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An autoethnographic study: An identity lost and a passage discovered

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AN AUTOETHNOGRAPHIC STUDY: AN IDENTITY LOST
AND A PASSAGE DISCOVERED

by

Simone S. Martinez

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2018

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By

Simone S. Martinez

DEDICATION

This doctorate is dedicated to my Uncle Eric Van Sloan I. Many years ago, when I was a little girl, I told him that one day I was going to be a doctor. Since that day he has been my biggest supporter. I may not call or see him on a regular basis, but throughout this process, when I was feeling like I wanted to quit or that I could not find the right words, I remembered all the times he told people that one day I was going to be a doctor. It was me thinking about those words and seeing him in my mind that kept me motivated. This is also dedicated to my husband who stood by my side during this process. It has been a long process but well worth it. Thank you for sticking by me. Last but not least, my mother, Cynthia Sloan. Thank you for encouraging me to get an education and to pursue my dreams.

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AN AUTOETHNOGRAPHIC STUDY: AN IDENTITY LOST
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Abstract

By Simone S. Martinez

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2018

The professional careers of teachers with a chronic illness can sometimes be devastating. This study addresses the insufficient understanding of the identity crisis a teacher goes through when one is suddenly diagnosed with a chronic illness. While researching different types of theories, identity theory best fit this topic and my interest. Within identity theory, there are four perspectives to view identity. The four perspectives are Nature, Institution, Discourse, and Affinity identities. In order to understand identity, one must understand how identity is formed. Chronic illness identity is a change from all other identities that have been constructed. This study uses a qualitative analysis method to explore chronic illness and its effect on identity and disclosure in the teaching profession. Autoethnography was used as a research tool to explore personal experiences. Studying a disability can change society's perspective on how invisible disabilities are viewed. The following study is the chronicled written account of a teacher with multiple chronic illnesses. Trauma impacts the way one perceives themselves. Chronic illnesses are just the type of trauma that can be a dream assassin or a dream deliver. Writing uncovered a multidimensional intersecting identity. It was not just about the lost identity, it is about changing my fixed mindset and revealing the identity that was thought to be lost. Hopefully someone will find solace in finding their passage to reconstructing their identity.

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Chapter 1: Introduction

-I'm only 27 - Simone Martinez

My religion teaches me that God has already written my plan and created my story, my only wish is that I could read ahead to be ready for the next assignment! No one can prepare you for being on top of the world then falling off, but myself catches me every time. When I catch myself, I often wonder how I will survive the fall. The epiphany is learning not to be afraid of the fall. “An epiphany is a life turning moment that alters an individual’s self-concept and leads to a new level of insight” (Karnilowicz, 2011, p. 278). In 1998, my world came crashing to an abrupt halt. I was diagnosed with an Osteosarcoma (malignant bone tumor) and then in 1999, life exploded again. This time the diagnosis was Focal Segmental Glomerulosclerosis (kidney disease). I was only twenty-seven and a second-year teacher. Twenty-seven is a pivotal number, twenty-seven changed my life and identity forever. Funny how you can be playing jump rope with a schoolyard full of first grade students and the next moment you are being wheeled into an operating room. How scary it was to lie on that skinny metal table looking up only to have the doctor tell you if you wake up quickly, it is not just a lesion.

Not only would I have to learn how to become a better teacher, I also had to face the challenges that come along with having cancer and then a year later losing my kidneys to an autoimmune disease. In the chaos of it all, my only thoughts were to return to teaching, I just never took the time to define what teaching meant for me as a teacher with a chronic illness. When your identity has been that of a teacher and that identity suddenly changes after an illness diagnosis, the question becomes how to fuse your old self to your new self and express yourself as an educator with a chronic illness (Beijaard & Vermunt, 2000; Charmaz, 1995). This chapter

will provide the background, the description of the problem, conceptual framework, purpose of the study, research questions, description of the study, and the researcher's perspective.

Background

-One in a billion people in the world, tag . . . I'm it.

In the United States, 117 million people suffer from one or more chronic illnesses, one in four adults have two or more conditions (Center for Disease Control or Prevention, 2017).

Osteosarcoma (2017), a malignant bone tumor and Focal Segmental Glomerulosclerosis (kidney disease) have become part of my daily narrative. According to the American Cancer Society (2017), osteosarcomas accounts for about 2% of childhood cancers, but they make up a much smaller percentage of adult cancers. Although osteosarcoma is a common malignant bone tumor, it is still rare with less than 1,000 new cases each year in the United States (St. Jude Children's Research Hospital, 2017). The diagnoses of Focal Segmental Glomerulosclerosis (FSGS), kidney disease followed shortly after. Both are a type of chronic illness and the reality of a chronic illness leaves you angry, pining, yearning, disorganized, disoriented, but not ever feeling fully recovered or accepting of this new life (Olasinde, 2012).

The professional careers of teachers with a chronic illness can sometimes be devastating. Some of the difficulties that arise from chronic illnesses are absenteeism, decreased energies, and feeling like your illness can threaten your career (Beretz, 2003). Accepting the terms of your chronic illness and coping with shifts in self-identity is a process (Kralik, Koch, Price, & Howard, 2004) of becoming a teacher with an illness. Professionals with chronic illness want to continue working (Munir, Yarker, & Haslam, 2008). In order to productively work and cope with a chronic illness, it requires managing multiple illnesses and restructuring the discourse for the new identity (Charmaz, 2000; Williams, 2000).

Individuals may be motivated to define and express their individual self-identities (Karnilowicz, 2011). The concept of self is a combination of many factors, such as cultural, values, ethics, and family. Identity is the individual characteristics that defines how we see ourselves as individuals (Sharpe, Alderson & Collins, 2013). Living with a chronic illness requires the self to constantly reconstruct itself throughout the experience of the illness (Frank, 1995). The effects from illness can be unconquerable, but one can gain control over the effects by taking some ownership of the illness (Karnilowicz, 2011). A positive self-identity can help an individual through the ownership process. Motivation to continue life as usual is a key factor when engaging in your health and self-identities (Charmaz, 2005).

Concealing a condition can be stressful (Goodwin & Morgan, 2012). Individual experiences, attitudes, and other's feelings all contribute to the delicate process of disclosing a chronic illness in the workplace (Telford, Kralik, & Koch, 2006). Choosing to disclose your chronic illness comes with risk and fear (Petronio, 2002). Along with fear and anxiety there is a potential risk for peer rejection, discrimination, loss of employment, and self-identity crises (Petronio, 2002). "Research on self-disclosure has found that the ability to reveal one's feelings and thoughts to another is a basic skill for developing close relationships." (Mikulincer & Nachshon, 1991, p. 322). Disclosing a chronic illness in the teaching profession can cause teachers to possibly feel vulnerable to stigmatization or feel they are being devalued (McGonagall & Barnes-Farrell, 2013).

Description of the Problem

This study addresses the insufficient understanding of the identity crisis a teacher goes through when one is suddenly diagnosed with a chronic illness. Researchers tend to be more interested in social problems associated with chronic illnesses than in how people respond to

tackling them (Bury, 1991). Chronic illnesses can create an identity crisis for teachers causing them to struggle through the disclosure process (Bury, 1991; Chaudoir & Fisher, 2010). There is a body of research on identity and disclosure of a chronic illness, there is limited research on the role teacher identity has in disclosing a chronic illness in the workplace. The problem impacts teachers because researchers have contributed a considerable amount of qualitative research on experiences of people with a chronic illness through in-depth interviews (Patterson, Thorne, Canam, & Jillings, 2001), but not specific to teachers.

Many possible factors contribute to this problem but most disclosure research has focused on identity factors that affect disclosure (Chaudoir, Fisher, & Simoni, 2011) and how disclosure interacts with identity. Other research focuses on the stigmatization of chronic illness (Corrigan & Rao, 2012; Goffman, 2009; Joachim & Acorn, 2000; McGonagall & Barnes-Farrell, 2013). There is a need for more information about chronic illness disclosure in the educational setting. This study contributes to the body of knowledge needed to address this problem by researching what the previous research has missed; the outcome disclosure has on teacher identity when the teacher is diagnosed with a chronic illness.

Conceptual Framework

After being diagnosed with a chronic illness, identities may take a sharp turn to the left. People take on all types of different roles, society may even recognize them for these different roles (Hogg, Terry, & White, 1995; Charmaz, 2000; Stets & Burke, 2000). A person can be a teacher, a capitalist, a gang member, the list is never exhausted. People can be a certain kind of person one day and a different person the next depending on the interactions they are having at the time. The self is composed of multiple identities that are connected to how people perform in the societal settings they are in (Beijaard, Meijer, & Verloop, 2004).

In order to include identity in the study it is necessary to discuss how identity is constructed. As a teacher, my biggest fear was how my identity would change when I began to recover from the kidney transplant. Learning to live with chronic illness as part of my new identity was complex. Identity theory can trace its roots back to 1934, from the writings of George Herbert Mead (Stryker & Burke, 2000). Mead's work did not present a testable theory. The theory evolved overtime to make society and self researchable. According to Stets and Burke (2000) identity theory can be defined as, "the core of an identity is the categorization of the self as an occupant of a role, and the incorporation, into the self, of the meanings and expectations associated with that role and its performance" (p. 225). There is an interest in how people build identities through experiences and how these experiences mold into their identity portfolio (Gee, 2000). People are effected by all aspects of Gee's (2000) identity perspectives. These perspectives might lead to a reinvention of one's self.

While researching different types of theories that would fit my topic, I found that identity theory best fit my interest. Within identity theory I found Gee's (2000) four ways to view identity. Gee's (2000) four identity views are: Nature (N-identity), Institution (I-identity), Discourse (D-identity), and Affinity (A-identity). Figure 1 shows a graphic representation of the four views of identity.

Being diagnosed with two illnesses in a period of two years, felt like my identity died. Who I was or was about to become was lost. I experienced grief as if a loved one had passed away. I no longer knew how to identify myself or if I would ever recover from the loss. The graphic represents my identity loss and my attempt to fit into the new identities that chronic illness has created. The conceptual framework based on Gee's (2000) identity views will be

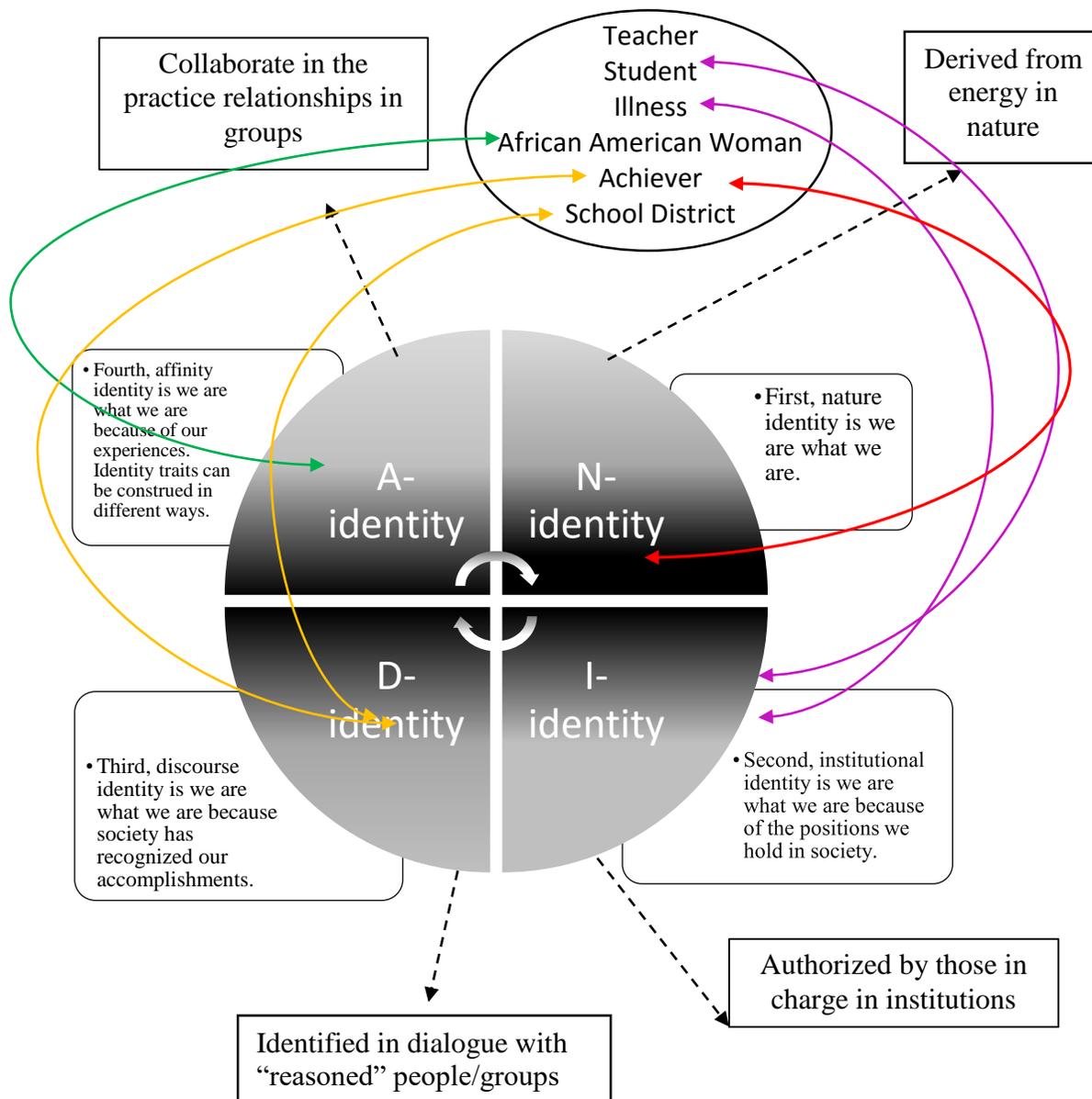


Figure 1: Model of Four Views of Identity According to My Identity

discussed at length in the literature review. The literature review will discuss how the identities are affected by chronic illness.

Purpose of the Study

The purpose of this autoethnographic study was to examine my teacher experiences rebuilding my self-identities as a teacher after being diagnosed with several chronic illness.

Research Questions

1. How and in what ways has my identity as an educator been reconstructed after disclosing my chronic illness in the workplace?
2. How can writing about my experiences disclosing my chronic illness help me heal and understand why my identity changed?
3. How and in what ways do educators continue life as an educator after being diagnosed with a chronic illness?

Description of the Study

This study uses a qualitative analysis method to explore chronic illness and its effect on disclosure in the teaching profession. This method of research was chosen to address insufficient understanding of the identity crisis a teacher goes through when one is suddenly diagnosed with a chronic illness. In order to accomplish this task, the researcher used autoethnography as a qualitative method.

Autoethnography is a research method used in many research fields, but this study is based in education (Alasuutari, 2008). In order to explore personal experiences many researchers use autoethnography as a tool (Ellis, 1995). Autoethnography analyzes people's lives and the experiences of the researcher (Ellis & Bochner, 2000).

According to Ellis, Adams, and Bochner (2011), autoethnography can be defined as an approach to research and writing that seeks to describe and systematically analyze personal

experience in order to understand cultural experience. Chronic illness is a common theme in ethnographic research (Ellis, 1995). The strength in writing an autoethnography is the story, the story of the realities of a teacher living with a chronic illness. Autoethnography is a narrative, a narrative of the researcher's life experiences. It is connecting the personal to the cultural (Ellis & Bochner, 2000). Autoethnography allows a person to find meaning in their lived experiences and can help one take psychological ownership of the illness (Karnilowicz, 2011).

Often times, an autoethnographer writes about their "epiphanies", remembered moments perceived to have significantly impacted the trajectory of a person's life (Bochner & Ellis, 1992). Taking ownership of a chronic illness can cause an epiphany. While some traditional researchers dismiss autoethnography as an invalid theoretical framework, authors work rigorously to establish their ability to relate one's personal experiences to the broader social experiences of others (Allen, 2015). The ultimate goal of writing this autoethnography was to find the "epiphany" (Bochner & Ellis, 1992).

Significance of the Study

The significance of the study was to explore my experiences with a chronic illness and how it has affected my identity. I chose my experience because it has been difficult for me to disclose my illness in the educational setting, especially since it is not visible. Chronic illness is a theme that fits autoethnographic research (Ellis, 1995). This study addresses gaps in the literature about how a teacher's identity is restructured through disclosure after being diagnosed with a chronic illness. This study explores the role disclosure has on restructuring the identity of a teacher. By researching the self as an educator living with a chronic illness I can now be an advocate for social change. It was important to share my story. Through my narrative, the words are a catalyst for educational change and gives a voice to those who feel too stigmatized to

talk about their illnesses. I analyzed my experience with multiple illnesses and how the illnesses have affected my life and work. Until writing this narrative, I have never confronted my illnesses. I never thought that I would ever have to reflect on my illnesses and how they have shaped my teaching experiences, but I believe now more than ever, that I needed to tell my story and help someone else who may face a chronic illness while continuing to teach. I live in fear that one day cancer may strike again or my kidney may fail. I hide the pain and frustration of taking medicine that upsets my stomach and sometimes makes my head spin. I often lie about having migraines instead of saying my creatinine levels are a little high, migraines are easier for people to understand. I wrote about my experiences and what allowed me to show up to the classroom every day possible. I used this dissertation to heal my mind and put me at peace with the decisions I have made about my career. I have added quotes at strategic points in my writing to add as much evidence as possible to prove how an autoethnography can be therapeutic and to add life to my experiences. Since I am part of the authoritative voice of this paper, my voice was needed to add strength to my arguments. According to University of North Carolina at Chapel Hill (2018), quotes should be used when the writer's words are relevant and powerful, my words are powerful and very relevant to the subject.

This topic is relevant to education because teachers are the educational facilitators that are responsible for helping students develop critical knowledge. Gone are the days that teachers can sit in isolation and teach. Collaboration is a critical component of teaching and in order to collaborate, teachers have to be in the room. By researching the self as an educator living with a chronic illness I became an advocate for individual change and have the insight to inspire others in my situation to continue to teach and find your identity, every day. This study is significant to

the current body of research because the research examined my teaching experiences while rebuilding my identities after being diagnosed with a chronic illness.

Researcher Perspective

Studying a disability can change society's perspective on how teachers with chronic illnesses are viewed. The goal of writing an autoethnography is to emancipate. By researching through a disability interpretive lens, the researcher humanizes the disability and it is no longer seen as a defect (Creswell, 2013). The researcher may find the epistemology to contain multiple truths and when constructing the narrative reality may be subjective. As the researcher, I held myself accountable for the fair representation of the story told in this study (Fink, 2000). Thus, the researcher must be engaged and present in the ethnographic study (Creswell, 2013). In the case of an autoethnographer, the researcher is a complete insider; a researcher who is an established participant in the setting in which the data is being collected (McMillian & Schumacher, 2010). A challenge was for me as the researcher to remain in the role of the researcher. As I interviewed myself, I was careful not interject my own beliefs into the interview (Creswell, 2013). I remained in the role of the interviewee as the interviews occurred.

Definition of Terms

Fistula: A fistula is a vascular access in the arm. It is a surgical procedure used to create a vein in order to remove and return blood during dialysis (University of California, San Francisco Department of Surgery, 2019).

Kidney Failure: Kidneys function to remove waste to avoid toxic build up in the body. Waste is eliminated through the production on urine. Kidney failure is the progressive loss of this kidney function (Hollingsworth, 2006).

Peritoneal Dialysis: Peritoneal dialysis is performed every day at home by the patient. The patients must conduct manual exchanges of dialysate fluid 4 to 5 times a day. This occurs manually or through automated exchanges from a tube surgically installed in the peritoneum (stomach). The treatment is usually conducted at night while asleep (Rubin, Fink, Plantinga, Sadler, Kliger, & Powe, 2004).

Hemodialysis: Hemodialysis is a dialysis treatment that is performed at a dialysis clinic. Patients attend the clinic 3 times a week and sit connected to a dialysis machine 3 to 4 hours each treatment (Rubin, Fink, Plantinga, Sadler, Kliger, & Powe, 2004).

California Clear Teaching Credential: A California teaching credential is a basic multiple or single subject credential obtained upon completion of a bachelor's degree and after completing a credentialing program that meets the prescribed professional education requirements (Commission on Teacher Credentialing, 2019).

Chapter Summary

This dissertation is organized as follows. Chapter 1 presents a preview to the information that is contained in each chapter. It is a glimpse into the study that occurred on chronic illness, identity, and disclosure. Chapter 2 chronicles the research that already exist and the findings of previous researchers. Chapter 3 presents the methodology that was be used to conduct the study. Chapter 4 draws the reader into my narrative experience in the form of a chronicled story. Chapter 5 is the analysis, findings, and the conclusion of the study.

Chapter 2: Literature Review

-One in a billion people in the world, tag I'm it! Simone S. Martinez

To address the identity crisis and disclosure dilemmas created by a chronic illness, the researcher must look at the self. The researcher may choose to do a study on self-identity and disclosure related to chronic illness, the nature of disclosure, or factors related to self-disclosure. I chose to center this literature review around identity and disclosing a chronic illness in the teaching workplace and the effects on self-identity.

This literature review focuses on four specific areas. First the literature review focuses on chronic illness as this is the basis of one's identity being changed. Next, the review focuses on identity development and what it means to be whom you are and how who you are affects one's decision to disclose an illness. Identity focuses on Gee's (2000) four perspectives on identity. Finally, how identity is reconstructed after acquiring an illness is accomplished.

Chronic Illness

Researchers have not been able to agree on a precise definition of chronic illness. Merriam-Webster's Online Dictionary (n. d.) defines chronic as continuing or occurring again and again for a long time. Illness is defined as a specific condition that prevents your body or mind from working normally: a sickness or disease (Merriam-Webster's Online Dictionary, n. d.). These definitions taken together, chronic illness can then be defined as a specific sickness or disease that is ongoing for a long time. Rolland (1987), for instance, found that the chronic phase of an illness is the time span between the initial diagnosis and the readjustment period. According to Ironside and colleagues, chronic illness can be defined as "a disease or injury that has lasted more than six months and has caused an individual to significantly alter his or her day-to-day activities" (Ironside, Scheckel, Wessels, Bailey, Powers, Seeley, 2003, p. 172). This

definition was compiled from the participants in the study. Bury (1991) defines chronic illness as a “long-term and perhaps permanent event in a person’s life (p. 452). This is the definition of chronic illness that will be referred to throughout this review. Bury (1982) characterized chronic illness as a disruptive event, but Giddens (1979) used the term “critical situation” to define chronic illness.

The term “critical situation” (Giddens, 1979) is the devastating effect chronic illness has on many individual’s lives and identities. Individuals often think of chronic illness as something that only happens in the distant future (Bury, 1982). Teacher’s everyday wellness is taken for granted. Bury’s work conceptualizes chronic illness as a major disruptive experience (Williams, 2000). Chronic illness is very different from an acute illness. Acuteness is temporary, short lived, and generally do not cause life to be permanently changed as a result (Rolland, 1987). Chronic illnesses are a permanent part of an individual’s life and life will never return to normal. Motivation to continue life as usual is a key factor when engaging in health and self-identities (Charmaz, 2005). Individuals with an invisible social identity, such as chronic illness, struggle to acquire and maintain legitimacy within social interactions at work (Clair, Beatty, & Maclean, 2005).

Chronic illness invades a person’s “moral universe” because their “normal” pre-illness identity no longer “fits” (Jacobson-Widding, 1983). It then becomes necessary to revise one’s life. Chronic illnesses are lived with every day. The daily routine must be arranged around the illness. Chronic illness creates a disruptive discourse between what the self wants to be and what the self actually is (Charmaz, 1987). People diagnosed with a chronic illness suffer from a loss of self as they observe their former selves crumbling away (Charmaz, 1983). The experiences people have with chronic illness are often products of a social construct while symptoms are

experienced inside the person (Charmaz, 1983). Bury (1982) put it eloquently, chronic illness is not only an assault on the body but also a biological disruption to the self. According to Hitlin (2003), the self is “one of the greatest discoveries in the history of social sciences” (p. 118). As the self begins to change due to illness, so may the way others perceive and define the sufferer (Kelly & Field, 1996). As the body changes due to chronic illness, so does the situations. Individuals feel it is important to be the same person they were before the illness (Williams, 2000). Charmaz (1983) states that the suffering that is felt from being chronically ill is the loss of self. That loss results in the current self being faded to black (fade away). Withdrawal from self and other social interactions are a major feature of chronic illness (Bury, 1982). Charmaz (1983) also noted that being diagnosed with a chronic illness causes the self to become lost.

Living with an illness requires the self to constantly reconstruct itself throughout the illness experience (Frank, 1995). According to Telford et al. (2006), the burden of living with a chronic illness is often compounded by stress between the public self and private identity. When diagnosed with a life altering illness, people are forced to reexamine their identities to fit in the pieces of that illness. Having a chronic illness can become a threat to one’s identity. Chronic illnesses cause people to have to psychologically prepare and accept permanent changes to their once normal lives. To understand how to put those pieces together, it is important to look at how identity is constructed.

The Identity of Self

Identity theory can trace its roots back to 1934, from the writings of George Herbert Mead (Stryker & Burke, 2000). Mead’s theory states that only certain people can influence our perception of ourselves and only during certain periods of our lives (Mead, 1934). Mead’s work

did not present a testable theory. The theory evolved overtime to make society and self, researchable. According to Stets and Burke (2000) identity theory can be defined as, “the core of an identity is the categorization of the self as an occupant of a role, and the incorporation, into the self, of the meanings and expectations associated with that role and its performance” (p. 225). “Identity theory is a family of views on the relationship between mind and body” (The Internet Encyclopedia of Philosophy, n. d.). The “self” grows out of the mind, the mind then develops out of interactions in social situations (Burke & Stets, 2009). The next portion of the literature review will focus on what the research says about chronic illness and identity.

People are motivated to define and express their individual self-identities (Karnilowicz, 2011). The concept of self is a combination of many factors, such as culture, values, ethics, and family. Identity is the individual characteristics that define how we see ourselves as individuals (Sharpe, Alderson, & Collins, 2013). Identity is attached to us by the groups we reside in. Identities are multifaceted and are forever transforming due to outside and sociocultural perspectives (Gee, 2000). Part of identity comes from the thoughts that a person claims (Hitlin, 2003). These thoughts become our personal identities. Identity is what we have attached to ourselves by ourselves and others.

Identity is focused on role-related behaviors (Hogg et al., 1995), or how a person behaves in a particular environment or situation. It is the person’s perception on how they should behave. A person’s experiences are a stage performance that has multiple ways of being interpreted (Finley, 2005). Identities are like scripts (Thoits, 1991), the meaning and purposes of these scripts (behavioral expectations) act as a guide in life. A positive self-identity can help an individual through the identity process.

Identity is always being negotiated because it is not fixed (Riddell & Watson, 2014). According to Maydell (2010) identity is always subject to change because life, social interactions, and the groups we belong to are ever changing. Identity attributes are something someone is born with, but identity takes a lifetime to develop (Kelly & Field, 1996). Identity identification is an ongoing process. Individuals constantly interpret and reinterpret their experiences as they evaluate themselves. Each researcher (Ashforth, Harrison, & Corley, 2008; Hogg et al., 1995) has a different take on how identities are built and change over time. Identity therefore, is ever changing and never complete.

The following sections focus on Gee's (2000) identity research: nature, institutional, discourse, and affinity identities. When individuals act in any given situation, others may perceive them as being a certain kind of individual. Research has developed a perspective on identity that is focused on four perspectives on what it means to identify as a certain kind of person (Gee, 2000). The four perspectives are, Nature, Institution, Discourse, and Affinity identities. In order to understand identity, you must understand how identity is formed. Chronic illness identity is a change from all other identities that have been constructed. Gee's (2000) views on identity reveal that people construct their identities through interacting with others. Gee's (2000) four perspectives touch on "what it means to be recognized as a certain kind of person" (p. 100). This theory fits my desire to be recognized and not defined by an illness. The following paragraphs focus on the four perspectives of identity.

Identity: Nature

Society recognizes people as being a certain type of person. When individuals are asked who they are, most respond by giving social descriptions and attributes of themselves such as, African American, teacher, woman, wife, mother, the list goes on (Thoits, 1991). These

identities are not fixed, they are not the nature of human beings (Gee, 2000; Riddell & Watson, 2014). Nature-identity cannot be controlled, it is an identity that comes from the forces of nature (Gee, 2000). Nature-identity unfolds outside of the influence of society (Gee, 2000). An example of Nature-Identity is the anatomical sex you are born, this is out of the control of society and powered by nature (Gee, 2000). Gee (2000), for example, states that he is an identical twin. Being an identical twin is not a result of societal influence or because of anything he has accomplished. It is fixed. Being African American can be treated as an institutional, discourse, or affinity identity, for the purposes of this review it will be used as a nature-identity. Phinney (1990) states, “self-identification refers to the ethnic label one uses for oneself” (p. 9). African American ethnicity is nature that cannot be outwardly changed (Gee, 2000).

African American ethnic woman. What does it mean to be black or African American? Is there a direct definition that relates to one’s identity? Racial identity has an effect on a person’s behaviors and social interactions (Sellers, Smith, Shelton, Rowley, & Chavous, 1998). African American identity is an individual’s connection to a particular ethnic group (McMahon & Watts, 2002). Stets and Burke’s (2000) concept of identity is similar to N-identity in that through the process of self-categorization or identification, identity is formed. This is an identity that cannot be changed according to society. African American ethnic identity has been described as a sense of self as subject to prejudice, racism, and exclusion from opportunities in White society (Oyserman, Gant, & Ager, 1995). Being African American plays a significant role in ethnic identity and influences situational behaviors. The cultural themes of religion, slavery, death, survival, overcoming, and social expression has an effect on the chronic illness experiences of African Americans (Becker & Newsom, 2005). Although Black and Miles (2002) researched African American Women with HIV, the feeling of being stigmatized,

shamed, and a strong need for support can be generalized to other hidden illnesses. If African American women feel stigmatized, this may hinder their disclosure of an illness.

Nature identity becomes our base identity. From the base identity, all other identities are formed. The natural self-identity only deals with the nature of identity, but it is the experiences that guide our behaviors (Bailey, 2003). These experiences include institutional identity and the affinity group one belongs to.

Identity: Institutional

According to Driedger (1976), institutional completeness is an important factor that influences identity. Self-concept within an organization regulates how people behave. Most become attached to the organization when they incorporate these behaviors into their self-concept (Ashforth, Harrison, & Corley, 2008; Burke & Reitzes, 1991; Dutton, Dukerich, & Harquail, 1994). Illness is stigmatized by society, and people who belong to that particular group are aware if their workplace is open to accommodations (Beatty, 2004). This can become a factor when choosing to disclose an illness (Beatty, 2004). If an individual is aware that an identity (such as someone with an illness) is devalued by fellow employees, this can have a detrimental impact on identity and the choice to disclose to the organization (McGonagall & Barnes-Farrell, 2013). Organizations or work groups are part of people's identity. The self is concerned with how it perceives itself within the organization (Ashforth et al., 2008). Dutton et al. (1994) suggest that if members of an organization experience negative outcomes, the member may either disengage from the organizational task or leave the organization altogether. While McGonagall & Barnes-Farrell (2013) found that when individuals feel confident in their abilities to perform one's job effectively within the organization, this may become a resource to prevent an identity crisis.

Swann, Polzer, Seyle, and Ko (2004) observed that individuals strive to verify their identity in the workplace in order to avoid having their identity being misconstrued. Chronic illness does not exclude people from productively participating in the workplace (Clair et al., 2005). Having a chronic illness can be psychologically demanding coupled with a career, such as teaching, and can lead to a further loss of self (Charmaz, 2000). The institution is full of stage props and scenes that are related to teachers' identities and the cultural scripts (Beijaard, Verloop, & Vermunt, 2000) they perform to.

Teacher. "Becoming a teacher involves the construction of a person's identity, and identity forming process" (Danielewicz, 2014, p. 3). Emotions, life experiences, and internal and external factors all influence a teacher's identity over time (Beijaard, Meijer, & Verloop, 2004; Beauchamp & Thomas, 2009). It is important for educators to connect their professional life and learning with their personal reflections on the illness in order to foster growth (Wideman-Johnston, 2015). The teacher identity is a process that a teacher must adopt. Taking on the identity role of a teacher is a social role that can either be easily adopted or the position is never fully realized (Danielewicz, 2014). Teacher identity roles are reflective of norms and values placed on the teaching profession by society and the institutions they work for (Beijaard, et al, 2000; Beijaard, Verloop, & Vermunt, 2004). The culture of the institution largely affects how teachers perceive their professional identity (Beijaard et al., 2000). Being a teacher means you realize that your identity is not fixed but that you commit to show up and teach every day. Teacher identities are constructed through interactions with others in a professional context (Beauchamp & Thomas, 2009). Teaching with a chronic illness adds to that volatile state of construction and reconstruction of your teaching identities (Danielewicz, 2014). Therefore, the identity of having a chronic illness becomes a sub-identity of the teacher identity.

Chronically ill teacher. When your identity has been that of an educator and that identity changes after an illness diagnosis, the question becomes how to fuse and express your new self as an educator with a chronic illness. The professional careers of teachers with a chronic illness can sometimes be devastating. Some of the difficulties that arise from chronic illnesses are loss of teaching time, decreased energies, and threatened careers (Beretz, 2003). The practice of reflection is a core activity that leads to long-term growth in the profession (Walkington, 2005). Wideman-Johnston (2015) for example, wrote about balancing being an educator and managing an illness. Most chronic illnesses do not change the intellect of the teacher, they still have the ability to think and teach (Beretz, 2003). Pinnegar (2005) defines “generic” teacher as being assigned to teach courses. Teacher roles are not fixed, but fluid (Pinnegar, 2005). Researchers have concluded that professional identity is related to teachers’ images of self and those images determine the way they teach, while others argue that professional identities the emphasis is placed on the role of a teacher (Beijaard, et al., 2004; Knowles, 1992; Nias, 1989; Volkmann & Anderson, 1998). Professional identity boils down to what images society accepts and expects of teachers paired with what images teachers, themselves, feels are important. Being a teacher is an ongoing process of the merging of the personal and professional self. Slay and Smith (2011) believe that successful professional identity is related to career success. The researchers examined the effect stigma has on one’s professional identity development.

Teachers can be bombarded with negative stereotypes, minimized social interactions, and have their physical, mental, and emotional competence challenged (Goodwin & Morgan, 2012). Teachers fear change and learning to live with a chronic illness is complex. Accepting the terms of your chronic illness and coping with shifts in self-identity is the process (Kralik et

al., 2004) for becoming a teacher with an illness. Ashforth et al. (2008) argued that institutional identification is a form of social identification. Social identity is formed through group identity. To become a teacher, you must master the discourse of the profession (Alsup, 2006).

Identity: Discourse

Discourse identity is we are what we are because society has recognized our accomplishments (Gee, 2000). It is an identity that is formed through observations from others. Discourse is much more than spoken or written language, it is the different ways people interact with verbal and non-verbal language to “map out” social groups (Gee, 2000; Foucault & Nazzaro, 1972). Identity is not your core self, it is who you are in the world at any given time, like being a “good student” or an “overachiever” (Gee, 2000). Discourse and identity are linked (Alsup, 2006). Individuals are recognized by the discourse (verbal or written language) being used in the group (Gee, 2000).

Identity: Affinity

Affinity identity (groups) are primarily focused on a common set of practices, where the people of the group come second (Gee, 2004). Ashforth et al. (2008) describe social group identity as knowledge being shared by the members of the group. Gee (2000) explains affinity group as people who share little besides their interest, dialogue, and allegiance to participation in those specific practices. Although people affiliate within these groups, they may actively disaffiliate once the issue is resolved (Holt, 1999). In the case of individuals with a chronic illness, this disaffiliation may be due to negative outcomes of disclosure (Holt, 1999). Resolution may also mean that the person has learned to cope or they have moved on to other aspects of the illness. The practices of the group are distinct. For example, being part of Beyoncé’s Beehive. The Beehive is global and everyone in the group shares their allegiance to

the singer and behave in certain ways to show affiliation in the group. Health organizations offer another type of affinity group affiliation example. Health organizations put together social gatherings around these illnesses to create allegiance to that health organization or the illness they represent.

Affinity identity is we are what we are because of our experiences. Identity traits can be construed in different ways. People can negotiate how their identities manifest, and how they are seen by others. After being diagnosed with an illness, people become part of new groups (Gee, 2000). Patient identity becomes an A-identity (Gee, 2000). As a patient, you follow a specific set of distinctive social practices and share a culture that is unique to being a patient.

Patient. Each patient has a story of suffering, which only makes sense to the patient's life (Kleinman, 1988). The identity of a patient with an illness, such as cancer, will undergo an identity transformation. The stigma, stress, and strain will make it imperative for patients to re-negotiate their identity status with their various social groups (Mathieson & Stam, 1995). Instead of being known as a person, you suddenly become your illness. Doctors and specialist enter the person's life and communication is mainly about the disease (Mathieson & Stam, 1995). Being a patient is highly impersonal., the healthcare setting is full of symbols that strip the patient of their former self (Vanderford, Jenks, & Sharf, 1997). Patients have no alternative but to look to their social "horizons" to re-evaluate their identities (Mathieson & Stam, 1995).

If patients feel their identity is threatened by change or adversities, this can affect their image or personal identity (Beijaard, et al., 2000). This threat can have direct implications on whether or not an illness is disclosed. Being open about a chronic illness can lead to individuals

being stigmatized. Corrigan & Rao (2012) studied mental illness disclosure and the process and the individual and social steps that influence disclosure.

Illness Disclosure

This is the age of information. This is a time where controlling information is vital to someone suffering from a chronic illness (Stutzman, Capra, & Thompson, 2011). Disclosing an illness to colleagues, administration, parents, or students is a complex choice. The person must consider the numerous factors that play into that choice. According to Chaudoir and Fisher (2010) disclosure is a powerful choice that shapes almost every part of a chronically ill person's life. One of the earliest definitions of disclosure is offered by Jourard (1971): self-disclosure is the "act" of making yourself manifest, showing yourself so others can perceive you (Chaudoir & Fisher, 2010, p. 5). Disclosure can be defined as a process that allows people to let themselves be known to others by exchanging any information that references the self (Derlega & Grzelak, 1979; Mikulincer & Nachshon, 1991). Disclosure can be verbal or nonverbal. Verbally disclosing reveals private thoughts, feelings, attitudes and beliefs to others (Vogel & Wester, 2003). Nonverbal, for example, can occur through observances from others when people take medications, time off work, or have the need for modified working conditions. Disclosure in the workplace could be necessary if the illness involves a modification to the workspace or to effectively manage the illness (Munir, Leka, & Griffiths, 2005). Research has found that disclosure causes a vocational and psychological dilemma when people choose to conceal their illness or disability (Allen & Carlson, 2003). This can mean you will suddenly have to deal with feeling that the "self" has been devalued. A person may feel that their job will be jeopardized.

Existing research (Ragins, 2008; Verrecchia, 2001) presents models of disclosure consisting of individual and social factors and individual and social outcomes. A simple model compiled from this research is presented in Figure 2. This model proposes that individuals contemplate disclosure first then go through the process of analyzing the risk and benefits before actually disclosing. Each component will be discussed in the following sections, while risk and benefits are discussed within the content of each section.

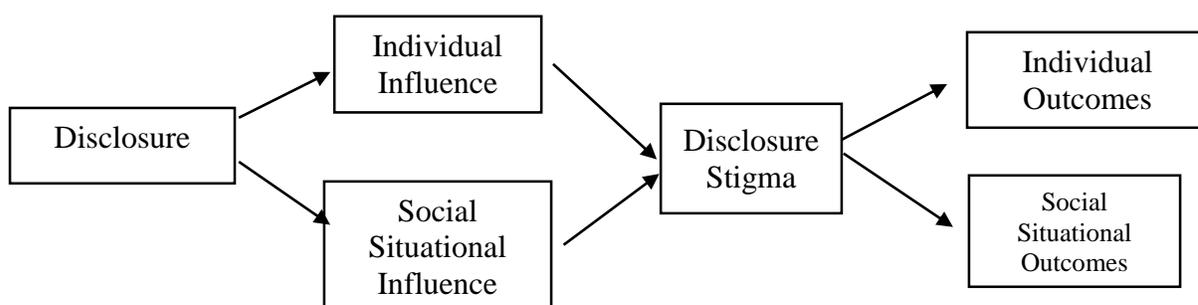


Figure 2: Model of Disclosure

Individual Influence

Individuals struggle with disclosure because it can be a double-edged sword. Individuals feel that disclosing will be a benefit because they will receive support, feel loved, accepted, and gain information about their illness (Greene, 2000). The risk of disclosing can send individuals into an identity crisis. They feel they will be rejected, discriminated against, and their basic needs may be threatened (Vickers, 1997; Greene, 2000). The benefits of disclosure must outweigh the risk before individuals decide to disclose (Black & Miles, 2002). People who have

an invisible disability have a choice whether they want to disclose or not. Disclosure difficulty arises when people believe that the responses they get from sharing will be negative (Joachim & Acorn, 2000). People do not want to be discredited or worry about employer reactions (Vickers, 1997). Individuals believe that their illness is private (Charmaz, 2002). Therefore, it is important for them to protect themselves and control who, what, when, where, and how information is issued. Disclosure then becomes a planned event with the purpose of telling people about their condition (Chaudoir & Fisher, 2010). Individual factors tell an incomplete story of disclosure. People are part of social situational groups that are also factors to consider when choosing to disclose.

Social Situational Influence

Social situational factors tend to have an effect on disclosure. For example, Davis & Franzoi (2013) found that disclosure is greater when more intimate topics are discussed in a social setting between friends. Social status is another factor that impacts disclosure. Choosing to disclose is influenced by factors such as stigma, liability of illness, access to accommodations, and social support (Munir, Leka, & Griffiths, 2005).

Disclosure of a hidden illness to a confidant or group can be beneficial if said confidants react in a supportive and positive way. Disclosing in a social setting, such as work, may be necessary because the illness may require illness management during the workday (Munir et al., 2005). Social support is an influential factor for disclosure. Chronic illness can be extremely stressful. Having a chronic illness can be psychologically demanding coupled with a career that is intense can lead to stress related absences (Clair, Beatty, & Maclean, 2005; McGonagall & Barnes-Farrell, 2013). Disclosure can happen in situations where the individual does not feel a risk or where it may be unavoidable. This can happen when a person must announce that they

cannot do certain things because of the illness (Joachim & Acorn, 2000). For example, when returning from a doctor's appointment where the information or diagnosis was or was not favorable, emotions could run high and disclosure may be a result of a spontaneous utterance (Kleinman, 1988). The utterance makes disclosing unavoidable.

Social situational disclosure can be assessed in terms of risk and rewards. Researchers have argued that social interaction, such as, disclosure can be analyzed in terms of an individual's strategies they use to achieve risk/reward goals (Miller & Read, 1987). Individuals choose particular strategies of self-disclosure across many social situations. The "rules" or knowing the social interpersonal context effect disclosure. Knowing who to trust with private information is a fundamental consideration when revealing an illness (Petronio, 2002, Stutzman, Capra & Thompson, 2011). In social settings, gossip is a factor that one must consider. Social situational interactions are no longer limited to physical contact. Contact through social media adds another degree of apprehension when deciding to disclose. In a study conducted by Stutzman, et al. (2011), the researchers found that social network sites add risk to those who choose to disclose.

Goffman (1978) noted that when a person socializes they typically conceal parts of themselves to give the impression of being infallible. Although people have the ideal qualifications for performing the roles they are in, having and disclosing a chronic illness could change others general impression of said qualifications.

Disclosure Outcomes

People risk being stigmatized or targets of rejection, therefore, disclosing can either be a benefit or cause harm (Chaudoir & Fisher, 2010). People tend to ask themselves is: what function will disclosure serve or what is the motivation behind disclosing? Individuals may be

motivated to disclose because it may create pleasant or rewarding outcomes (Davis & Franzoi, 2013).

Disclosure stigma. The word stigma is frequently found in literature in association with chronic illness conditions (Joachim & Acorn, 2000). Unlike all other illnesses, such as a cold, a broken limb, or allergies, chronic illnesses require long term treatments and sometimes accommodations in the classroom (Goodwin & Morgan, 2012). Often times a chronic illness can cause fatigue, sudden onset of nausea, or dizziness that can cause teachers to take time off of work or to leave early (Bury, 1982; Corbin & Strauss, 1990; Williams, 2000). When colleagues are aware that you have an illness, it can be stigmatizing because the illness is not visible you can be seen as a hypochondriac when you mention how you are feeling on any given day. Different types of illnesses carry different symbolic connotations (i.e. visible and invisible illnesses) (Williams, 2000). Chronic illnesses are often hidden from normal view, but the symptoms may be seen by colleagues and administrators as interfering with the work day. These diseases often make it difficult to balance the illness and the demands of an academic career (Beretz, 2003).

As a society, we equate good health with being fit for employment and being able to do our job, society finds it hard to separate illness from ability. Goodwin and Morgan (2012) found research on stigma that generally suggests that concealing a condition can be stressful. Although there are laws such as, the American with Disabilities Act of 1990 (1990), requires employers to provide reasonable accommodations to employees with disabilities (U.S. Equal Employment Opportunity Commission, n. d.), there is no provision that protects from the sigma and covert discrimination that may come from colleagues and administration. Individuals are often characterized as normal or not normal. “Normals” do not possess any visible stigmatizing

attributes, they often believe that individuals with stigmatizing illnesses are not human (Joachim & Acorn, 2000).

Individual Disclosure Outcomes

Openness about an illness may bring about public discrimination. Corrigan & Rao (2012) found, for example, people with mental illness, disclosure brought about a sense of power and control over their lives. Individuals disclose as an attempt to reclaim their lost identities. Psychological resilience is the process of successful adaptation despite challenging circumstances (Butler, Koopman, Azarow, Blasey, Magdalene, DiMiceli, Seagraves, Hastings, Chen, Garlan, Kraemer, & Spiegel, 2009). Individuals who disclose for self-image reasons demonstrate low psychological benefits than individuals who disclose for compassionate reasons (Garcia & Crocker, 2008). When an individual chooses to share their protected personal information and shift it to a social context then disclosure moves from individual outcomes to social situational outcomes.

Social Situational Disclosure Outcomes

If individuals sensed that disclosing their illness would cause someone to become upset, they would either modify or withhold information (Dewar & Lee, 2000). Information is also withheld if the individual sees themselves as being below social standards. Falling short of societal standards can cause a split between society and self which can lead to self-hate (Goffman, 2009). Society can then stigmatize the person and attach a negative social label to them. This can taint a person's self-identity and can also be a cause of self-hatred (Alonzo & Reynolds, 1995).

Self-disclosure can also be a reward. Cozby (1972) characterizes self-disclosure as a social reward. People are motivated to disclose to society when self-enhancement is a motive.

People have a fundamental desire to expand their self-concept to include positive connections with others. They want to gain the feeling of belonging to a larger group (Ashforth, et al., 2008). It is human nature to want to be part of something greater. The reward is improved self-esteem and being positively viewed by others. Individuals systematically strive to promote the perception that they are a “worthwhile person” (Ashforth, et al., 2008). Disclosing can enhance their worthwhileness by promoting their self as a strong person that can persevere through adversity.

Identity loss or change often accompanies an illness diagnosis (Vanderford, Jenks, & Sharf, 1997). A person with a chronic illness may mourn the loss of his or her identity (Vanderford et al., 1997).

Identity Reconstructed

Identity is not a solo task. Identity creation involves groups or collectives connected to social institutions (Danielewicz, 2014). Creating or reconstructing a new identity also involves adding a new discourse that comes along with it (Charmaz, 2000; Williams, 2000). Individuals do not have the luxury of refining and incorporating this new reality autonomous from everything around us. Individuals with chronic illnesses are forced to find ways to negotiate the social world to recover one’s identity it is vital to locate methods to bear this loss (Dewar & Lee, 2000). Individuals assign goals for their reconstructed identities (Charmaz, 1995).

Yoshida (1993) suggest that the reconstruction of identity after being diagnosed with a chronic illness is much like a pendulum, the reconstruction swings back and forth between the nondisabled and disabled self. Based on an individual’s new situation, some aspects of the identity become lost, redefined, or a new identity is created altogether (Asbring, 2001). Creating a new identity involves a transformation on the part of the individual. This transformation can

cause conflict with the old self as the new reality has not been fully accepted. While the illness itself is not denied, the consequences of the illness are not affirmed. Women try to retain their pre-illness identities by maintaining their social networks, continue working, and living much the same as they always had (Asbring, 2001).

Concealment is a strategy individuals use to cope with the loss of self-identity (Allen & Carlson, 2003). The self, attempts to cope with the impact of an illness by minimizing the effects on identity. People begin to “struggle against illness” (Hubbard, Kidd, & Kearney, 2010). People repair the loss of self by re-engineering themselves in order to regain control of their lives and reconstruct a pre-illness sense of self and identity (Charmaz, 1995). The ultimate goal of finding a lost identity is reconstructing that identity to normalize one’s life.

Normalization is a form of coping in that individuals compartmentalize the illness so that the effect on the identity is slight (Williams, 2000). People attempt to normalize by keeping their pre-illness lifestyle, by maintaining as many pre-illness activities as possible, and/or incorporating their illness into the new lifestyle (Hubbard, et al., 2010). A large part of rebuilding one’s self-identity is the management of impressions that society, you believe, will form as you interact in social settings.

Impression management (Leary & Kowalski, 1990) is the process by which people control the images others form of them. This is how the self presents to others. To some degree, it also involves the efforts people make to control their impression of themselves (Greenwald & Breckler, 1985). Morris (2004) suggest that as people engage in the process of self-reinvention, narrative storytelling can be used as part of a rehabilitation method.

Although one never fully recovers their identity, they face reality and learn to manage the circumstances. There is always an ongoing uncertainty about health, life quality, and the

potential for additional loss all due to the magnitude of the life change that occurred (Dewar & Lee, 2000).

Chapter Summary

Taking ownership of a chronic illness can cause an epiphany. The epiphany is a life turning moment that alters an individual's self-concept and leads to new levels of insights (Karnilowicz, 2011). Individuals can decide to take control over the event or let the event take control over the individual. Living with the illness requires the self to constantly reconstruct itself throughout the experience of the illness (Frank, 1995). The effects from illness can be unconquerable, but one can gain control over the effects by taking some ownership of the illness (Karnilowicz, 2011). A positive self-identity can help an individual through the ownership process. Motivation to continue life, as usual, is a key factor when engaging in your health and self-identities. You can gain control of self by letting go (Sharpe et al., 2013).

In the next chapter, I will discuss my research methodology for this study. This study focused on autoethnography. I explain what autoethnography is and why it was my choice as a research method.

Chapter 3: Method

Model of Epistemology and Inquiry was the name of the class where I discovered what kind of researcher I became. Who knew scholars could research their experiences? After reading an article on autoethnography and cancer, the topic hit me like a gut punch. Reading about someone else's experiences opened up a whole new avenue of research for me. How perfect this thing was called autoethnography when I am seventeen years out from a bone cancer diagnosis, sixteen years out from a kidney disease diagnosis, and ten years since my transplant.

This study examined and addresses the insufficient understanding of the identity crisis I, and possibly other teachers go through when suddenly diagnosed with a chronic illness. This study examined my own experiences teaching after being diagnosed and treated for an osteosarcoma, dialysis, and subsequently a kidney transplant. Being diagnosed with several chronic illnesses felt like death, death of my self-identity. My self-identity was gone and I experienced grief as if a loved one had passed away. This study is meant to share my experiences on losing my identity as a teacher and disclosing my illness in the workplace. I never thought that I would ever have to confront my illnesses but I believe that I needed to tell my story and possibly help other teachers who may face a chronic illness.

This study addressed gaps in the literature about how a teacher's identity is restructured through disclosure after being diagnosed with a chronic illness. It explores the role disclosure has on restructuring the identity of a teacher. It brings my challenges as a teacher living with a chronic illness to life in an effort to illuminate a growing number of teachers who are facing chronic illnesses, Méndez (2013) states, "an important advantage is the potential of autoethnography to contribute to others' lives by making them reflect on and empathize with the

narratives” (p. 282). This study provides teachers with hope that they too can continue to teach and rebuild their lost identities.

Chapter three will provide information on the methodology, participants, how data was collected and analyzed, and limitations to the study.

Methodology

Qualitative research has been defined, characterized and used by many researchers, this is due to the fact that it covers many research disciplines (Snape & Spencer, 2013). Denzin and Lincoln (2011) offer the following definition:

“Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that makes the world visible. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.” (p. 3)

Qualitative studies tend to vary in their research designs. Instead of being fixed they are flexible and do not follow a strict sequence, but there should be a reflexive process throughout the study (Maxwell, 2013). In qualitative research, researchers make the assumption that no data is unimportant, every detail is recorded and thought to make contribution to ultimate understandings (McMillan & Schumacher, 2010). Qualitative methods are used when the goal of the researcher is to provide “rich descriptions of complex phenomena.” (Sofaer, 1999, p. 1101). In order to design a qualitative study, the researcher should know a few factors such as; the ontology, the epistemology, the purpose, the goals, and the audience, to name a few (Snape & Spencer, 2013).

As a teacher living with several chronic illnesses, I realize my experience as a teacher may not be unique, but my experiences as a teacher with a chronic illness will add to the body of knowledge. The specific phenomenon I want to study is my experience I had as a new teacher,

in a new school, with a new chronic illness, disclosing to others and how my identity was lost in the process. In thinking about creating this study, I sat down and began to reflect on the questions I had from an insider perspective. A useful qualitative research method to analyze one's experiences is an autoethnographic study (Ellis & Bochner, 2000). The question that I continued to return to is: What is it like to be a teacher who is experiencing chronic health issues while continuing to pursue a teaching career? That question further led me to think about: What were and still are the concerns I have about disclosing my chronic illness diagnosis? These questions are not the central research questions, but they guided my decision to settle on autoethnography as a research method for this study. Using autoethnography as a method helped to answer how my identity as a teacher changed as a result of a chronic illness.

Methods

This study is an autoethnographic study. An autoethnography is a qualitative research method that enables a researcher to recall their experiences in order to express themselves and write in a highly personalized style (Wall, 2008). Authors use their own experiences to look deeply within themselves and reflect on those experiences (Holt, 2003). An autoethnography intends to link the cultural and the personal in nontraditional forms of inquiry and expression (Ellis, 2004; Wall, 2008). Jones, Adams, and Ellis' (2016) autoethnography handbook states:

“The following purposes are what make autoethnography, as a method, unique and compelling. They include: (1) *disrupting norms of research practice and representation*; (2) *working from insider knowledge*; (3) *maneuvering through pain, confusion, anger, and uncertainty and making life better*; (4) *breaking silence/(re)claiming voice and “writing to right”*; and (5) *making work accessible.*”
(p. 32)

Writing an autoethnography can alter the writer's perceptions about past events and change your view of the future (Custer, 2014). My autoethnography used my personal narratives presented in story form that incorporated my experiences and reflections (Ellis, Adams, & Bochner, 2011).

Autoethnographies have been abound with criticism (Jones et al., 2016). Authors of these documents have been told that these narratives are not rigorous enough to be thought of as a journal article (Holt, 2003). Another criticism is that these narratives evoke unpleasant feelings and exposes the author's inner thoughts that require honesty (Méndez, 2013). This honesty can lead to some ethical difficulties. This honesty is the heart of the narrative story. The purpose of the narrative is to emancipate and gives others the right to tell their story (Richards, 2008).

The process, data gathering, the psychological journey of the author and time all added to the rigor of my narrative. My narrative provides rich experiences into my life and enhances the study. While some traditional researchers dismiss autoethnography as an invalid theoretical framework, authors work rigorously to establish their ability to relate one's personal experiences to the broader social experiences of others (Allen, 2015). The ultimate goal of writing this autoethnography was to find my "epiphany".

Autoethnography was the method that works for the type of questions I posed because the questions are about myself. This form of ethnography uses the experiences to understand the self (Balaam, 2011).

Description of Participants

This research project involved a personal narrative, this narrative came from me as the central participant. The personal narrative was constructed from my experiences and how chronic illness has impacted my teacher identity. As of 2012, 117 million people had one or more chronic illness (Center for Disease Control, 2017). Each year there are more than 1.5 million cases of cancer diagnosed in the United States each year (Center for Disease Control, 2017) and an estimated 4.9 million Americans have chronic kidney disease that is more common among women than men (National Center for Health Statistics, 2017). I am a 46-year-old

African American woman who is also, an assistant principal, a teacher, a wife, a daughter, and a step-mother. These are just a few of my identities that shape my story. This story comes out of me being sick and writing about those experiences. “The autoethnographer is first and foremost a communicator, a storyteller, or a performer” (Bochner & Ellis, 2006, p. 1). This research study is about exploration, not about proving the research questions right or wrong, therefore I am the primary participant in this study.

Data Collection

My data collection started with writing about my personal life experiences. As I wrote I reflected on the feelings, emotions, and attitudes that the writing evoked. The majority of the data came from my writings. I journaled daily. The journaling started in November 2017 and concluded in July of 2018. Reflection and writing about the process was part of my autoethnographic data collection (Wall, 2008). Writing in this manner came at a cost. As I begin to emancipate myself from the chronic illness that had consumed me, the experiences I wrote about had a profound psychological and emotional effect on my life. Duncan (2004) cautioned against emotional writing and encouraged reflection to increase honesty. My reflections provide a true and honest account of the emotions I felt at the time.

Autoethnography is interested in process and understanding through words. From the words come meaning. I gathered countless hours of data through journaling, Facebook memories, pictures, and medical records. In a traditional autoethnographic study data is collected through interviews, documents, artifacts, participant observations, and research diaries (Wall, 2008). Data collection in an autoethnographic study is not always done in isolation from data analysis. Often times the data collection process is intertwined with the data analysis process (Chang, 2016). Participants’ past experiences are selected on the bases of the research

focus and how they fit the data collection criteria. I wrote about old and new memories and of feelings and thoughts as they happened. My writing was a chronological account of those memories. Another source of data was collected from my notes and journals. Based on the data analysis central themes were developed. Data collection traditionally comes from the researcher's artifacts, but most autoethnographers do not rely solely on memories as data for their work (Ellis & Bochner, 2000; Duncan, 2004; Wall, 2008) therefore, in order to look at my experiences analytically and consider the way others my experience my epiphany, I used reflexive interviews to gather in depth information about my experiences (Ellis et al., 2011).

Reflexive dyadic interviews. Reflexive interviews was another procedure I used to collect data. Interviews provide in-depth information pertaining to participants' experiences and viewpoints of a particular topic (Turner, 2010). Ellis, Adams, and Bochner (2011) explain reflexive interviews as:

“Reflexive, dyadic interviews focus on the interactively produced meanings and emotional dynamics of the interview itself. Though the focus is on the participant and her or his story, the words, thoughts, and feelings of the researcher also are considered, e.g., personal motivation for doing a project, knowledge of the topics discussed, emotional responses to an interview, and ways in which the interviewer may have been changed by the process of interviewing.” (p. 276)

Ellis and Bochner (2000) suggest that the researcher do intensive interviews that include five to six participants that you interview a number of times in order to build a relationship and trust. For this research study, I chose to interview myself three times over the course of a week (see Appendix B). Each interview lasted between 30-45 minutes in length. I constructed each question carefully in order to allow myself to dig deep into the experiences and/or my knowledge to collect the maximum amount of data possible (Turner, 2010). The interview questions were open ended to allow myself to talk about my chronic illness and teaching experiences. There

was no need to develop a system to protect my identity as I was the sole participant in the interview.

After each interview, reflections on the interview experience was recorded in an online platform. The online documents become my simple research diary (Nadin & Cassell, 2006). Some of the comments will include reflections on how well the interview has gone, what I felt during the interview, and what dominant themes may come out of the interview (Nadin & Cassell, 2006).

Data Analysis

Thematic analysis was used to interpret the data collected. According to Braun and Clarke (2006), thematic analysis is the first analysis a novice researcher should learn because it provides a foundation for future more complex types of research. Thematic analysis can be characterized as placing data into categories to develop themes. Braun and Clarke (2006) define thematic analysis as a method for identifying, analyzing, and reporting patterns and themes in data. Thematic analysis is a six-step process (1) succinct labels (coding), (2) searching for potential themes, (3) construct and reviewing themes, (4) describe and define themes, (5) summarize themes, and (6) writing the analysis, interpret the patterns (Attride-Stirling, 2001).

The first step to data analysis was reading my narratives, the medical documents, Facebook post, and the transcribed interviews. During this time Maxwell (2013) suggest that the researcher write notes on what ideas about categories and relationships emerge. I took this suggestion and wrote notes while reading the narratives and interviews. Coding was used to effectively analyze the data. Coding was accomplished by using the online program Dedoose. Following guidelines from Gorden (1998), I utilized Dedoose to code the data and produce

categories. Before beginning to code data, it was important to remember the research questions. This helped to keep me focused on relevant information and codes (Stuckey, 2015).

Trustworthiness

There are four criteria that Lincoln and Guba (1986) suggest qualitative researchers should use in pursuit of trustworthiness: (1) credibility, (2) transferability, (3) dependability, and (4) confirmability. Ensuring credibility is one of the most important factors when establishing your trustworthiness (Lincoln & Guba, (1986); Shenton, (2004). To obtain transferability, a thick descriptive narrative was developed about the content (Lincoln & Guba, 1986). Thick description goes beyond just writing what a person is doing, it presents detailed context full of emotions, attitudes, beliefs, history, and it establishes the significance of the experience (Ponterotto, 2006). “Thick description builds up a clear picture of the individuals and groups in the context of their culture and the setting in which they live” Ponterotto, 2006, p.541).

Dependability and confirmability are established through reflexive journal. All decisions and rationales made throughout this study and the design was recorded and reflected upon in a reflexive journal (McMillan & Schumacher, 2010). The reflexive journal was kept on paper and electronically. Audibility is another process that was used. Audibility is techniques and decisions about how data will be managed and maintained throughout the study (McMillan & Schumacher, 2010). These decisions were also written in the online journal.

To address trustworthiness, I used reflective commentary after each interview session. Reflective commentary was used to journal and record my feelings, reactions, and thoughts after the sessions (Shenton, 2004). This commentary and journaling helped me to identify emerging patterns to inform and guide my results. A summative content analysis approach was used to further explore patterns and themes that emerged from identifying the frequency of the

appearance of particular words in my written material. Researchers in the health field use this approach to analyze manuscripts either by hand or computer (Hsieh & Shannon, 2005).

Ontology. Ontology is concerned with the nature of reality (Ponterotto, 2005). The ontology of an autoethnographic study is to emancipate. My research, helps others see how I developed a “more sophisticated” (Seale, 1999) understanding of teaching with a chronic illness. This study shows a range of different realities (Lincoln & Guba, 1986).

Axiology. Axiology is concerned with the role of the researcher (Ponterotto, 2005). In autoethnographic research the researcher is the main instrument of data collection. The researcher’s values and lived experiences are part of the research process (Ponterotto, 2005).

Epistemology. Epistemology is concerned with the relationship between the researcher and the participants, the “would-be knower” and the “Knower” (Ponterotto, 2005). In autoethnography the epistemology is the notion of “lived experiences”, subjectivity, and meaning within contexts (McIlveen, 2008). Therefore, I wrote my narrative from my personal truth and the truth of the experiences.

Researcher Bias

Bias in research is inevitable, it is up to the researcher to do as much as possible to limit that bias. My bias began as soon as I picked this topic. My personal beliefs and values are reflected in the topic, methodology, and in the interpretation (Mehra, 2002). Story interpretation is another bias. Based on my own experiences, I could have misinterpreted the experiences of because of my own biases.

Assumptions

Disabilities are no longer viewed as a defect (Creswell, 2013). Studying a disability can change society’s assumptions on how you are viewed. The goal of writing an autoethnography is

to emancipate. By researching through a disability interpretive lens, I humanized the disability and it is no longer seen as a defect (Creswell, 2013). I found the epistemology to contain multiple truths and while constructing the narrative reality was subjective.

Limitations

This study will not be applicable or generalizable to every teacher who has ever been diagnosed with a chronic illness. An autoethnographic narrative analysis has no right to be generalized, but its potential to stimulate a reader through personal meaning and stimulation allows one to accept this limitation (McIlveen, 2008). When writing an autoethnography on chronic illness, you are writing about the self. I collected data that was sensitive and often involved stories about traumatic events in my life. Ellis and colleagues (2011) state that when researchers conduct and write research, others are implicated in the work. When using personal experiences, researchers write themselves into the experience and often implicate others who are close to them (Ellis, 2004). If the researcher mentions a husband or a child it may be difficult to protect that person without altering the meaning of the story (Ellis et al., 2011). While others were implicated in my narratives, I took great care to change names, dates, locations to protect identities but not to alter the meaning of the story. Data that is collected is never an exact representation of the conversation that took place (Fink, 2000). Unintentional mistakes in translation can occur when transcribing interview data. In this case, I was able to clarify my understandings of the interview data through reflective conversations with myself.

Chapter Summary

The purpose of this autoethnographic study is to emancipate, researching about yourself can be freeing and therapeutic. Can my experiences as a teacher, wife, cancer survivor, dialysis patient, kidney transplant recipient, and doctoral student provide therapy to others who may be

experiencing the same thing? My experiences may not offer therapy but may encourage others to write out their own profound experiences and reflect on how these experiences have shaped their identities. Clough and Nutbrown (2012) state in a small survey they conducted that, student's research to bring about change, and self-development for greater understanding. I believe that I choose to research my experiences as a teacher with a chronic illness for the purposes of self-development. I challenged my own understanding of the world around me. I do not know if my research will change the world, but I do hope that it will at least inform readers who are on a similar journey. I hope someone will find solace from no longer being lost.

Chapter 4: The Chronicle

-Some people think that to be strong is to never feel pain, in reality, the strongest people are the ones who feel it, understand it, and accept it. -Unknown

A chronicle is a factual written account of important or historical events in the order of occurrence (Merriam-Webster's Online Dictionary, n. d.). The following is the chronicled written account of a teacher with multiple chronic illnesses. At the time of my diagnosis, there were likely multiple teachers battling in similar hospitals all around the world. This is the chronicle of one of those teachers. Joseph Campbell researched thousands of stories and found a common thread that every hero follows the same journey (Campbell, 2008). "That trauma is such a transformative experience, those impacted gain unique perspectives and the courage to effect change (theshaderoom, 2018)." This chronicle will be my journey into, through, and beyond the trauma of being a teacher with multiple chronic illnesses. The names of places presented in this chronicle are pseudonyms, fictitious names intended to conceal places that I wish to remain anonymous.

The Dream

I had always known I wanted to be a teacher. I knew who I was going to be. For as long as I can remember, I have always wanted to be a teacher. All I knew was that I wanted to teach. Teaching is a privileged, not just a job. I enjoyed teaching so much, I even played school with my dolls and used a television guide as my scantrons. I loved learning, so teaching was a natural choice. Teaching also allowed me to enter a world of privilege that for so many women of color that world is closed off. I wanted to be considered privileged. As an African American woman, only an education would get me there, at least this is what my grandparents had always told

me. All through high school, my main goal was to go to college. I knew that I was going to go to junior college and then transfer to a State University. That is exactly what I did.

Education is and always has been the basis of the individual I continue to become. I would become a teacher. High school told me I would be a teacher. College, though, had other ideas and informed me I was going to work in the financial district. College courses confirmed that. In my twenties, I was not interested in a long college stay and had strayed away from Liberal Arts because there were too many classes to take. Business Administration sounded a lot better. Plus, that seemed more lucrative than my life-long dream of becoming a teacher. Business, not teaching, would raise my social status. A six-figure salary would grant me passage into a hidden world. It would give me privilege, privilege that I never thought I had. When I graduated, business finance was my first stop. I outfitted my identity with clothes to do finance work. I dressed the part. I went to work in an office. I could not get enough of wearing high heels and business attire. Playing dress up every day is just as fun as it sounds. Soon that dream was not enough. Working at a place that did not allow me to instruct and shape young lives did not excite me. Being stuck in an office no matter how much money I could have made just was not my dream. I thought that a desk job making six figures would make me happy, I was so wrong. Finally, in 1998, I applied for my first teaching job. I was about to realize my life's dream. No more using the television guide to scantron stuffed animals. I can now scantron real students. Let the scantroning begin!

The First Catalyst

Before I was diagnosed with an osteosarcoma, running a marathon was the next big step in my young life. The path to run a marathon was clear and on the horizon. I used to weigh over 200 pounds, depressed, and not feeling very good about myself. Fate smiled upon me when I

met someone who was a fitness guru. The decision was made that it was time to get fit. The compromise to getting fit occurred for two reasons: (1) living in southern California, home of the beautiful people and I wanted to be one of the beautiful people; and (2) running was becoming my passion. I was outgoing, in college, and I loved to go out to have fun and party. Getting fit gave me a new personality. Restrictions being placed on my life was not in my future, riding the wave of success was. You never stop to think about when the party would be over. I applied for a gym membership. I took full advantage of that membership. Running added just the right amount of enthusiasm into my day. After a long day of teaching, going to the gym and running helped to reduce stress. Not only was I running at the gym, riding my bike, and running on the beach became the norm. As I continued getting fit, I could see that I would soon be ready to find a short marathon to test out my skills. Who knew that this decision was a foreshadowing of the marathon of events to come? Enjoying running, being outdoors, teaching, and making an impact on students' lives exceeded my expectations and was preferable to working in an office ten to twelve hours a day.

Fall 1998

The day I started teaching was the day my life changed forever. I had finally found where I belonged. My identity was set. I was teaching, which by society's standards, is a respectful job. Society would notice that I had taken my place among the ranks of teachers and be proud of my accomplishments. Teaching was worth my college degree. Being full of spirit and grace, it was my mission to be the best teacher they had ever seen. Teaching at an institution where principals, who later became role models, teachers, and students all resemble me, laid a foundation for learning and growing. Score! The years into and through 1998-2001 became the catalyst for the best and worst years of my life. It all began in September 1998. Elementary

School became the battleground. It was also for the first time in my life I had medical insurance and I did not even need it. That was the best part.

My first teaching experience was just that, an experience. It is difficult enough to be a first-year teacher, but to also start the school year late, adds to the gargantuan task ahead. Being a brand-new teacher, there was no support, no supplies, and I had no teaching skills. Guiding myself using the teacher's guides was basically how teaching occurred in my classroom. Turning pages seemed like the best approach. Somehow it all came together and the students started learning. Before starting the teaching job, I had enrolled in a master's program for teaching. Somehow, I thought that was how I would get a teaching credential. I should have researched that one a little better. So, my days consisted of teaching, school two nights a week, and training for a marathon. The joy in my life came from teaching and working on my master's degree. Life was exulting. Jubilation and merriment were how I described teaching. Students come to the class as empty slates waiting on me the teacher, to fill them up. When you see their eyes light up when they get a concept, there is no better feeling. I felt I had accomplished a great deal when I left the classroom every day.

The hole. One day, while walking students out to the bus, I took a shortcut through the grass and stepped in a hole. I buckled a bit, but I did not think anything of it. Later that evening I went to the gym like normal. During the night I had an unbearable ache in my left leg. I popped a pill and went to sleep. For the next few weeks this routine continued, teaching, going to the gym, and popping pills. I was losing weight and feeling good about myself. Slowly over a course of several months, my workouts began to be unproductive. My usual five-mile run dwindled down to a slow saunter. Pill popping continued. I convinced myself that the pain was all because I had started a new job where being on my feet all day interacting with the students

was part of the teaching protocol. Pushing through was my only option. Walking more, running, and no longer wearing heels on a regular basis was my rationale for the pain I was feeling. I did not think much of it until I began struggling during my workouts. How odd it was to go from running to walking slowly. I was winded in a matter of minutes. Still, I did not think anything was wrong.

Finally, in May, the pain became unbearable and running was no longer a choice, I went to the doctor. The initial diagnosis was that there was a lesion on my left knee. The doctor prescribed more drugs and informed me that it would require a small surgery. The procedure would consist of cleaning out the lesion and packing it with cement. Within a few weeks, I would be able to return to work.

Spring 1999

The initial lesion diagnosis was in May of 1999. School was coming to an end and since it was going to be a small surgery, I would be able to take care of it over the summer and would not miss any work. This was important because I did not want to miss any time teaching. The first surgery occurred in early June of 1999. Arrival at the hospital was uneventful. This would just be a routine procedure, nothing to worry about. The last time I had been in a hospital for surgery was in the 6th grade having my appendix taken out. All I kept thinking was do I have to get on that cold steel slab again? I was prepped and waiting for it all to begin. I was calm because it was going to be a small surgery. While in the operating room, I took note of my surroundings. The slab was not cold, but a skinny table that felt like I was going to fall off of. The last words I remember hearing from the doctor were, "If you wake up quick, it is not just a lesion." I did not have time to panic because before I knew it, I was awake again. Did I even go to sleep? My internal thought: Damn! It is not just a lesion!

Osteosarcoma. American Cancer Society (2017) defines bone cancer as cancer that forms in cells of the bone and begins to grow out of control. The National Cancer Institute (n. d.) defines bone cancer as cancer that forms in cells of the bone. This type of tumor occurs in youths under the age of twenty-five. I had just turned twenty-six, but the tumor could have been growing for months. Bone cancer is rare, but osteosarcoma is the most common type of cancer in the bone. Intermediate-grade osteosarcomas are the most uncommon. Osteosarcoma is a musculoskeletal tumor often localized in the knee (Toepfer, Pohlig, Mühlhofer, Lenze, von Eisenhart-Rothe, & Lenze, 2013). It accounts for only 5% of all osteosarcomas and is localized on the proximal tibia (Toepfer et al., 2013) and femur. Osteosarcomas are characterized by a painless swelling in the affected area (Toepfer et al., 2013). This type of tumor can grow for months without detection because it is often symptomless. The malignant tumor was diagnosed through a biopsy.

Summer of 1999

I cannot remember the exact date, sometime in June, but I can remember the exact moment the word cancer was uttered by the doctor. It was a regular California summer day. I was on crutches which meant my uncle had to drive me to the hospital. The results of the biopsy had come in. The only reason why he had to drive me was because at that time my car was a stick shift and you need two feet to drive a stick. As we were driving all I could think about was, what was the doctor going to tell me? I remember thinking back two weeks earlier when I went in for the first of many surgeries to come. After being wheeled into the operating room the doctor said, "If you wake up quickly, it is not just a lesion. I will never forget how quickly I was awake. Here today, driving down the road to hear the outcome, felt like I was found guilty of an unspeakable crime and now I was headed for sentencing. We arrive at the hospital, park, and

saunter inside. Sitting in the waiting room making small talk with my uncle did not ease the anxiety. Small talk is just a way for us not to talk about the obvious or the not so obvious. It is just a matter of perspective when you are in a waiting room for a lesion that may not be a lesion. I was called back to the doctor's office and the doctor, who looked like a celebrity by the way, started talking. What did he say you ask? I am not sure. I only heard one-word CANCER. Cancer, the big C, death, it is all over, badda boom, badda bang, the fat lady sang, that is exactly what I heard. Up until that point, I did not have any symptoms. Up until that point, my knee was fine. As soon as the doctor uttered the word Osteosarcoma, cancer that mimics a benign tumor, my knee swelled up like a grapefruit. It reminded me of a person who is driving home and has to pee, you are fine until you round that corner to your home and all of a sudden, your bladder is about to burst. Cancer, all I can do now is ask what happens next and when would I be able to go back to work.

I had cancer! My second surgery occurred in July of 1998. It left a long scar on my beautiful left leg. From that point, I knew I would never wear shorts or short skirts again. Why, because I thought my students would only focus on the scar not the lesson. My left knee and tibia were replaced. When I came out of surgery my leg was set in a cast. The way my doctor had turned my leg caused a nerve to be pinched. When I finally came out of the cast and was put into a soft cast, I could not move my foot. What a sight to see. I was walking around the classroom with a cane picking up my leg and setting it down looking like a horse. Anything was better than having cancer and walking funny would not stop me from teaching. I would recover from surgery. I would recover from the treatment. I would return to teaching with nothing more than a soft cast and crutches.

I returned to teaching in the fall of 1999. When I left for summer break, I had not told any of my colleagues that surgery was in my future. Protocols are put into place for a reason, but no one explains to new teachers that you have to report to the district's risk management office that you had any type of surgical procedures. The principal was glad I was back but expressed concern that I had not told anyone. The principal sent me to risk management and I obtained clearance to return to teaching, crutches and all. Returning to teaching supported my recovery and a return to commonplace. Teachers welcomed me with open arms. Teachers at the school were more than willing to help with decorating the classroom. The first month was not easy. I was grateful for the wonderful teachers at my school. I felt the support from the community. Teaching in a soft cast and a crutch, caused me to sit down a lot. Students had to take responsibility for being my right hands. Through the months, progress and recovery continued. Missing a day of work was not acceptable. Teaching brought joy and solace knowing that I was cancer free. I kept myself busy so that I would not think about not being able to run a marathon. That was no longer my dream. I just wanted to finish my master's degree and obtain a clear teaching credential.

The year went on and I continued to recover. I honed my craft and learned all that I could about what it takes to be an effective teacher. I had lost a lot of weight. I could now fit into all the cute teacher dresses and pants that I could not wear before. I became the queen of flats, since I had to ditch the heels. These changes I accepted. Teaching had become my passion just like preparing to run a marathon. At this point, I was not a teacher with a chronic illness, I was just a teacher who had survived cancer.

The Second Catalyst

I was very inexperienced in teaching. I was in my in master's and credential programs, when my faith was tested again. The cancer had come and gone. I was able to walk with very little pain. I had not been feeling quite well. There was a noticeable and significant loss of appetite. Believe me, my appetite was different because I love food and food loves me. There was also a prominent increase in the number of headaches that I was experiencing. The headaches were becoming unbearable and starting to affect my teaching that I decided to visit the doctor. Migraine sufferers are common in my family, such that there was no cause for alarm. The diagnosis at that time was hypertension. Hypertension could be controlled with a regiment of pills and a healthy diet, and exercise. The doctor also ordered other tests to see if hypertension had caused any other damage.

I rarely listen to cell phone messages anymore. I can attribute that to the phone calls I received from the doctor. The doctor called and said that I had missed several appointments and I needed to be seen right away. Missed appointments are not my style, so I could not understand why I was being told that I had missed several. Now I am sitting in the doctor's office waiting for the outcome once again. The diagnosis was End Stage Renal Disease. My body went numb. Will I be able to continue working, was the only question I had for the doctor. What an odd question to ask at an odd time. What I should have been asking was and when I was going to die, could I have children, and what does this diagnosis mean? It was suggested that I might want to take a leave of absence and go on disability. This was not an option. I went to work the next day like nothing happened determined to resume life as normal.

Not Just a Case of High Blood Pressure

I was diagnosed with Focal Segmental Glomerulosclerosis (FSGS). Eventually, over time this condition led to End Stage Renal Disease (ESRD), where my kidneys stopped working altogether.

Focal segmental glomerulosclerosis. Focal Segmental Glomerulosclerosis (FSGS) is defined as some sections of the kidney filters are scarred (National Kidney and Urologic Diseases Information Clearinghouse, 2012). FSGS cannot be traced to a single disease or cause. It can be caused by infection, drugs, genetics, or an autoimmune disease like lupus (National Kidney and Urologic Diseases Information Clearinghouse, 2012).

End stage renal disease. Chronic kidney disease such as FSGS, causes the kidney to lose function overtime (Mayo Clinic, n. d.). The kidneys no longer can filter waste as they were designed to. African American are more likely to contract this disease (Mayo Clinic, n. d.). The loss of function is gradual over time. I noticed that something was wrong because I would go hours without eating, loss of appetite is a symptom, going to the bathroom became non-existent, and nausea and vomiting had become the norm.

Eventuality

Focal Segmental Glomerulosclerosis lead to a year of doctors trying to slow the progression of the inevitable, End Stage Renal Disease (ESRD). Let the medicine begin. When I was diagnosed with Focal Glomerulosclerosis my Nephrologist asked if I wanted to go on disability. The thought briefly crosses my mind, but I was only twenty-five and the thought of staying at home doing, what, nothing, for the next thirty years, seem like a death sentence more than the actual disease.

I continued to teach while being treated for FSGS. Teaching was the only normal occurrence in my life. Teaching was the one consistent identity I could count on day in and day out. More medicine, more doctors. Medication is full of side effects, and of course, I had every side effect that was written on the paperwork. Determined to give my students a great education overrode the effects from the medication. Planning lessons took the place of depression that might have leached into my spirit if I had let it take hold.

Hospital smell. There was one incident that I remember vividly. The incident led me to the realization that I was truly sick. I was once told that I “smelled like a hospital”. I actually remember stopping to smell myself and he was right, I smelled like medicine. I smelled like that rank, antibiotic, iodine, and the antiseptic smell of a hospital. I smell it every time I enter a hospital. The smell permeates my nostrils and stings with the fear that one day I too shall return. Trying my best after a knee replacement to resume being a normal teacher, I never realized that medication seeping out of your pores will cause you to smell. That day caused me great embarrassment. Life keeps it real. As real as life was, I continued to teach with the same enthusiasm before the moment was announced. Here I am teaching a great lesson on phonics and now all I can think of is I smell like a hospital. I did not know anything was wrong. I thought since I had been out of a cast for a year, that the smell of iodine could not possibly still be fresh on my leg, or perhaps it was some healing that was still occurring. I went home that night and soaked my body. I was not going back to work smelling like a hospital.

This was the beginning of another painful downfall from teaching grace. My kidneys were failing, and I was smelling like urine. The smell of urine is unpleasantly gross. The urine smell is a symptom of kidney disease. It is a buildup of urea or uric acid. Urine was seeping out of my skin. Not literally but there was a faint odor on my skin that caused me to smell like a

hospital. How long had I been smelling like this? Could other teachers smell me? Why had I not smelled myself before? I made the decision to just stay away from the other teachers.

Conversations would only happen in the mornings when I was freshly showered. It became a good idea to carry spray and fragrant lotion. Baby wipes would also become a purse staple. Can urea cause you to turn yellow? Students have no filters, I am sure they will let me know.

The Angry Teacher

That painful memory. It haunts me to this day. I take so much medicine that I still often feel like I smell like a hospital. More than anything I am so self-conscious about this that I smell myself all the time. I know the student did not say it to be cruel. Maybe that was a warning from God. Maybe that was my guardian angel prompting me to get prepared for what was to come. Whatever the reason that day I was told that I smelled like a hospital. Those words changed my world.

Side effects from medication are almost as worst as having the disease. One medication led me to contemplate leaving the teaching profession altogether. I was on a steroid that one of the side effects was mood swings. During this period that I was on the medication, I was not a nice teacher. I would be sad, angry, depressed throughout the day. I began to let my classroom management slip, my class ran amuck, and I did not do much teaching at all. I was often asked if I were feeling well, I would either cry or say harsh words. That was not me, that is not who I was. After a month I asked the doctor to take me off the medication. As I look back I do not know if that was the right decision, it may have sped up the deterioration of my kidneys, but I could not continue to be an effective teacher on it. I had no right to have others suffer because I was trying to prolong the inevitable. My identity was lost to medication.

From June 2000 through May 2001, I battled to try to stop the progression of kidney disease, knowing that eventually, I would have to go on dialysis. The doctors had already told me that I had until June or July of that year and I would have to go on dialysis. In March of 2001, I went for a teaching position in northern California. The interview for the School District went well. I would start a new job in August. A change was needed. Moving to be closer to my family would help me keep my thoughts in a safe place. I did not know how dialysis would affect my ability to work as a teacher. Deciding to move and leaving a teacher support system to be closer to a family was the right choice.

Credentialing

I was in the district credentialing program. Part of the commitment to obtain a clear credential was to dedicate three years of service to the district after you received the credential. This is a promise that I was not going to be able to fulfill. I had to go to an exit meeting. I knew I was going to be asked what my intent was. It came time for me to answer the question and I answered with a solid no. The interviewer and the rest of the class looked at me. I was not ready to disclose that my kidneys were failing, and I would have to go on dialysis. I saw the look of wow on the faces in the room. How did I just say no? I was not intending on not working for a district that had given me so much in such a short amount of time. I simply stated, it is not that I do not want to continue working for this district, I was diagnosed with a disease that would lead to me being on dialysis. I simply do not know how I was going to continue to work without the support of my family. The tears started. Not just from me but from everyone in the room. I blurted out that I was afraid that I was going to die and that I did not want to die! Rounds of hugs and apologies followed. I did not mean to put a damper on such a happy occasion. We had all just completed our program and gotten our credentials. At that moment I made the decision

not to tell anyone at my new school because I did not want to relive this day ever. I packed up my classroom after the school year was over and said goodbye to the teachers who had supported me through cancer to embark on adventures in a strange new place.

I was leaving the teacher identity I had known for an unknown teacher identity that would be changed by my new location. Instead of feeling embraced and part of a family, I felt that I would be alone working in isolation. I knew all too well that student success is built around teacher collaboration. According to DuFour (2004), teachers who are part of a professional learning community know that they must work together collaboratively to ensure learning for all. That identity was gone. Collaboration with strangers was not going to happen.

The teacher, cancer survivor, and patient identity was lost the moment I left the School. The demographics changed. I knew that I had lost my social support and connection. Decisions to leave or stay at a job required a lot of weighing of the pros and cons. I did not want to leave my students. In the three years, I had taught at an elementary school, I had grown attached to the multitude of characters that I called my students. Relationships were built with families and members of the community. The teacher identity of collaboration, inclusion, culture, and equity was constructed by the social group that I belonged to. This social group did not exist where I was going.

New Surroundings

Part of my identity died upon being diagnosed with cancer and then the other part of me died when my kidneys failed. Dialysis was going to require me to sit there for, four hours three times a week. The doctor explained that the only treatments for kidney disease was hemodialysis, peritoneal dialysis, or get on the list for a kidney transplant. I opted for hemodialysis. I made the decision because I could not imagine anyone else's organs inside of

my body. I was already suffering from an identity crisis, why further complicate things with taking on the habits of someone else (at least that was my rationalization to avoid surgery at the time, the organ was not going to change me). I did not know how hemodialysis was going to affect me. My only concern at the time was if I was going to be able to be productive at work and hopefully it fits into my schedule so that no one would find out.

Fall 2001

I have been working for the school district for many years now, but I still remember my first day. No one else was like me there, I was the only person of color. There were no other African American teachers, no one else walked with a limp, and certainly, no one else was leaving right after school to sit for hours on dialysis. Where I had come from a majority of the teachers were African American. It felt like family there. It felt like I could tell the teachers my story and be absolutely comfortable sharing it over a breakfast of grits and eggs. How would I navigate in this new world of teachers? I certainly was not going to tell them about my conditions. I wanted them to know me, Simone, not the teacher on dialysis. I wanted to establish my name, my pedigree, my teacher ways, and I wanted them to think I was a good teacher even when I did not think that about myself. Time to put on the swanky little teacher smock and teach.

There was no connection between the teachers at this new elementary school. My identity would surely change with the interactions with new teachers. I rarely spoke to the teachers. At first, I did not find a social connection with them, they were simply coworkers. I found myself doing what I could to separate myself from them. I again immersed myself in teacher dress and teacher talk. Which to some may have seemed like I was arrogant or smug. I was perceived as a mad black woman. In reality, I was just the opposite. I was not mad at all, I

was just protecting myself from them finding out the truth. I did not have that bond with them that I had with the teachers from my previous school. I did want their support. I was a private person. I just wanted to do my job, go to dialysis, and then go home to rinse and repeat.

I continued to educate myself. I would go to workshops on my own, pursue other degrees, and when I would try to share my knowledge, it was perceived as being boastful. I thought I had to gain more knowledge because that is what was going to guarantee that if I ever had to take an extended leave of absence, I would have a job when I came back because my knowledge of teaching strategies was valuable to the organization.

Teaching on Dialysis

Focal Segmental Glomerulosclerosis ultimately led to dialysis for seven years. I began dialysis in June of 2001. It was an unforgettable day. My mom went with me to the dialysis center. We were given a tour and a breakdown of what to expect. Scared does not describe the feeling when you think that for three days a week you were going to have two large needles shoved into your arms. The nurse came over to review the paperwork. She saw that I was a teacher. She asked if I wanted to apply for disability. I simply replied, no. Was there a conspiracy going on in the universe? Was I supposed to go out on disability? I was positive that there were people in the world who work and were on dialysis.

Hemodialysis lasted for four years. My life consisted of teaching, dialysis, teaching, dialysis, teaching, dialysis, again rinse and repeat. I was always mindful of teaching and working after school with students to make sure that I made it to dialysis on time, but I also wanted to be normal. To maintain the guise of normalcy, I took on an after school job tutoring. My identity was not that of a teacher on dialysis but just a teacher. Dialysis is something I never spoke about. If they only knew that I was leaving every other evening to go straight to sit for

hours on a hemodialysis machine. Four years of no real restful summer breaks or meaningful vacations became my definition of survival. I still wore my teacher outfits, only now I incorporated teacher sweaters and cardigans. Teachers love sweaters and cardigans especially the ugly ones. This was my uniform to hide the long ugly scar on my arm. How do I explain to my students what the little drops of blood that would sometimes appear on the sleeve because the vein did not completely clot?

Emergency lesson plans have a purpose. I never wanted to use emergency lesson plans, so I would make plans two weeks at a time. Who wants to go to work when all you can think of is, I hope my fistula does not stop working because if it does that means more time off work to get it de-clotted. My plans and teacher materials would be on my desk and at the end of every evening. I made sure that if something happened after the school I would not be called out by administration for not having plans for the substitute. This is something I had witnessed during staff meetings and I was going to make sure it did not happen to me. Most of my colleagues thought that I was super organized and prepared. They did not know that it was because I was scared that I would not return. I was really living a double life. I was a pretend teacher by day and a compliant patient by night. Pretend teacher, well, I felt that I fell short of devoting all my time to my students. I would often volunteer to stay after school and help with carnivals, after school programs, and anything that would make me feel like I was a super teacher. Sometimes emergencies happen.

No heartbeat. I had a habit of listening to my arm. I would be in the middle of a lesson and I would hold my arm up to my ear just to make sure I could hear the blood rushing through my fistula. I even slept with my arm close to my ear. One night in the middle of the night, I did not hear anything. My fistula was clotted. No blood was rushing through. I panicked. I was up

for the rest of the night. I had not left my usual plans because I was changing my students focus based on the data I had collected. There was nothing I could do. As soon as the dialysis center opened, I rushed there to see if the fistula could be de-clotted. It could not. Later that day I had minor surgery to have a dialysis catheter place the vein and artery of my heart. The catheter was hanging on the outside of my chest. Again, all I could think about was what I am going to wear to hide this catheter to protect my identity. I wore turtleneck blouses. Turtleneck blouses, sweaters, cardigans, and Aerosol shoes, a teacher outfit for champions. I could not expose myself to that type of torture again. I made up my mind, I was no longer going to go to hemodialysis again, and I was going to try to do dialysis at home through Peritoneal Dialysis.

Teaching and Living on Peritoneal Dialysis

After four long years of being stuck in the arm, having a port placed in my heart, and watching other people on dialysis sit across from me three days a week, I decided that I had, had enough. I wanted to take vacations, to stay after school for longer than one hour, and I wanted to become a better teacher.

There has to be something better than hemodialysis. I had two options, peritoneal dialysis or transplant. I asked my doctor to put me on the transplant list. A transplant was not an option for me before because I was opposed to having a foreign organ in my body. Now it was the only option that would free me from the misery currently plaguing my life. The state that I was currently in did not allow me to progress as a teacher. I would always be confined to a dialysis chair. I would start with peritoneal dialysis while I was placed on the transplant list.

Teaching in isolation. I knew one day I was going to get into an accident on the freeway because I was always trying to get to the clinic as soon as possible so that I could get in and out of the chair. Often times a chronic illness can cause fatigue, sudden onset of nausea, or dizziness

that can cause teachers to take time off work or to leave early. Being diagnosed with any type of illness is filled with many emotions. I found it easy to talk about being diagnosed with cancer. Maybe because cancer is almost normal to society. I never talked about being diagnosed with Focal Segmental Glomerulosclerosis. Dialysis became my dirty little secret. I went to work, did my job, and left at exactly fifteen minutes after the dismissal bell rang. Colleagues often asked where I would go. I have a second job was my mantra. I recall the time when I made the decision to stop going to the dialysis clinic and do dialysis at home. That meant that I would have to do one treatment while at work in my classroom. This meant that I would no longer spend my lunch in the staff lounge, I would be confined to my classroom. The fear of having to tell the principal, let alone my grade level partners, was paralyzing. I wanted more freedom and peritoneal dialysis was the answer. I was banished to my classroom to do dialysis. Although, most of my dialysis took place at home, I had to do one exchange, which included draining the old dialysis solution from my abdomen and filling it up with clean fluid in the classroom. Eating lunch in the staff lounge was no longer an option. I endured looks from others and I became known as antisocial mad black woman. I was criticized by because I was not available after my 30-minute uninterrupted lunch and yet I endured. I did not feel it was necessary to tell my colleagues about my illness and what was preventing me from interacting with others.

While I thought home, dialysis would give me the freedom to further my education, be there after school for my students, and allow me not to feel so rushed to get o the dialysis clinic, only part of that was true. Home dialysis was only part of the answer. It did give me some freedoms. I was able to take some vacations and I enrolled in another master's program (Master of Business Administration). In other ways, it isolated me from the teacher community. I was isolated in the classroom doing my exchanges during lunchtime. I was no longer able to help my

students during lunch. It took all of my 45-minute lunch to do the exchange and meet my students on the yard to bring my line in on time. Again, my teaching was dictated by dialysis.

A False Sense

Three long years, that is how long I taught in isolation. That is how much time I lost to be engaged in collaborative conversations with my grade level partners. All my preconceptions or misconceptions about being a teacher comes from television sitcoms and movies. Does the instruction of teaching focus on identity? What characteristics do you need to possess to be considered a teacher? Did I create a false identity of a teacher in order to seek society's approval? Society says a teacher is supposed to wear many hats and be everything in the classroom. None of those hats included a hat for my own personal illnesses. The institution of education demands that those "issues" are to be left at the school entrance. There is no room for your personal life inside the school walls. When you come to teach you are there for the students and nothing should interfere with that. It was many a day when I did just that. The one time my outside "issues" invaded the almighty educational walls, it all went horribly wrong.

Transplant

The day that I received the phone call for the transplant the most wonderful day. It was more wonderful than being informed that I was cancer free. The nurse on the other end of the line revealed that I would finally be getting a kidney transplant. At first, I did not know if I was ready to undertake such a major surgery. Teaching eighth grade was challenging enough without adding transplant recovery to the mix. After seven years of functioning as a teacher on dialysis finally, things would be back to normal. I would finally be able to have lunch in the teacher's lounge again, drink as much water as I wanted, and take a real vacation.

Betrayal. Talking about taking an extended leave of absence was very difficult. I could hardly keep it together while telling the story. I thought I was reciting my truth in confidence. Later that day without my permission, my truth began to be told. I would have said it was my story except for the fact that it was not my story. I heard the story being told that I had been suffering from kidney disease since I was a young child. I am sitting there saying no that is not true at all. I made eye contact and gave a face like stop. The story telling did not stop it continued. The broadcast was that I would be out because I was getting a kidney. I was so mortified. Yes, it was true, but it was not anyone's story to tell. I felt like I had been outed, exposed as doing something horrible. I was sitting there all eyes on me. I did not want my colleagues' sympathy and I did not want anything from them. I wanted to make up my own story. Why should I expect less from an education system that I believe does not hold value for an African American woman? I make this statement because, I was once asked or told on the 50th anniversary of Brown vs the Board of Education that I was glad that I could work at a school. So just as that question did not shock me then, the public shaming that I felt was not a shock either. I never said a word. I just sat quietly in my chair about to burst with anger, tears in my eyes, and just accepted the lie that I had always been sick. In that moment as an African American woman about to undergo life altering surgery, I decided that it was not worth correcting. I wanted to have surgery and come back to work without any problems.

December 4, 2007. As I tried to relax while waiting in the pre-operation room, my mind was on my students, my life thus far, and the possibilities of no longer being tethered to a machine at night. Panic ensued with every thought. I began wailing, hyperventilating, and asking God to bring me through. I could not stop crying. With every breath came more tears.

The anesthesiologist came in and administered medicine to calm me down. Instantly, a tranquil haze engulfed my surroundings. I awoke with a new functioning kidney.

Epilogue/Prologue

It was the 2008-2009 school year and I was back as to work as a Literacy Teacher. This position change marked the beginning of my time spent outside of the classroom. The epilogue is the moment that you come to the conclusion of a story. The kidney transplant was the epilogue to the long days and nights on dialysis that I left behind. The prologue is the introduction to my new life. I was excited at the prospect of being able to again stay after school and interact with my students. I loved working as a literacy teacher. Working with students was a passion and now I was directly nourishing their minds to assist them to read and comprehend.

Life carried on. I felt great. Routine lab work and doctor visits were now my new reality. During this time, I received my administrative credential. I did not have aspirations of becoming a principal, I was just overjoyed that I was able to again continue my education. Peace and comforting existence ensued. I continue to get stronger and learn how to live with a transplanted organ. Life once again allowed me to breathe. I was a teacher with an invisible chronic illness that for now was at bay.

Change is Perpetual

Like everything in this life, change is perpetual. The knee pain started in September 2011. This pain started with a series of cortisone shots to the left knee. The shots were painful but offered the relief that was promised. I had a series of two shots over a two-year period. This pain free period allowed me to participate in teaching with my full attention. During this time in my teaching career where I was embarking on a new position as a Program Specialist, essentially a teacher on special assignment. I had already been out of the classroom since 2008 as an

Instructional Coach, but I was still interacting with the students and teaching class on a regular basis. This new position would take me further from the students and I did not know if I was prepared for such a change. It must have been fate that I was hired for the position when I was.

October 2011. On October 25, 2011, I was diagnosed with a closed fracture of the patella (knee). I was on track getting healthy again and going to the gym. I decided to take a Hula dancing class. During the class, I went down into a squat position, stood up, and heard a pop. The pain sent me to the ground. My knee was fractured, and I was put into a soft cast. For the next six weeks, I worked from a wheelchair. Having 33 students in a classroom does not make it wheelchair friendly, but I was lucky that I was working in the office and was able to recover with no time off work.

Implantation. The fracture eventually healed, but something else was wrong. I was in terrible pain. After numerous doctor's visits, I was scheduled for implantation of an artificial left knee joint on November 17, 2014. After the surgery when I returned to work, I often joked that I had to go in and have some parts changed in order to be the best me for as possible.

Necessary Disclosure

I made the decision to tell my whole story. What prompted me to tell, well, I was feeling pretty low about all the events that had taken place during the week beginning with me accepting that I would again have surgery to replace what cancer had taken away. I was in the middle of narrating my need to take time off and suddenly out of nowhere, I began to tell the story of how I discovered I had cancer. This is the story I had the courage to tell.

Testimony. I was a runner who could no longer run. There were no other symptoms, well no other symptoms that would be cause for alarm. Yes, I was tired and yes, my legs would hurt at night, but it was never painful enough to go to the doctor. I used to run on the treadmill

daily, which ended in a matter of months. I went from five miles to walking for five minutes then being so winded that I quit going to the gym altogether. What made me finally go to the doctor was stepping in a hole. The pain was so bad, I finally made an appointment. When I think about how and why I answered so quickly I guess it was because we were no longer going to work together, and I knew that I was not going to have to look them in the eyes again any time soon. Funny how I stopped at cancer and did not move beyond to tell them about the kidney disease. I think it may have been because cancer is so known and common, that I just stopped there and did not go into any more detail.

Identity Lost

Recovering from cancer was hard. Not hard because of the treatment or the recovery but hard because it was cancer. I would forever be known as the bionic woman. At least that is how I identify myself when I refer to my limp. My daily life has been impacted by fatigue, daily meds, side effects, and sometimes the inability to control my daily lifestyle as usual due to a doctor's appointment here and lab test there. Both illnesses have caused me to reflect on my life choices. The best life choice I made was to continue teaching and learning. Being diagnosed with two illnesses in a two year period felt like death. I have experienced grief as if a loved one had passed away. I was blunt and angry, I pined and yearned, I was disorganized, disoriented, but did I ever fully recover and accept my life (Olasinde, 2012). I did not want anyone to know. I did not want sympathy, I wanted to be normal. After all of these years of sickness, recovery, and rinsing and repeating, the one thing that has remained consistent, being a teacher.

Dream Not Deferred

Teaching was a life-long dream. Playing with my stuffed animals, sitting them in rows, and using the television guide as papers to correct seem so long ago. I thought that this dream

would never be fully realized when cancer came into my life and again when my kidneys failed. The dream was not deferred, it was not put on hold I made it through the storm and continued to be there for the students. I do not think of myself as a hero, only as a teacher who was engrossed in a hero's journey. Trauma impacts the way one perceives themselves. Chronic illnesses are just the type of trauma that can be a dream assassin or a dream deliver. I refuse to let this assassinate me!

Chapter Summary

This has been a chronicle of the life and times of a teacher teaching with chronic illness. This has been a chronicle of how that teacher has journeyed from runner to now an Assistant Principal. Can this chronicle truly reach the end of the road? This journey is not over. Each new school year brings new and reoccurring challenges. I welcome each challenge like a breath of fresh air. The events that proceeded this summary were a true account of how I remembered the events through pictures, medical reports, and journal entries. This chronicle is a snapshot of a stage play. My experiences are my performances that I have interpreted in multiple ways. As my identities changed throughout the chronicle so did the script. These scripts are now the guides to my life.

Chapter 5: Analysis, Findings, and Conclusions

-I ain't scared of the fall. I've felt the ground before. -The Weeknd (2015)

I often wonder that if I told people about my illness, other than the cancer, would they understand. Would focal segmental glomerulosclerosis sound like some deadly contagious disease that would have teachers moving away from me in the hall? I think it was easier to just tell people I had cancer and that I was still suffering from the side effects. Almost everyone either knows someone who had or has cancer themselves. Cancer as a social norm influenced my decision to disclose to some and conceal from others. Social norms theory states that behavior is influenced by how individuals perceives the groups behavior (Elster, 1989). Cancer is widely known and accepted to the point where it has become a social norm to be a cancer survivor. I talk about my cancer in almost all social situations. Cancer explains all my ailments, true or not. Cancer, therefore, seems to be a mainstream disease that is easy to explain. Societal awareness of kidney disease is not as prevalent as cancer. There is an air of morbidity to kidney disease which is a taboo conversation (Zimmerman & Rodin, 2004). This perceived morbidity is what restricts or limits my speaking about my having a transplant because death is unmentionable in a polite society.

Even though I thought I had my medical records tucked away for safekeeping before moving to our new house, this was the first time I actually went to look for and read them. I took it for granted that I had packed them away in a safe place. I had no intention of ever reading or looking at the x-rays ever again. I honestly thought I knew where the files were, but never did I think they would not be there for me to revisit the procedures and doctor's visits I had. Funny the things you do find while you are looking for the thing that you want. My classroom teacher life was tucked away neatly into plastic bins marked with labels such as classroom library,

health, language arts, and math. The materials inside preserved in plastic bags separated by theme and months. The carefully labeled bins are meticulously stacked inside of a garage where all things have a place. All except the medical records, my mind remembers carefully packing away. Strange how things that should be important get lost in the shuffle. This realization started a multitude of emails, phone calls, signing the release forms, and the cleaning out of the classroom teaching materials. The classroom library was donated to the teachers who needed picture books and the rest to good homes. Obtaining medical records that are more than ten years old proved to be difficult, but as the bits and pieces came in the form of emails, a grand picture began to emerge. The floodgates opened and the memories began to spawn a Technicolor vision of the teaching and chronic illness experiences.

This interview (see Appendix B) feels so strange. I wonder if I am really hearing my voice as I speak into the microphone. Every single word I speak during the interview is a reflection on how I felt then and how I feel now. My voice crackles and splinters into a universe filled with an infinite path of stars that lead to a different pouring out of emotions. As I listen to the playback I refuse to believe that it is me who is speaking on the type of teacher I was, became, and grew back into after a loss of identity that was so profound that it shook my core to the point that I was changed forever. I had no intention of confronting the issues that I covered up by becoming a highly qualified teacher. This is so overwhelming. I was not prepared for the memories, the hurt, the anger that the questions stirred up. Five questions took me about two hours. I had to stop and catch my breath several times. I broke down in tears because, despite all my accomplishments, I feel like a failure. No matter what I have achieved, I am still a black woman with a chronic illness and every time someone finds out, I feel like I just told them I have HIV. I cried because I could not be my true self. I had to become better than what the institution

expected. I had to become a super teacher. I had to become larger than life to hide the lie I was telling myself. A kidney transplant will fix it all. Things, life, being fixed us just an illusion. It is just a temporary fix to a lifelong illness. I have heard many times in my life that it helps to talk about it. The interview was a conversation with myself about myself. I held back nothing and gained everything.

Analysis

Trauma experiences are often heard in a classroom through the stories of the students, rarely is the story that of the teacher. Educational systems and special education policies related to health are not developed around services to support teachers with chronic illnesses. Remembering and writing about my experiences was laborious. Writing to engage readers and piece together chronological fragmented pieces into a relatable storyline was difficult but fulfilling (Ellis et al., 2011). Writing became my daily release from the trapped trauma I had neglected all these years. Writing this piece of literature has taken on a life of its own. This was not just an experience to explore my own trauma, but also an experience to explore my teaching and how it has progressed. This writing is not just a representation of my life as I think others want to hear it, it is what I did, thought, felt, and what I observed as an insider. The events at the time seemed fanciful but as unreal as it may seem, it is the life I lived.

As I wrote, reviewed medical records, and self-interviewed, I made notes after every writing session to preserve the feelings and thoughts about a particular piece of material. While taking notes, I took care to identify themes that were emerging. I used word cloud analysis that revealed words such as, teacher, balance, identity, and time (see Appendix A). These few simple words occurred many times. Although the Word Clouds revealed other words such as time, because, students, social, think, question, identity, and changed. I chose to focus on the word

identity because it evoked the most emotion while reading the word clouds. The other words identified were incorporated into the paragraphs of the analysis. Words such as fear and social were not as large as other words but they were important to my identity as a teacher. These words became as important to me as I continued to reflect on my essential questions.

There were several queries investigated during this study: the impact chronic illness has on teaching, how chronic illnesses have affected my identity, social stigmas associated with chronic illnesses, and the impact this study has had on myself. There were several themes that emerged out of writing my journals, reviewing medical records, and an interview. The themes that follow were identified after writing my personal narrative, reflections, and interviewing myself.

Research Question One

How and in what ways has my identity as an educator been reconstructed after disclosing my chronic illness in the workplace?

As I sit down to write I cannot help but think back to my little smart teacher smock. The teacher smock was an integral part of my teacher identity. Society forms opinions based on bits of fabric. The clothes I chose to wear told the world how I was presenting myself (Weber & Mitchell, 2002). The smart teacher smock is how I identified and told the world that I participate in an exclusive group called teacher. The smart smock was my body adornment.

Identity is developed in many different ways. Identity takes on many different perspectives depending on the situation. A person can manipulate how they want to be seen by themselves and others. Your identity can be your natural identity, institutional identity, discourse identity, and affinity identity. As I reflect on how my identity changed alongside my teaching, has changed and grown over the course of 20 years, my time spent writing, allowed me

to sit down and immerse myself in the illnesses and how my teaching grew out of the development of my identity. Everything that I have done, every move that I have made, was to move myself so far away from my illness that having an illness is no longer a factor. As I look back over the years, I have lost my identity. I let the institution and their narrative discourse define myself.

Multidimensional identity. Who am I as a person? I guess it is best to begin with my outward appearance. I am seen by the label society has placed upon myself as an African American woman. I identify as an American heterosexual woman. I am a wife, a daughter, and a teacher. Since I am a teacher, I am not a typically marginalized statistic. I survived high school without becoming pregnant and graduated college, multiple times. My social class is multidimensional, meaning I move in and out of many different social realms. I am able to navigate the complex working of various economic classes with ease. My outward appearance during the week reads as someone who has a professional career. I tend to dress very professionally. Sometimes over professionally. Although I have always made it a point to dress like a teacher, often in a teacher type uniform, more recently, I make it more of a point to dress like a principal. That just means that societal views are very much part of my consciousness when I am purchasing clothes for work. My weekend attire often reads as what society considers lower middle class. I wear sweats and tee shirts, sometimes even pajamas in public. I may have accomplished what so many others have, I am still judged on my appearance. Unless my career is disclosed, society does not assume I have a career. My social class is determined by society and society builds its characterization of me based on appearance. The steroids that I take daily changed my identity because the side effect of steroids is weight gain. So often we are judged by our weight, that being overweight can be seen as a hindrance to you doing your job. Weight gain

did not change my identity nor my abilities it just changed my outward appearance and how I viewed myself in society. Race can be defined based on phenotype characteristics such as skin color, differences in biology, and facial features that clearly define race (Caldwell, Popenoe (1995; Feldman, Lewontin, & King (2003). According to this definition, I belong to many races. I am a human and I belong to the human race. I am an American and I proudly identify as an American rather than an African American. I am a teacher and I belong to the teacher race (we are a race of our own). As a teacher, I began my training much the same way as a lot of teachers. I went through a credentialing program as an intern, on the job training, and after two years I was a “real” teacher. I say “real” because that is how I defined my identity after completing the credentialing program. When I was diagnosed with a chronic illness, my identity changed yet again. I was still part of all the above races only now, I belonged to a new one, disabled. I now belong to the differently abled race. Additionally you can belong to many different types of races, yet society still identifies you by your outward appearance. I realize that all of these identifiers are constructed by society. My ethnicity is determined by nature but it is society that places a label on who I am. This goes back to Gee’s (2000) identity theory. Race can be part of my N-identity, my I-identity, and my D-Identity. I speak multiple languages. Not languages such as Spanish or German, but languages as in my ethnic language, my teacher language, and my chronically ill language. All these languages shape and reshape my identity. I have been adding to my discourse for a long time. My identity is not fixed. I have a home identity, a work identity, a student identity, and a patient identity. These identities are not separate identities that can be taken on and off like a pair of shoes. They cross like the laces. I am always a patient. My chronic illnesses invade my time constantly. With every step, every ache, I am reminded of what I have gone through. The patient identity crosses with my teacher/administrator identity that

certainly crosses with being a student. I consider myself an over-achiever, not only am I a doctoral student, I am also clearing my Administrative Credential. Sometimes these identities blend so seamlessly other times I feel a distinct separation. For example, I talk to myself and become immersed in the results of my lab test because that morning before work I went to the hospital to take a test for my creatinine. My only thoughts for the day, I hope my levels are within range. For that day, all other identities become annihilated and the patient becomes the dominant identity. I sound like a crazy person. I sound like I have multiple identities. Maybe I do. Other days my teacher/administrator identity takes over. I run like the wind and reduce my pile of work to ashes. I am in the zone. Some days, “we” all come together harmoniously, synthesis, and function, all identities playing a part to shape who I am. Who am I as a person? I know that I am a multidimensional African American woman who has accomplished a great deal in life. Who am I as a person? I do not know.

Social stigma identity. As a society we equate good health with being fit for employment and being able to do our job, society finds it hard to separate illness from ability. Dialysis was the most drastic change to my identity. The illness itself is an invisible illness. Conducting dialysis in the classroom meant I was no longer able to be a part of the social teacher group. Through isolation, I became stigmatized by my decision to separate from the group. Unlike all other illnesses, such as a cold, a broken limb, or allergies, dialysis requires long-term treatments and sometimes accommodations in the classroom (Goodwin & Morgan, 2012). The disease made it difficult to balance my identity, dialysis, and the demands of an academic career (Beretz, 2003). When colleagues are aware that you have an illness, it can be stigmatizing because I often felt like a hypochondriac when I would mention how I was feeling on any given day. This caused me to create an alternative identity where I would put on a brave face that

never showed others how I was feeling. I was never tired, never absent, always happy. But it really pushed me to do better and become a better teacher. I did not want teachers, parents, and the administrator to think that I had limitations because of dialysis. After receiving a kidney transplant and having to take a lot of medication that often had side effects further pushed me into silence about how I was feeling. I did not want people to think I was limited in what I could do. I was always just proving to others, or at least I thought I was proving to others that I was a competent teacher, but I was really proving to myself that these illnesses would not change me but in fact make me better. The stigma of teachers being perfect, they do not get sick, and they are there for the students despite what they may be going through is an institutionally created barrier and perception. Teachers are expected to be there 180 days of the year. Yes, there are sick days but are these in contracts out of courtesy or because it is the law. Often times you are frowned upon if you are sick for an extended period of time. A teaching career depends on teachers being there. The career itself then becomes your identity. Removing the institutional stigma of teachers being perfect would help.

Teacher identity. I knew what it took to help the students. What I did not know was how I was going to incorporate having an illness into my teaching identity how was I going to incorporate dialysis into my teacher identity. I know my identity changed because I dressed the part. I wore my cute little teacher smocks, top, teacher pants. Then on dialysis, because I had a fistula in my arm I stopped wearing those tops and started wearing long sleeves. I used to hear people say you dress like a teacher, you look like a teacher. Teachers are looked upon as heroes and I felt that as a teacher with a chronic illness I was not a hero because I did not know if I would be able to keep up with the demands of teaching. Recess was hard enough with two good legs, but with one good leg recess was a nightmare. Having a limitation led me to work harder to

prove myself. I sacrificed the recovery of my self-identity in order to maintain the teaching environment that parents, students, and other teachers expect. Instead of questioning the institution and the unwritten contract that I signed, I put the illness to the side and focused on the becoming a great teacher. I lost the identity of a teacher with a chronic illness and took on the identity of the ultimate teacher.

Student identity. Depression controlled my life. Depression was the result of no longer being able to pursue my education. My identity as a student had to change. I had to be home at a certain time before I did peritoneal dialysis. I had to be home at a certain time for school three days a week to have dialysis. When I was on peritoneal dialysis I had to go home and be hooked up to a machine at a certain time. Peritoneal dialysis changed my identity and what I had put on hold, again became a reality. Makes me wonder if I could have finished my doctorate a long time ago. I eventually got up the courage while I was on peritoneal dialysis to go back and be a student to further my career. At least what I thought was my career, I thought about a doctorate or another teaching credential, but I ended up getting an MBA because at the time that program fit into the time frame that would allow me to get home in enough time to hook up to my dialysis machine.

Change in identity. As a teacher, my biggest fear was how my life would change when I began to recover from the kidney transplant. Learning to live with a chronic illness is complex. Individual experiences, attitudes, and other's feelings all contribute to the delicate process (Telford et al., 2006). According to Telford and colleagues (2006), the burden of living with a chronic illness is often compounded by stress between one's public and private identity. As I sit here and begin to write, I think about my story and how much I have accomplished and how much more I have yet to complete. I felt and questioned whether I was making the right decision

to pursue another degree. I should be happy with the degrees and what I have accomplished so far despite being ill. As I write, I begin to discover that it is not just about the degree, it is about changing my mindset and revealing the identity I thought was lost. I was the fun-loving party girl and cancer, dialysis, and transplant took that away. Depression and loneliness were collective agreements in my professional and personal life. For me, I became bitter and mean. I tried to blame the medication as a side effect, but no I was mad and took it out on everyone around me. I became the mean teacher at work and the mean, short-tempered person at home. I became the person no one liked. Although the devastating life events that happened, I was determined to overcome my circumstances and focused on a quick recovery. I am still working on recovery. Identities sometimes change for the worst, but also in the midst of the storm you can become a caring person. The storm can be characterized as the stages of grief. As I progressed through the stages of disbelief, yearning, anger, and acceptance, I made the choice to change and not live in the storm (Maciejewski, Zhang, Block, & Prigerson, 2007).

The person I became is more sensitive to others. I focus less on recovery and more on making sure students are receiving an equitable education. I do not have any biological children, so my students have become my quasi children. I am more caring because once you have dealt with cancer it is easy to be a caring supportive person. The key for me is to let the grieving process happen naturally. I made the choice to continue working and that meant I had to be strong for my students and build relationships with them. Simply, trauma has led me to care and reflect and along the way I found a deeper understanding of how trauma shaped my life. This is how my identity changed. Accepting the terms of your chronic illness and coping with shifts in self-identity is a process (Kralik et al., 2004) of becoming a teacher with an illness.

Research Question Two

How can writing about my experiences disclosing my chronic illness help me heal and understand why my identity changed?

Writing as therapy. I never kept any of the medical records that you receive after each doctor's visit. I was just glad that the appointment was over and I could carry on as a normal person. I would say that this was a terrible idea now that I am writing my doctorate. But I was determined to continue to explore and reflect despite the limitations that had arisen while conducting my research. Writing has led me to an understanding of my chronic illnesses and to become more familiar with the concept of closure. Writing about my chronic illness felt like a good breakup with a significant other who had been holding you back from reaching your full potential. Writing has allowed me to say just about everything I needed to say about teaching with chronic illnesses and although it is not completely over, I can continue to grow from this experience. As I write, I begin to discover that it is not just about the outcome, it is about the journey, changing my mindset, and healing my mind. While reflecting on my daily writing, I am drawn back to Campbell's (2008) research where he studied thousands of stories and found that every hero follows the same journey. Every hero has trauma and through that trauma, you gain a unique perspective that allows you to become a catalyst to pass on the knowledge you have gained from the experience. Writing my narrative led me down a road that I was not willing to travel down before. In the back of my mind, I have always known that I pushed myself harder than necessary. I often told myself it was because I did not want to be defined by my illnesses but that was far from the truth. My illnesses were second in the grand scheme of society. Through writing, I discovered that my drive was fueled by the color of my skin. Yes, I was chronically ill, but I felt I had to prove my worth and recover faster than my White counterparts.

This was my epiphany. Writing my story allowed me to construct scenes and dialogue with myself about how I felt to be an African American teacher with a chronic illness in an educational institution that was designed for the superhuman teacher. As teachers, society has made us superhumanly responsible for the future of all society (Wiebe, 2016). Television teachers influence the perception society places on teachers (Swetnam, 1992). Even though many of these expectations are unrealistic and based on a White idealistic society, I tried to live up to that persona in my profession. My writing evoked feelings of sadness and sorrow about how much time I spent trying to hide my illness from the world, but it also incited a riot inside my brain at how the illnesses that I hid forced me to improve and push myself to greatness. Hiding my true self from and portraying what society wanted me to be as a teacher was part of the problems that arose within myself. This misrepresentation of who I was as a teacher created an alarming distortion and I see now that therapy was needed (Swetnam, 1992). Silence can no longer suffice as therapy, writing has taken its place. I became my own therapist during the writing process. Wright (2009) stated that writing and being your own therapist allows you to understand the fragmentation and unity of the self in the process. Narrative ethnographies present text in the form of stories that intertwine the experiences of the researcher into the description and analysis of others from the same cultural group (Ellis et al., 2011). Although autoethnographies contain elements of an autobiography, it is writing that goes beyond the self and crosses over into professional and personal lives and the writer then becomes a human subject (Denshire, 2013). Writing has not only allowed me to tell my truth, it has allowed me to free myself from the self-inflicted chains of secrecy.

Healing. When considering an African American teacher identity it is necessary to know ethnicity, race, and class in order to accurately describe the healing experience (Simien, 2007).

For example, how as a teacher with chronic illness I dealt with the institutional idea of being a perfect teacher by immersing myself in becoming the ideal teaching pushing the chronic illness to the side. Race cannot be separated from the equation because I could not hide my nature identity. Simien (2007) references ethnographic studies which found that women facing illness undergo life reconstruction based on lived experiences and intersecting patterns of discrimination. In the institution of education chronic illness is an unspoken discriminatory practice that hindered me from speaking out about my illness. Kimberlé Crenshaw (1991) first coined the term intersectionality to describe the exclusion of Black women from White feminist discourse. Intersectionality is a theoretical framework that helps us understand how multiple social identities, such as, gender, race, and disability, intersect with systems of privilege (Bowleg, 2012). Intersectionality is the idea that different identities intersect to create identities that are different from the nature identity (Crenshaw, 1991). My diagnosis came when I was just entering the teaching profession and I was fearful of “double-jeopardy” (Simien, 2007), meaning do I tell my new employer I had a disability. For all the ups and downs of battling to become a perfect teacher, my healing comes in my realization that all my multiple identities intersect to make it possible to adhere to the privilege that comes from teaching in the educational system. My many identities that intersect shape the dimensions of my employment experience as a black woman.

The best part is I found a healing voice, one that did not pass judgement, one that did not criticize for being who I am, and a voice that just listened. The lesson I learned from this experience is that I need to continue to work on my identity. I am not the person I want to be. I am still allowing my chronic illness to define me. All my identities are inextricably linked to each other. These links helps me to understand my identity.

Research Question Three

How and in what ways do educators continue life as an educator after being diagnosed with a chronic illness?

Part of continuing to work as an effective educator is managing your chronic illness. Consistent routines and habits minimize lost time at work. Martinez-Marcos & De la Cuesta-Benjumea (2015) conducted a study where women with chronic illnesses were caregivers found that self-management helped them balance their own illness and that of the dependent relative. Learning to manage for me meant trying hard to return to “normal”, learning to forget but being forced to remember, and finding the right mix of work, school, play, and rest.

Balancing act. Balancing a chronic illness and working as a teacher can be a challenge. The demands of teaching 30+ students daily can take a toll on the body and mind. Often times it is very hard to teach when you are experiencing an uncomfortable day due to illness, symptoms of the disease, or side effects from medications. The challenge is being aware of your limitations and develop sustainable coping techniques. Self-management becomes an important part of balancing those demands. The self-management techniques identified by Martinez-Marcos et al. (2015) were: (1) self-regulating the treatment, (2) regulating their strength, and (3) controlling their emotions. Resilience is one factor that allows educators to show up and educate students. Butler, Koopman, Azarow, Blasey, Magdalene, DiMiceli, Seagraves, Hastings, Chen, Garlan, Kraemer, & Spiegel (2012) state that psychological resilience is the process of successful adaptation despite challenging circumstances. Work and job satisfaction are valuable experiences, despite having stressors and impaired health (Pretsch, Flunger, & Schmitt, 2012). Work can be seen as therapy and increase mental and physical well-being (de Vries, Brouwer, Groothoff, Geertzen, & Reneman, 2011).

I remember when I was diagnosed with Focal Glomerulosclerosis my nephrologist asked if I wanted to go on disability. The thought did cross my mind, but I was only twenty-five and the thought of staying at home doing, what, nothing, for the next thirty years, seemed like a death sentence more than the actual disease. The most important reason I continued to work was I wanted to feel important, feel that I had a purpose other than dying. I wanted to continue to educate students who may someday grow up and find a cure for the very thing that ails me. Even to this day, I do not create time to rest. I feel compelled to continuously keep going. I cannot recall a time when I was not in school. I do not miss work if at all possible. I push until my body is no longer able to push. I know this is a big part of self-care but I feel like I do not have time to slow down. I think this is also a side effect of being a teacher. Teachers put in a lot of time and effort to ensure that our students have our time sometimes even at the expense of our health and family. When it comes to balancing teaching and chronic illnesses, you have a lot of people to consider such as your students and your administrators. The balancing act would have been easier if I had let my administrator know that I was on dialysis up front. After 10 years of having a transplant and 20 years cancer free, it is an easy balance. I have my medicine routine. I have my doctor appointments routines. I have my lab routines. They all coincide or fit into the schedule of work to where I no longer have to take days off to go to the doctor appointments. I do not miss any important events at school. It has truly taken 15 to 20 years to get to this point. It has not been easy, it has affected my life but not my passion for teaching students. I still make time to be available after school to help students, past and present. I still come early and stay late. I stand at the gate so that I can tell our previous students who are now high school students "Hey if you need help, I am here to help you, come on by my office, stop and talk to me." I do not have to rush off to dialysis to get hooked up to any machines. Time has just helped

and made all the difference in the world. I have had time to learn schedules and routines. I have had time to know when doctors work from their schedules. It had not been easy to balance the demands of teaching and being on dialysis. I did not have time after school to do anything I had to make sure I left work on time to make sure that I was getting hooked up to the machine so I would not be the last person in the clinic. I had to be really organized and structured. Now I find that I can leave things for the next day. I have relaxed a lot but I have kept the organization piece. I leave work for the next day but it is very organized. To be able to balance all the pieces of my life into a harmonious song where every note resounds with the struggles of the day. That song brings my life into balance. The struggles are no longer struggles but welcomed distractions from the daily reminders of the illnesses. The students that I interact with on a daily basis are the joyous part of the balance equation. Seeing that lightbulb of learning makes this long fought battle of balance worth it.

Overcoming fear. I have heard the negative thoughts other teachers have when someone has a chronic illness and request accommodations. I do not think that teachers are mean and heartless, but they are human. My primary fear was that I would be seen as an ineffective teacher and that administration would apply pressure or have to talk with me about being absent. Although there are laws such as, the American with Disabilities Act of 1990 (ADA), requires employers to provide reasonable accommodations to employees with disabilities (U.S. Equal Employment Opportunity Commission, 2018), there is no provision that protects from the sigma and covert discrimination that may come from colleagues and administration. I did not want to be the topic of conversation. I did not want any accommodations, even if I needed them. Administrators seem to become really impatient when it comes to teachers being ill and the time they take off to recover or manage their illnesses. I wonder now if my decision not to disclose

my illness to anyone is why I was accused of being a drug abuser. It was never said to my face but I was told later by a friend. I decided I needed to tell them the truth. We shared a common secret regarding managing illnesses. I said to them in truth I do take drugs, the only difference between me and a drug abuser is that my drugs are legal, but I abuse them just the same. What I mean is I need the drugs to stay alive, I need the drugs to be able to come to school and teach every day, and just like an addict, I feel sick if I miss a dose. I will forever as long as I have this kidney be dependent on drugs. As long as I have this kidney I will be an immunosuppressant junkie. My feelings have changed over time. I stopped being angry but, I do feel myself sometimes getting upset because I know that a kidney transplant is a temporary fix. Although it has been ten years it is still only temporary. I know that I will be back on dialysis and on the transplant list again. But this time will there be a kidney for me. I think I got lucky the first time to find a match but what are the chances to find another match. And will that kidney work as well as this one has for the past ten years? So, although my feelings have changed from anger, disgust, despair, and depression to being happy, able to go on vacation, and being able to enjoy life, I know that this upswing is going to come crashing down into a crescendo in years, month, weeks and only God knows, but I know in the back of my mind that, that is to be expected.

Resources. The resources that I had during this process is counseling to help process some of the feelings remembering and writing brought to light. Speaking to a trained professional helped me to reflect and feel as if I did something wrong. What chronic illness meant to me at the beginning of the process was death, now it means life. I have a life that allows me to drastically affect the outcome of far more lives than just my own. I am a force, and through this process, I have tapped into resources that I would have let sit on a shelf and never touch for fear of releasing uncontrollable skeletons into the universe. I have a family to rely on, I

have teacher friends with similar illnesses, and there is a network of groups to join to talk about almost anything. Groups allow you to grieve your loss of identity and find solace. I feel less alone.

Findings

Sometimes I do not know who I am. Sometimes I cry at night because I want to be the greatest teacher in the world, I suppose that is every teachers' goal, but I really want to be great because if I am great and healthy then the students will learn and be great. Sometimes I do not know who I am. Sometimes I take on too much and need to slow down. I just do not want anyone to know that I am sick so I lean on the podium during the staff meeting and deliver a half thought out explanation about the importance of homework to teachers all the while thinking, I just want to go to bed. I end the meeting early because I do not really believe what I am saying because homework to parents is important but we need to give the right kind of homework. Homework that makes a difference in student's lives. That is what I should have said, instead I asked a few questions from the book we are reading, bid everyone an ado, and end the meeting. I go home and reflect on the day. Yes, tomorrow is another day. I wonder who I will be tomorrow.

Find your voice. There was never any dialogue between the administration and myself. Being able to have an honest and open dialogue with the administration is an important part of finding your identity. One should feel comfortable having that open and honest dialogue with the administration. Find your voice to let them know what you are going through and educate them about your illness. The administration often has these very conversations with parents of students with chronic illness and make accommodations for them. Teachers should feel that they can have those same conversations to come up with accommodations for themselves together.

The conversation should be kept between the teacher and the administrator. It should be the choice of the teacher to disclose to other colleagues if they want to. It is going to take work to remove from the institution of education the stigma of if a teacher is not 100% healthy, that the teacher is not and cannot do their job effectively or that the illness may cause job loss. Teachers are closed-mouthed about illnesses because they do not want to lose their jobs. Teachers love and need their jobs. It is that stigma of the institution saying that if you cannot be here you need to quit. The funny thing about it is that even parents are not supportive of teachers being ill.

Until that stigma of teachers being different, it is going to be hard for a teacher with a chronic illness. It is going to be hard to ask for support from the school and the institution of education. I do not know what in the future is going to help remove that stigma. Teachers need to know that they are not in fear for their jobs or that they will be accepted back unconditionally. Just as we are concerned with the social-emotional health of students we also need to be aware that teachers also need social-emotional help sometimes. How do we start to have those conversations with the district and administrators? How do we remove this stigma? Until this is addressed I do not think we will be able to come up with any accommodations that will remove the feeling of not being supported by the education system. It is going to take changing societal perceptions of teachers not being seen as superheroes but as human beings in order to create a new way of thinking.

Although the life events that happened were devastating, I am determined to overcome my circumstances and continue to focus on a recovery. A school environment that does not allow a person to talk about their feelings and emotions surrounding the illness can cause a high level of stress (Butler, et al., 2009) whereas if the school culture is a supportive social-emotional school culture, this can contribute to teacher resiliency. It is important to have social, emotional,

and psychological support when recovering from a traumatic event such as a chronic illness diagnosis. Teachers must take time to rest and find balance. I rarely take my own advice, even to this day I do not create time to rest. I feel compelled to continuously keep going. I cannot recall a time when I was not in school. I do not miss teaching days. I push until my body is no longer able to push. I know this is a big part of self-care but I feel like I do not have time to slow down. I think this is also a side effect of being a teacher.

Reflection

Deciding to become a teacher was the best and the worst thing that ever happened to me. As you get older, sharing some things simply get easier. My late twenties began a series of unfortunate events. As a result of these events, as the questions come about why I limp, I feel secure enough with myself that I can finally talk about it. Throughout the process of reflection and writing, I have gained a comfortableness talking about why I was hurting but not the disease itself. I have since told more colleagues about the replacement but not cancer or the transplant. It has been difficult to reveal the private side of my life but it has also been healing. Like so many other memories, I tried to repress the ugly shadows of cancer and kidney disease to deepest recesses of my mind. Like my visible scars, I tried to cover them up with concealer and makeup, but they are still here and when I take the remover and wipe off what I thought I erased, the memories return. This was a work that turned those concealed memories into a piece of art where the beauty of the words are meant to heal.

Visible Invisible Scars

Chronic illnesses are often hidden from view. The symptoms may be seen by colleagues and administrators as interfering with the workday, but symptoms may be insignificant when compared to the illness as a whole. My scars run deep. Cancer left very visible scars on my left

leg, dialysis left scars on my chest above my heart, my neck, and my right arm, while the kidney transplant left visible scars on my abdomen. While I can hide the scars on my skin, I cannot hide the scars that the trauma has left behind and changed my identity forever. These diseases often make it difficult to balance the illness and the demands of an academic career (Beretz, 2003). When colleagues are aware that you have an illness it can be stigmatizing. Hidden illnesses can make you seem like a hypochondriac when you mention how sick you are feeling on any given day. Teachers can be bombarded with negative stereotypes, minimized social interactions, and have their physical, mental, and emotional competence challenged (Goodwin & Morgan, 2012). *The Secret Teacher* (2014) put it all into perspective, “It’s not the kids that make teachers feel dread returning from an illness, and it’s the way they are treated at school.”

Chris Crutcher’s (1993), *Staying Fat for Sarah Byrnes*, focuses on the theme of body image and how this issue is ever present in modern society. This is one stigma that is visible to colleagues and students. Social stigmas cause one to become separated from the group or groups they belong too. Physical disabilities are visible to everyone around and society may consider them ugly. Unlike all other illnesses, such as a cold, a broken limb, or allergies, chronic illnesses require long-term treatments and sometimes accommodations in the classroom (Goodwin & Morgan, 2012).

Lessons Learned

Twenty-seven was a pivotal number, twenty-seven changed my life and identity forever. I not only had to learn how to become a better teacher, I also had to face the challenges that come along with having cancer and then a year later losing my kidneys to an autoimmune disease. I wanted to return to work, I just never took the time to define what that meant for me as a teacher. Many administrators would prefer that a chronically ill teacher return to work and

continue to educate students (Lipoff, 1991). Not surprising that most teachers want to return to work and normalcy. I wanted that normalcy more than anything.

I learned that in order for colleagues, parents, and students to understand and be sensitive to absences and accommodations I may have needed to be willing to talk about my particular illness (Lipoff, 1991). Being surrounded by other African American teachers in the the district made it easier to go back to work and feel comfortable. As I have come to spend many years in the school district, I have created another kind of support system. I feel like I have a lot of community support now because the community I serve is a community that I lived in and watched many students grow and become parents themselves. This also helped me to learn and grow in my craft. Through this process, I have discovered a mentor. My mentor is easy to talk to and I feel she understands all that I am going through. Her advice is so valuable.

Acceptance and Peace

Everything that I have done, every move that I have made, was to move so far away from my illness that having an illness is no longer a factor. I have to admit that I have worked at the school for many years now and people know about the kidney disease, thanks to the institution's disclosure of my story, I still have not told my story. As I look back over those years, I lost my identity. I did not know who I was. I let the school define my identity. I let the institution and its discourse define myself. Writing had helped me to find who I was, am, and will become. I am an African American woman that happens to be a teacher and administrator with several chronic illnesses. Being held to a different standard by administration had nothing to do with being ill but everything to do with being ill and African American. Being African American is something that I cannot change but seems to have been reason enough for some to impose their understanding of my illness upon me. Being African American was also reason enough to

remain isolated during my dialysis years. The ideals of a teacher with a chronic illness being an ineffective teacher comes from society and even after researching this topic it still mystifies me. Society cannot define who I am. I choose not to have my identity defined by society's standards and forge ahead to create a new discourse.

The significance of this study was to explore my experiences with a chronic illness and how it has affected my identity. This study provided some insights as to how my identity changed over the course of dealing with illness after illness. Even though this was written about my experiences, something in the words written on these pages could help and inspire others to write about their own experiences.

Gee's views on identity reveal that people construct their identities through interacting with others. Nature identity formed my base identity. I will always be an African American woman, that is the part of my identity that I cannot change but it is not the complete me. My Institutional or I-identity has been formed through the stage props and scenes that are related to teachers' identities, patient identities, and the cultural scripts (Beijaard, et al., 2000) that go along with those identities. Discourse is much more than spoken or written language, it is the way I interact with others who in turn interact with myself. Disclosure is now a discourse language I can add to my identity as writing has helped to define what that discourse bellows from my soul. My Affinity identity has evolved because of my experiences. Conducting research as added yet another affinity group to my repertoire. Research has opened up avenues of groups that previously were closed.

Emancipation

According to Horkheimer (1982) to emancipate oneself is to liberate yourself from the circumstances that enslave you. The institution of teaching and the unspoken narrative of

teacher perfectionism can foster a drive to overachieve. Perfectionism is a personality style defined by vigorously fighting for flawlessness and setting of excessively high standards that may be impossible to obtain (Stoeber & Rennert, 2008). Performance is accompanied by the tendency for being overly critical of your behavior. The battle with perfectionism is twofold, the need to live up to society and the educational idea of a teacher and a need to suppress the imperfectness of chronic illness. Perfectionism in an educational culture can be daunting or emancipating. Perfectionism can foster a healthy relationship with the multiple identities of chronic illness. My experience has been to strive toward perfectionism to boost my perceived self-worth in the institution of teaching.

Chronic illness can be enslaving. This research was an attempt to highlight my process in finding my identity to help others find emancipation from concealing a chronic illness. Education became the purpose of my life and by writing a dissertation, I have found freedom from this crowning achievement. After reading this dissertation, my hope is that teachers find their own emancipation from concealing a chronic illness. The primary responsibility of teachers is to teach students, illness or not. The very nature of education is penalizing. The nature and complexity of teaching can cause conflict when you have a chronic illness. For so long I protected myself from the penalizing nature of the educational institution. I feared the repercussions from being absent and struggled to find support within the educational community. My lived experiences act as a roadmap to guide other teachers as they journey through the chronic illness experience. Of all the things that are beneficial to teachers with chronic illness, telling your story to an administrator may be the most important. Your story holds value and that value can lead to an administrator's understanding of your personal educational philosophy. When a teacher reads my story, I want them to find their voice to speak

up and remove that fear that keeps them from being the teacher they want to be. The teacher should not feel that they must take the blame for being absent and limited student progress because they are dealing with life. The aim is to open the conversation and start to build trust with administration. Teachers who choose to dialogue should then be willing to be a part of recovery and develop a plan that will lead to increased motivation and continued student achievement. In order for teachers to be effective and empower students, teachers must develop their own self-images and free themselves from the fears of failure that holds them back. Take the journey in stride and hero on.

By reading this dissertation, can administrators help teachers feel safe while they are recovering from a life altering trauma event? Absolutely, there is learning that takes place after reading my story. Healing and recovery are a big part of my story and emancipation from the trauma begins with safety and relationship building. Administrators can facilitate improving relationships with a teacher with a chronic illness not by trying to understand what the teacher is dealing with but by creating a supportive educational culture. Alrubail (2015) suggest that administrators should foster an environment that supports collaboration and team building. This leads directly to a school culture where relationships are valued. Teachers then feel empowered to communicate their thoughts without fear of being stigmatized. With lack of trusting relationships, teachers will mostly likely not engage in meaningful conversations (Ghamrawi, 2011). Teachers will flourish when they feel safe and that they can recover and return to a trusting professional environment. My story is meant to provoke a conversation between administrators and teachers. The story is meant to provoke thought on how the institution of education is built upon the hidden moral judgements of the institution itself when it comes to a teacher with chronic illness feeling unsupported. How can teachers start the conversation and

not be shut down or penalized for speaking unspoken truths? Administration must be willing to change the unspoken narrative of teacher perfectionism and be open to hearing, not listening to the needs of the teacher. Through conversation comes emancipation. Emancipation leads to changing society's view of teachers living with chronic illness.

Implications for Further Research

There has been a lot of research that focuses on teacher job satisfaction, but little has been done on teachers who continue to teach while battling a chronic illness and job satisfaction. Work task, psychological well-being, and personal growth are factors that have been found to influence job satisfaction (Collie, Shapka, & Perry, 2012; Wright & Cropanzano, 2000). What role does the unwritten rule of teacher perfectionism play in a teacher's decision to return to the classroom after an illness diagnosis? The institution of education is full of cultural myths around teacher image. Britzman (1986) describes how her personal experiences teaching interact with common cultural myths of teaching and how these myths play a role in creating a teacher identity. There needs to be more research on how to bring these nuances of the unwritten rules into the light.

Job satisfaction has been measured worldwide to determine general levels of satisfaction (Glick, 1992). Some job satisfaction variables are financial rewards, co-workers, advancement opportunities, and security (Glick, 1992). Although a quantitative study seems daunting, one area to explore is how do chronically ill teachers perceive support from the institution of education and perceived job satisfaction using the Multidimensional Survey of Perceived Organizational Support as a research tool. Kraimer and Wayne (2003) defines perceived organizational support as the employees' global beliefs that the organization values their contributions and cares about their well-being (p.210). Along with perceived support, to what

extent do teachers with chronic illness feel that the organization cares about their well-being? Is this support shown through policies, practices, and treatment of the chronically ill teacher? What factors lead to that perceived organizational support?

Teacher morale has been shown to be the single most important factor in increasing student achievement. If this is the case, then the question becomes what can administration and colleagues do to help chronically ill teachers increase their morale and stay on the job? Teacher commitment to student learning increases when administrators collaborate and develop a relationship with the teacher (Nir & Kranot, 2006). The illness is less of a factor when it comes to student achievement. Student achievement seems to be dependent on teacher morale, job satisfaction, and the school's common vision and focus on student achievement.

Conclusion

That trauma is such a transformative experience, those impacted gain unique perspective and the courage to effect change (theshaderoom, 2018).” I do not consider myself a hero, not even close. I do not even think that I will become a hero after writing this carefully thought out work of art, but I do believe that I followed a hero's journey. The trauma of being diagnosed with cancer and possible amputation transformed my life and career. That trauma led me to believe that as a survivor, I could push through and by teaching effect change. Chronic illness is trauma. In order for trauma to be tolerable and not become a stressor, it needs to be buffered by supportive relationships and learning coping skills (Beyer, 2018). One way administrators can build supportive relationship with a teacher going through trauma is periodically checking in with the teacher. The administrator could send a blanket email to all staff asking if they are experiencing any special circumstances, working a second job, or caring for others. This small

act of kindness could help a teacher with a chronic illness feel that they have the support of the administration.

When you know who you are, you develop a confidence. I was a teacher and I was confident. After my first year, I was encouraged to seek my teaching credential by the teachers I was surrounded by. I enrolled in the District credentialing program. I was ready. Who knew being ready meant there would be trauma involved?

The very topics of cancer and chronic illness hit me like a gut punch every time I think about taking time off. Reading about someone else's experiences opened up a whole other avenue of research for me. Autoethnography is a narrative, a narrative of the researcher's life experience. It is connecting the personal to the cultural (Ellis & Bochner, 2000).

Autoethnographic researchers are the participants, the observer, and the interviewer.

As I watch the vibrant black dog in the dog park I think to myself, there once was a time when I used to run free and strong until one day that life was all gone. I ran for miles. I ran on the beach, the gym, and on the playground with my students. I took running for granted. Running meant I could discover new places and find inner peace. My swift legs carry me far and wide. Strength is no longer my legs, but my ability to teach students to chase their dreams.

I used to chase my dreams like the ball the dog is constantly chasing. Dreams were my security blanket. Unlike the dog who catches the ball everything his owner throws it, I do not catch mine. My dream of running a marathon is a dream I will never catch. I wonder what it would feel like if I did catch it. Would I run around the whole track with the participant ribbon in my mouth? Would I want the marathon organizers to organize another race and throw the ball so I could catch it? Funny how I used to chase my dreams.

I used to be powerful. Powerful enough that I could power through anything. I could jump up and go at the drop of a dime. I could play all day under the sun, sniffing the world around me. I did those things when I was younger and irresponsible. As time when on I became an adult with a career and could no longer spend hours at the park mingling with friends. Now I am lucky if I get one weekend a month. Slowly I slow down the fun things I used to do and life seems to pass like a blur. Funny how I used to be powerful.

I am still alive! I may not be able to chase the ball around the dog park or chew on every rubber toy around, but I am alive. I may not have the strength and power to run but I have strength and power to create new dreams and chase them in different ways. Yes, I used to chase my dreams, now I walk the hero's journey in order to catch my dreams.

I do not know if my research will change the world, but I do hope that when I am finished that it will at least inform readers who are on a similar hero's journey. I hope someone will find solace in finding the identity they lost.

I am an identity that has been built, broken, reshaped, is still evolving into an identity that is unique to me. What consistently remains the same is my nature identity it remains unchanged a constant I can rely on during any time doubt creeps into my senses and causes my identity to ripple. Who I am at this moment may not be who I am tomorrow. Chronic illness lurks in the background ready to pounce and start the chain of events that impact my identity over and over again. Chronic illness can overshadow the important work of teaching, the key is to find that balance between who you are as an educator and an educator with a chronic illness.

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APPENDIX B: INTERVIEW PROTOCOL

“Reflexive, dyadic interviews focus on the interactively produced meanings and emotional dynamics of the interview itself. Though the focus is on the participant and her or his story, the words, thoughts, and feelings of the researcher also are considered, e.g., personal motivation for doing a project, knowledge of the topics discussed, emotional responses to an interview, and ways in which the interviewer may have been changed by the process of interviewing.” (p. 276).

My study seeks to understand how being diagnosed with multiple chronic illness impacted my experience as a teacher. The literature focuses on how teachers help students cope with chronic illness and less on the teacher with the chronic illness. The study also seeks to understand how society shapes the way teachers with chronic illnesses think about themselves, their community, and their teaching. The aim of this research is to document how I see myself as a teacher with a chronic illness and how it fits into my life. The interviews will last approximately 30-45 minutes during which time I will be asking myself about my experiences with teaching while living with a chronic illness.

1. What did I use to notice so much about my behavior and personality before I was diagnosed?
2. What do I notice about my behavior and personality today?
3. Would I say I have changed since being diagnosed? How? In what ways?
4. How has my teaching changed since being diagnosed?
5. What is my perceived future regarding my personal and professional life as it relates to my chronic illness? As perceived by others who are significant in my life? As perceived by my self?
6. What are my physical, emotional, social changes, and limitations in my life? What are my perceived abilities to perform and function as a teacher while constructing my new identity?
7. What resources do I have during this process?

8. How would I describe the way I feel when I remember something about the past after diagnosis at any given time? Have these feelings changed over time?
9. Could I describe my most challenging experience as a teacher with a chronic illness?
10. Could I describe a time when I had to disclose my chronic illness? How did it make me feel? What were the circumstances?
11. How do you balance the demands of living with a chronic illness with my passion for teaching students? What have others written about this?
12. What barriers did I face as a teacher with chronic illness in education?
13. What accommodations do I suggest that would help remove the barriers for future teachers with chronic illness?