the positive internal and external factors that interfere or disrupt poor outcomes from risk. One of the challenges of using resiliency

theory for researchers is the definition of resilience has changed over the past several decades. In the content below the evolution of resiliency theory with a brief overview of the first, third and fourth waves and then a deeper description of the second wave of resiliency theory which will be used in the context of this research.

Masten and Wright (2009) describe four waves of resiliency research over time. The first wave of research was description. In the initial stages of resiliency inquiry, researchers attempted to provide a description of resiliency and determine methods of measurement. Scholars such as Block and Block (1980), and Davidson, et al. (2005) spent a great deal of time looking at characteristics within a person that leads to resilience. The first wave of resiliency research was able to find common themes related to qualities in people, relationships and resources that predicted resiliency. Examples of protective factors that were found to promote resiliency during first wave research are: social and adaptable temperament, stable and supportive home environment, positive community characteristics, effective schools, good public healthcare, positive outlook and faith or a sense of meaning to life (Masten & Wright, 2009).

The third wave looked at resilience through the intervention process. One such example was Brooks and Goldstein (2001) who developed an intervention to promote development of strength, hope and optimism in children. Their program found positive outcomes in building resilience in children. This level of resiliency research moves beyond the informational stage of the who, what and how, and tries to answer the question of how do we create more? For practitioners and researcher who are interested in direct intervention between subject and risk, the third wave of resiliency inquiry shifted the conversation in a favorable direction.

The fourth wave of research looked at the molecular and neurobiology of resiliency building. These processes explore the physiological influence that may or may not make children more or less sensitive to positive or negative variables. Masten (2001) is one such researcher well known for his fourth wave research. His research explored areas such as sensitivity to context and susceptibility to negative outcomes from risk.

The second wave of resiliency research, and the one used in this dissertation moved from a description of what resiliency looks like to focus on the processes that might lead to resilience (Masten & Wright, 2009). The second wave led to development of the three most popular models of resiliency: compensatory, protective and challenge or mitigating. All three of these models look at promotive factors that may mitigate the poor outcomes often associated with risk. Promotive factors in the literature are referred to as assets or resources. Assets incorporate the positive internal characteristics which keep students from experiencing negative outcomes. These include such variables as competence/hardiness, coping skills and self-efficacy. Resources focus on the external factors that lead to resilience. Common resources include parental support, mentoring or community and recognize the social and environmental influences on those exposed to risk (Fergus & Zimmerman, 2005). Resources orient resiliency outside of just internal personality traits and recognizes that resilience influences are fluid and that others can help change the negative trajectory often associated with risk.

The compensatory model was one of the first models to come out of the second wave of resiliency research and looks at promotive factors as a means of neutralizing risk. In this model the compensatory factor acts independently of the risk factor (Fergus and Zimmerman, 2005). One such example in the research found that adult monitoring was a compensatory

factor for youth violence in poverty stricken areas (Edari & McManus, 1998). The protective factor model moderates risk instead of compensating (Prince-Embury, 2014). A study by Zimmerman, et al. (1995) found self-esteem acted as a protection to reduce the amount of risk experienced by Native American youth when exposed to alcohol. The last model is the challenge model. This model posits that the relationship between risk and promotive factors is not linear and that a moderate level of risk provides the optimal opportunity to learn to overcome the negative outcomes of the risk without giving up (Fergus & Zimmerman, 2005). For researchers of this model risk and promotive factors are considered one and the same. For example, if one does not experience the conflict associated with financial constraints, one may be less likely to manage finances appropriately, however if one has experienced moderate financial constraints over his or her life time, it is more likely they will have learned budgeting techniques that lend themselves to fiscal responsibility. The major addition of the second wave of research is an answer to “how” people become resilient. Looking at internal and external factors allows researchers to explore the complex nature of all variables that help people overcome risk.

In the course of this research project, resiliency theory as applied in the second wave models, was deemed the best fit for this population. There are several reasons for this. One, there is a large gaping hole in resiliency research as applied to college students with chronic illness. One cannot design an intervention to promote resiliency without truly understanding how students on college campuses with chronic illness are successful. Second, fourth wave research explores the gene-environment interaction of building resiliency, however the second wave does not limit resilience to the interaction of environment with genetic markers assigned in utero. The assumptions present in second wave resiliency theory is risk must be

present for resiliency to occur. With the population of chronically ill college students, the risks associated with experiencing the illness are almost always there, albeit at different levels of severity and duration. Second wave resiliency theory also assumes multiple promotive factors and risks are experienced independently and simultaneously. As students with chronic illness arrive on college and university campuses, it is logical to assume they face multiple internal and external factors to mitigate and protect them from the risk associated with going to college and managing their illness. For the researcher, this means one must look at the cumulative nature of risk and promotive factors experienced during the college years. A small number of empirical studies have already explored pediatric chronic illness and found evidence to support resiliency mitigating risk (Perfect & Frye, 2014; Gerhardt, et al., 2003; Kim & Yoo, 2010; Mu, 2008). The applicability of resiliency theory to the pediatric population makes a compelling argument to apply resiliency theory to adolescent and adult college students who experience chronic illness.

Even though many theories have been applied to the college going population with a chronic illness, for this study, I use a combination of resiliency theory and the anti-deficit achievement framework. There are several positive benefits to this pairing. First, resiliency theory recognizes that there are inherent risks that occur in life that can challenge a person's success, but instead of focusing heavily on those risks, the theory focuses on the navigation of risk through the use of internal assets and external resources. Exploring both the internal and external recognizes that navigation of risk is a complex process. In this study, I needed a theory that was broad enough to encompass complexities associated with a chronic illness at the college level, and resiliency theory was a good fit. However, I also needed a framework that was strong in its practice of creating an anti-deficit narrative and was clear in how to

capture marginalized student experiences through the research process. The anti-deficit achievement framework is such a framework. The anti-deficit achievement framework, originally used to understand how black males in STEM succeeded in higher education institutions that could sometimes be racist and culturally unresponsive, is a step-by-step guide to conducting anti-deficit research, and is ideal for researching other marginalized populations. This framework explores the pre-college factors that contribute to positive college aspirations, but also explores more broadly how students navigated classroom and out of classroom experiences. The anti-deficit achievement framework is well matched to resiliency, and its clear focus on pre-college factors influencing college success factors, matches the idea that resiliency building is complex and is not built in a day.

### **Chapter 3: Methods**

College students with chronic illness face numerous challenges that are faced by the general college going population, but with the additional challenge of addressing the needs and management of their illness. In addition, chronic illness often hits in populations who are already marginalized by another aspect of their identity. These students graduate at much lower rates than their non-ill peers, even taking into consideration other identity factors (Zimmerman, 2013). Low graduation rates for this population have long lasting impacts in the form of job and resource acquisition (Maslow et al., 2013).

The purpose of this anti-deficit achievement phenomenological study is to understand how college students at a large public university become resilient, despite navigating their chronic illness. During the course of this study, chronic illness will be defined by the criteria listed by the AADE Self-Management Outcomes (2003). In this chapter, I present my research paradigm and methods for the study. Next, I address the aim, philosophical foundations and limitations of phenomenological research. Last, but not least, I describe in detail the setting and data sources for the study, data collection procedures and methods of analysis for the interview data.

#### **A theoretical framework for college students with chronic illness**

In order to truly understand how students with a chronic illness navigate their college experience, an anti-deficit theory is needed that is broad, but also one which understands the complexities of an individual's life, all the while experiencing a particular phenomenon. For this study two individual theories are combined in order to adequately represent the experience of college students with chronic illness.

**Anti-deficit achievement framework.** The attitude toward the population of student with chronic illness must shift away from points of failure to points of success. In order to do so, one needs to find a theory that sets the standard for looking at the achievements of this marginalized student group in order to ground all other theories. The anti-deficit achievement framework (Harper, 2010) is such a framework. Even though it was originally applied to black males in STEM fields, the framework is an ideal shift in understanding how to research any marginalized group. First, the research questions in this framework take a deliberate anti-deficit approach. For example, instead of looking at where students fail because of deficits, it looks at where students succeed, despite barriers, risks, biases, etc. Secondly, the framework looks at three points of time in the higher education pipeline: pre-college socialization and readiness, college achievement, and post-college persistence. During the pre-college socialization and readiness, the framework explores the role relationships play in a student's desire to achieve before entering campus. During the college achievement phase, the study looked at how students navigate identity conflicts, and social environments, which are sometimes culturally unresponsive (Harper, 2010). It shifts the narrative and research investigation of marginalized college student populations from one that looks at where students fail to one that looks at achievements that keep the population persisting. The anti-deficit achievement framework encourages a new mindset to researching marginalized populations and invites participants to share their stories and what they bring to academia. It also is the ideal companion to resiliency theory, which in its own way is an anti-deficit process oriented model.

**Resiliency theory.** Resiliency theory for the purpose of this study is one of the best theoretical matches for determining the how and why students succeed in school. Resiliency theory in general has been used for many years to explore how youth navigate risk exposure (Masten & Wright, 2009). Resiliency, as is used in this study, is viewed as a process, not a static trait, indicating that it can be built over time (Fergus & Zimmerman, 2005). One of the benefits of this process oriented model is that students with chronic illness cannot be looked at dichotomously, as a person who has resiliency or does not. Additionally, resiliency is an anti-deficit model that explores an individual's capacity to move around and through risk, by a combination of assets and resources (Prince-Embury, 2014). Anti-deficit exploration is beneficial to participants, researchers and practitioners because it takes the conversation away from where participants fail to one looking at where participants succeed, which can potentially be replicated for other students. Last, but not least, resiliency is a broad enough theory that it takes into consideration the complexities of an individual experiencing risk by looking at internal and external factors in the form of assets and resources.

### **Research Question**

This research study considers the following questions within an anti-deficit achievement framework:

How do college students use assets and resources to build resiliency, despite navigating a chronic illness?

### **Qualitative Research Paradigm**

Even though the limited research on college students with chronic illness uses a variety qualitative, quantitative and mixed methods (Adler, et al, 2008; Herts, Wallis & Maslow, 2014; Jung, 2002; Kranke, Taylor & Floersch, 2013), for the purposes of

understanding the resiliency of this population, qualitative is the more ideal approach. There are several reasons why this is true when working with chronically ill college students. In order to quantitatively describe the experience of college students with chronic illness on campus, a researcher must be able to reach a critical mass of students in order to find applicability to a population. However, as the research indicates, there are numerous challenges to determining an accurate population size for students with chronic illness (Adler, et al, 2008; Herts, Wallis & Maslow, 2014; Jung, 2002; Kranke, Taylor & Floersch, 2013). These students are often disconnected from one another, disability services and even student health (Kranke, Taylor & Floersch, 2013). This has inherent problems, as students with chronic illness are often not utilizing the two facilities on campus most likely to track them: the disability office and student health (Herts, Wallis and Maslow, 2014; Kranke et al, 2013). If this population of students, who often remain unidentified due to the non-apparent nature of their condition cannot be accurately tracked by the university itself, it would be next to impossible for a researcher to determine a minimum sample size necessary to provide a good quantitative study. Eliminating a quantitative approach also eliminates the chance of developing a strong mixed methods approach, which relies on a mix of quantitative and qualitative data, leaving qualitative research as the only logical method to truly explore the resiliency of this population in-depth.

Qualitative research should always begin with a well thought out paradigm. A paradigm often is defined as a worldview and is one that also discusses the researcher's ontology, epistemology and methodology (Lincoln & Guba, 1985). Ontology asks the question what is the nature of reality (Creswell, 2013). My chosen research ontology is critical constructivism. Constructivists hold that there are many truths and what is truth

ultimately lies with the individual (Guba & Lincoln, 2005). *Critical Constructivism*, an ontological concept introduced by Joe Kincheloe (2005), on the other hand is founded on constructivist ideas, but is also grounded in the thoughts of Paulo Freire's *Pedagogy of the Oppressed* (1970). There are several key components of critical constructivism that stand out in this ontological view. First, critical constructivists seek to maximize variables instead of reduce them in order to develop a more rich understanding of the world (Knoble, 1999). Critical constructivists are also deeply concerned with the role power plays in the construction and validation of knowledge (Kincheloe, 2005). Those constructions are often what develops into privileging or marginalizing certain groups. The critical constructivists become the investigators in constructing views of the world that are inclusive of knowledge and meaning making of groups who are traditionally dismissed by the dominant culture. Due to legislation and misunderstanding, as well as intersections with other marginalized identities, students with disabilities and chronic illness have historically been oppressed in our school systems and higher education institutions (Department of Education, 2007; Goodwin & Morgan, 2012; Kranke, et al., 2013). I take the opinion that this historical oppression has repercussions on the construction of identity and knowledge, as well as interactions with others. Through the course of my research I intend to support construction of a new narrative of chronic illness on higher education campuses, by allowing the participants' voices to be heard through rich descriptions of their own experiences.

Unlike ontology, which seeks to define how reality is constructed, epistemology explores what is considered knowledge and the relationship between researcher and participant (Lincoln & Guba, 1985). In qualitative research, knowledge is produced through the inquiry process (Polkinghorne, 1989). Information about a participant's construction of

reality is gathered from their own voice. The researcher in this paradigm becomes the facilitator of collecting and describing the experiences of the individual. The epistemological and ontological position selected by the researcher has a major impact on the methodological approach taken. Below is a more detailed description of the phenomenological methodology chosen for this study.

### **Phenomenological Research Design**

To reiterate, the goal of this research project is to describe the resiliency of college students diagnosed with chronic illness. To study this, I have chosen a phenomenological research method. A phenomenological study is well suited for this type of research as it is the study of structures of consciousness experienced from an individual's point of view (Husserl, 1965). One of the main arguments of phenomenology is that phenomena is to be studied by looking at sensory data in the participant's consciousness, and how that data rationally comes together to form knowledge about the world (Husserl, 1965). In other words, the phenomenologist never assumes that because they cannot see what the participant is describing that he or she is not experiencing the phenomenon in another manner, namely through another type of sense. The basic purpose of this type of research is to reduce the individual experience into a composite description of the essence of the experience for all individuals (Moustakas, 1994). At the same time, the phenomenological researcher in no way diminishes the lived experience of the participant, but simply tries to identify the *what* and the *how* of the experience. Phenomenological research does not try to analyze or explain the essence of the experience, but focuses on providing a complete picture to the reader (Moustakas, 1994). Phenomenology also moves away from only looking for empirical evidence.

Phenomenology emphasizes a strong philosophical perspective instead of a purely scientific view as the researcher searches for wisdom. First, phenomenology seeks to suspend all judgments about the reality of the phenomenon until they are found within the research with a substantial level of certainty (Moustakas, 1994). As previous research has shown, one of the major barriers for students with chronic illness is the judgment, presupposition and lack of awareness non-chronically ill persons have about these students condition (Jung, 2002; Goodwin & Morgan, 2012; Kranke, et al., 2013). A phenomenological research approach suspends all preconceived notions about the participants, while still acknowledging the researchers previous experience with the phenomenon, in order to describe the experience of others. Using this approach allows the voices of the students experiencing chronic illness to stand out and educate others about the essence of their condition while on campus. Phenomenology also recognizes the intentionality of consciousness. The idea behind intentionality of consciousness is that as conscious beings, not only do we interact with our environment, but we are also aware of these interactions (McIntyre & Woodruff-Smith, 1989). These interactions give one a sense of self and allows the self to give meaning to interactions between subjects and objects. By recognizing this concept, the idea of the subject-object dichotomy is refuted (McIntyre & Woodruff-Smith, 1989). As described above, the reality of an object or condition is only substantiated by the experience of the individual who assigns the object or condition meaning. In the case of students with chronic illness, the student is conscious of their college experience and interactions on campus and with others. It is important to understand how they assign meaning and design their reality in order to truly understand how they develop resiliency while completing their degree.

Outside of the philosophical leanings associated with phenomenology, there are also seven defining features of a phenomenological study, which match well with the study at hand. The information below comes primarily from Moustakas (1994) who is one of the major researchers of the phenomenological method.

**Emphasis on the phenomenon.** One of the key components of phenomenology research is the focus on a single phenomenon. This can be a single concept, idea or event. Phenomenology lends itself well to this study as it focuses on the participation of college students with chronic illness, the phenomenon being the college experience.

**Exploration of the phenomenon with a particular group.** The entire study explores the issues of chronic illness with college students. Once a group is identified, typical phenomenological studies explore the experiences of 5-15 persons (Smith, Flowers & Larkin, 2009). My target participant group was 10. Ultimately, I ended up with 13 participants and 12 completed the entire study.

**Philosophical discussion.** Another key facet of phenomenology is a discussion of the philosophy behind this type of research. As mentioned in the phenomenological section, phenomenology clearly refuses the subject-object dichotomy. The participant's experiences are relegated within the confines of the phenomenon, in order to identify commonalities with others also experiencing the phenomenon.

**Researcher bracketing.** In many phenomenological studies the researcher brackets himself/herself out of the study. This does not mean the researcher has no experience with the phenomenon, but that those experiences are clearly identified to the reader so they may determine whether or not the researcher can focus on the participants experience without

bringing their own ideas into the picture (Husserl, 1965). In the case of this study, I have described my experience with the phenomenon in a later section of this chapter.

**Interviews as a major data collection tool.** My data collection section emphasizes the semi-structured interview. In many types of qualitative research interviews are a primary, and sometimes the solitary means of collecting data (Merriam, 2009). Since phenomenology looks at phenomena experienced by the individual through sensory data (Husserl, 1965), it only makes sense that interviews be used to seek that information out. Interviews are absolutely necessary when researchers need to understand how participants interpret the world around them, which is the main goal of phenomenological research (Merriam, 2009). I wanted to hear about the phenomenon from the student's voice, and semi-structured interviews provided direction, but also give the students' ample opportunity to share what they value and feel is important during their college experience. This strategy also directly impacted the ease of data analysis. In the case of this study, participants really stepped up and revealed their college going experience in great detail, providing quality data.

**Data Analysis that moves from narrow to broad.** Because the goal of phenomenological studies is to describe the essence of the experience, in this case those with chronic illness attending college, the researcher moves from narrow statements made by individual participants to broader meanings across the group in order to summarize the what and how of the experience.

**Conclusion describes the essence of the experience.** After data analysis is completed, the phenomenological study ends with a section that accurately describes the essence of the experience. This section is the culmination of the commonalities college

students with chronic illness experience on campus. It gives the reader a sense of what they go through and how they interact with the college student environment.

### **Challenges of the Phenomenological Approach**

Phenomenology provides a deep understanding of a phenomenon as experienced by a group and is inherently what makes this approach desirable. On the other side, phenomenology requires at least a broad understanding of philosophical assumptions, which can be difficult to communicate (Moustakas, 1994). As mentioned in the introduction, because students with chronic illness often have non-apparent conditions, finding a group of individuals experiencing this phenomenon while on campus could have proved difficult. In addition, phenomenological data studies typically interview small numbers of participants. Due to the varied nature of the chronic illness experience, finding commonalities among the college student population could have proved challenging, although in this case, the experiences of students had strong commonalities that crossed conditions, gender, ethnicity, SES and first generation status. It could have also been challenging to remain bracketed out of the study with the knowledge and experience I have had with former students and family diagnosed with chronic illness. However, I worked hard to let the students speak for themselves and their experience, and tried to minimize talking as much as possible. Despite these potential limitations a good phenomenological study provides sufficient amounts of data to allow the reader to judge whether commonalities among participants are sufficient to describe the essence of the student experience with chronic illness. This study was successful in describing the phenomenon of students with a chronic illness.

**The Researcher's Role**

My current perceptions of higher education, what makes successful students and chronic illness are based on my past work experiences and interactions that I have had with chronically ill students and family members. I started working in the TRiO program, a Department of Education grant funded program for first generation, low income college students or students with disabilities in 2002. Through this program I was a peer tutor and mentor to a group of smart, vibrant students who came from a variety of complex backgrounds. Several of the students I worked with were diagnosed with chronic illnesses and experienced multiple hospitalizations while pursuing their degree. I also worked to try to accommodate the student's health conditions as much as possible by adjusting time and location of services offered.

A few years after graduation I returned to working in higher education full time as a Success Center Coordinator and Advisor. During the next five years, I worked with hundreds of traditional aged college girls in a small residential women's college in the Midwest. Due to the size of the institution, staff wore many hats. In my role, I often worked with students with chronic illness to provide accommodations inside and outside the classroom. I saw multiple students go on to graduate, but others who had repeated withdrawals from classes and the semester. A large section of these students dropped out due to repeated stressors associated with the illness and often the private institutions inability to meet their needs.

Eventually I transitioned to a large public research university as an advisor, Success Center and TRiO Coordinator. Even though the roles I took on at these two institutions were similar in nature, the scope of my work grew dramatically. As an advisor I maintained a caseload of over 500 students each year. While students with chronic illnesses would often

come in with parents during summer registration and disclose their illness and I advised strategies for success, many times that meeting was the last contact I had with the student. Within a major advising load, a more intrusive advising strategy was unrealistic and unless students sought out support or a faculty member flagged them for academic or attendance reasons, my attention would often be focused elsewhere. In spite of these challenges there are several students with chronic illness with whom I developed close advising/mentoring relationships. I watched these students experience setbacks and successfully overcome these setbacks and move on to graduate. These students often continued their education at the graduate level and went on to have successful careers.

Until recently, I never considered myself a person who personally shares conditions of someone with a chronic illness, but when determining criteria for participants to recruit for this study, I realized I meet multiple criteria from the AADE (2003). I currently manage vast amounts of environmental and food allergens that affect my ability to function on a daily basis. Without regular management of medication, air purifiers, immunotherapies, food modification, etc., I would not be able to manage my condition to the level I need in order to meet my current responsibilities. Last semester, during a perfect storm of a moldy classroom, high pollen counts, and open windows, I had to leave class due to a severe attack. Typically, I take the power through it mentality, but the older I become, and the more allergies I develop, the harder it is to do so. I would be remiss not to recognize that how I manage my own immunological condition could impact my view of others.

These experiences over the years have led me to repeatedly question the differences between those who overcome the risks associated with a chronic illness and those who do not. In my personal work with students, I take a strengths based approach. I believe that all

students, despite their associated risks, have the potential to be successful. I am often frustrated by the deficit modeling of underrepresented groups in both research and practice. As a practitioner I provide support in a way that works with student's abilities, passions and strengths, instead of trying to fix areas in which they are weak. I believe each student's experience is unique and it is the combination of these individual realities that create an education that is value added for the whole group. When higher education institutions fail to recognize the value each student brings with them to campus and fails to communicate that value to the student, retaining students becomes much more difficult. This is one reason I chose a qualitative research paradigm informed by resiliency theory. Resiliency theory highlights and even celebrates a person's ability to overcome stumbling blocks, and I believe if we share these narratives the mindset of higher education practitioners can be changed from one focusing primarily on deficit modeling to asset modeling.

### **Research Design**

**Setting.** This study was conducted on the campus of a large public research university in the Midwest. The interview process began in the early spring semester and at the beginning of an intense cold weather pattern and one of the worst flu seasons in history. The research university is centered in a town of approximately 150,000 during the semester. While the public university enrolls a large portion of students in the state, due to active recruitment in other states, close to half the student body comes from outside the state. The institution offers bachelors, masters, specialist and PhDs in a combined total of over 250 degree programs.

### **Recruitment of Participants**

A good data collection strategy in a qualitative phenomenological study is able to develop understanding of a phenomenon. I used two primary methods of data collection: semi-structured interviews and journals. Due to the topic of the study being college students with chronic illness, I used criterion and snowball sampling. Criterion sampling is used with all individuals studied represent people who have experienced a similar phenomenon (Merriam, 2009). One of the major challenges of this research project was locating a group of students on campus with often non-apparent conditions. The research indicates that less than half of students with chronic illness disclose their illness to the disability center on campus or have a relationship with student health (Kranke, et al., 2013; Herts, Wallis & Maslow, 2014). In order to find participants I invested in snowball sampling as a method of recruitment. First, I employed the help of key staff on campus to send out the invitation to participate in the study. As the group of people I asked to send out the invitation grew, so did the snowball as new information-rich cases develop (Patton, 2002). As a researcher I did not have access to the list or the number of students reporting a chronic illness on campus. Academic advisors on campus maintain list serves for all registered students under their advising load. Advisors have some of the greatest access to students on the campus of study, next to faculty. Key advisors that served a variety of populations across campus sent out the invitation to their students. In addition I contacted staff that served male dominated organizations in an attempt to boost male participation in the study.

I also made use of student organizations on campus dedicated to supporting students with chronic illnesses. I made myself available to attend organization meetings and was clear and upfront about my research, and my own intersections with the chronic illness identity. I

emphasized my interest in co-constructing knowledge around the topic for a wider audience in order to build trustworthiness and recruit potential participants.

Second, I placed the invitation to join the study in the campus information bulletin. This weekly email provides the entire campus information on events, research opportunities and other activities. Due to the broad coverage this email receives, placing an ad in this format allowed participants a chance to receive notice of the study if not contacted by staff members. For this study, placing the ad in the campus bulletin, and at the top of the bulletin, was a key to recruiting the vast majority of participants.

A third method of potential contact was through flyers placed in strategic locations on campus. Several campus buildings see thousands of students on a daily basis. Each building has strategic locations to post flyers in main traffic areas. The buildings chosen were mainly classroom buildings that served faculty across many majors. At the end of the recruitment period the flyers were taken down.

Students interested in participating were given an email address to contact. An email was sent back to the participants with a Qualtrics survey link in order to screen participants (Appendix F). Potential participants had to verify they were a currently enrolled college student diagnosed with a chronic condition according to criteria set by the AADE (2003). The screening process ensured the participants interested in the study met the criteria of experiencing a chronic illness. In order to incentivize students to participate, the invitation offered a \$30 gift card to qualifying participants upon completion of the post interview. The initial email also included a copy of the informed consent so they could completely understand the protocol of the study and feel comfortable with proceeding to apply to participate.

**Participants.** The participants in this study are current undergraduate students who have a current or previous, but ongoing, medical diagnosis of a chronic illness. To be classified as a chronic illness, potential participants had to meet at least three of the criteria of the AADE self-management outcomes (2003). Table 1 below describes these criteria.

*Table 1*

Outcome	Description
Activity Level	The intensity of the exercise and duration of the activity is significantly influenced.
Eating	Eating involves a complex set of behaviors including when to eat, what to eat, how much to eat and how many times a day.
Monitoring	Monitoring includes monitoring vitals, illness symptoms or reactions and being able to interpret the results.
Medication	Medication is taken for the illness or symptoms resulting from the illness, and includes a variety of management skills for administering the proper dose.
Problem Solving	Recognizing and responding to unanticipated situations related to the illness.
Complications	The person actively seeks out ways to understand and prevent complications related to the illness.
Psycho-Social Adaptation	The illness creates behavior changes, and sometimes barriers must be overcome to create these changes, such as monitoring psychological well-being and relationships.

Participants were required to be enrolled at least halftime during the semester and degree seeking. The goal of the research project was to take an anti-deficit achievement approach to evaluate resiliency in college students with chronic illness, when there are other marginalized or privileged identities that intersect. I interviewed 13 students for the pre-interview. Twelve students engaged in journaling and completed the post interview. Initially, I planned to stop at ten participants, but with the challenges of the semester, being diagnosed with a chronic illness and a particularly harsh winter, I decided to proceed the study with all 13 participants instead of selecting the most diverse sample possible in terms of gender, race, and SES status. However, demographically my participant group ended up more diverse than

expected, with the exception that it was incredibly challenging to find males who wanted to participate in the study. Studies on chronic illness tend to recruit higher proportions female samples (Ravert, Russell & O’Guin, 2016, Balfe, 2009, Ramchandani, 2000), so was not unexpected and the reason early on in the project I reached out to organizations on campus that were male dominant in order to boost participation in my study. Participants were diagnosed with a variety of conditions that included: diabetes, asthma, Hashimoto’s disease, lupus, celiac disease, multiple sclerosis, Ehlers-Danlos syndrome, postural orthostatic tachycardia syndrome, hidranetis supprativa, epilepsy, fibromyalgia, chron’s disease, and irritable bowel syndrome. Several of the participants were diagnosed with one or more of the above conditions. Table 2 shows the participants and their demographics.

Table 2

Participant	Gender (Self-Identified)	Race (Self-Identified)	Low Income	First Generation	Condition	AADE Criteria Met?
KBFY	F	Black		First Gen	Hidranetis Supprativa	Yes
JWMN	M	White			Diabetes	Yes
KBFN	F	Black			Diabetes/MS	Yes
CHFV	F	Hispanic/White			Ehlers-Danlos/POTS	Yes
BWFN	F	White	Yes		Diabetes/Celiac	Yes
HWFN	F	White			IBS	Yes
AWFY	F	White	Yes	First Gen	POTS/ Fibromyalgia Chronic Fatigue	Yes
EHFN	F	Hispanic			IBS	Yes
MWFN	F	White			Diabetes	Yes
JWMY	M	White	Yes	First Gen	Chron’s	Yes
RWFN	F	White			Epilepsy	Yes
AWFN	F	White	Yes		Lupus	Yes
BBFY	F	Black	Yes	First Gen	Asthma/Hashimoto’s	Yes

**Data Collection.** Once I identified the 13 participants, I conducted an initial 60 minute semi-structured pre-interviews with each individual, recorded the interviews, and transcribed them. The semi-structured interview started with a set of predesigned questions based on the anti-deficit achievement framework and very loosely based on the Resiliency Scale for Adults (RSA) (Hjemdal, Friberg, Martinussen & Rosenvinge, 2001) (Appendix A). One benefit of using the anti-deficit achievement framework is its focus on understanding the capital (assets and resources) that students bring with them into the college environment, but also current college achievement. The benefit of the RSA is that it is an empirically tested scale, which tests high for internal consistency and reliability. Out of three tests for construct validity, coherence, discriminant and correlational, all three were strongly supported (Hjemdal, Friberg, Martinussen & Rosenvinge, 2003). The RSA is divided into five different competence areas: personal competence, social competence, family coherence, social support and personal structure (Appendix B). The main crux of the initial interview was not to explore the RSA categories as in depth as the journal questions, which will be discussed in more detail later, but to explore internal characteristics and external supports. While this interview is not a quantitative study, there is some merit to using a tested scale as a guide for qualitative work.

Consistent with an anti-deficit achievement framework, I explored the internal and external assets and resources they had prior to college, and compared that to college and their current achievements (Harper, 2010). The interview was guided by the developed questions, but did not completely dictate the direction of the interview (Smith, Flowers & Larkin, 2009). The advantage of semi-structured interviews is that I had the opportunity to follow up and explore important points in real time (Smith, Flowers & Larkin, 2009). This allowed the

interviewee to take an active role in how the interview proceeded. Interviews were done at a time and location on campus that was convenient to the participant, with the guidelines of it being a quiet area, away from distractions. It was important that the interviews were conducted in a way that considered the health of the participant. Interviews were conducted while classes were in session.

At the pre-interview, participants were instructed about the use of an electronic journal in Canvas (the universities learning management system) to record their experiences of managing their illness while completing their semester. Journaling allowed the participant to record their experiences as they occurred, enabling participants to reflect on their health challenges, but also the strategies for overcoming these challenges in real time. Journaling is a method long accepted as a way to collect rich, qualitative data (Hayman, Wilkes & Jackson, 2012). There was no set number of journal entries required, but weekly reminders and optional prompts based on the RSA were sent out to remind participants about reflecting in their journal (Appendix C). One of the reasons I sent weekly reminders is it is shown that reminders and prompts promote participation and confidence in the information shared (Van Horn & Freed, 2008). I chose to use Canvas as a primary method for journaling, as it is a secure service that is password protected and easily accessible. I requested a Canvas site from the University specific to this project. I enrolled only selected participants in the study and disabled the email feature so participants would not accidentally be able to email others and disclose their identity. There were several benefits to using Canvas as a platform for journaling. Since students used Canvas already as their Learning Management System, there was essentially no learning curve with this system. Since none of the participants were first semester students at the institution there were no questions about how to submit entries. In

addition, students were accessing Canvas regularly due to other class requirements. Using Canvas put the journal at the forefront of their login screen making it more likely they will journal on a regular basis. During the pre-interview, I let participants know that I would be reading journals, but would be unlikely to respond. The only times I responded to participants journals is when there were logistics questions. For example one student asked if her post was long enough and another asked if their gift card would be penalized if they submitted their journal late. I do not know whether responses to questions encouraged students to journal more or not. There is no clear evidence on increased participation in the research, however 12 of the participants completed their journal prompts by the end of the project.

At the end of the semester, post interviews were conducted to determine whether participants gained anything from the study, and whether there were any new insights about themselves and other resources that they used to help manage their illness through the semester. It was during this interview I asked questions that probed further into how chronic illness impacted their life on campus. These two reflective areas are the foundation in learning how students with chronic illness build resiliency, which is why a post interview was important. At the conclusion of the post-interview, a gift card was distributed to each participant by email. Overall, the process was smooth and the participants seemed happy with the project and the ease of fulfilling requirements. It is interesting that my research notes indicated that participants who completed the post interview seemed overall more upbeat and positive about life and the semester. This is in spite of the post interviews taking place the week before finals, when one would typically assume students would be most stressed.

**Ethical Considerations.** In the course of working with a potentially vulnerable group, that of college students with chronic illness, there were several ethical considerations that were addressed. As a researcher, I made very clear the purpose of the study by providing detailed information about the research procedures and potential risks. I also verbally and in written form went over the purpose of the study and informed consent document to ensure any questions the participant may have were answered. The participant was not be pressured to sign the informed consent document and was told that they could leave the study at any point.

Part of doing this phenomenological research project was to obtain good, thick rich description through in-depth interviews and journaling. However, in order to achieve this goal, and gain access to personal information I had to consider reciprocity (Harrison, MacGibbon & Morton, 2001). Reciprocity, in the field of critical constructivism, is a give and take of social interactions to co-construct knowledge. By asking participants to engage in member checks, of which three did, before publication for example, I gave the participant the ability to verify their experience was as written. Another way researchers can give back to the participants is to provide them with a tangible take away. For this project, I provided participants with information on resources available inside and outside the campus community to support their higher education experience at the end of the post interview. As Lather (1991) points out, there are two main reasons for attending to reciprocity in critical research: one, collaboration advances emancipatory theory, and two, it can empower the researched. My goal in doing a phenomenological study was not only to co-produce knowledge for a higher education audience, but to ensure participants felt empowered through sharing their story in their own words. Member checking and providing a list of

resources are two simple ways to help clarify that I as the researcher am not out to exploit or objectify their experience for my own gain.

A second ethical consideration was sensitivity to the needs of a chronically ill population. This group of students often faces stressors in addition to those faced by the non-ill college going population (Adler, et al., 2008; Haas & Fosse, 2008; Royster & Marshall, 2008; Fedele, et al., 2009). During the course of the pre and post interviews, I worked with each participant to meet them in a natural, comfortable setting, away from distractions. I also rescheduled interviews when students were unable to make it due to academic obligations or flare up of symptoms. Journals did not need much accommodation. Once a journal question was opened, it remained open for the remainder of the study. Participants knew in advance they had the flexibility to journal when convenient. Most participants finished on a weekly basis. For those participants that did not finish journaling before the final interview, I just rolled those questions into the interview process so the data collection was consistent across participants.

Confidentiality of participant information is of vital importance throughout the study. Participants are entitled to protection of their rights at all times (Cresswell, 2013), including information that could lead to a loss of anonymity. Participants are referred to by four letter pseudonyms to protect identity. Any identifying information during interviews, such as specific names and locations were also given pseudonyms. In some circumstances in the data, identifying information has been removed and [...] replace the information. In addition, in such cases where the condition may lead to identification of a participant, I used a more general terminology of the illness or focused on the experience instead of the diagnosis. This strategy not only focused on protecting confidential information, but also kept the study

focused on the participant's experience, not their diagnosis. For example, Dercum's disease is an extremely rare disorder where a person develops painful growths of fatty tissue just below their skin. This disease can cause severe pain and limit daily functioning (National Organization for Rare Disorders, 2016). Due to the rarity of the disease, naming this disease in my study could easily lead to identification of the participant. To protect the participant's identity I will generalize the condition, turning Dercum's disease into an autoimmune disorder where the immune system attacks healthy tissue. This places the participant's condition into a more general body of illness, without reducing the impact of the condition on day to day functioning in college.

Another consideration in the course of this study is potential power imbalances. I do hold faculty and administrative roles in the location of study. I interact with hundreds of students on a regular basis. This has the potential to create an imbalance of power in addition to the one that could be created by simply being the researcher. In order to avoid potential conflict in this area I ensured potential participants the study was voluntary, and in no way would affect services they were provided/offered. I also avoided using any leading questions in the course of the interview.

The last ethical consideration of note is potential researcher bias. As outlined in the researcher's role section previously, I have over a decade of experience working with college students with chronic illness. While they have not been the majority of the population I have worked with, the potential for bias exists. In qualitative research, the researcher cannot fully separate himself or herself from the participant and at times the participant identifies the researcher as an insider or an outsider, which can affect disclosure (Dwyer & Buckle, 2009). The benefit of being an insider researcher is that participants are often more open to share

their experience, as there is a level of trust and openness due to perceived shared understanding. However, the drawback is that participants may make assumptions of similarity and focus on that experience and fail to fully explain their individual experience (Dwyer & Buckle, 2009). For example, even though participants of color clearly identified as a person of color, they did not talk about issues of racism experienced on campus when discussing barriers to their educational experience throughout the course of the study. While I cannot explicitly state that my insider/outsider status (white, female, first generation, with a chronic illness) impacted disclosure, it is possible that bias based on my status, and interactions with them as a researcher, made them provide a narrative in which they felt I could relate. Due to my previous background, it was of vital importance that I use authenticity criteria to ensure the quality of my data collection and analysis. The authenticity criteria for quality assurance are described in the sections below.

### **Data Analysis**

Typically, data analysis has been described as an iterative and inductive process (Smith, 2007). Over the course of my study data was analyzed in a multistep process to ensure the experience of college students with chronic illness was accurately represented. I tried as much as possible to analyze data as I went, so that if there were trends or concerns in the data I could adapt. My first step of analysis was to analyze the initial interview. I transcribed the interviews using Dragon Naturally Speaking, and I and a colleague looked over the transcription for errors. My original intention was to use this process for the post interviews as well, but it proved too time consuming, so I sent out the final interviews through a secure server to a professional transcriptionist in the medical field. I analyzed the electronic journal data as the semester progressed. Once again, there were benefits to

analyzing data as it occurs. Number one, it is a great deal of work spread out over time, instead of a great deal of data at one time. As much as I wanted to remain current and analyze weekly, it ended up that I was able to look over the journal data about once a month. However, because of this periodic overview of the data, I was able to make adjustments if I noticed any trends or students responding or not responding in particular ways. The other benefit to analyzing data as I went along is that I was able to tailor the post-interview to the specific individual if I noticed trends or stories that I would like to get more information about. For all actual data analysis I used Smith, Flowers and Larkins (2009) book on interpretive phenomenological analysis as a guide to this process.

**Step 1: Reading and re-reading.** The first step in analysis was immersing oneself in the data to develop a clear picture from the written transcript. Reading in great detail allowed me to immerse myself in the participant's experience (Smith, Flowers & Larkin, 2009). Through the multiple iterations an appreciation of the narrative was built and slowly themes began to emerge. Over the course of the project, I read each journal entry and interview transcript on average 3-4 times.

**Step 2: Initial noting.** Initial noting was done on the transcript to identify points of interest, while I kept an open mind and gained more familiarity with the content. Notes helped me developed an understanding of the way the student thought, felt and talked about the experience of having a chronic illness on campus. The goal of this step was to produce a comprehensive set of comments on the data without assigning meaning (Smith, Flowers & Larkin, 2009). I used Dedoose as an electronic method to find key terms across the transcript. This helped me identify key elements to take note of as important to the participant.

**Step 3: Developing emergent themes.** After completion of commenting the transcripts was working with a much larger set of data. Whereas step two in the analysis process involved looking at the data in great detail, step three broadened the view, and I looked for patterns, commonalities and connections primarily in the exploratory notes (Smith, Flowers & Larkin, 2009). In this stage I attempted to form an accurate picture of the phenomenon based on the words of the individual. Due to the nature of phenomenological studies, units of data are viewed to determine the participants lived experience (Van Manen, 1990). At this point in my research working electronically became somewhat of a hindrance to categorizing and re-categorizing data. I ended up printing off all the initially categorized data, cutting each excerpt into an individual piece and arranging them until the patterns started to emerge and themes became clear. This step resulted in 12 individual themes.

**Step 4: Searching for connection among themes.** After a set of themes were identified and ordered, the next step in the analysis process was to map how the themes fit together to describe the experience of chronic illness in the undergraduate population (Smith, Flowers & Larkin, 2009). This was a purposeful process with the ultimate goal to produce a structure that accommodates the most interesting and important information in the participant's narrative.

**Step 5: Looking for patterns across cases.** The last step in analysis was to look for patterns across participant narratives (Smith, Flowers & Larkin, 2009). In the course of mapping themes for each individual case, a variety of patterns developed. These patterns were tracked on a spread sheet so I could compare what participants indicated as an internal asset or external resource (Appendix E & F). The process required a reconfiguring or reordering of themes. These themes were mapped and compared to resiliency theory and the

anti-deficit achievement framework in order to answer the research question of how students use assets and resources on their path to a degree. By the end of the analysis process I had combined initial themes into four overarching themes with related subthemes. These themes were then tied back to resiliency theory and the anti-deficit achievement framework and sorted into assets (internal) or resources (external).

**Step 6: Presenting the information.** While presentation lies outside the steps of analysis it is the culminating work of the analysis, which provides readers a clear understanding of the phenomenon. A final presentation of the results of the study attempted to describe the how of the phenomenon, in this case resiliency for college students with chronic illness and develop an essence of their lived experience with an anti-deficit achievement mindset (Moustakas, 1994). I did this by narrating the story as told by the participants themselves. In this study I was fortunate enough to have thick, rich data from participants. They were able to clearly and easily articulate their lived experience, which created a large collection of quality data to analyze and present.

### **Standards of Validation for the Study**

In research there are multiple methods of validation (Merriam, 2009). Triangulation was one primary process for finding themes in the data. Instead of relying on one single data source, evidence was collected through multiple sources, strengthening the validity of the study (Cresswell & Miller, 2000). In this study I collected data from pre and post-interviews as well as journals throughout the semester. This provided sufficient data to find themes at multiple instances in time across multiple participants.

A second major method of validating data was to clarify researcher bias. This allowed the reader to determine if the researcher's past experiences shaped the interpretation

or approach. In order for a reader to clarify researcher bias transparency of process and product must take place (Bazeley, 2013). Transparency requires critical self-reflection or reflexivity. Over the course of the study I took notes about how I was conducting the research and my approach to data analysis in order to be completely transparent about my qualitative method.

A third major approach to validating the study was member checking. Member checking allowed the original participant of the study to check for accuracy and credibility of the account (Merriam, 2009). In the course of the study I openly described any potential bias I may have had as the researcher, and also provided participants to the option to look over the final themes. By doing member checking, I added credibility to my study by giving participants the opportunity to comment on the accuracy of the phenomenon of living with a chronic illness on campus. For this study three participants volunteered to member check the results.

Last, but not least, I believe good qualitative phenomenological studies include thick, rich descriptions from participants. The purpose of providing thick, rich descriptions was to give the reader the opportunity to delve into the experience being studied (Cresswell & Miller, 2000). This allowed credibility to be established through the lens of the reader, who can experience the phenomenon through the life of the participant. The results section contains multiple descriptions from participants so the reader has the ability to verify the phenomenon exists as described.

### **Significance and Potential Contributions**

This study is intended to provide staff, faculty and educational leaders' strong insight into the everyday experience of college students living with chronic illness. Through the use

of a qualitative phenomenological study, undergraduates at a large public university completed semi-structured interviews and journals so that readers could hear the voices of those experiencing the phenomenon of going to college with a chronic illness. Using an anti-deficit approach and a resiliency frame the study uncovered the assets and resources used by students with chronic illness as they work toward degree completion. In order to ensure validity of the data I used a combination of reflexivity, member checking and thick, rich description. Transparency of the research process was of high priority throughout the study as the participants shared an active role.

This study redefines the college going experience for students with chronic illness and assists others in recognizing these students bring with them a wealth of capital in forms that society may not readily recognize (Yosso, 2005). Understanding the assets and resources that students with chronic illness use to build resiliency may also assist educational leaders in building intervention programs to offer appropriate and beneficial supports to this community. For students with chronic illness feeling properly supported can improve retention and matriculation rates leading to improved employment opportunities over a lifetime, making this research vital.

### **Limitations of the Study**

First, there are some limitations to resiliency research. Resilience was found to change based on context, population, the risk, promotive factor, and outcomes (Fergus & Zimmerman, 2005). That resilience is not a static trait sometimes makes it difficult for researchers to identify universal factors that lead to a person becoming resilient. Second, the research that explores resiliency long term typically means looking at a participant at only two points in time, which does not accurately measure a person's development of resilience.

One of the ways I have attempted to navigate this challenge is by not only interviewing participants at two points in time, but also allowing them to journal over time. Most longitudinal studies may have a tendency to regress toward the mean and not show significance when compared to the general population over time (Fergus & Zimmerman, 2005). However, during the course of this study significant patterns among participants did emerge.

A second major limitation of the study was the potential for participants to become severely ill and not be able to continue. Initially, I had 23 applicants who wanted to participate in the study. Most withdrew before the initial interview. The majority of those who withdrew before the initial interview were male, and two did so due to ongoing health conditions. The others essentially indicated that did not have the time to commit or gave no reason for not responding to repeated interview requests. After three attempted invites to schedule an initial interview I advised I was discontinuing contact. Overall, with the exception of having very little male participation, the response was what I expected for the study.

A third limitation of the study is that the line of questioning used in the study was not direct enough in uncovering the lived experiences of having a chronic illness and dealing with marginalities from other aspects of the participant's identity. The anti-deficit achievement framework looks at how students successfully navigate institutions that are sometimes racist and culturally unresponsive, and asks specific questions about identity and how that contributes to additional challenges that need to be navigated (Harper, 2010). My line of questioning did focus on barriers at the college level both related to the illness and not, but I did not specifically ask about race, gender, and sexuality as related to having a

chronic illness, and students did not voluntarily disclose. The lack of explicit questioning leaves a gap in understanding the complex world of having a chronic illness or disability status in addition to another marginalized status, and also does not disclose the power dynamics at play when experiencing multiple marginalized identities.

### **Chapter 4: College Students with Chronic Illness Findings**

Today's college students experience higher education at a time where they are exploring their identity, finding their place and space, and determining future possibilities (Arnett, 2004). However, the diagnosis and symptoms inherent with most chronic illnesses add additional risk outside of those for the average student. There are currently no guidelines to transition youth with chronic conditions from pediatric to adult care in conjunction with college health services (Lemly, et al, 2014). This lack of transition care means these students must manage the demands of college life at the same time as the full range of health related tasks associated with managing their chronic illness. The goal of this phenomenological study is to look at how college students with a chronic illness(es) use assets and resources to build resiliency and successfully navigate their college experience, despite having the additional risk of a chronic condition that could be a barrier to their success. Not only is this study using resiliency as the theoretical underpinning to explore the phenomena, it also uses the anti-deficit achievement framework as the foundation, which gives a unique view of the phenomenon not previously studied. A better understanding of this phenomenon, and one that is not deficit in nature, will allow educational leaders to potentially build interventions and ensure a successful college experience for student with chronic illness.

This chapter presents the key findings obtained from 13 in-depth participant interviews, one at the beginning of the semester and one at the end of the semester, as well as ten weeks' worth of journals from 12 participants. The research question this study seeks to answer is:

How do college students use assets and resources to build resiliency, despite navigating a chronic illness?

As mentioned in chapter 2 and 3, this study uses the anti-deficit achievement framework and resiliency theory as part of the foundation of its findings. The two areas of the anti-deficit achievement framework that were explored were the pre-college and college achievement time periods. During those two periods, relationships students had to support their college aspirations were uncovered and during the college achievement phase, how students navigated their experience to be successful in an environment not always culturally responsive to disability status was investigated. The anti-deficit achievement framework works well in combination with resiliency theory as it also explores how students navigate barriers or risk. A key part of resiliency, or the ability to adapt positively in the face of risk is dependent upon varying amounts of internal assets and external resources. Internal assets are characteristics and behaviors a person exhibits and could include personality traits, thoughts, attitudes, and values to name a few. On the other side, external resources are outside supports such as people, services, and organizations. Four major findings emerged from this study, two related to internal assets of the participants and two related to external resources possessed by the participants:

1- Personality Traits (Internal Asset): Participants overwhelming shared certain personality traits and these traits were often referred to as a key to their successful navigation of college with a chronic illness. These traits included overarching positivity, personal agency and for about a third of the participants, a faith in a higher power. These internal traits allowed them to develop skills they needed to navigate academia, to build supportive relationships and to sometimes navigate situations where people were unresponsive to their needs as a student with a chronic condition.

2- Adaptability (Internal Asset): Participants credited their ability to adapt to self-awareness of their body and the environments in which they resided, but also a sense of realism on what they were physically capable of completing. This often allowed them to be flexible in action and decision-making and achieve in the college environment, even in situations where their condition or lack of understanding from others tried to disrupt their college trajectory.

3- Social Supports (External Resource): Participants credited a range of people as being key to their success in college while navigating their condition. Some of these relationships offered support of college aspirations prior to their enrollment, and some were there to support their college achievement when they felt marginalized by others or unable to continue because of their condition and the rigors of academia. Examples of people who were key supports were family, friends, significant others, and instructors or professors.

4- Institutional Supports (External Resource): The key difference between this category and the previous is that participants often did not look at institutional supports as a resource because of the people in the organization, but for the service or feeling the organization provided. Institutional supports offered services to improve the students' academic experience in both classroom interactions and out of class engagement. Examples of institutional supports participants credited with helping them navigate college with a chronic condition was the Disability Center and Student Health. The remainder of this chapter will present rich descriptions of these themes.

One important point to note, and is mentioned throughout participant's stories: internal assets and external resources typically do not act as independent units helping students with a chronic illness develop resiliency. As seen throughout the chapter, there are

many instances where the internal asset and external resource work simultaneously to support student's resiliency.

### **Internal Assets**

**Finding 1: internal personality attributes.** Participants cited a range of personality attributes that they felt gave them an innate ability to navigate the ups and downs of their condition with the ups and down of their college experience. However, there were several patterns that were displayed across participants as supporting their college endeavors. The following discussion breaks down the subcomponents of this theme.

**Positivity.** A primary and overarching internal assets expressed by all thirteen participants was an overall positive outlook on life. Some students expressed this positivity as an inherent component of their personality, which helped them to navigate times when college was challenging in general, but especially when their chronic illness flared during college semesters.

*I think that my positivity is just like the biggest element that gets me through everything and probably what other people see because, you know, they think oh, if I was in that situation I would have just quit (KBFN).*

*No matter what I go through, I'm always pretty positive. People call me sunshine. I think that embodies my ability to be positive no matter the circumstance. Whatever I'm going through, I'm still pretty positive about it. I like to think that going through surgery and different things makes it to where there's nothing I can't get through, so I just try to be positive (CHFV).*

One participant even used strategies to support maintaining her positivity:

*I use a gratitude calendar with all 365 days hanging on my wall, and I try to write one thing that I'm grateful for on the line for each day. This isn't necessarily connected to my body or conditions, but it does feel nice and simple to be able to see three full months of days displayed in the form of grateful and happy moments (BWFN).*

These examples are very direct, clear insights into student's use of positive thought in order to navigate their college experience with a chronic illness. It should also not be deeply surprising that college students navigating higher education with a chronic illness successfully exhibit a tendency toward the positive. There is solid consensus in the research that positivity or a positive outlook is a coping mechanism for managing chronic conditions of ill-health and disability (Coyle & Atkinson, 2018; Livneh & Martz, 2014). Deeply related to positivity, happy people are shown to use humor as an adaptive strategy to maintain happiness or positive thought in the midst of adversity or challenging life conditions (Ford, Lappi & Holden, 2016). If humor is in its own way a coping mechanism for managing adverse conditions, it is no surprise that several of our participants also identified humor as integral to who they are as people and that humor helped them to navigate their condition and is substantially connected to overall positivity.

*I'm an understanding person [...], I have good humor in the sense that I don't get offended easily. I can joke about myself or anything, so yeah, I think that's a primary way I would identify myself (MWFN).*

*I also have a funky sense of humor, so that's definitely a big one, just because, you know, sometimes things are just a little bit better if you can find a way to laugh at the situation. I'm almost always smiling, so that helps inside and out (KBFN).*

*My humor is important, just whenever I'm freaking out over trying to finish this semester and especially my housing, like I kind of like use my humor as a mask to cover it up and just like try to calm myself down, but then it also just makes my life more light-hearted (RWFN).*

One student even shared a sense of humor with her brother, who was also experiencing symptoms from a chronic condition:

*We both understand that we deal [with the condition] through humor. We make jokes at our own expense. There are a lot of things that are funny to us, but if other people make jokes, sometimes it's funny and sometimes it's like, well that's just how my life goes (AWFY).*

This participant in particular used humor to cope with her condition, but at the same time to develop a stronger connection with another family member, who had also been recently diagnosed. In this circumstance humor and her brother was a support. But the participant in the interview later indicated the support was reciprocal. She and her brother supported each other's success through humor as they navigated their illnesses.

*We were not always that close, but we got a lot closer when we were both diagnosed. I know that he helped me out a lot. Like sometimes he'll be there and we both have to drink a lot of water, which is always a fun one. So we'll joke around and will be like how much water have you had to drink? Like I've had two Liters, well.... I had 2 1/2! Like it would like a competition to try keeping each other on our toes. Making sure we on medication and like everything and it's like well; I have had more than you!*

Last, under the positivity realm, participants displayed high levels of optimism.

Positivity and optimism are highly connected, but there are some subtle differences.

Positivity is the tendency to think with positive thoughts, whereas optimism is the expectation of positive outcomes usually based on past experiences (Oettingen, 2015).

Optimism exists in various forms: dispositional, comparative, situational, strategic and realistic. In the context of the current study, two optimistic patterns developed: dispositional and comparative.

Dispositional optimism, the first type of optimism found in the research literature, is described as the general expectation that more positive things will happen in the future than negative (Peterson, 2000). Interestingly, Peterson (2000) identified dispositional optimism as the idea of big optimism, and pointed out that dispositional optimism is relatively stable as a personality trait. The data showed that all participants displayed some level of dispositional optimism, with a positive outlook toward the future. Below are several examples where dispositional optimism was very evident:

*I see myself in five years out of school and completely financially free. I'll be 26 and will have visited many different countries and will be starting my life's endeavor by speaking life and wisdom to a wide variety of audiences on the public speaking circuit. I see myself as a role model for other young people my age as proof they can do it [accomplish their dream] (KBFY).*

*One way I see myself is as a graduate of an MSW program, practicing social work in a clinical or school setting. In this aspect of my future, I don't see my chronic condition influencing this choice (BWFN).*

*I often think of New York City. It's always been a dream of mine to move there after college. I will be working a full time job in producing and creating content that is impactful and hopefully activist driven (BBFY).*

*Years from today I will be getting ready to enter a medical residency (JWMY).*

*I see myself finishing grad school. I will be living in Colorado and finding a job with art therapy and starting the next chapter of my life (EHFN).*

These participants all expressed a very clear picture of the future and their future was bright. Optimism held true even if others tried to dissuade them. One participant acknowledged that several people, out of ignorance of her condition and perception of her low income status, tried to dissuade her from going to a more expensive institution away from home, but she clearly saw herself and where she was headed, and this optimism helped her to ignore the doubters and develop a sense of agency to fulfill her dream (BBFY). They could easily and optimistically visualize that future and that ability enabled them to continue to push forward even during difficult periods at school and with their illness.

The second related optimism theme was more surprising. Eight of the participants used comparative optimism as a means of navigating the college experience, disclosure and their condition. Comparative optimism is defined as the expectation of good outcomes relative to a similar other (Radcliffe & Klein, 2002). In the case of this research students used comparative optimism to compare their situation with a chronic condition to someone else

with a chronic condition, known or unknown. In holding onto their optimism they were able to relegate their challenges into risk they perceived as manageable.

*When I first got to college, I was private about both conditions because I don't want people to sympathize with me. I'm ok. I'm totally fine. Yeah, I have these conditions, but everyone has their own thing, I'm going to be ok (KBFN).*

*Whenever I think about my condition, I know that there's someone out there that has it much worse than I do and I'm always kind of someone who puts myself in a 'it could be better, it could be worse' situation. So I keep it in my mind that things could be way worse. I know people with [my condition] who are wheelchair bound, can't get out of bed or can't go to college. I definitely have it good (CHFV).*

*I keep explaining to people that it could be worse. I want to try to look at the bright side of things. I'm dealing with hand discomfort and a rash. Like this could be worse, and that has helped me to explain to other people, to help them not be worried. I don't want them to worry about me; things could be worse (AWFN).*

*I'm always like you know it's not that big of a deal, but yeah it's the same reaction every time. I don't know why they're making such a big deal about it. It's like they hear the word disease and freak out, but it's really not that big of a deal. I just try to brush it off and I'm like hey, it's not like I'm dying (JWMY).*

Interestingly, in participant's use of comparative optimism, they not only use the trait as a coping strategy to navigate the perceived severity of their symptoms, but also as a way to downplay their condition to the outside world. It seems that this ability helps participants navigate some of the disclosure process to get perceived positive reactions instead of negative ones (e.g. sympathy, worry). This way of processing self, and displaying self to the outside world, appeared to be a key factor in the participant's ability to build resiliency and was evident across varying demographics and diagnoses.

Participant's demonstration of positivity and optimism seems to be a strong support in their ability to build resiliency and contribute to their overall well-being in the face of challenging health and academic needs. Although this research study was specific in trying to identify internal assets, there is a common link between positivity, optimism and well-being

among college students (Yu & Luo, 2018). These factors helped them achieve inside and outside the classroom. Resiliency is very rarely achieved without a strong set of internal assets, and for college students with chronic conditions, the data shows a strong relationship between positivity, optimism and resiliency which leads to successful college navigation. This internal view of themselves, their conditions and college can be strongly connected to the ability to act on their beliefs about their capabilities. The ability to act on one's own behalf emerged as a second major finding in this category.

***Personal or human agency.*** Personal or human agency is defined by Bandura (1997) as the “human capability to exert influence over one's functioning and the course of events by one's actions” (p. 4). The more simplistic way of understanding agency, is the ability of a person to develop plans of action and carry those actions out. The development of agency is influenced by two main components, self-efficacy, or the belief that one is capable of bringing about a specific outcome, and by one's actual skill (Bandura, 1997). Eleven of the participants in this study displayed substantial agency in their ability to regulate their chronic illness, but also to successfully work through the semester while navigating their chronic illness. One participant displayed personal agency in working with classes where the professor was not accommodating or culturally responsive to his health needs and disability status.

*If I could tell that the class structure was pretty rigid, I would usually set up a safeguard for myself, that's when I would use the piece of paper I had to request accommodations (JWMN).*

In this manner, the student was able to evaluate the structure of the class and proactively ensure his success and ability to make it through the semester successfully should his condition impact him.

Others identified agency in the way they took control of management of their condition or even selecting treatment that was right for them and their body.

*So I went to and from the hospital after school for a week and got steroids put in my system to give me the ability to walk. Then I tell my parents I don't want to do physical therapy anymore, so they are like jokingly, 'well, what are you going to do, teach yourself how to walk?' And I was like, well I guess that's my last option, so that's what I did (KBFN).*

*When my doctor tells me something, I'm very adamant about knowing what I feel is right for me, what kind of medication I want to take, because in the end, it's going into my body and I'm choosing to do it. So I've become very....that it's okay for me to speak up to my doctors and let them know what I like and what's not working. Even though I've added on this chronic illness to my life, which seems like a lot, I refuse to let it stand in the way of my goals or what I want to do (BBFY).*

One participant expressed her personal agency even in the form of uncertainty.

*I think the best thing I do is just take a deep breath and be like okay, so this diabetes thing is crazy and like there is a balance between like being ok, and then being ok with the parts you can't control, because I can control some aspects of it. Like [with my other condition] when I go to the dining hall website and see what is gluten free and what isn't, I grab what I can (BWFN).*

In this example, the participant recognized that her conditions did have variability that were out of her realm to change. At the same time, she still had a level of personal agency because she also recognized that while she had some limits, overall should could influence and could take proactive steps to control certain parts of her conditions and achieve a better outcome.

One last example of exercise of personal agency shown by the participants was the selection of institution. Several of the participants chose their institution despite others trying to discourage them from going.

*They were really not on board at first. I'm the baby out of everyone, besides my two little cousins, and have an older brother, and they were just like we're not going to let you go to this place where we don't know anybody. They were really against it, and then I said I will save money, but I am going there and you need to get used to it (EHFN).*

While the above example is not the only participant who experienced something similar situations with their family members, it clearly outlines the use of agency; the ability to take control of one's direction and life and then carry those actions out. Interestingly, for participants who used this form of agency to direct their choice of institution selection, the families in all but one situation eventually came on board with their decision. Family pre-college support is also reflected as a key factor in the anti-deficit achievement framework and is a benefit that successful students bring with them to the institution.

Personal or human agency was discussed as an important positive internal asset for these participants. They described agency as providing the ability to overcome obstacles, but also the belief in the ability to direct their own life course, whether it be success in a class, medical treatment or choice of institution. Their belief in their ability to direct their life course superseded even the attitudes of those power figures on campus and in the medical community who held a more limited belief in what they could achieve.

***Faith in a higher power.*** Faith in a higher power was a salient subtheme in the data for five of the participants. While the study did not expressly ask about religious faith or belief systems, this subset of participants emphasized that their faith in a higher power was of substantial importance to their ability to navigate their college experience and chronic illness. It is also interesting to note that four of the five participants that expressed this characteristic as important were minority participants, and all the participants expressing this type of faith were female. Participants primarily used this belief system in two different ways: one as a coping mechanism when times became difficult, but also as a way to view their ability to control their situation. Their excerpts are below:

*So like trying to be strong in my faith has definitely helped me be more relaxed, which has helped when I have worse episodes to at least calm my body and not tense up (EHFN).*

*I think it was last week, I was just really angry and I was like he's your father [God], so you could tell him that, which is good. But then it's also just like, I don't know, you have to hope for something, and that it's going to get better and so it just helps that...it just helps being able to know that there's a higher power outside of you (KBFY).*

*I feel like for me personally, like God wouldn't give you anything you can't handle, and you're going through it for a reason (KBFN).*

*Knowing that God only gives his toughest battles to his strongest warriors is what gives me the confidence. I know that the pain I go through is only temporary, my life is not just mine; there are people to be touched from my testimony. That is pretty much the only thing that got me through. And the fact that I know pain is only temporary (KBFY).*

An important point to note about the above quotes, is that these participants, while expressing their faith in a higher power, were also expressing forms of positivity and optimism. This was true for participants throughout the course of the project. While not all participants displaying positivity as an internal asset expressed faith in a higher power, all participants who did express faith in a higher power displayed other forms of positivity in their life. This relationship could potentially indicate that positivity and faith in a higher power are intertwined, and warrant further exploration.

*I grew up Baptist, but I was very much like mom, stop shoving your religion in my face, and it wasn't until I came to college I was like, okay, I guess whatever. But I really think, because in moments of extreme pain with my chronic illness, like praying definitely helps...So if I'm like having a really, really, really bad moment, and I'm just sitting there, my stomach's just dying, sitting here praying, like okay, deep breaths, I'm going to get through this, that kind of thing (EHFN).*

*It's very new to me, but I have...I have prayed and asked God, and it was like I'm having a terrible day, like I really need to go to class, and I can't miss this class, we're having a test, I don't want to reschedule. And then, I don't know. I don't know if it's like God actually working or like me having that whole placebo effect, but then I feel slightly better or at least like someone understands and believes that I can do it. So I have prayed to God to ask that like certain days are better or that my heart rate goes down, and I think it helps (AWFY).*

These last two quotes are interesting in that the participants seem to be expressing some personal agency through prayer. Using the definition of personal agency from Bandura (1997), prayer and belief in a higher power seems to have given these participants a sense of control over their life course and the feeling of power to take action to move forward toward positive outcomes. So while it might not seem that faith in a higher being controlling outcomes leads to agency, for the above two examples there is some indication that that belief lead to feelings of control over the condition and then allowed them to take steps to support their academic endeavors.

An important point to note is that for these participants, faith does not necessarily equal a connection to organized religion. With the exception of one participant, who indicated they went to an informal Bible study group on campus, no one emphasized that a religious organization or institution was an important external support. The lack of mention of religion as an external support makes it clear that faith in a higher power is an internally connected asset that aids the student in building resiliency. Within this internal asset, there does appear to be some connection between positivity, personal agency and faith in a higher power. For the purposes of this study, that question will remain unanswered for now. For these five participant's lived experiences, faith in a higher power is an additional internal asset that aids them in overcoming the risk of their condition and going to college, allowing them to exhibit resiliency throughout their higher education experience.

**Finding 2: Adaptability helped participants overcome risk.** Adaptability is defined by the American Psychological Association as “the capacity to make appropriate responses to changed or changing situations; the ability to modify or adjust one’s behavior in meeting different circumstances or different people” (VandenBos, 2015, p. 18). Adaptability can also

be seen as cognitive, behavioral and emotional regulation that assists one in responding to change and uncertainty (Martin, Nejad, Colmar, & Liem, 2012). Within these definitions it is clear that adaptability centers on change, modification and adjustment. For example, a college student may adapt to an additional earned scholarship by adding a study abroad experience. Resilience, which is a related construct, also centers on change, modification and adjustment, but to risk. A student new to campus may seek out new friendships to have social connections, but some of those social connections may be centered on binge drinking. At this point the student has to make the change and adjustment of creating new social interactions, but there is risk associated with binge drinking. In this case binge drinking may lead to additional peer connections, but could also create serious safety and health situations. While similar concepts, with adaptability the change can be positive or negative, whereas the risk referred to in resiliency encompasses any situation, which could result in a loss or damage, causing adverse results (Stoddard, Zimmerman, & Bauermeister, 2012). Thus, a participant's lived experiences would be expected to involve some level of adaptability. In essence it would be nearly impossible to display resilience without some form of adaptability.

It is also important to recognize that adaptability is related, and can be based on, the idea of personal agency or the belief that one can plan and carry out an action. However in this section, adaptability is not just a belief system that one can carry out a plan, but is the actual modification or adjustment of behavior. While still an internal asset, adaptability is action oriented. Within the data participants displayed remarkable adaptability with almost hyper self-awareness of themselves and their body. At the same time they were realistic and flexible in action when change needed to occur. One point to note in the data is that many of the participants recounted their flexibility in certain situations within higher education and

having a chronic illness. However, it seems that even though participants were describing themselves as flexible, they were more accurately describing their adaptability in given situations that challenged them. While broadly speaking the two terms are often used interchangeably, flexibility is more associated with pliancy, or the ability to bend, and is typically thought of in the short term (Bailey, 2014). In the case of the participants in this study adaptability is more accurate because while the initial development of the adaptation may be made in the short term, the skills built from the adaptation were used over the course of their academic careers. So one could make the argument that the degree of flexibility in the participant in a given situation leads to how willing one is to adapt and make the changes long term. Below is a discussion of adaptability and its related subthemes that aid in the participant's ability to develop resilience and navigate college with a chronic illness.

*Sometimes I have to have to make up excuses in order to navigate [challenging] situations. You must be able to think quick as there isn't much warning when an attack may come (HWFN).*

*I just have to remember that I need to be flexible, and adapt to whatever circumstances may arise. I am confident that I will face the challenge, because 1) there's not another option and 2) I've adapted and overcome the same challenge a countless number of times (HWFN).*

*I think being flexible helps because I could get all upset and in a fit about like how the medicine's not working and stuff like that. But I'm just trying to take it as it comes and I'm putting a lot trust that things will adjust and work out (AWFN).*

These two quotes emphasize the participant's adaptability, but at the same time also display levels of positivity and dispositional optimism, or the idea that more good things will happen than bad. In the case of the second quote, it was a proven pattern of positive outcomes, and in the third quote a general emphasis that positive things will happen. Adaptability also helped participants navigate situations with inherent risk. From navigating

food to social parties, participants adapted quickly to the setting and any risk that could derail their health. One example in particular talked about how they navigated drinking at parties.

*I drink. I'll get a little drunk here and there. But I have a quicker limit than everyone else, so I have to chug water later and figure out how much insulin to take (KBFN).*

Other participants indicated they chose not to drink at all or always offered to be the designated driver, which is more socially acceptable and better for their health. Adaptability or the ability to adjust and modify one's behavior in given situations does not always appear in one way. Analysis distinguished between two unique and specific forms of adaptability discussed by participants: self-awareness and realism.

***Self-Aware.*** Adaptability has to start somewhere. For the participants in this study, adaptability typically began with an intense awareness of self, their body and their environment. Self-awareness can be looked at as a state-like or trait-like quality. In a state-like experience self-awareness allows one to become the object of one's own attention, to reflect on their experience in the moment, and aids in meaning making for the decision making process (Dishon, Oldmeadow & Kaufman, 2018). This study argues that it is really a little of both, but that self-awareness leans more toward a state of being, which in the case of these participants gave them a unique ability to adapt to the risks associated with having a chronic illness and navigating their higher education experience. Participants' descriptions of self-awareness and its aid in helping them navigate their condition and higher education are below.

*Nothing works right 100% of the time. So you combat that by the book information with stuff I've learned as a kid mostly, you know, if I have high blood pressure, dose, if your blood sugar is low, eat snacks, check your mood if you're in public. Like if you're getting irritated about something, your blood sugars probably out of whack, so try to do this... (JWMN).*

*So if I'm going to do something big, I'll make sure I'm not doing anything big in the days leading up to it. Like before a concert, one of my friends was like, hey, let's go shopping and I was like I cannot. I'm going to a concert in two days and I have to space it out. [...] I take extra salt, and drink drip drop in the morning. The morning of I'll drink extra drip drop and take extra salt and then during the event I will take salt pills and drip drop and water (AWFY).*

*The only rule that I have followed is that I need to do what my body tells me. This is very broad in the sense that it applies to literally everything. If I'm feeling like I can't go to school, I don't go to school. Or if my stomach is hurting because I haven't eaten anything, I will skip everything to make sure to get something that is not vending machine food (JWMY).*

*I'm very intune and aware of my body and my health. I think having chronic [...] from a very young age, you learn about the medicine you're taking, you learn about how your body reacts to certain medications, so now with [two chronic conditions], I'm very aware of it also. I feel like I know what's good for me and I know what's not. So I'm confident in making medical decisions now (BBFY).*

The self-awareness exhibited by the participants not only allowed them to sense body changes, but also to better plan for future events, which also ties back to an earlier finding of self-agency. Self-awareness, self-agency and adaptation appear to work hand in hand for the participants in this study. The deep awareness of body and changes, even small ones, enabled participants to understand how to take control and action over their condition when adverse symptoms presented themselves. Interestingly, this self-awareness did not seem to be impacted by external parties. In the data, participants did not change decisions about what was good or not good for their bodies based on the opinions of faculty, peers or medical personnel, but emphasized they were the experts on reading their own body and did what they knew was best. For the most part, the data indicates that this strategy of meaning making created positive actionable strategies to regulate their condition in stressful environments. The data make it clear that self-awareness is a key to building resiliency as it allowed participants to proactively rather than reactively adapt to the situation when they experienced a negative symptom of their condition.

*Realistic.* Strongly related to self-awareness is the tendency to be realistic in their decisions and actions. Whereas self-awareness creates meaning for the participant, being realistic in action helped them take decisive actions that matched their ability. Roughly 50% of participants indicated that being realistic in their navigation of college with a chronic illness was one of the keys for moving successfully forward.

One participant expressed that when she came to college, she had to learn that she had to be realistic about seeking support and could not complete school without the proper resources.

*I realized that it is okay to have help when I need it. It's about being prepared, not having an excuse. Getting ahead of the situation in college was a big thing for me. So I asked to register with the Disability Center (KBFN).*

Other participants expressed similar sentiments:

*I used to be, you know, passive and say you know I can do it, I can like do everything, but I just kind of learned to say, like, no I can't do that thing or like a I need to take a day off, and so like I think I've just kind of been able to gain that confidence to say when I can or can't do something, and it's been to my benefit (HWFN).*

*I just know there are certain things I can and cannot do. I take naps when I need to. I try not to do it frequently, but when I need it, I do (CHFV).*

*It took a lot of digging and being motivated to be okay. I had to understand that it was okay to not be okay at this time, but also to know that I was going to be okay in the end (KBFN).*

The inherent nature of chronic illness is unpredictability. The unpredictable nature becomes its own form of risk. Add that to the everyday stressors of school and the sometimes unpredictable nature of being on a college campus, and life can be particularly challenging for the college student with a chronic illness. However, for the participants in this study their ability to pivot from one routine or plan of action to another in a realistic way aids them in their ability to persist when unplanned events or symptoms occur. Adaptability is an internal asset for the participants that aids them in their ability to build resiliency and overcome risk.

## External Resources

### **Finding 3: Participants identified social supports as a critical external resource.**

While the above discussion focuses on internal assets used to build resilience, assets only make up one piece of the resiliency process. The other piece used in the resiliency process are external resources. An external resource in the resiliency process is any resource outside of yourself that helps with the navigation of risk. One of the primary external resources found in the development of resilience is having caring and supportive relationships inside and outside the family (American Psychological Association, 2018). The current study proved similar results with participants identifying family and peers and primary forms of support with a smaller subset identifying a significant other or faculty member as a means of support.

**Family.** Family was found to be a predominant means of support for 12 out of 13 of our participants as a means of support. While there were a variety of ways that family supported participants, parents were most often mentioned as the primary support system.

For many of the participants, parental support fell into the category of practical support, offering to do a task or providing financial assistance or some other supply.

*My mom's super supportive. Any time I've needed something, she's gotten it for me and you know, she's my mom, so yeah, I'd definitely say my mom (JWMN).*

*My mom supports me in the sense of...even though she's never been to college, and she's learning just like I'm learning...so she'll learn something, then take care of it for me. She's very supportive and when it comes to finances, she's on top of everything (BBFY).*

*They're really supportive financially as well, which eases a great deal of stress for me. I'm still on their insurance plan, and I single-handedly meet the family's deductible each year, and they help me with the copays for doctor's visits. I honestly don't think they could be more supportive (BWFN).*

*My dad is my best friend. He's always there for me, even when I'm not having a good day. He checks up on me every day, even from a thousand miles away. Like every other week, I'll get a package at the same time to my dorm. All with these ice packs, so I don't have to buy them. He always sends them to me. He sends care packages and he's on top of my Dr. stuff when I'm not (CHFN).*

Outside of the practical support, parents were also identified as being a strong emotional support system to help participants navigate difficult times.

*My mom is one of the most positive people I know. And it's not necessarily saying everything's fine, but she's more like change the way you think and change the way you say things. So instead of saying I can't, but I will do this. So I definitely think she has a huge impact on me and on the way I think even now (KBFN).*

*I'll call my mom because I know there are certain days where it's like...like I saw this guy and he was taking two stairs at a time and I just like...it was a nice day outside and he was like so excited and it was like, I want to take the stairs two at a time, and so I tried. And it didn't work out very well, so I got real sad and I was like I can't even be like a normal college kid and skip upstairs. And my mom will listen and then I'll realize I'm doing really great, like from last year (AWFY).*

*One of my doctors was basically saying that they might want me to do surgery, and I was pretty upset. But I didn't really want to think about it. My dad actually cried. I don't really see him cry that much. So that was interesting for him to sit down with me and talk [...]. He was able to open up and I was able to open up, so that was pretty cool (CHFN).*

*My mom has been my backbone so to speak this semester. She is the one who I call when I'm having a bad day or when I am particularly in a lot of pain. She keeps me grounded and helps me manage my stress or tells me when I need to chill out. I know she can't really understand how I feel, but she listens when I need her, which is good (KBFY).*

*My mom was talking to me and she just really wanted to make sure I was okay. And finally I was just like its overwhelming and I don't know what this means for me. We had a really good conversation. My mom and I are really close, so we just had another layer that made us closer (AWFN).*

Only one participant (JWMY) out of the group indicated a lack of family, especially parental support. For this participant it appeared they offered no practical help, even though they had the means to do so, and were quick to offer advice, but as indicated by the participant, were not empathetic to his condition or the symptoms related to his condition. It is also worth

noting the participant seemed to have a general distrust of people in general, but did mention one mentor that had briefly been supportive in offering advice on getting into medical school.

*Socially, I don't get involved with people who I shouldn't get involved with, so I guess that's reduced the stress factor a little bit. I mean I guess it just keeps me from getting into the stuff that I know I shouldn't be getting into in the first place. Whether it's like I get like an STD for being with someone I shouldn't be talking to, or dealing with mental stuff I shouldn't be dealing with from interacting with people (JWMY).*

For four of the participants, siblings were also a source of emotional support as they were navigating college and a chronic condition.

*So I have an older brother and a younger. Those are probably my two best friends in the whole world. I talk to them every once in a while, but they just, I don't know, keep me on track and happy (KBFN).*

*If I want to go home my brother will be like, look, I was the same way freshmen year. [...] He tells me to stick it out and gives me a lot of advice about when I'm homesick and how to handle it (CHFV).*

*We were not always that close, but we got a lot closer when we were both diagnosed. Like sometimes he'll be there and we both have to drink a lot of water, which is always a fun one. So will be like how much water have you had to drink? Like I've had two liters, well I had 2.5. Like it is a competition to try keeping each other on our tow. Making sure we are on our medication and like everything (AWFY).*

Like parents, siblings offered emotional support for dealing with college challenges and risks associated with their condition and aided participants in developing resiliency. The concept of family aiding in support of success is also documented in the anti-deficit achievement framework. Family was often found as key indicators in helping students develop pre-college readiness and the findings in the current study back that idea.

**Peers.** Outside of family, 12 of 13 participants listed peers as the next most influential resource for college students with a chronic illness. This is not surprising as peer support is a known resource for college students and also for college students with a chronic illness (Ravert, Russell & O'Guin, 2016). Peers are also found to be important predictors of college

GPA, adjustment and even commitment to college (Dennis, Phinney & Chuateco, 2005). For the participants in this study friends were primary means of practical, social and emotional support. Participants often indicated that support could come from peers in major ways, such as dealing with a condition flare up, or small ways. However, it is also important to note that methods of disclosure of these needs varied by participant.

*If I'm not carrying a purse and I'm like, hey can I just put this in there [medical supply] real fast, like no one's going to deny me for that. I mean a) it's kind of rude, but b) like they really don't mind. Like they understand that I have to take my medicine at a certain time and it doesn't bother them, which is cool (RWFN).*

Peers were often accepting of when participant's health condition needed to be accommodated in a social setting.

*So like the other day, we went to this party on traditions plaza. So I played Frisbee and we hung out and it was really nice. During one point, we were playing Frisbee and my heart rate got really high and I got kind of dizzy so I was like I'm going to sit down and we'll reevaluate. They were like ok, we'll just play right here. It's nice to know that there are people who understand, or even if they don't, they're willing to not go get ice cream every other day because it's a lot of walking for you, or they offer to drive you places so you can go too (AWFY).*

*There was one point in the semester where I wasn't feeling great at all. My friend C stopped everything she was doing to go pick me up dinner. She was able to come to my room and just spend time with me (BBFY).*

For six of the participants, peers within an on campus organization provided a means of social support and belonging that helped them navigate the challenges of school and dealing with their chronic illness. These groups were also exceptionally supportive and accommodating to the participant's chronic illness. The quote below emphasizes how one student felt about her student organization:

*For the first time I encountered a group of people where they had mental health issues or were really sick, so it was comfortable to say, hey this is what's going on, and to put my story out there. They're always really understanding that when I say that I'm sick, they now I'm actually sick, but they don't poke into it to see what's going on. So doing that group for a while was really helpful (EHFN).*

About a third of the participants also emphasized the importance of friends who believe you when you tell them about their condition, and in a variety of ways that gave participants a sense of empowerment. It also allowed them to feel comfortable disclosing their condition.

*Having a friend believe me has helped me to see that people can and will take my condition seriously, and see my condition as both a part of who I am and as separate from my core identity. I think having a friend who is so supportive of my health and wellbeing also empowered me to advocate for my health in new ways (BWFN).*

*I'm totally fine with telling my story, just because I never know when it's going to help someone else (KBFN).*

*I used to be really shy about sharing anything, so much to the point where I would sacrifice my own health in order for people to know not something was wrong. Luckily, I have grown out of that and realized no one is going to judge me for having the disease and my health should be the most important thing, not what people may or may not think (MWFN).*

However, even with participants who indicated that friends were a significant level of support, about half indicated they didn't disclose their condition to peers or didn't disclose the full scope.

*I mean a lot of my friends know I am [diabetic], but honestly, I don't really like to go out of my way to say anything. It's just kind of become a part of my life and that don't really like explaining because I'm used to it (JWMN)*

*When thinking about who to share my condition with, I think of how long the friendship will last, how well they really know me, and what type of mindset and support system they will be for me. I felt that although I should try to spread more awareness about it, my condition is very personal and not everyone needs to know your personal business (KBFY).*

Reasons for not disclosing seemed to revolve around two main areas for participants: somewhat of a shame factor for three of the participants and a disinterest in being a pseudo-ambassador for their peers whenever anyone had any questions about the condition. Despite lack of disclosure, these same participants indicated that their peers offered them a great deal of support as they navigated through school. Participants who did not disclose their condition

or disclosed only pieces of their condition to peers heavily relied on family, in particular a parent, for emotional and practical support with their condition while at college. One way or the other, peers were important factors to successful navigation of the campus experience, and helped participants develop social connections that made participants connect to campus and feel a part of campus life. This follows the pipeline narrative in the anti-deficit achievement framework as well. Peers were found to be significant influencers of college achievement, as mutually supportive relationships were found to keep students on track toward degree attainment.

***Significant Other.*** Another source of people support that four of the participants indicated were important was a significant other. In many ways participants indicated the significant other was one of the few people that had knowledge of all parts of their identity and their condition. They were also acknowledged to be significant sources of encouragement when school and their condition were particularly rough.

*My boyfriend, I've been with him since the beginning of college and he's actually back home and he's all I had for college in a time full of change and he completely gets my [condition] and knows what's going on (MWFN).*

*He's been with me since high school. So he knew something was wrong and I wasn't feeling good, and it was pretty serious about a year ago, so there's a lot of different tests that needed to be done, but yeah he had to be there for all that (HWFN).*

*It's nice because I don't have to explain everything to him because he already knows a lot. He helps hold me accountable to things like my blood sugar, or taking my insulin. I think having someone who I don't have to feel self-conscious around and someone who gets it, makes life easier (KBFN).*

At the time of the study, participant's relationships with their significant other were all described as long term. The length of relationship provided participants a sense of stability, but also gave the significant other time to fully understand the participant's condition and how to be substantial support. Significant others also saw participants as fully capable of navigating higher education and their condition, which may have reinforced the

participant's own beliefs about their ability to persist despite challenge. This ability to encourage the participant's to be successful led to increased optimism and agency, strengthening participant resiliency.

**Professors.** Participants in this study repeatedly acknowledged that professor reaction to their illness disclosure and decisions regarding accommodations made a significant impact on their academic success. It is however important to note participants did not make any distinction between professors, instructors, graduate assistants or adjuncts, but rather lumped all persons engaged in teaching into one professor category, so this study will refer to all teaching personnel as professors to match the data. Participants also never directly referred to professors as a go-to resource to ensure their success, but participants were clear that professors held the ability to make or break their semester. So even though participants did not directly view professors as a resource, their acknowledgment that a professor's understanding and willingness to work with them and the results of their condition, made professors a vital component to helping students overcome the risks associated with having a chronic illness and academic success. The quotes below emphasize that relationship:

*I definitely feel supported by all my professors that I've dealt with. They're easy going about my condition. So one time I missed the deadline to submit a paper because my migraine was so bad. So I emailed my professor at a time before class the next day. I was like, I know this is not like a regular thing, but I have the paper, I completed it. My professor was fortunately very understanding (KBFN).*

*She was like, I don't take attendance. You have two tests; make sure you visit the disability office. Everything else looks perfectly fine. I was like, wow, this is a lot less stressful than I thought it would be! It was wonderful because that was one of the things I was going to be more stressed about if I had to sit down with teachers and talk about what's going on. They were just so accommodating (AWFY).*

Supportive professors, as noted above, reduced stress and anxiety for some participants. In these cases professor understanding and accommodation also positively impacted the

participant's academic success, as they were able to miss class due to their chronic conditions without penalty. Having this supportive relationship encouraged resiliency for these participants as they navigated the sometimes unpredictable symptoms from their chronic condition that put them at risk of negative academic outcomes.

While professors were generally noted to be supportive, eight of the participants had stark recollection of a negative interaction that caused stress and need for additional action or disclosure, and where professors were often culturally insensitive to the chronic illness community or outright bothered by the student when support was sought. Within this situation participants exhibited self-agency and adaptability. When one path was hindered to their success, they decided on an alternate course and took action to make change. The quotes below are evidence of the interaction between participant's internal assets being utilized when they had a professor who was not acting as an external resource.

*Some professors said, yeah okay no worries, you take care of yourself. You can take your final when you get back or we will figure out how to do it. I had some teachers who were kind of, not unsupportive, but a little hasty about it. They were like, oh well if you're going to be gone for that long, maybe you shouldn't be in my class. But I would always assure them I was going to be successful, so I did whatever it took, even if it was stressful (CHFV).*

*If you tell a professor you're sick and they're like yeah right, you're just hung over and you didn't come to class. I guess if they have an attitude like that I'll tell them, hey, I have this disease. It's an actual thing. But if they don't say anything or are like, yeah, no big then I don't. I guess it just depends on how they respond to you. Like the guy I was telling you about, he gave me a big attitude when I decided to stay home sick the other day. So I might tell him I have it [...] and if they still don't respond the right way, then I'll go up the latter, but a lot of my other professors are really great (JWMY).*

The anti-deficit achievement framework connects faculty to persistence by their ability to enrich a student's educational experience inside and outside the classroom.

Findings support that students with chronic conditions turn to professors either proactively or

reactively expecting understanding and support. When that support is received, professors are a key resource in the resiliency of college students with a chronic illness, enriching their education, and helping them overcome the risk associated with their condition, which sometimes takes them out of the classroom or makes them unable to turn in assignments on time. When cultural insensitivity or lack of understanding is at play, professors may become significant factors in a student's failure to pass a class or graduate.

Overall, prior research indicates that social support is key to physical and psychological wellbeing (Ozbay et al., 2007). Some research even supports a physiological resiliency connection to social support and being able to moderate stress reactions (Karatsoreos & McEwen, 2013). The current results back these previous findings. For the current participants, people were really a key to their well-being and ability to navigate stress and discomfort. More explicitly people were often the ones who encouraged the participants to push through, even when their inclination was to quit. Participants who expressed high levels of positivity often had people in their lives who also were positive and optimistic. Participants also for the most part had people who encouraged their self-agency, and once in college allowed them to control their own destiny.

**Finding 4: institutional supports were a major resource.**

The majority of participants used services on campus and attributed those services or accommodations to their success. These services were critical resources for students to ensure their academic success, while navigating a chronic illness. However, participants expressed little to no attachment to the people who delivered those services, and participants did not view the person themselves as a resources in these organizations. It was the services

made available by disability services and student health that college students with chronic illnesses considered valuable in developing resiliency and overcoming negative risk factors.

***Disability Services.*** Seven out of thirteen of the participants used the Disability Center on campus as a means of receiving accommodations for their condition. While two of the participants signed up with the Disability Center upon their initial entry into higher education, the other five signed up once their condition made it challenging to navigate their school experience without support. For the most part, participants who waited seemed to believe that they were in enough control over their condition to not need accommodations. Considering the high levels of self-agency expressed by participants in this study, the idea they had control is not surprising. However, once they realized not everything was in their control, they took a realistic view of their condition, adapted to the situation, and enrolled. This is consistent with the idea that in the resiliency process, internal assets and external resources are often revolving together to overcome the risk at hand.

*So I decided not to register last semester because I kind of wanted to try not using some disability things I used in high school, to see if it would work. I had to realize that wasn't going to happen. I approached second semester and needed more time on my tests, and I wasn't doing as well as I thought I would be doing and I just need the accommodations (CHF).*

*There was one time I had to miss an exam because I had a migraine, and I like couldn't even see straight, it was that awful. So like I said, I registered at the Disability Center. So I emailed my professor and they're really understanding about it, and I just had to you know...Normally, like before I registered I would have to fight through it or I'm going to have to forfeit. Like it was either/or, there was no in-between (KBF).*

For the students who registered upon initial entry, several of them knew ahead of time that due to the nature of their condition they would need accommodations. For instance, due to one participant's condition, she knew she would have to have control the temperature settings in her room and access the disability bathroom with a chair in the shower, as

fluctuations in temperature could cause her to pass out (AWFY). Students who chose not to register with the Disability Center indicated that they did not need the services because their symptoms were either 1) not severe enough to need accommodations or 2) they were in tight enough control over their condition that symptoms did not cause any academic impact.

Despite not registering, all but one participant acknowledged they knew the services were available to support their condition if needed. In the case of those who used disability services, participant's use of the service was a key resource in overcoming the hurdles associated with their chronic illness, and even in the circumstance of those who did not use the services, the knowledge that the service was available if needed was a form of comfort. This in turn helped them to be resilient when their medical challenges threatened their academic trajectory.

*Student Health Center.* Nine out of the thirteen participants indicated they used some piece of the Student Health Center on campus. With the exception of two participants who had really bad individual appointment experiences, the overall perception of the Student Health Center and associated pharmacy was positive. The participants who had bad experiences indicated that those experiences were mostly due to working with inexperienced practitioners, who did not listen to their concerns. In those two cases there was a misdiagnosis and a delayed diagnosis. Participants used their personal agency to navigate what they perceived was a lack of concern and seek out other practitioners whom they felt had more knowledge of working with patients with chronic illnesses. However, these two experiences seemed to be the exception, not the rule. Participants mostly emphasized the convenience of access as the reason they viewed the center as a primary on campus resource

in helping navigate their condition on campus more easily. The participant's experiences with student health can be seen in the excerpts below.

*They [the student health center] have been super helpful. They have some good outlines or like some ideas about how to be realistic with college students that have diabetes, so I've found them to be the best (JWMN).*

*I think it's good the hospital is close. I like that you can get in quickly to have appointments. They definitely make an effort to hurry up and get you in fast or be responsive to your needs. I really like that because I could just wait until I get back to school. There was even a couple of times I could do same day appointments (KBFY).*

The accessibility of the service was of primary importance in this circumstance.

When a participant's symptoms flared, there was a risk of their condition impacting other areas of their life, including their education. The participant's ability to be realistic about their condition gave them the agency to make the decision to access these services. The ability to access healthcare and treat conditions that are not being well managed helped them overcome possible negative consequences. So while this resource is not the only resource participants used, it is clear that this resource is important to college going students with a chronic illness.

### **The Development of a Resiliency Model among College Students with Chronic Illness**

Resilience, researchers agree, is a complex process that is in some ways as unpredictable as the weather, and "is not a one-dimensional thing," says Arthur Reynolds, a professor of social work at the University of Wisconsin (as cited in Gorman, et al. 2005). Humans are led by a complex set of ideas and behaviors, so it is logical to assume resiliency would not be built in a simple linear fashion either. The same is true for developing resiliency with a chronic illness in higher education. Resiliency as a whole cannot be boxed in a linear manner. Participants have access to resources that in some circumstances allow them to develop internal assets. For example, strong family support can act as a resource that

allows those with chronic illnesses to develop a sense of agency, and in many instances in the data, those family members were actually encouraging development of self-agency.

However, the opposite also holds true. Sometimes the participant's internal assets created a resource seeking mentality. For example, participant's adaptability (self-aware, realistic) led students to seek out disability services, professors, family and peers when the going got rough. Those resources gave them the emotional or practical support they needed to overcome the risk associated with school or with their chronic illness. So really it is not one or the other, but it is a constant interplay of assets and resources that work in tandem in students with chronic illness that keep them building resiliency. In the model below internal assets (orange) are represented as gears that are constantly turning with external resource (blue gears). If one of the gears is removed, the resiliency process may not continue. The process can slow down or even cause loss of utility in another gear. In other words, without all four of these gears, the resiliency process for the participants is less effective and efficient and may stop all together. The outcome of resiliency is persistence through normal adolescent development, academic coursework and any associated medical needs.

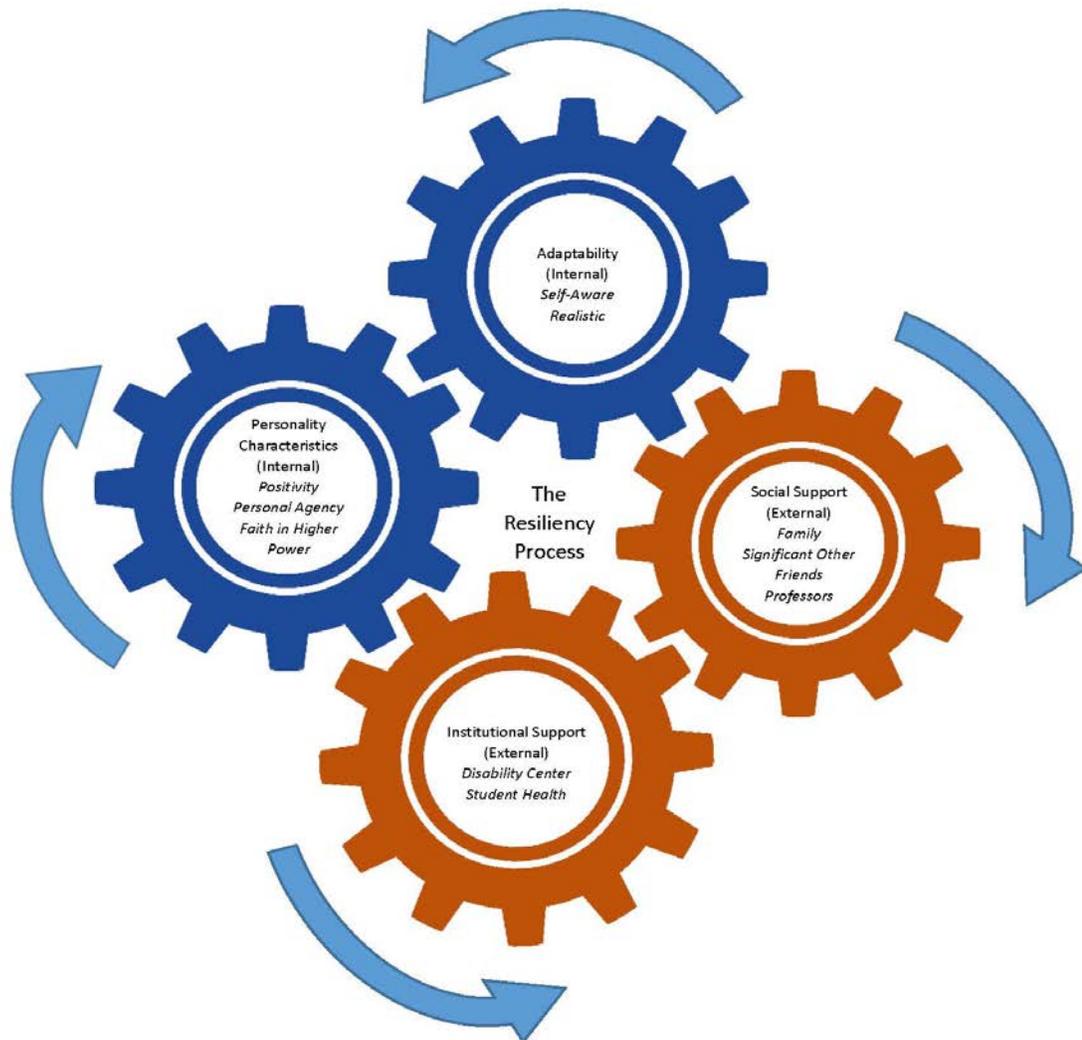


Figure 1

### Findings Regarding Intersectionality

Originally, based on previous literature on chronic illness, intersectionality was expected to be a fundamental component of access to resources. I assumed that intersectionality would be surface in the interviews and diary entries. Based on the demographics of the population being fairly varied, it was easy to assume that marginalization and privilege within the sample would affect student's access to

development of internal assets and external resources. However, the data in this study did not support substantial evidence of intersectionality at play in the resiliency process for college students with chronic illness. While I have no direct data as to why this was the case, especially when other studies found intersectionality to have a role in the success of those with chronic conditions (Dispenza, Varney & Golubovic, 2017; Helgeson & Zajdel, 2017; Etherington, 2015), there are several possibilities.

One, this is a small sample. Intersectionality is a complex interplay of factors that represent why some populations are marginalized and others are not. It is possible that with the small number of students in the participant pool, intersectionality, as it exists with these students, was not readily vocalized. When analyzing data I looked at factors of chronic illness compared to gender identity, economic status, first generation status and race, along with combinations of those factors (e.g. minority female vs. non-minority female). There were no distinct patterns that stood out indicating that one group or subset of groups had power or privileges not provided to other groups, and in fact it was surprising to me as the researcher how similar the experiences they described were, despite having different conditions, being of different races, genders, economic statuses and first generation statuses.

Secondly, using the anti-deficit achievement framework as a theoretical underpinning for developing interview questions may have led participants away from talking about ways they were either marginalized or privileged. A key tenet of the anti-deficit achievement framework is to develop a line of questioning that focuses on the student's strengths or their ability to overcome, instead of deficits. In this manner, the questions really did not explicitly ask about ways they felt they were either privileged or marginalized by their condition or other aspects of their identity. While the questions did cover a lot of ground looking at risk

factors and areas they felt unsupported, I did not ask if they felt oppressed in any manner related to their identity. In retrospect, this was an oversight that could have added valuable insight into this population's experience. This lack of direct questioning created a limitation in my findings.

The demographics of the participants themselves could also indicate a common form of privilege that is not clear to outsiders. The participants were all traditional college students; students who enrolled in college at the age of 18 and went directly from parent's house to residence hall. This in itself could minimize the differences in identity, as being supported by parents from high school to college is a form of privilege in itself that may mediate other marginalization. Ten out of 13 of the participants had already been diagnosed with a chronic illness prior to college. In order for a student to reach college with a chronic condition, it is likely to assume they are more highly resourced and set up for success than the non-college going population. Even though the United States touts higher education as being accessible by all, there are barriers set up to keep some of the most marginalized among the citizenship out. So it is possible that a student who overcomes barriers to enrollment in higher education may already have underlying assets and resources that mitigate barriers the general population with a chronic illness is unable to overcome. In this particular study for example, all students had access to insurance and regular healthcare providers, which is a privilege not offered to everyone in the United States. This topic would be an interesting area of exploration in future research.

Third, research indicates that sometimes the identity of the researcher can impact what participants volunteer. In qualitative research, the researcher cannot fully separate themselves from the participant and at times the participant identifies the researcher as an

insider or an outsider (Dwyer & Buckle, 2009). An insider is a member of the community being researched, whereas an outsider is not. The benefit of being an insider researcher is that participants are often more open to share their experience as there is a level of trust and openness due to perceived shared understanding. However, the drawback is that participants may make assumptions of similarity and focus on that experience and fail to fully explain their individual experience (Dwyer & Buckle, 2009). This may have been the case in this study. I disclosed my insider status with a chronic illness on the initial interview. While I cannot explicitly state that my disclosure of a chronic illness impacted participants, the data overwhelmingly focused on interactions with their illness, not other aspects of their identity where I would be perceived an outsider. The idea of insider/outsider status may have limited their disclosure of marginalization due to other aspects of their identity and could explain why intersectionality is not salient in the data.

Whatever the reasons may be, intersectionality is not readily apparent in the data from this study. That does not mean that it does not exist, as previous evidence suggest that populations with chronic illness often experience marginalization based on other aspects of their identity (Dispenza, Varney & Golubovic, 2017; Helgeson & Zajdel, 2017; Etherington, 2015). However, because there is no salient evidence of intersectionality in the data, I discuss intersectionality in the literature review and chose to remove the concept from my theoretical framework. I chose to spend little time in this study exploring the ways students with chronic illness fail or are underrepresented among degree earners, but instead chose to emphasize their ability to navigate the higher education world, while experiencing a chronic illness.

## Chapter 5: Discussion and Conclusion

The educational attainment and resiliency of college students with chronic illnesses are due proper attention and support in higher education research and practice. Prior research indicates that students with chronic illness graduate college at half the rate of non-ill college students (18% vs. 32%) (Herts, Wallis & Maslow, 2014). As graduation from a higher education institution is often a significant factor in future capital accumulation, matriculation is a far reaching issue for this population (Maslow, et al., 2012).

However, what little research that exists on this population typically explores failure points for these students (Herts, Wallis & Maslow, 2014; Kranke et al., 2013; Fedele et al., 2009; Adler et al., 2008; Sankey et al., 2006). Focusing on failure points is a reactive lens to understanding the population and does a great disservice to students as a whole. Not only does focusing on failure points put the emphasis on these students as destined to fail, but creates deficit stereotypes in the minds of researchers and educational leaders (Harper, 2010). Looking at where these students fail, while important to acknowledge, provides no clear answer to what assets and resources students have who are succeeding.

The present study took a new anti-deficit resiliency approach to uncover the lived experiences of college students with a chronic illness and learn how they are able to build resiliency during the higher education career. In order to truly uncover the participants lived experience, the phenomenological method was an appropriate match, as phenomenology looks at the phenomena to be studied by looking at sensory data in the participant's consciousness, and how that data rationally comes together to form knowledge about the world (Husserl, 1965). In other words, the phenomenologist never assumes that because they cannot see what the participant is describing that he or she is not experiencing

the phenomenon in another manner, namely through another type of sense. Phenomenology is particularly useful in this case because much of the student's experience with a chronic illness remains invisible, so in order to truly understand their lived world, one has to use a strong qualitative method.

The study began with hour long interviews at the beginning of the semester to explore the student's history, how they overcame barriers, their view of themselves, how they identified and what current assets and resources they viewed themselves as having. The exploration of history, achievement over barriers, assets and resources is in keeping with both the anti-deficit achievement framework and resiliency theory as it is important to know where students are coming from in order to understand their current experiences. Journals were also kept by the participants to record their experiences throughout the semester in real time. Last, student participants were interviewed at the end of the semester to debrief about the project and determine any additional insights about the student's experiences in higher education during the semester.

The sampling strategy used also attempted to develop a strong demographic mix of participants with a wide variety of conditions. The logic behind this strategy was to determine if patterns existed across demographics and conditions. If so, then it would more likely indicate a relationship that would hold true in larger demographics. Once data was collected, each individual set of data was coded using the resiliency framework as the foundation. After each interview and journal entry was coded for the participant, patterns were investigated across participants. Once these patterns were established, the patterns themselves were categorized into themes and placed into one of two overarching categories, internal assets or external resources.

The main goal of the study was to build an understanding of the internal assets and external resources used by these students to accomplish two specific goals. One, that the conversation around the population could be changed from one focused on deficits to an anti-deficit one, and two, so that educational leaders could develop proactive support programming that catered to the student's strengths and helped them capitalize on those strengths from the moment they step on campus.

The previous chapter presented findings of the study by organizing this data into categories that developed a readable narrative of the student's lived experience. The discussion below takes into consideration the limited research available on college students with chronic illnesses and in particular resiliency research for those with chronic illnesses. The implications of these findings will add to the understanding of how some college students with chronic illnesses are able to use assets and resources to build resiliency and continue on their educational trajectory when the vast majority do not.

### **Research Question**

This research study considered the following question within an anti-deficit achievement framework:

How do college students use assets and resources to build resiliency, despite navigating a chronic illness?

### **Summary of Findings**

A key part of resiliency, or the ability to adapt positively in the face of risk is dependent upon varying amounts of internal assets and external resources. Internal assets are characteristics and behaviors a person exhibits and could include personality traits, thoughts, attitudes, and values to name a few. In contrast, external resources are outside supports such

as people, services, and organizations. Four major findings emerged from this study, two in the internal asset category and two in the external resource category.

**Internal Assets.** Participants overwhelmingly shared certain personality traits and these traits were often referred to as a key to their successful navigation of college with a chronic illness. These traits included overarching positivity, personal agency and for about a third of the participants a faith in a higher power. In addition, participants indicated that their ability to adapt was useful when risk factors related to their illness or school arose. They most often credited their adaptability to self-awareness of their body and the environments in which they resided, but also to a sense of realism on what they were physically capable of completing. This allowed them to be flexible in action and decision-making. These internal assets were fluid and worked in tandem with external resources to build resiliency in the face of risk from their chronic condition.

**External Resources.** In addition to internal assets, participants identified two main external resource categories that were key to helping them overcome risk associated with attending college and having a chronic illness: social and institutional supports. The most common form of external resource mentioned by participants involved social supports. Participants credited a range of people as being key to their success in college while navigating their condition. Examples of people who were key supports were family, friends, significant others, and instructors or professors. Outside of social supports, participants also identified institutional support systems as the next key to overcoming risks associated with their condition and academic progress. Examples of institutional supports participants credited with helping them navigate college with a chronic condition was the disability center and student health. While participants did not directly identify people within these units as a

support system, they acknowledged the services provided were vital to their success. These services and resources often supported them practically, but also with encouraged the development of positivity, personal agency and adaptability, displaying once again a connection between the internal and external in development of resiliency.

### **Recommendations for Scholarship**

#### **Personality Characteristics Strongly Connect to Resiliency Development.**

Analysis identified several personality characteristics that appeared to facilitate the development of resiliency and navigation of risk. The leading characteristic that appeared to support student's ability to build resiliency is positivity. All participants indicated some level of positivity in their ability to navigate their condition and higher education.

While there is limited research on positivity and the college going experience for student's with chronic conditions, several scholars have identified positivity and humor as adaptive strategies for navigating adverse conditions (Ford, Lappi & Holden, 2016), and for managing chronic conditions (Coyle & Atkinson, 2018; Livneh & Martz, 2014). A growing body of research shows that personality traits are the most important measures of positivity, and as Ford, Lappi & Holden (2016) brought out account for overall well-being and navigation of life than demographic and quality of life. The authors go on to point out that two related constructs, humor and optimism are positively correlated and these characteristics tend to stay over time, in other words, they tend to be used as overall outlooks on life, even when negative circumstances arise. The research in this area backs the findings of this study, which found that students described themselves overall as positive people, and that their positive outlook and tendency toward optimism and humor helped them navigate difficult circumstances.

Despite some previous research that helps substantiate the findings of the present study, the qualitative data collected here takes current research a step further. For example, Abraido-Lanza, Guier and Colon (1998) did find that positive affect of Latina's with chronic illness promoted positive well-being, but was limited to the Latino population and did little to explain how the participants in the study used positive affect to navigate their condition. The present study provides an in-depth picture of how participants thought about themselves, and how their positive viewpoint helped them to navigate the sometimes unpredictability of their condition and higher education. The current research study indicated that positivity was inherent to the participant, but was reinforced or nurtured by external forces.

Previous research emphasizing a strong connection between chronic illness and negative self-concept were not supported by the current study. Olney & Brockelman (2005) argued that the nature of invisibility of adolescents chronic conditions cause negative self-concept. Balfe (2007) also emphasized that young people with chronic conditions so often experience discrimination and rejection that they negatively view themselves as individuals, but also negatively view their campus interactions. The current findings provide evidence that research on college students with chronic conditions warrants a resilience/anti-deficit approach into how college students view themselves on campus. Participants overall viewed themselves and their campus experience positively, despite navigating negative experiences during the educational path, but these were minimal compared to the strengths and positive experiences they expressed. During difficult junctures participants emphasized they used this positivity to help them bounce back from any type of negative experience. In reality these participants admitted coming into the institution with a positive optimistic frame of mind.

However, personality characteristics on their own were not the only component of resiliency development found in this study.

**Self-Agency.** In addition to personality traits, development of self-agency was found to be a vital skill to the development of resiliency for college students with chronic illnesses. Not a personality trait, self-agency is a belief that one is capable of bringing about a specific outcome, and by one's actual skill (Bandura, 1997). Participants in the current study described many examples of agency during their time in higher education. Self-agency allowed them to believe they could overcome any negative risk when it appeared and take concrete steps to allow them to change their navigation in the face of uncertainty.

There is currently no discourse found in the course of this research study that has studied the personal agency of college students with chronic illnesses and resiliency. However, there is significant research that explores personal agency, and psychological well-being (Moore, 2016; Kotan, 2009). More limited research in medical management also found that participants with self-agency were planning their lives consistently in order to create a semblance of order out of conditions that were sometimes difficult to control (Koch, Jenkin & Kralik, 2004). Prior research conducted by Thoits (2006) found that personal agency in the stress process lowered psychological distress. She argued that people with more agency may have higher levels of well-being because they construct their lives in order to eliminate or dampen the effects of stressors or seek social support to bolster their endeavors. Her argument is in line with the current study as participants frequently used agency to minimize or eliminate risk factors to their health and academic progress. Smith, et al (2000) found similar results in their study that explored the relationship between personal agency, perceived control and psychological well-being. This study was originally conducted on 482

adults with age related conditions. What is new in their approach is they found that social support had a strong influence on sense of agency.

Welzel & Inglehart (2010) also identified the connection between agency and social interaction. In their article they acknowledge that much of agency is socially constructed. In other words societal ideologies dictate limitations on humans and as humans understand what is socially acceptable their capacity for agency unfolds. What makes the study slightly different from previous research is that they look at the intertwining relationships between self-agency, socialization and value systems on human development and motivation.

The ideas in Smith et al.'s (2000) and Welzel and Inglehar's (2010) study supports the earlier argument of the present research which is that self-agency and external support are intertwined and there is no clear way to separate the two. What makes the present research stronger is in-depth qualitative data from participants into how those variables interact and how agency connects to a college student's ability to navigate risk at the physiological and academic levels and build resiliency. The current study also extends Koch, Jenkins and Kralik's (2004) study, which hints at the idea of resiliency, without directly naming the experience, by exploring in great detail the ties between health management of a chronic condition and its connection to agency, in addition to other variables.

**People and Institutional Resources.** The current research study emphasizes the important role people and institutional resources play in the success of college students with chronic illnesses. For example, this study adds to the current discourse that patients with chronic conditions are benefited from having social connections (Coret, et al, 2008; Kralik, van Loon & Visentin, 2006). The current study also backs the findings of Wodka & Barakat's (2006) study which found that family support was key for college transition for students with chronic illnesses, and that those families can act as a protective factor for coping in light of additional stressors. These protective factors are key for building resiliency in the college student's lives.

The current study also brings to light the importance of institutional resources to the success of college student's chronic illness. The discourse connecting healthcare services and college student matriculation is severely lacking. One study conducted by Lemly, et al (2014) surveyed college health services across the country and the only consistent finding was that services were severely lacking. The current study findings suggest that adequate access to healthcare services plays a strong role in academic progress and physical well-being of students with a chronic illness. The focus on disability service offices and college student success is under slightly more focus in the literature. Herbert, et al (2014) and Fichten, et al (2013) both found that academic and matriculation outcomes improved for students with a connection to disability services.

What the previous research lacked was an understanding of how people and institutional support services actually supported students with chronic illnesses on campus. Participants in the current study often described key people and institutional resources working hand in hand with other resources and internal assets to help them build resiliency.

For example parents were often a key driver of a student's development of agency. That agency led to student's resource seeking behaviors when risks arose. So the current study adds additional implications for research and highlights the need to fully understand the complex lives of college students with chronic illnesses.

**Reflection as Intervention.** One interesting outcome of this study's research method was the participant's extremely positive response to the design of the study. All twelve of the ending participants reported positive views of the project. Students in particular were openly fond of the journal questions throughout the semester.

*I liked all the prompts. I thought they were all helpful. I also liked how you included that you could talk about something else. It was nice to reflect on my illness, and then think about the things going right, the things going wrong, and be able to express my feelings about it (CHFV).*

*I like the idea of journaling, because even if you only do it once a week, you can look back and reflect on your mindset, and it's easier to see your progress in words (KBFY).*

In the final interview, students indicated that the course of the project and reflection associated with the project allowed them to sit and reflect on their experience. This reflection resulted in positive outcomes and even a change in perspective for participants. Some of those experiences are highlighted in the quotes below.

*This study actually helped a lot with figuring out how my identity connects to my illness. I've never been asked about my condition before and never really had to articulate how it affected me, beyond that I'm a diabetic and it's part of who I am. Do I think that's [the reflection] helped me navigate my condition better (BBFN).*

*The reflections were something really different because I never really think about half the things that were asked. I never really stopped to think about how these things affect me or even my friends or situations, so I thought it was really interesting to see how it affects me because then it would lead me to think of what I can do with that. You know, like what kind of friends am I looking for, and I never put that together. So it was really nice just to be able to stop for a couple of minutes and just connect a couple of pieces together that I never thought about (HWFN).*

Some participants even made changes in their behaviors or planned to make changes due to their reflections.

*I wish something like this would have been done before I moved here; it would have provided a better basis for me to get to the spot I needed to be sooner, than taking an entire year to figure it out. [...]. These journals kind of helped me to realize, this is not just something people are telling you, it's something you need to focus on. I was just kind of avoiding things as long as I could, but these journals forced me to think about things and helped me make better choices (JWMY).*

*It helped me see how far I've come and how far I have to go, but it also reinforced the idea that I want to reach out to other people who struggle with the same situation (KBFN).*

What initially was a reflection of participant experiences and an acquisition of knowledge, ended up for some students impacting their end of semester outcomes. The idea of reflective practice connected to learning was developed in the early 1980's by Schön (1983). His theory postulated that learning occurs by experimenting with reflective strategies to overcome problems and builds the individual's domain specific knowledge necessary to complete prescribed activities. Despite Schön's work being theoretically based, research backs up positive outcomes associated with journaling or reflective practice. Wilkes and Jackson (2012) point out that journaling often leads to deep learning, problem solving and clinical reasoning, and are often successful methods for identifying healthcare interventions. The participants in another study on managing chronic conditions found completing entries in an incidents diary was a useful tool to reflect on self-care (Ravert, Russell & O'Guin, 2017). In higher education research, Clegg (2006) found that reflection allowed graduate students to produce valuable insights about academic life and was a tool for in-depth knowledge production.

Overall, the results of this study indicate that approaching research of this population through an anti-deficit achievement lens can be an extremely effective approach to understanding student's lived experiences with a chronic condition. Adding reflective

practice to the research methodology is also a significant way to have participants reflect on their experiences and participate in the knowledge creation process. As indicated from participant quotes above, a research methodology with required reflective components sometimes helps participants develop a better understanding of themselves and be able to articulate their experiences, providing high levels of qualitative data.

The dominant discourse surrounding college students with chronic illnesses is one filled with deficits (Devine, 2016; Agarwal, Moya, Yasui, & Seymour, 2015; Lombardi, Kowitt, & Staples, 2015; Oswald, Huber, & Bonza, 2015; Sniatecki, Perry, & Snell, 2015). In fact deficit modeling in schools has dominated the research conversation since its inception (Valencia, 2010). The deficit mindset of exploring student populations, especially those underrepresented in higher education, is being challenged in this study. What this study has emphasized is that there is much to be gained by exploring this population through an anti-deficit achievement and resiliency lens. Not only have these frameworks uncovered internal and external factors possessed by these students, but helps us understand, from their own mouths, how they use these factors to navigate risk and build resiliency.

It is time to make a theoretical shift. Researchers have spent years deficit theorizing college students and marginalized populations in general. Increasingly scholars are beginning to recognize a new path that doesn't rely on existing theories and conceptual models that repeatedly look for failures, but instead use models like the anti-deficit achievement model to reframe lines of questioning in research to deliberately attempt to discover how students succeed (Harper, 2010). It is a new way of understanding how the world works, but one that is beneficial for both the participants, who are able to explore their abilities to navigate the

world, but also educational leaders and practitioner, who develop a more positive view of college students, especially in marginalized populations.

However, in making these recommendation, it is important to take a moment and recognize some of the areas this study did not incorporate, but may limit its applicability to the general population. The sample for this study consisted strictly of volunteers who responded to flyers and the campus bulletin, thus the study may have self-selection bias which could limit the generalization of results to the population of students with chronic illnesses. This study's use of the anti-deficit achievement and resiliency framework does create limitations in research design. With this combination of theoretical background, questions, while semi-open-ended, are geared toward looking at specific aspects of student's lives and questions are framed from an anti-deficit approach. While I am a large advocate of this way of research development I also acknowledge that using this approach will not provide an in-depth view of marginalization that students are experiencing, as was the case in this study. It also makes it slightly more difficult to understand if students are treated differently based on other pieces of their identity.

Secondly, this study was a phenomenological study of 13 participants in higher education in one university. The demographics of this sample were also limited in some areas. The study ended with only one male participant, which limits conclusions that can be drawn for college students with chronic conditions identifying as male. In addition, participants were all what are considered in academia as "traditional" college students or students who came directly to college from high school and were still dependents of their parents. Last, but not least participants were selected from a large public, highly resourced university in the Midwest. Some of the key areas students pointed to, such as the disability

center and student health, are easily accessible and fairly decently funded. The university hospital system is in walking distance from most dorms and there are systems in place to work with students to meet all healthcare needs. I recognize that this in itself is a form of privilege not extended to all college students with chronic illnesses. So even though there were strong consistencies in describing their experience, the experiences of the sample in this study may not broadly apply to the entire population.

Future studies on this population are necessary to develop a deeper understanding of the lived experiences of college students with chronic illnesses. In light of the limitations of the study, the following should be considered in future research:

1- A further study using the same criteria should be undertaken among students represented in this study, but also looking for samples of diverse demographics, with a special focus on recruiting more males to the study. It would also be beneficial to consider doing a multi-site study with institutions that serve non-traditional student populations.

2- Since the current study operated on the idea that intersectionality would exist in the population, but did not explicitly ask about marginalization related to race/gender/income status, it would be beneficial to take on this topic once again. Future studies could take a more deliberate approach to exploring whether race, gender or income status make a difference for students with chronic illnesses.

3- Based on the limitations of the current study, it is proposed looking at this population through grounded theory. Grounded theory is a theory which is inductively derived from the phenomenon it represents and meets four central criteria: fit, understanding, generality and control (Strauss and Corbin 1990). Developing theory that meets the fit of the

data may uncover new insights and prevent the research team from leading participants in a particular direction during the interview process.

4- During the initial advertisement of the study, there was a great deal of interest expressed by graduate students in participation. For this study, graduate students were excluded, but it would be worthwhile to apply this study's methodology for the graduate population.

What is clear from this study is that this population has a great deal to contribute to practitioner and researcher understanding. Practitioners need to actively be seeking resources on how to better serve college students with chronic illnesses. Researchers also clearly need to put greater emphasis on making sure these students are adequately represented in higher education discourse by continuing to study the experiences of this group.

### **Recommendations for Policy**

One of the major resources that participants routinely pointed to as a key to success was having access to medical personnel and pharmaceutical access. In addition, participants commonly pointed to the benefits of having good insurance as key to being able to treat their condition appropriately. They also connected high quality insurance to the ability to afford investing in higher education. At the same time as this research study emphasizes the important connection between degree attainment for students with chronic conditions, Americans are increasingly struggling to access the health care system. Currently, close to 40 million people lack basic health insurance coverage, and this number is growing (CDC, 2017). Not only are some people losing their insurance coverage, but the size of uninsured in vulnerable populations is growing. Since it is clear that access to healthcare is vital for

college students with chronic conditions, higher education needs to take a stand in promoting access to all students in higher education.

At the local level, colleges and universities need to create policies that help improve access to healthcare services for their student body. While the focus of this research is college students with chronic conditions, students in general face a wide variety of complex physical and mental health needs (Skorton & Altschuler, 2013). Student health centers focus on the well-being of campus and contribute to a safer overall campus. College health centers are often times the most accessible care for students as well, when regular health services are difficult to obtain an appointment. This point was made clearly by several participants who found the ability to make an appointment and see a practitioner in the next day or two extremely valuable supporting their condition when it was medically hard to control. However, educational leaders need to invest significant resources into the student health center. It is well known that preventive healthcare leads to better overall outcomes, but if there are not significant staff available to see students, or if services cost, it may lead students to not seek these resources out until there is significant health risk.

There is also disconnect between most universities' disability policy and actual implementation to support those with immunological disabilities. At the institutional level self-identification is the first step to requiring the university to make reasonable accommodations as required by federal law. However, the concept of disability and chronic illness is still hazy as seen in the current study where faculty made references to the student not looking sick or not really being sick, but just hungover. Even among students themselves, they may feel their condition does not warrant disability status, thereby limiting the accommodations and services they could receive to support their academic endeavors and

well-being. One study participant even indicated they avoided use of services due to feeling they were not really disabled. Lack of disclosure contributes to the invisibility of chronic illness on college campuses and reduces opportunity to represent their experiences in higher education. One policy change that could improve access to education for students with chronic illnesses is making flexible class formats available. A combination of in-seat, online and self-paced courses would allow students who need flexibility to choose the level they feel can ensure their success.

At the national level, higher education leaders and institutions can no longer stay out of the conversation around universal access to health insurance and healthcare. While there is not a great deal of data that investigates the number of students dropping out due to healthcare issues, a recent study done by LendEdu (2018) found that 11% of the 1000 college dropouts polled left due to health reasons. If this number is remotely accurate, there are a significant number of students whose health is impacting their ability to graduate, and higher education institutions should be working with policy makers at the national level to extend access of healthcare to the college level. It was made clear by participants in this study having medical access was vital, and each had access to health insurance that allowed them to participate fully in needed medical care, but what of those without medical access? While there are some metrics in place by the federal government to expand access (e.g. the ACA), loopholes and the ability to opt out of options intended to be mandatory have essentially gutted the original intent of the bill, so more is needed. The United States needs to work toward a universal system of healthcare that is currently successful in much of the developed world. Universal access to medical care would give all college students with chronic illnesses support no matter their ability to pay.

**Recommendations for Practice**

Within the present research study, there are several implications for practice that are useful for practitioners and educational leaders to take note of when interacting with college students with a chronic illness. First, students take note of experiences, both negative and positive in interactions with individuals on a college campus. Participants biggest issue overall was wanting to be believed by those to whom they disclosed. They also did not want sympathy for their condition, but more so a willingness to listen to their needs, even when those needs did not present themselves physically. Over and over again, participants wanted to be valued for their contribution to campus and looked at as giving their all to finish their degree. This idea flips the discourse of discussing this population in higher education to one that is resilient and anti-deficit.

The benefits of a new anti-deficit achievement approach is staff who think more futuristically about student needs, but that thinking is based on time taken talking more and listening more closely to students with chronic illnesses as needs are fluid and constantly evolving. When practitioners listen closely to students and actively listen for ways to improve support, they also educate themselves. Increasing knowledge of better ways of practice at the individual level can impact students at the campus level, thus improving support for more than just those students with chronic illnesses. Just as important, there is a higher payoff to supporting or serving students proactively as they are less likely to find themselves in situations dire to their academic success because they already understand what resources are available and have the skills and understanding to access those resources.

One of the major objectives of this study was allowing participant's voices to be heard. Thus, an effort was made to identify recommendations participants felt should be

made in practice to improve overall support for their population. Although participants overall were very positive about their institutional experience, ten of the thirteen participants had minor suggestions for institutions to better support students with chronic illness. The most common suggestion was to improve communication and education about students with chronic illnesses on campus. Two participants also advised the institution to do better connecting students with chronic illnesses together socially. Several students felt like educational leaders and faculty did not take chronic illness seriously because it was a non-apparent condition. The quote below emphasizes this perception.

*I feel like awareness wise, they harp on anxiety, suicide, and depression. All of that makes sense, but there's a good majority of the campus that are struggling with a bunch of other chronic illnesses. I feel like professors and administrators don't really get the knowledge of and they don't take into consideration for some things. I feel like some of my friends who have bad ADD, they have opportunity to take an exam at another place to another time, and for me that didn't really take that into account, because it's like when you don't have a problem concentrating, you just take it with everyone else. I guess the gap is between the administration and the professors just like the policies. The syllabus runs down everything in they're like well if you qualify for the ADA, we can work around your accommodations, but they have to put that in there. I think that's just the problem that I've experienced, which is really frustrating from my point of view, but I don't know if there's really any room for improvement. Especially for what I have. I don't know how many other students have it, so I feel like they just can't hone in on people who have [my condition] (RWFN).*

*Just like to make that effective, there needs to be effective communication too. So they need to make it clear to their student, who probably doesn't feel comfortable talking about it, I would imagine, that they can share it with them, and then they can communicate back with them about their condition and needs without being super uncomfortable about it. (JWMY).*

Additionally, two other participants said that communication about the disability center on campus was lacking and that some students were not aware of how the center could support that condition. Participants felt that emphasizing the benefits of the disability center early on could help students seek the resource sooner. For example, participants indicated a more thorough coverage of the disability center's benefits in the ADA syllabus statement the

first week of class could be a good place to start communicating services. In addition, as the disability center is one of the primary means of communicating issues surrounding chronic illness to staff and faculty, disability centers should consider offering more comprehensive training on working specifically with students with chronic illness. For campuses where the disability center is not offering such trainings, staff, faculty or administrators could request training opportunities or offer to work together to build such opportunities to improve understanding of chronic illness on a college campus. These educational opportunities could improve the cultural responsiveness of practitioners when working with students with chronic illness, creating a more inclusive campus.

The next most commonly recommended suggestion was to work on making the campus more accessible to students with chronic illnesses. Part of that recommendation was also focused on educational leaders and faculty educating themselves on what accessibility really means. Participants felt that with that education would come an increased understanding toward students with chronic illnesses. One participant pointed out a need she had that is not typically thought about.

*There's nowhere to put needles that I can see really. A residence hall had one in one of the bathrooms, but otherwise I can't just carry around a bag of used needles. I can't just put it in a trashcan because of the needles because someone could get poked (RWFN).*

Another participant really honed in on the educational piece of making campus accommodating and the fine line between knowledge and prying:

*I think educating professors better on how to handle students with chronic illnesses and not needing to know every single detail about type 1 diabetes or Crohn's or, you know, whatever illness it may be, but like knowing that they exist and they're like legitimate things that will impact students and their coursework at times (KBFN).*

A third consideration is making the college environment more inclusive of the support systems of students with chronic illness. Participants overwhelmingly referred to family as their number one support system. Educational leaders and practitioners could find additional ways to connect to family by offering opportunities to participate in activities on campus with their student, but also could keep families informed on campus happenings, without violating FERPA. For example, newsletters on campus events, student achievements, and tips on supporting students on campus could be a cost effective, efficient way to make families feel included and valued on college campuses. This in turn will enable families to offer even timelier, effective support during the semester.

In short, participants were overall happy with their higher education experience, but when asked to offer advice gave simple areas for improvement. While physical accommodations on campus could require facility investment, the most commonly emphasized suggestion was really to do with educating people and communicating more broadly. First, and most simply, training on working with students with chronic illnesses should be done with all faculty and staff. This training would not be necessarily about working with particular conditions, but an overall training on active listening, accommodations, and recognizing stereotypes and biases that impact student well-being. Practitioners and educational leaders can be at the forefront of making those investments in accommodation and communication to improve the educational experience for students with chronic conditions, but these changes would also improve the experience for campus at large.

### **Conclusion**

In conclusion, I hope that I have generated a desire to know more: more information, more stories, and that desire will generate interest in continuing research in this area and give

insight to those contemplating new directions of inquiry for this population. With more and more children with chronic illnesses reaching adolescence (Maslow, Haydon, McKee & Halpern, 2012), this group is now seeking additional educational opportunities in higher education institutions. These higher education opportunities often also lead to future career opportunities and capital accumulation. As college students with chronic illness experience additional risk in their educational career outside of the non-ill student, it is important for educational leaders to understand how these students navigate their educational endeavors. Understanding their assets and resources will enable higher education institutions to help this population capitalize on their strengths to ultimately improve retention and graduation rates. This new strengths or anti-deficit based understanding also enables higher education institutions to identify any structural barriers that exist for students with chronic illness and provide them an opportunity to remove those barriers.

This study was really a collaborative effort between myself and the participants. These participants willingly gave of their time and energy to share their experiences with us and put sometimes even sensitive information out for the world to view. While the participants reflected on their learning process, I learned as well, which reminds me of the saying that the “student becomes the teacher”, and so as I close, I want to express gratitude for all the participants, who taught me so much over the course of this project, and hopefully you, as the reader, are just as inspired.

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**Appendix A: Sample Questions for Initial Interview**

- 1) Tell me a little bit about yourself.
  - a. If you were to describe yourself to someone you were going to meet, how would you identify yourself (e.g. focus in pieces of identity they would want to share)?
- 2) Why did you choose to come to Mizzou and did your chronic illness impact your decision?
  - a. Expand, if necessary, on whether anyone else was involved in the decision making process? If yes, did the other person consider your chronic illness as a factor in school selection?(Try to get as much detail as possible on their process, if they looked up information about the school, did they visit the school beforehand, who did they talk to on or off campus)
- 3) What would be your ideal job after graduation? How did you make that decision? Was having a chronic illness a factor in that decision?
- 4) Tell me about your experience navigating Mizzou with a chronic illness so far, positives, negatives, etc.
  - a. Is Mizzou's environment supportive to students with a chronic illness?
    - i. Dig to see if participant feels supported as a student/as a student with a chronic condition
    - ii. In your opinion, are there things Mizzou is doing well and are there any areas that need improvement (services, curriculum, policy, etc) in serving students with a chronic illness?

- 5) Have you experienced any challenges so far in being at Mizzou? (related to or not related to the chronic illness)
  - a. If student answers yes, how have you dealt with those challenges?
  - b. Is there anything in your prior experience or background that helped you deal with those challenges?
- 6) What are some of the resources you've used at Mizzou so far (related or not related to the illness?)
  - a. Depending on students answer, dig into why they decided to use the resources they did.
- 7) What kind of personal attributes do you think you possess that have helped you while in school and navigating your chronic condition?
- 8) Depending on the answer to question 4) dig into whether answer in question 5 or 6 helped them to deal with the challenge.
  - a. Did any of those challenges change your outlook on school or the way you do school?
- 9) Is there anything else about you, your experience at Mizzou, or the resources you've used that I haven't asked about, but you feel is important for me to know?

**Appendix B: RSA Questionnaire**

The factor solution for the non-clinical sample showing the distribution and loading of items in the five dimensions;

1 = personal competence, 2= social competence, 3= family coherence, 4= social support, and 5= personal structure (N = 276)

Dimensions:

1)

I believe in my own abilities

Believing in myself helps me to overcome difficult times

I know that I succeed if I carry on

I know how to reach my goals

No matter what happens I always find a solution

I am comfortable together with other persons

My future feels promising

I know that I can solve my personal problems

I am pleased with myself

I have realistic plans for the future

I completely trust my judgements and decisions

2)

At hard times I know that better times will come

I am good at getting in touch with new people

I easily establish new friendships

It is easy for me to think of good conversational topics

I easily adjust to new social milieus

It is easy for me to make other people laugh

I enjoy being with other people

I know how to start a conversation

I easily laugh

It is important for me to be flexible in social circumstances

I experience good relations with both women and men

3)

There are strong bonds in my family

I enjoy being with my family

In our family we are loyal towards each other

In my family we enjoy finding common activities

Even at difficult times my family keeps a positive outlook on the future

In my family we have a common understanding of what's important in life

There are few conflicts in my family

4)

I have some close friends/family members who really care about me

I have some friends/family members who back me up

I always have someone who can help me when needed

I have some close friends/family members who are good at encouraging me

I am quickly notified if some family members get into a crisis

I can discuss personal matters with friends/family members

I have some close friends/family members who value my abilities

I regularly keep in touch with my family

There are strong bonds between my friends

5)

Rules and regular routines make my daily life easier

I keep up my daily routines even at difficult times

I prefer to plan my actions

I work best when I reach for a goal

I am good at organizing my time

### Appendix C: Weekly Journal Prompt Sample

Participants are not required to write about these topics, but it is suggested they reflect on them as they do their weekly response:

Key to resiliency competencies:

Blue= Personal Competence

- 1) When you think about your future, describe where you see yourself in 5 years?
- 2) Describe a time this semester where you've faced a challenge. What got you through the challenge and how confident were you that you would be able to face the challenge?

Pink= Social Competence

- 3) Describe for me a new person you've met this semester. How did you first meet them? What was the setting? Did you connect with them on any particular level and do you plan on maintaining this relationship?
- 4) What has been your experience with socializing on campus this semester? Please share a story from the semester where you've socialized with others.

Yellow= Family Coherence

- 5) What role has your family played this semester in your college experience and can you share a specific example?
- 6) What are some of your family traditions, activities (cultural or otherwise) that you particularly enjoy and have you been continuing those activities/traditions since you've been on campus?

Green= Social Support

7) Who are your go to people this semester when you need someone (crisis or support), and why did you choose those particular people?

8) Who are the people on or off campus you've shared your diagnosis with, since arriving at Mizzou? Why did you choose those people and how did you decide how much to share?

Orange= Personal Structure

9) Describe any rules and routines you've followed this semester to make daily life more navigable.

10) Reflecting on the semester, have there been any times that your routine has been thrown off (due to the chronic illness or something else) and has that affected your health/academics?

### **Appendix D: Post Interview Sample Questions**

Final interview questions may be tweaked depending on patterns found in the initial interview and semester data

- 1) First off, can you provide a snapshot for me of some of your highs and lows this semester with completing school and having a chronic illness?
- 2) On times when there were challenges dealing with your illness or not, what were some of your go to methods for navigating those challenges?
  - a. Were there any resources/people specifically at Mizzou that were helpful at navigating challenges?
  - b. Were there any challenges you felt you weren't able to navigate as successfully as you wanted to?
  - c. Was there anything you would have done differently now looking back on those challenges?
- 3) What personal attributes do you believe helped you navigate your chronic illness this semester? Can you provide an example?
- 4) How did you feel about reflecting on your college experience with a chronic illness over the course of the semester?
  - a. Did reflecting on your experience change your actions or feelings about your ability to overcome challenges?
  - b. Did reflecting on your experience change your view on completing college with a chronic illness?
- 5) Reflecting on this semester: how do you feel Mizzou/your department does supporting college students with chronic illness?

- a. Prompt for support on living, academics, policy, etc.
- 6) What recommendations would you make to the University to improve support for students with chronic illness? (Encourage them to be specific)
- 7) Is there anything else you wish to share about the semester, the project or ways students with a chronic illness can be supported by colleges and universities?

**Appendix E: Participant External and Internal Factors**

Table 3

External Factors

Participant	Disability Center	Student Health	Friends	Professors	Family	Significant Other
KBFY		X	X		X	
JWMN	X	X	X	X	X	
KBEN	X	X	X	X	X	X
CHEN	X	X	X	X	X	
BWFN		X	X	X	X	X
HWEN		X	X		X	X
AWFY	X		X	X	X	
EHFN	X		X	X	X	
MWFN			X	X	X	X
JWMY	X	X				
RWFN			X		X	
AWFN		X	X	X	X	
BBFY	X	X	X	X	X	

Table 4

Participant	Positivity	Comparative Optimism	Dispositional Optimism	Agency	Faith in a higher power	Adaptable	Realistic	Self-Aware
KBFY		X	X	X	X			X
JWMN			X				X	X
KBEN	X	X	X	X	X	X	X	X
CHFN	X	X	X	X			X	X
BWFN	X	X	X	X				X
HWFN			X	X		X	X	X
AWFY	X		X	X	X			X
EHFN			X	X	X			X
MWFN			X	X			X	
JWMY		X	X	X		X		X
RWFN	X		X	X				X
AWFN	X	X	X	X		X		
BBFY			X	X	X			X

Internal Factors

## **Appendix F: Sample Transcript**

**The first thing is just can you tell me a little bit about yourself your family and where you're from.**

My name is K; I'm from New Jersey. My parents are divorced I live with my dad and my older brother is 22. He is a senior in college at the This University of South Carolina. I am from New Jersey so this This University was not really on my radar at all. I had never really heard of it. They offer a pre-veterinary program, and I want to go to vet med. I got into the early acceptance program for the veterinary school so there's about 20 or 30 of us here that are in this program. At University, if I maintain a certain GPA automatically be admitted to University's veterinary school. After that, I was still unsure about this University. I also picked it because after I heard about this This University I was granted a full ride scholarship so all my expenses here paid for my food, my tuition, my books and my travel. It has been a huge blessing and it made pick this University.

**So was this a competitive scholarship or was it like an automatic scholarship?**

It is a new scholarship that this this University just started to offer. It's a national scholarship that is offered at over 40 universities. The family, the Stamp family, they're just passionate about funding kids' educations. There's a whole application process. I think there was about 500 of us that applied. We flew down for a weekend. I made the top 25. We flew down for interviews and did luncheons over the weekend and got to know this University. Then I made the top five, and then I got a scholarship.

**What were the initials qualifications to be able to apply?**

Initial qualifications were to have a certain GPA; a certain ACT or SAT score, a resume with bios and a long essay. The essay question, if I remember correctly, was what your dream and how are you going to achieve it through having the Stamps education?

So that was exactly a year ago. This weekend the next round of Stamp scholars are coming to campus. We are going help interview tem, meet them and show them around campus.

**Were you a part of the first cohort of Stamps' scholars?**

Yes. The Stamp family follows 40 universities and this year they picked This University as their next school.

**On that initial weekend, when you flew in here for the first time, what did you think about University?**

In all honesty, I liked this University. I didn't really know the extent of the scholarship that I was would be receiving and it was a big deal. I didn't realize how much it would change my life. I didn't realize that I wouldn't have to pay for college and it didn't really register in my mind. I wasn't exactly set on University. I didn't think I would get it, first of all and secondly, I just kind of picture myself going to East Coast school because, I'm from the East Coast. I really didn't see going a thousand miles away. Maybe a couple hundred, but not 1000. I did like the campus and the people. Once I received the scholarship I came back. I because I should obviously use the best financial resources but it should also picked the school that I

love. I came back the second time, and I fell in love with the school. I'm so glad I am at This University, because I love it here.

**Financially, it sounds like it was a big impact on her decision. Did the condition that you have play any sort of factor in what school you're thinking about going to?**

It did. My senior year, about 14 months ago, I had major brain surgery. I missed 3 1/2 months of senior year. I missed a decent amount of school and I was recovering from brain surgery. There were some complications and it just didn't go the way they plan. So I sat down with my dad and he suggested maybe it was it's best to go to Rutgers, TCM J or Penn State, somewhere if something were to happen, my dad could be there in just a few hours. Part of me didn't really want that.

With the scholarship that I had a new what a great opportunity it was. I knew I should be going somewhere that I am going to get a great education. I'm part of this great Stamps program, but there was a time where I thought, maybe, I can't take this. Maybe, I need to stay home. I decided not to.

**Was it just an epiphany of this is what I'm going do?**

Yeah, I have had these conditions my whole life and there have been times where I've needed like I've been an hour away from camp my dad needed to come. There've also been times where I just work through it. I know how to take care my body now; I'm 19 years old. When I was 12, maybe I didn't, but now 19 and if something were to happen and I needed my dad out here, I have the This University Hospital. I have been admitted on my own. I can go on my own and get the medication and procedures that I need. Honestly, it was time to be independent this is not an opportunity I should turn away from.

**What were you diagnosed with and when was your original diagnosis?**

I have a few different illnesses. The first major ones of I have is POTS, which is postural orthostatic tachycardia syndrome. I'm not sure if you have heard of it, but it developed about halfway through my sixth grade year until 11 or 12. In the eighth grade, I guess I had in my whole life, but I was diagnosed with Ehlers-Danlos syndrome. Ehlers-Danlos syndrome is a connective tissue disorder. My whole life I've had Chiari malformation, which is what I had brain surgery for. Chiari malformation is when the bottom of your brain in nonscientific terms, basically protrudes from your skull and sags. You have your brain head is just a little saggy in the back. It was impeding with my brainstem and my spinal cord, creating headaches all the time, balance problems, sensitivity to light and noise and tingling.

These things were always bothering me something. It is you're born with, and by the time I got to 6/7 grade, which is when my illnesses started further developing, my symptoms started to get worse. I didn't have surgery to my senior because of such a major surgery. At that point I was done applying to college and done with trying to get good grades in high school. My workload was lighter, and senior year was a good time to have that surgery. I have minor things like anemia and gluten intolerance. In addition to my postural orthostatic, I have chronic daily headaches, which developed from POTS. I've had a 24/7 headache for seven years.

**How do you navigate being on a college campus and having all these conditions at the same time? What are some things you do to manage your conditions?**

Since I develop my conditions, I just know that there are certain things that can and cannot do. I take naps when I need to and I try not to do it frequently, but I need it.

My body gets rundown. I always drink water. I take my medications. I love going out with my friends, being social and doing activities; some nights I just need to do my homework and go to bed. Whether I have to go to bed at nine or seven, I'll do it, because I know I have to. The next day, I will regret not doing it.

**How did you decide that you wanted to go to vet school?**

My whole life I want to be a veterinarian. It kind of started with my mom. My mom wanted to be a veterinarian but didn't have the financial means to put herself through vet school. She was paying for college all by herself. My family has always had at least two dogs and cats in the house. I spent a lot of time volunteering at animal shelters in high school. I started working at a vet clinic as a vet tech in New Jersey and I fell in love with it. I knew it was exactly what I wanted to do. It was nice that This University offered me an early acceptance. There were certain that schools that I always wanted to go to, but if I didn't get into those, I could always go to University. Once I start working with University's vet school more, I may fall in love with it. I'm already accepted. I'm very excited and I know that's what I want to. I plan on working with domestic animals, so dogs and cats or even exotic animals. I'm doing Spanish minor, so I can work in developing countries with homeless animals or maybe an exotic sanctuary.

**Did any of your diagnoses impact what you decided to do or was it of this is what I'm going to do, no matter what?**

Whenever my illness is flared up, and when I was diagnosed with it in sixth grade and throughout high school, I had times where I thought maybe I can't become a vet. I thought I had too many medical problems and that it will impede me from doing what I want to do. I realized that being a vet is really the only thing that I wanted to do. Just because I have these illnesses doesn't mean I can't accomplish that.

**You mentioned your dad was pushing for you to go to a school closer to home. Was anyone else giving you advice on where they thought you should go or what they thought you should major in?**

I think I had a very good group of friends when I was in high school. We all talked about college a lot. We all talked about where we should go or would say, "You should look at this school". My friends all knew that I wanted to be a vet, so they never push me in a different major direction because they knew that was what I wanted. I did have some of my friends say, a lot of them, said you should go to Missouri. You have this major scholarship and you should go. I did have a few friends that said maybe you should stay back with your illnesses. You should go to Delaware, Penn State or somewhere closer. I took all those in the consideration, for sure, because I really valued my friends' opinions. In the end, I knew it was going to be a decision between my family and I because of financial reasons. My friends are not the ones paying for college; it is me and my family that are paying for college.

**If you were to meet a brand-new person and they were to ask you to describe your personality, what kind of personality traits would you describe?**

I would say positive. No matter what I go through I'm always pretty positive. So people call me Sunshine. I think that embodies my ability to be positive. I am well rounded and I did a lot of different activities in high school. I had to stop playing contact sports. I was a very competitive soccer and lacrosse player up until seventh grade. I had to stop because my illnesses. I did a lot of clubs and community service. I did a bunch of different things. I would say passionate I think. I obviously knew I wanted to be a vet and a passion about that. I'm passionate about women's rights. I went to the march a few weeks ago.

I love getting people informed about those kinds of things. I did a lot of community service in high school and it's hard not having a car here. I can't really travel and go volunteer. I'm doing things for my sorority.

**Since you just mentioned your sorority, lets talk about your sorority. What kind of sorority is it? Is it a service, academic or social sorority? How did you decide to pledge for sorority and how has the sorority been with navigating on campus and transitioning to campus with a chronic condition?**

I didn't really know if I was going to rush or not. I knew it was kind of the bigger thing here then a lot of East Coast schools. I thought about it, and when I met my roommate on Facebook; we randomly picked each other. She was like you know, I'm going to rush, and you should do it with me. It should be fun and if not, you could just drop out. I decided to rush, I love my sorority and I am so glad I joined. It is Chi Omega. It's a great group of girls with great people. They were a lot of help in the beginning of semester just because you see someone wearing a Chi Omega shirt, you know, a great I can go talk to them. It was easy way to make friends and that was a great way to help transition.

**Talk about your first semester here. What was your first semester like transitioning from New Jersey to Missouri but also the transition from high school to college?**

The first few weeks for me felt like summer camp because I was rushing. I really didn't have a lot of work because it was the first week or two. The first few weeks I really didn't miss home because I'd already been gone for two weeks. It didn't impact me that much. I was ready to leave, I was not upset, but nervous because I knew it was going to miss home. I was the first my friends to leave for college, because most of them went to East Coast schools and they start later. I was rushing and I started much earlier. The first few weeks didn't really faze me. I was just meeting new people doing new things and then once mid-September hit, I got a little homesick. I actually flew home. I wasn't supposed to go home until Thanksgiving, because that's when first break was. I flew home in October because I really missed my dad and I missed my friends. They were all home for fall break, which we don't have.

I flew home to see them and then I came back. I guess the first semester for me was a lot of ups and downs. I would have a good week, get my work done. I would see my friends here and not really think about home. When the weekend came, I noticed a lot of kids would go home for the weekends. A lot of my friends are from Missouri, which makes sense because I'm at University. I'd either be alone or not really something on campus and I felt alone. I'd be sad and kind would be home. Definitely a lot of ups and downs.

In transitioning from high school to college, I was a pretty diligent worker in high school. I prided myself on getting good grades, doing well in school, and being a good friend. This was a big thing for me in high school. Having a good group of friends and being there for each other. I definitely developed that here have a great group of friends. They are very similar to the ones back home. We are all tight knit. Transitioning for schoolwork, I'd say I get some more passionate about my classes here. You have to take everything. Here, I'm taking classes that I really like and I'm excited to take. Which makes it easier to study for them. I want to learn what I'm studying. Not that I didn't in high school, but here I am taking more science, and I love science. Getting to do all science is pretty fun. All science and Spanish is what I like. I guess the course load is little different, it's much more independent. In high school, teachers will remind you and will be like don't forget this is due tomorrow. Here, it's more like I got a check canvas, and if I forget to check canvas, and I haven't done my homework. Here it is more independent, but not a bad way.

**When you were in high school and managing your chronic health conditions and coming to college, was it pretty similar or was your dad and family more involved in high school and transitioning to more independent management?**

In high school my family was pretty involved. They would always take me to doctor's appointments and would always schedule. I kept track of my medications, but whenever I would forget, my dad would be like hey take your meds; or you forgot this one; or don't forget, you have to change that dose. He kind of monitored me and helped me throughout college, but it's much more independent. I don't have anyone remind me to take my medicine. I don't have anyone to remind me to call this doctor or do that. I was here I think, in October, and my headache was getting really bad. I was like you know what I need to get go to the This University Hospital. They do this drip, which helps break your headache. I would do them a lot at home at Children's Hospital. It works and helps me. I tried the This University Hospital here. I didn't even tell my parents until after I left the hospital. I didn't want them to worry first of all, but I also didn't need them to come out and fly out for five hours. It wasn't that big of a deal. I was much more independent. It has helped realize how to take care my body, and to make sure that I do that, or ill regret it.

**Overall since you been at This University tell me some of the highlights and low lights of being at University. It could be related to having a chronic condition or could be in general**

Some of the highlights were joining my sorority. I really like the girls; it's been a good time. I love the friends I made. I love my friends. We get lunch every day together and dinner and hang out at night. Which is really cool, just because you're constantly with your friends. In high school, you see them in school and maybe after school and you get lunch, but it's different here. You're not just sitting there in the lunchroom with your entire class. You specifically go with your friends. You go to class and you're with them 24/7. Which is cool.

Some low lights would be missing home for sure. I think will be get better at time for time, but for right now, it's hard being so far from home. I guess with my condition, maybe explaining it to people. I didn't talk about it a ton in high school. My close friends knew. My high school knew when I had surgery just because I was out for so long. Here sometimes it's hard to navigate when to tell people, and when to not tell people. If I'm skipping out on a lot

of events or just not being myself because I've had a really bad headache and I'm not really talking in a group setting.

People ask what's up and instead of saying hey I just don't feel well, because, I might not be feeling well for the whole week. So it sounds like an excuse to say that in front of people all the time. Sometimes it's hard to say that in front of people all the time.

Maybe I need to explain more. Sometimes it's hard to navigate when to tell people about my condition. Especially if we are good friends and I feel like that they should know, that can be kind of tough.

### **When you do tell people what's the typical reaction that you receive?**

I guess it depends on how I say my illness. I never really tell people about Ehlers-Danlos, because it's one of my minor conditions, or gluten intolerance. People don't need to know that. They don't need to know I'm anemic. Why would they care? It's not something I tell people. If I say oh I'm feeling well, people will be like "oh you're not been feeling well recently are you okay?" I usually say I have this condition called POTS. It makes pretty run down pretty and tired. I also have chronic daily headaches. I have had a headache 24/7 for seven years now. This is something I deal with. Normally, when I say that part, they say, "wow, a headache for so long?" I respond with: yeah, I've had it for a long time, but its part of my life now. It is something that flares up. Some days they are really bad, and some days they are pretty minor. When I say that, they are caught off guard and respond with a "well that sounds terrible". I like to keep it in my mind that they could be way worse. I know people to have POTS who are wheelchair-bound can get out of bed, or can't go to college. I definitely have it good.

### **Let's talk about the faculty side of things. Have you disclosed to faculty or do you pick and choose who use close to? How you make that decision?**

Last semester, I was actually planning on having surgery again. Over Thanksgiving break. I was going to go home for Thanksgiving break, have surgery and then not come back until this semester. I would have skipped finals and taken then when I got back. At the beginning of the semester, I had to tell my teachers about that. In my animal science class, I told all my different teachers because they needed to know about finals. I ended up not having the surgery. I decided to postpone it or possibly cancel it. That is a whole another story. When I disclose to them, I said, "hey, look I would be treated like any other student". I know in high school I used special accommodations. I had extra time for testing. I had a quiet room and I didn't really use it that much. In high school some kids, when you're given special accommodations, people might think that you're trying to cheat the system or that you don't really need them.

Since a lot of people didn't know about my condition, I was just like you know what let's just not. I never needed the extra time. I sometimes use it for extended homework if, I was in the hospital for the weekend, so I could finish the projects. Then I would use it for that. It was a thing between my teacher and I. It was not for the whole class to know that I could turn my project in and on time. Here haven't really told any teachers this semester because I don't really feel the need to. If I start falling behind in work because of going to the hospital or being ill, then I will tell them. Right now, I'm doing pretty well.

**When they you told the faculty members last semester did they seem like they were pretty supportive or did you have mixed reactions?**

**I had mixed.** Some teachers said “yeah okay no worries, you take care of yourself you can take your final when you get back or we will figure out how to do it”. I had some teachers who were kind of, not unsupportive, but a little hasty, about it. They were little like, oh well if you're to be gone for that long, maybe you shouldn't be in my class this semester or maybe you should just take this semester off.

Which was more of my decision than yours, but I understand where you're coming from.

**I know you had accommodations in high school but decided not to use them have you register with a disability center here or you just waiting to see?**

I started the process back in September. I filled out the forms and there was supposed to be up follow-up meeting. Once I got to be an email about the follow-up meeting, I was like you know what, I don't think I need the accommodations. I haven't registered. Sometimes, I think maybe I should, just in case. Probably better to get the ball rolling now, in case I need accommodations in junior year, if my condition gets worse. I probably should do that I just haven't gotten around to.

**As far as resources that you use on campus, it sounds that like your sorority may be somewhat of a resource. Outside of your sorority, are there any other resources that you've used on campus? It could be for any reason, but any other support systems?**

I have gone to the student Health Center a few times. That's where I get my medications filled. The doctor there, I don't know if he knows me on a name basis, but I know him on a first name basis. Going there helps, that's where I get my meds and that's where get things done. My sorority and my friends are big help for me. I've always been a very friend oriented person. I go to my friends when I have problems and they come to me. My dad, he's not a campus, but I call him. My brother. That's probably it. The library, I use library a lot for my schoolwork.

**Earlier I asked about your personality traits so how do you think that your personality traits of connect with you being able to navigate your chronic conditions?**

Positivity. I would say because whatever I'm going through I'm still pretty positive about it. I like to think that going through surgery and going through different things makes it to where there's nothing I can't get through. I just try to be positive about it.

Well-rounded, I think having an illness makes me a little more relatable and well-rounded. I have a friend who been diagnosed with diabetes in high school or something with a serious illness I'm someone they can come to about it.

I feel as though I am well rounded on the activity that I do, but also on the types of people that I can talk to. Having gone through these things myself, I can relate to others. Passionate, my illness has definitely made me passionate about advocating for them.

Chiari malformation, I did a fundraiser my school for Chiari malformation. I started a club in high school for kids with chronic illnesses. I started it sophomore year and only had five members. At the beginning of the end of senior year, we had maybe 50 members.

We do fundraisers all the time. We did one for diabetes, because my friend had diabetes. We had one for Chiari malformation. We had one for mental health, which are a big advocate for. I think is not talked about enough. We had weekly meetings, which were kind of support groups. We would all talk about our illnesses and that really made me realize that I could do something positive with my illness.

**If you were to pick one person who's been your biggest personal resource, what person would that be?**

There's been a good amount. I've had a great support system, which is amazing. I'd say my dad. My dad is my best friend. He's always there for me, even when I'm not having a good day. He checks up on me every day, even from thousand miles away. He asks about my illness. I use ice packs, probably every day for my headache. I keep them in my backpack and I use them all the time. I think like every other week, I'll get a package, at the same time at the dorm. All with these ice packs so I don't have to buy them. He always sends them to me. He sends care packages. He is always on top of my Dr. stuff when I'm not. Not like when I was 14 or 15, I knew how to schedule a doctor's appointment, but not to the extent that I needed. He is always doing things for me.

**Are you the first person your family, at least in the family that you are around that has been diagnosed with any sort of chronic condition? Yes**

**You stated that your brother is older than you, so I'm assuming he started college a couple years beforehand. Did he give you any brotherly advice about how to navigate college?**

Yeah, he still does. If I'm really homesick, I'll call him. If want to go home and he'll be like, look, I was the same way freshman year. He goes to South Carolina, so he is a decent ways away from home. He said that he wanted to go home. I almost transferred and I'm so glad I didn't. You have great opportunities there and I had great opportunities in South Carolina that we would not be able to get being 30 minutes from home, at Rutgers. He tells me to stick it out and he gives me a lot of advice about when I'm homesick and about how to handle it. He gives me a lot of advice about classes, even though we are in totally different majors. He's a smart kid so he helps me navigate classes and how to pick the right classes and all that kind of stuff.

**Your mom and went to college and did your dad go to college as well?**

Yes,

**I know you got a full ride to school, so financially that super helpful. Have you faced any financial impact from having a chronic condition on the college campus or do you feel like you're able to navigate that pretty well? What has been your experience financially?**

I think in high school financially things were, not a problem, but a little tight. Since I was diagnosed in six grade, with so many illnesses and being in the hospital for weeks, doing different trials. I have flown all over the country for my condition. I've been so many universities so many different places to try to help break my headaches. That obviously racked up money. My dad has great insurance, and he always says "you know insurance will

cover” and it normally does, but even if it doesn't, there is a little of worry while we figure out how to do it. Stamps has been such a blessing because I don't really have those worries that I had high school. I don't have as much problem in college. When I went to the emergency room in October for my headaches, I ended up getting a bill one month later. It was thousands of dollars for staying there for just a few hours. I called my dad and I was like oh my gosh! Is insurance going to cover this because I wouldn't have gone if it didn't. He had gotten a statement saying that it was free and that insurance paid for it. I definitely understand kids who do have to deal with that. I think that's horrible thinking that you couldn't go to hospital because you don't have the correct insurance. I know that there's some college students don't have that. I am very grateful for it.

**My last question is: is there anything else about you your experience at This Universityor resources that I haven't asked about that you think it's important for me to know for this study.**

I'm not sure if this goes along with the question, but possibly, I think there are a lot more kids on campus that have chronic illnesses than I would've thought. I think coming here there are so many different types of chronic illnesses and stuff in people's lives. I have friends have very minor ones that don't really talk about it unless it is when I talk about it. They want to contribute and say something or maybe they have one that's pretty severe. I've had friends in my sorority and she has diabetes and she has a pretty severe case. I think This University has helped me see that yes I'm different because I have all these illnesses but I'm also the same as others because so many people have illnesses.

**VITA**

The author was born in Columbia, Missouri. She attended Columbia College and graduated with a Bachelor of Science in Business and Management Information Systems. She also attended Stephens College and graduated with a Master in Business Administration. She began her doctoral studies in Educational Leadership and Policy Analysis at the University of Missouri in 2014. When the author is not working on research, she actively works with a TRiO Student Support Services Program at the University. In her free time she travels and can often be found on a beach somewhere warm and tropical.