The lived experience of student caregivers: a phenomenological study

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THE LIVED EXPERIENCE OF STUDENT CAREGIVERS:
A PHENOMENOLOGICAL STUDY

by

Lisa Polakowski Schumacher

A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Educational Policy and Leadership Studies (Higher Education and Student Affairs) in the Graduate College of The University of Iowa

May 2017

Thesis Supervisors: Professor Michael B. Paulsen
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CERTIFICATE OF APPROVAL

PH.D. THESIS

This is to certify that the Ph.D. thesis of

Lisa Polakowski Schumacher

has been approved by the Examining Committee for
the thesis requirement for the Doctor of Philosophy degree
in Educational Policy and Leadership Studies at the May 2017 graduation.

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To Finn, you made this study possible. I hope our experiences help many people.
Storytelling plays a big role in this process of development. As we tell stories about the lives of others, we learn how to imagine what another creature might feel in response to various events. At the same time, we identify with the other creature and learn something about ourselves.

Martha Nussbaum

Letter from *Take my advice: letters to the next generation from people who know a thing or two*
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Mom and Dad, thank you for passing along “the never quit genes!”

Rocky, Tyler, & Kat, thank you for being my partners in this fabulous journey. I love writing and it was such fun to work with you in a wonderful writing community.
ABSTRACT

The purpose of this dissertation study was to describe how students who provide care for a person with a disability or chronic illness cope with the demands of both roles. The Transactional Stress and Coping Model was the theoretical framework that guided this research. The way students cope with stress has a direct impact on overall health, which has an impact on learning, development, and retention. Student caregivers are considered nontraditional students; nontraditional students are more likely to drop out of higher education because of obstacles in their non-academic life. Historically, student affairs professionals have developed programs and services to meet the challenges of underrepresented students in higher education. More than half of family caregivers are between the ages of 18-49, due to the aging population. The number of student caregivers enrolled in higher education will continue to increase and they are not adequately represented in student affairs literature. While each student caregiving experience is unique, the fundamentals of student caregiving are consistent; student caregivers must often choose between completing academic tasks and caring for a human being. The participants represented a variety of disciplines, which highlights the need for student affairs professionals, faculty, and administrators across the academy to understand the specific challenges they face.

The research questions that guided the interviews were: What is the lived experience of students who care for a person with a disability or chronic illness? How do student caregivers cope with the role strain of juggling student and caregiving demands? How do student caregivers develop coping strategies within the academy?
Twelve student caregivers participated in in-depth semi-structured interviews. Four of those participants also joined a focus group to further reflect on their student caregiver journeys among peers who shared their experience.

Thematic analysis was used to mine the data for themes. Five essential themes emerged from the data and they are: (1) Timing affects everything, (2) Identities collide across contexts, (3) Structure and flexibility enhance capacity, (4) Coping facilitates health and growth, (5) Learning transforms the journey. The findings of this study suggest that student caregivers are at risk for stress-related illnesses, most participants in this study experienced anxiety and/or depression at some point in their journey. Institutional resources, such as health insurance, faculty and peer support, and counseling services helped to mitigate the negative health effects of negotiating two demanding roles.
PUBLIC ABSTRACT

The purpose of this dissertation study was to describe how students who provide care for a person with a disability or chronic illness cope with the demands of both roles. The way students cope with stress has a direct impact on overall health, which has an impact on learning, development, and retention. Student caregivers are considered nontraditional students; nontraditional students are more likely to drop out of higher education because of obstacles in their non-academic life. Historically, student affairs professionals have developed programs and services to meet the challenges of underrepresented students in higher education. More than half of family caregivers are between the ages of 18-49, due to the aging population. The number of student caregivers enrolled in higher education will continue to increase and they are not adequately represented in student affairs literature. This qualitative study collected data through a combination of individual interviews and a focus group to understand: who student caregivers were caring for, how they coped with their dual roles, and how the institution they attended supported them. While each student caregiving experience is unique, the fundamentals of student caregiving are consistent; student caregivers must often choose between completing academic tasks and caring for a human being. The participants represented a variety of disciplines, which highlights the need for student affairs professionals, faculty, and administrators across the academy to understand the specific challenges they face.
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Chapter 1
Introduction

“...the phenomenologist knows that one’s own experiences are also the possible experiences of others” (van Manen, 1990, p. 54).

2009-2012
My experience as a student caregiver began in the fall of 2009 while I was working on my master’s thesis. My youngest son, Finn, arrived 8 weeks before his due date, shortly after I finished data collection. My teeny baby was the length of a cordless phone and weighed less than a half-gallon of milk. He was bright orange from jaundice and had multiple tubes protruding from his body. The monitors he was attached to blinked and beeped and exacerbated my anxiety. Fear and exhaustion knocked me to my knees. I stayed enrolled in school because my health insurance was through the university but I had no energy or will to do the work for my research during the fall semester he was born.

At the beginning of the spring semester, I received my acceptance letter to the PhD program in Higher Education and Student Affairs. I knew that I had to finish my thesis in one semester so I could continue in the next program. I felt I had no choice but to continue my education so I had access to the graduate health insurance plan because I did not know what lay ahead for Finn’s health. I put the little energy I had into writing. Finn did not sleep well. There were days that the only way I could get him to sleep was to put him outside. I had to write, so I bundled him up in many layers with lots of blankets and put him on the deck outside my office. I left the door open so I could see him. I hunched over my computer with a winter coat, blankets and gloves with the fingers cut out. When I look back, I have no idea how I did it. I was totally isolated, I did nothing but care for my baby and work on my thesis. I rarely saw my husband, my other son, or any colleagues. I did not think anyone could understand what I was going through. And I had no time or energy to seek out people who might share my experience.

I thought I had endured the worst of my student caregiving experience while I completed my thesis; however, the first two years of my doctoral program challenged me beyond what I thought I could survive. Finn showed signs of developmental and physical delays. We went to weekly doctor and therapy appointments. I worked with him and followed every therapy recommendation. I was totally anxious about Finn’s health. I was also struggling with my identity as a PhD student immersed in an unfamiliar field with a department culture that I found intimidating. I was the oldest student and the only female admitted in my cohort. Again, I had no peers who had any inclination of my experience. And I did not know of any student services available to help me. I floundered.
My physical and emotional health suffered but my grades did not. Focusing on my studies gave me a visible sign of success. I needed something I could control and grades provided that for me. The research perspective I learned in classes also made me feel more in control at doctor and therapy appointments. Around Finn’s third birthday, he reached age level on all developmental and physical tasks. I transitioned from being a caregiver to “just” a parent. The shift was profound. It had a significant impact on my lived experience as a parent, my lived experience as a student, and my lived experience of health. The worry that consumed me, and the exhaustion I felt as a caregiver dissipated when my role was reduced to parent. I was able to focus on my studies in a more balanced way and I had the energy to build relationships with fellow students in my program. I have the benefit of understanding the experience of being a student as both a caregiver and as a non-caregiver. My personal experience as a student caregiver, combined with my academic path in student affairs, sowed the seeds for this phenomenological study.

**Significance and Methodology Rationale**

This study uses hermeneutic phenomenology as described by van Manen.

Hermeneutics originated from the Greek root *hermeneuin*, which means “to interpret” (Moran, 2000; Pehler, 2003). Hermeneutic phenomenology, from a Heideggarian perspective, studies phenomenology as *daesin* or “being in the world” (Pehler, 2003; Wojnar & Swanson, 2007). This perspective emphasizes that a person’s experience cannot exist outside the context of their values, family, traditions, political views, spiritual beliefs, and individual history (Wojnar & Swanson, 2007). The researcher is subject to *daesin* as well as the participants. The participant and the researcher interpret the phenomenon being studied together and co-generate meaning as they bridge “...understanding shaped by their respective backgrounds...” (Wojnar & Swanson, 2007, p. 175). Hermeneutic phenomenology aligns well with the goals and perspective of student affairs. Historically, student affairs and academic affairs have used a bifurcated approach to student learning (Keeling, 2004). Student affairs views the student as a holistic being and learning as happening within the context of student
development. On the other hand, prior to recent developments in learner-centered teaching, academic affairs traditionally viewed the student as a receptacle for the teacher to deposit information and then for the student to reproduce it later on demand. More recent research on learning suggests that transformative learning requires the student to integrate external information with her own prior knowledge and experience, and interpret how the information can be received and used given her individual history. "The most important factor is that student development education always occurs in the active context of the students’ lives" (Keeling, 2004, p. 12, italics in original document). Student affairs professionals understand that faculty and other professionals in academic affairs cannot quickly change pedagogical techniques that have been practiced for generations, so it is necessary for student affairs professionals to engage in research that demonstrates how teachers and students can co-generate a fresh interpretation of how the phenomenon is understood. Since health has an impact on learning, development and retention (Allensworth, 2011; Freudenberg & Ruglis, 2007; 1998; Silverman, Underhile, & Keeling, 2008) it is critical that student affairs professionals conduct more research that illustrates how health is understood within the context of the academy. There is an abundance of research in the education and public health literatures about how college affects long term health (Pascarella & Terenzini, 2005) and how health is connected to learning (Freudenberg & Ruglis, 2007; McKenzie & Richmond, 1998; Silverman, et al., 2008), however, there is a gap in student affairs literature that specifically describes the experience of students who care for a person with a disability or chronic illness. Student caregivers are at risk for stress
related illnesses as a result of their unique time constraints and intersecting roles that may inhibit time and resources to develop healthy coping strategies. The purpose of this phenomenological study is to describe the lived experience of students who provide care for a person with a disability or chronic illness.

My journey of how to frame this study started with two themes of research: nontraditional students and caregivers. As I read the literature about both populations, I found two studies that captured pieces of the puzzle of how to structure this dissertation. Maroney’s (2010) study used the transactional model of stress and coping as the theoretical framework to investigate how coping resources and strategies impact persistence for nontraditional students but neglected the specific concerns of caregivers. The way people cope with stress has a direct impact on overall health and is cited in caregiving literature as a factor in the presence or absence of stress related illnesses (Abel, 2000; Quinn, et al., 2008; Vellone, 2007). Maroney’s (2010) study provided two key pillars for my study: the theoretical framework and coping as a proxy for health. Paré’s (2009) phenomenological study describing the lived experience of mothers pursuing higher education emphasized the role strain student mothers endure. Managing role strain is a consistent struggle for caregivers who care for a person with a disability or chronic illness (Abel, 2000; Connell, 2003). Paré’s (2009) study informed my choice of methodology and provided context for the research questions of this study. Maroney (2010) and Paré’s (2009) studies together helped me conceptualize how role strain, stress, and coping fit together (see figure 1). The research questions of this
dissertation focus on describing the lived experience of student caregivers to understand how they cope with the stress of two demanding roles.

Figure 1 Conceptual Diagram of the Student Caregiving Experience

Understanding the specific challenges of student caregivers will help student affairs professionals design programs and learning communities that support this population. Student affairs encourages transformative learning, a practice that occurs in a state of “relaxed alertness” (Keeling, 2004, p. 12). Students engage in reflection on the experience of what they have learned. This element of reflection mirrors reflexivity in phenomenological research. Transformative learning uses personal experience as it relates to the content studied, and upon active reflection during the learning process new ideas are generated and interpreted. Reflexivity in phenomenology (Creswell, 2007) asserts that “…history, culture and personal experiences of the researcher” (p.46) inform our questions and “our questions change during the process of research to reflect an increased understanding of the problem” (p. 43). There are aspects found in student affairs literature that focus on instituting cultural change within the academy when there is a problem (Brus, 2006; Keeling, 2004; Rhoades & Quiroz, 2008).

Institutions of higher education do not provide programs specifically for student caregivers, which is a problem for both student caregivers and the academy. In spite of
budget constraints, “...higher education institutions must reach out to all potential student populations to remain competitive and relevant” (Maroney, 2010, p. 13). More than half of family caregivers are between the ages of 18-49 years old, due to the aging population and the increased presence of chronic illnesses as people age, and the number of college-enrolled caregivers will continue to multiply (Joshi, et al., 2015). This is a potentially significant problem because the health consequences of student caregiving affect learning and persistence. Although phenomenology is not meant to develop theory or to generalize (Merriam, 2009; Valle & Halling, 1989; vanManen, 1990; Wojnar & Swanson, 2007), the process of a qualitative interview allows participants and the researcher to reflect on their experiences and understand them in a new way (Kvale, 1983) which becomes part of the transformative learning experience for participant and researcher. A co-generated perspective rather than a hierarchical stance allows for an accumulation of student caregivers’ stories, which is critical for developing substantive policy and program changes at the institutional level.

**Definition of Terms**

*Student affairs* encompasses a vast array of services throughout higher education that focus on the relationship between student development outside of the classroom and student success within the classroom. Students are viewed from a holistic perspective, thus student affairs professionals posit that health and personal development are just as essential to student learning and persistence as academic success (Long, 2012). Professionals in student affairs fulfill both administrative and direct service positions for example: dean of students, diversity officer, director of
admissions, advisor, residence life director, and health and wellness coordinator. The goal of student affairs is to care for students’ social, emotional and physical well-being.

The profession developed early in the 20th century, as government policies, such as the Morrill Act, GI Bill, Civil Rights Act and the American Disabilities Act made it possible for more nontraditional students to enter higher education. Student affairs professionals created programs to meet the challenges of changing student demographics in higher education (Helfgot, 2005; Long, 2012).

Historically, nontraditional student referred to any student who was not white, male and wealthy (Ogren, 2003). However, the definition of nontraditional student has changed over time. In the last century it meant anyone 25 or over (Compton, Cox, & Laanan, 2006). The National Center for Education Statistics (2002) classifies all students over 24 as nontraditional who can claim at least one of the following attributes: delayed entrance into higher education, enrolled part time, no reliance on parents for financial support, maintain full time employment, are single parents, do not have a high school diploma, or are caregivers for dependent minors or adults. This definition encompasses students pursuing certificates at 2-year institutions as well as undergraduate, graduate, and professional students. Nontraditional students are often women, racial and ethnic minorities, and of lower socioeconomic status (Brus, 2006; Ogren, 2003). They are defined in contrast to the traditional student.

Caregivers are considered nontraditional students. There are two categories of caregivers, formal and informal. Formal caregivers are paid caregivers, such as nursing assistants, nurses, doctors, and therapists, who focus generally on one component of a
care receiver’s health needs. Caregivers in this study are informal caregivers: people who provide care for friends or relatives who need physical, emotional, financial, or legal support as a result of a disability or chronic illness. This study will focus on two types of informal caregivers: primary and secondary. Primary caregivers assume a leadership role in the caregiving tasks, they may organize care and personally deliver care. Secondary caregivers assume an “assistant’s role” to the primary caregiver. There are two main categories of caregiving duties: activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs are tasks such as bathing, dressing, toileting, transferring, eating, laundry, and housework and IADLs are tasks such as making legal and financial decisions and providing transportation. While gender roles are changing (Scott, 2006), men still accept IADL roles more often than ADL roles (Alliance, 2008; Kwok, 2006; Spillman & Pezzin, 2000). Each type of caregiver and the tasks they assume have been shown to experience personal challenges based on their caregiving role (Schumacher, MacNeil, Mobily, Teague, & Butcher, 2012).

Care receivers are people who are being cared for by either formal or informal caregivers. In this study, care receivers have been diagnosed with a chronic illness or disability and a student enrolled in a higher education program has provided or is providing assistance with their health and personal needs. The care receiver can be a parent, spouse, child or friend of the student.

Role strain happens when a person juggles multiple responsibilities that require simultaneous action. Students are responsible for organizing and completing assignments. The level of autonomy and control are generally determined by classroom
and institutional climate. Caregivers are responsible for the health and well-being for another person. The level of autonomy and control is complicated by acute and chronic crises, past and present relationships, and personal and professional obligations. Each role must take precedence at different times and when the immediacy of both roles collide it creates role strain.

Identity development in college is a significant focus in student affairs practice and research. Identity is a state of being, a way of understanding who you are as a person. Identity formation involves being aware of one’s strengths, emotions, and values and developing the confidence to be comfortable by one’s self or forming healthy relationships with others (Chickering & Reisser, 1993). In this study, identity development is connected to role strain. Role in this context implies action, student caregivers have different responsibilities that they are obligated to perform in their caregiving role and in their student role. Caregivers have concrete duties that focus on the health, well-being, and safety of a human being. Students have concrete duties that focus on completing academic tasks required for graduation. Student caregivers experience conflict when the actions they must perform in one role are not consistent with their identity in that role. An individual’s identity development is affected by the context or contexts in which it occurs (Jones & Abes, 2013). The constant moving between roles among student caregivers results in rapid and repeated shifts between multiple contexts, which can have substantial effects on their identity development.

Institutional resources, in this study, are specific to higher education institutions. They encompass programs and systems that student affairs personnel, faculty, and
administrators can implement to support student caregivers. Institutional resources build a framework for student caregivers to cultivate coping strategies and promote human capital.

*Human capital* is the development of knowledge, skills, and talents attained through the pursuit of higher education that are rewarded in the marketplace (Arum & Roscka, 2011; McMahon, 2009; Paulsen & Smart, 2001). The development of human capital is connected to health. McMahon states that “human capital is the knowledge, skills, and attributes acquired by investment in education and health throughout the lifecycle” (p. 41). The inclusion of the investment in health as a component of human capital exemplifies the importance of health to society. McMahon (2009) provides this example, when a mother has the knowledge to take her baby’s temperature and then bring her to the doctor if the fever does not subside contributes to long-term health for the child. Thus, student caregivers who have a parent with a college degree have the benefit of a parent with human capital and likely an awareness of health knowledge. Human capital fosters cultural capital.

*Cultural capital* refers to the “symbolic wealth” (Paulsen & Smart, 2001, p. 75) that is passed from middle and upper income people to their families. It is developed through educational attainment, familiarity with dominant communication styles, and a web of social networks with resources and power. There are different types of cultural capital; the type that is most salient for student caregivers, promotes college-going knowledge. College-going knowledge is information that is learned through parental modeling that provides time management, academic, and social skills that help students
to succeed in college. Student caregivers with this type of cultural capital are able to advocate more effectively for the person they care for than caregivers without this type of cultural capital as a result of knowledge, communication, and social advantages. Cultural capital provides resources that enhance social capital.

*Social capital* gives members of a group access to resources that are owned, controlled, or influenced by other members in the social group (Glover & Hemingway, 2005). Social capital relies on collective social ties, which are affected by human and cultural capital. Student caregivers who have social capital can connect with social networks that provide expert information and support which can mitigate caregiver burden.

*Lived experience* represents the way a person expresses and finds meaning in an event. It embodies the way an individual reflects on the event. Two people can experience the same phenomenon but express and interpret it in completely different ways. The reflection of a phenomenon is unique to each individual due to personal history, values, and relationships. In the context of this study, the participants all lived the experience of being a student caregiver. College going knowledge, institutional resources, and personal coping strategies interacted to create distinct ways of living the experience.

**Theoretical Framework**

_March – December 2012_

The day I received the email that indicated my first publication was in print I also received an email that my funding had been cut. It truly was the best and worst of times. Without a teaching assistantship I could not afford classes or the health insurance that we depended on for Finn. The fear of not being able to provide health insurance for my family was compounded by my fear that I would not be able to stay in school. I needed the escape, structure, and focus school offered.
The information that I did not have an assistantship came near the end of the semester, long after the majority of positions had been filled for the following year. I was desperate. I literally begged every professor I knew to keep an eye out for me—or just hire me. I applied for positions I did not have the right experience for, I applied for full-time jobs, I pleaded with my former employer to hire me as a massage therapist again. In the end, I took a graduate assistantship for which I was woefully under-qualified because I was frantic to keep the graduate student health insurance and stay in school.

The position was in the Education Technology Center—I never even used Google before I started graduate school. I wanted to learn everything right away because I was grateful that they had given me a chance. It was impossible for me to fake competence so I admitted defeat. My boss said, “Step back, and watch. Then you will learn, with technology even if you do everything right, sometimes it still doesn’t work. Do not take it as a personal failure. You will learn multiple ways to accomplish one goal and if none of them work, shut down the computer and reboot.” This sentiment transcended contexts. Inherent in his words of wisdom was a new strategy for coping—try, adapt, relax. This allowed me the freedom to say it wasn’t my personal failure that Finn was a preemie and it wasn’t my personal failure that my funding had been cut. I had done everything “right” and Finn still entered the world with a difficult start. I had done everything “right” and my funding still had been cut. It took someone, who did not know my struggle, in a completely new context, to help me cope with the burden I felt—that I had failed as a mother and teacher. When I tried to let go of my guilt, adapted my expectations to what I actually had control over, and relaxed in the present moment, my coping strategies improved.

The theoretical framework for this study is the transactional model of stress and coping (TMSC) developed by Lazarus and Folkman (1987). TMSC focuses on stress as a process, the cognitive appraisal of stress is a transaction between person and environment (Byers & Smyth, 1997; Lazarus & Folkman, 1987). Cognitive appraisal is an interplay between a person’s values, experience and history and the cultural and social construction of the environment. It is a progression of thought processes that evaluate the potential threat to well-being and the coping resources available to effectively respond to the threat (Quine & Pahl, 1991). Therefore, the evaluation of an event as stressful is unique to each individual. There are two components of cognitive appraisal,
primary and secondary. Primary cognitive appraisal evaluates the potential consequences of an encounter and the effect on a person’s health; it is affected by both the individual’s interpretation of the encounter and their core values and beliefs. Secondary appraisal analyzes the resources and strategies that are available for coping with the threat to well-being. The two tiers of appraisal work together to gauge the threat and establish if an individual has the coping resources and strategies to successfully meet the demand.

There is a distinction between the level of personal control in regard to coping resources and coping strategies. Coping resources are characteristics “…of the individual’s external and internal environment which are either not directly or completely under the individual’s control; they exist in a quiescent state ready to mediate in a positive or negative direction the individual’s response to the advent of a stressor” (Shapiro, 1983, as cited in Quine & Pahl, 1991, p.59, italics in original document). Prior knowledge, experience, educational attainment, and socioeconomic status shape the accessibility to coping resources. Coping strategies are actions that an individual can employ to reduce stress, thus they are more within personal control. Coping is a process, it is not an immutable characteristic or technique. The two cognitive appraisal factors respond to contextual conditions and help explain changes or variations in coping.

The theoretical foundation of this model aligns well with reflexivity and transformative learning—the underpinnings of phenomenology and student affairs—which emphasize that personal experience and prior knowledge affect how a lived
experience is interpreted. From the lens of transformative learning, a new understanding of prior knowledge and experience can facilitate development. Manen (1990) contends, from a phenomenological perspective, that an experience cannot be understood until it is reflected on, thus reflecting on a recent experience can alter the meaning of a past experience. The TSCM suggests that the emotional response to stress is not necessarily the cause of the stress, it is a combination of a person’s past experiences interpreted in the present context. The reverse is also true, a person can develop coping strategies through transformative learning and reflexivity and reappraise an event as growth rather than as stressful. “Persons should be viewed over time within the framework of their life stories...” (Lazarus & Folkman, 1987, p. 157) to understand how development and changing contexts affect patterns of coping.

Research Questions
Illustrating the lived experience of students who care for a person with a disability or chronic illness can provide insight into the needs of this population. As stated earlier, Maroney (2010) and Paré’s (2009) study provided a framework for my research questions. Maroney (2010) used the transactional stress and coping model to study how coping affects persistence for nontraditional students. Paré’s (2009) study described the lived experience of student mothers and emphasized that role strain was a significant component of their academic journeys. Role strain is a factor in health outcomes for both nontraditional students and caregivers. I will use positive coping strategies as a proxy for health. “Health creates capacity...” (Silverman, Underhile, & Keeling, 2008, p. 7) and focus on health should be part of the institutional structure.
Adaptive coping strategies must be facilitated within the academy to promote health.

Health is at the core of student learning and success. The questions this study will address are:

- What is the lived experience of students who care for a person with a disability or chronic illness?
- How do student caregivers cope with the role strain of juggling student and caregiving demands?
- How do student caregivers develop coping strategies within the academy?

Chapter 2 provides a comprehensive review of the literatures on nontraditional students, caregivers, and student affairs. I reflected on the literature in relation to my own experience. The components of my story that illustrate concepts from prior studies are integrated throughout. The vignettes are not in chronological order, they align with the content discussed, I have included the year the vignettes occurred to provide context for the reader. Chapter 3 explains hermeneutic phenomenology as the methodology for this study. The findings are discussed in Chapters 4 and 5. Chapter 4 presents the participants’ individual student caregiving experiences in a narrative style and the essential themes are introduced. Chapter 5 examines the essential themes and thematic elements using a combination of the participants’ own words and the researcher’s interpretations. Chapter 6 discusses the study’s findings and offers implications for practice and ideas for future research.
Chapter 2
Review of the Literature

“non-traditional adult students...face competing demands and stresses because of life circumstances that are different for them than for traditional [students]” (Maroney, 2010, p. 87)

Introduction

Student affairs’ function in the academy is to develop strategies that enhance learning and success for all students. There is a gap in student affairs literature that specifically describes the experience of students who care for a person with a disability or chronic illness. Student caregivers have challenges that may be even more overwhelming than other nontraditional students due to extra time commitments and the role strain inherent in caregiving. The dual roles have consequences for health and higher education persistence which have negative consequences for long term health outcomes. The “...minimization of the role of health in learning—and the historical traditions of health in higher education—compromises institutional effectiveness and undermines student success” (Silverman et al., 2008, p. 4). Traditionally, higher education was meant to train the mind, and health care professionals attended to the brain and body (Prescott, 2007; Silverman et al., 2008). Education, not learning, was the domain of postsecondary institutions. But the student is a whole being and brings her body and brain to class and health is inextricably linked with learning outcomes (Allensworth, 2011; Freudenberg & Ruglis, 2007;; Prescott, 2007; Silverman et al., 2008).

Seeing students as their component parts (body, mind, spirit), rather than as an integrated whole, supported the emergence of fragmented college systems and structures – academic affairs to cultivate the intellect, and student affairs to tend the body, emotions, and spirit (Keeling, 2004, p. 3).
Higher education culture has been slow to move away from the bifurcated approach of education and health and toward a view of learning as a holistic endeavor. “...student success is a unifying, comprehensive concept that links academic and student affairs educators in the education and transformative preparation of the whole student” (Silverman, et al., 2008, p. 7). The fundamental structure of how health is valued on campuses has significant implications for students who care for a person with a disability or chronic illness. Student caregivers are a subgroup of nontraditional students who can experience barriers to learning success as a result of the unique health risks of their intersecting identities. I have organized this literature review into sections about student affairs, nontraditional students, and caregivers. The rationale for this method of organization is to provide historical context for nontraditional students’ entry into higher education, highlight the specific challenges of nontraditional students who care for a person with a disability or chronic illness and demonstrate how student affairs is well positioned to serve the needs of student caregivers.

**Student Affairs**

Student affairs stresses that transformative learning happens while students are reflecting on their lives, both in and out of the classroom (Keeling, 2004). Health has consistently been the focus of my work life as a recreational therapist and a massage therapist and I always gravitate toward caregivers. During my first year as a student affairs student, I began the process of trying to learn how to incorporate caregivers in my course of study, while I simultaneously functioned as a student caregiver. I reflected and wrote about my journey as a learner for a class assignment during my first year as a doctoral student in the student affairs program. It highlights my struggle to be sure, but
as I reread it I am amazed at what a great example it is of transformative learning. I was applying what I learned in real time.

January 2011
“Working at Marklund, a pediatric nursing home for kids with severe and profound disabilities for my first job has scarred me for life,” I said to my friend while we watched the divers at Nationals. She, quite rightly looked at me like I was crazy, so I explained. A small fraction of children were there because of the “fault” of the parents, i.e. fetal alcohol syndrome, severe abuse, and/or neglect. Everyone else arrived because of an accident—an accident of nature, an environmental accident, or a parental accident. As the divers leaped head first into the water, I held my breath until they surfaced uninjured hoping no accident would happen on my watch.

“Exhaustion trumps all disease” (Zadoorian, 2009, p. 186). This is a quote from a book I have my students read about an elderly couple—she is in the final stages of cancer and is a caregiver for her husband who is in the mid to late stages of Alzheimer’s. I feel that exhaustion has trumped my development over the past two years. The current chapter in my life “as a course of study” began with Finn’s unexpected early arrival—I am a planner. I had a planned c-section for him (due to my previous birth experience). My plan was to have all stressful things in my life (data collection, GRE, and PhD application) completed by the beginning of my third trimester so that I could relax before the pain and exhaustion of recovering from surgery while caring for a newborn began. Finn decided to enter the world just weeks after my above list was completed. So I started a very long, scary journey already exhausted. For Finn’s first eight months I was so terrified of accidentally harming his fragile little body, I essentially isolated us from the rest of the world. With his preemie lungs, I thought I might go completely crazy if he got sick and had to go back in the hospital. I was afraid if I got sick I would surely make an irreparable mistake. All my experience as a recreation therapist told me not to focus on my fear or remain isolated for so long but I could not snap out of it until after the official end of flu season. Eight months is a long time to go with very limited contact with the outside world while combined with the tunnel vision of completing my thesis. The two experiences simultaneously made me hypersensitive to error.

I am going on nearly two years of sleep deprivation and it makes everything more difficult and increases the likelihood that mistakes will happen. My body can only handle what needs to be done. Last semester was about attending to what was most pressing—3 ER trips with my kids, nagging after effects of a broken rib, my mother in ICU, my husband losing more hours at work because of the economy, adjusting to a new department with new people and new expectations, and teaching on my own—all with a perpetually sick toddler who does not sleep well.
I planned to relax over break, but both kids were sick with incredibly high fevers. I even said to one of the doctors on call after my third call, “I am so exhausted, I’m just afraid I am going to miss something big.” I have regressed in order to maintain some semblance of equilibrium. I have become more dualistic in my approach to life and school. I seek black and white answers to information that is difficult, i.e., Finance. I am less likely to let Jake and Finn explore their environments because I don’t have the energy to clean up another mess. I keep us somewhat isolated because I can’t lose one more night’s sleep to illness. I do not feel like the “real me”.

I suppose my Accommodating Learning Style (Kolb, 2005) has allowed me the privilege of altering my methods in order to adapt. Some of the strengths of the Accommodator are getting things done, being adaptable, being practical and implementing solutions to problems (Kolb, 2005). By temporarily functioning in a more dualistic manner I completed assignments, led two classes, kept my kids from major harm and did not cause irreparable damage to my marriage.

I am navigating a “Leading Edge” (Hodge, Baxter Magolda, & Haynes, 2009). I am struggling with my identity as I juggle multiple roles—mom, wife, teacher, PhD student, and massage therapist. Mom, wife and teacher work well together, they seem to use the same muscles. PhD student and massage therapist are at odds and they upset the balance in the whole equation. As a student in an “elite” program, I feel pressure to be academic and as a massage therapist, I feel pressure to be practical. Our readings helped me articulate the difference.

Clinchy, Belenky, Goldberger, & Tarule (1985) and Hodge et al. (2009) have given me the language to address the dissonance I feel. For years as a massage therapist I felt silenced (Clinchy et al., 1985) by condescending people and I allowed clients to edit the way I communicated (Hodge, et al., 2009). There are two groups of people who come for a massage—people who want to feel better and people who want to be pampered. The latter treated me like staff that must stay in my place. Many in this group have PhDs or MDs and now I am in that group. It is tricky to be in an “elite” program while maintaining my role as a service worker.

There is a certain amount of silencing (Clinchy et al., 1985) needed to secure my income. I find myself at another Crossroad (Evans, Forney, Guido, Patton, & Renn, 2010) in my attempt to re-author my life. There have been several encounters with current and previous clients whose insensitive remarks shook me. For example, the person who told me I was vicious when I retreated to care for Finn instead of keeping her weekly appointment. I am still haunted by that word choice. Or the client who imagined I would be a good teacher if only I weren’t so short. As a massage therapist, I keep my mouth shut but as a PhD student it is difficult to be silenced.
When I unearthed this paper, I was shocked that I had been so forthright. My emotional memory of that time is that I did not share anything about my personal life in the classroom. The nature of the assignment, of course, encouraged self-reflection but I doubt I would have been so honest if anyone but my advisor—my safe person—had assigned it. Safety is an essential component of health, critical reflection, and transformative learning.

One component of student affairs practice focuses on creating safe communities on campus to nurture student learning and development. However, the culture of the academy still reflects the values of “…educating a very homogeneous, very privileged student population” (Brus, 2006, p. 37). Institutions of higher learning have been slow to adapt to the changing needs of nontraditional students and can create a chilly climate. Brus (2006) highlights the effects of a chilly climate in graduate school “While the insults that result from a chilly climate are most often small, unintentional and difficult to identify as discriminatory, they are continuous and unrelenting, thereby sending a powerful message to those affected: if you are not part of the normative culture, you lack what it takes to be successful in graduate school” (p. 37). First generation and minority students have similar difficulties in undergraduate education (Pascarella & Terenzini, 2005). Institutions must develop support systems that align with nontraditional needs (Kurantowicz & Nizinska, 2013; Taylor, 2010). Colleges and universities have the opportunity to develop safe communities because safety is an essential component for health and learning. Students then build the resources to
continue living in safe communities throughout their life, which promote positive lifetime health outcomes.

Students succeed in campus environments that enhance social determinants of health. Social determinants of health are conditions within a community that augment or diminish health outcomes because they affect the distribution of health resources (Brennan Ramirez & Metzler, 2008). Social determinants of health include socioeconomic status, age, race, gender, gender expression, and sexual orientation, social support networks, and personal characteristics that are influenced by how an individual is treated within their home environment. Table 1 delineates societal and psychosocial components of social determinants of health. Communities, colleges, and universities that promote equitable distribution of social determinants of health not only increase persistence and graduation rates they also affect health across the lifespan.

Education is the one social determinant consistently correlated with longevity and better health in all countries that have studied the intersection of health and education (Allensworth, 2011; Marmot et al., 2008). The Center for Disease Control and Prevention (2009) states that chronic diseases are the leading cause of death and disability in the United States, they increase the overall cost of health care and they are the most preventable form of ill health. Health status is determined by four components: genetics, access to health care, health behaviors and social conditions. Each component of health status is directly or indirectly affected by educational attainment; access to health care, health behaviors, and social conditions are directly
<table>
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<tr>
<th>Social Determinants of Health</th>
<th>Societal</th>
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<tr>
<td><strong>Social</strong></td>
<td>Freedom from discrimination</td>
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<tr>
<td><strong>Economic</strong></td>
<td>Food security</td>
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<td><strong>Physical Environment</strong></td>
<td>Safe housing</td>
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<tr>
<td><strong>Behavioral</strong></td>
<td>Access to health care</td>
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<tr>
<td><strong>Psychological</strong></td>
<td>Sense of self</td>
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<td></td>
<td>Optimism</td>
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<td></td>
<td>Resilience</td>
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<td></td>
<td>Health habits</td>
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Table 1: Social Determinants of Health
Adapted from Brennan Ramirez, Baker, & Metzler, 2008

affected (Brennan Ramirez & Metzler, 2008; Pascarella & Terenzini, 2005) and genetics are indirectly affected (Yehuda, 2015). How genes manifest themselves is influenced by environment, stress, and health habits (Sternberg, 2008; Yehuda, 2015) all of which are correlated with academic achievement. Sources differ on the percentage each component contributes to health status but they all consistently support
that social circumstances and health behaviors function as a greater portion of health status than genetics and access to health care (CDC, 2012, 2014; Marmot et al., 2008; Suozzi, 2009) (see figure 2).

Education impacts health in profound ways (Allensworth, 2010; Freudenberg & Ruglis, 2007). A study by Woolf, Johnson, Phillips & Phillipson (2007) found that 8 times as many lives would have been saved when they corrected for disparities in education-associated mortality rates than would have been saved with advances in medical care. Promoting equity in education has the potential to save more lives than medical advances. Education is such a significant factor in mortality rates that some states began reporting educational attainment on death certificates in 1989, and all states reported educational attainment on death certificates by 1996 (Woolf, et al., 2007). The health benefits of education are both direct and indirect (Pascarella & Terenzini, 2005) and each type of benefit becomes more significant as people age. There is an
abundance of research focused on the long-term effects of higher education on health (Pascarella & Terenzini, 2005). However, research on the experience of people who are at risk for stress related health issues in higher education is scarce. Nontraditional students are often from underrepresented populations and of lower socioeconomic status (Brus, 2006; Ogren, 2003). The primary reasons nontraditional students pursue higher education are to improve economic and social capital. Persistence rates among nontraditional students are lower than among traditional students (Maroney, 2010; Stecker, 2004). Persistence in higher education “leads to healthier lives by improving earning power, social status, and cognitive ability, which in turn influences positive lifestyle choices, an enhanced understanding of health issues, and better negotiation of the medical care system” (Allensworth, 2011, p. 332). Given this population already experiences disparities in health due to educational disparities, it is imperative that more research focus on the intersection of health and education for nontraditional students.

One goal of student affairs is to create safe communities for people who are traditionally considered “outsiders” in higher education so they can have equitable opportunities for learning and success. Prescott (2010) provides an historical overview of how student health services have influenced how nontraditional students were brought into the academy. “...college health programs...were intertwined with the dramatic expansion of higher education in the late nineteenth and early twentieth centuries...expanding preventative health measures and clinical services became a way for institutions to deal with the new issues created by an increasingly diverse student
population” (p. 3). Marginalized populations were at greater risk for health problems.

Student health programs were developed to help minimize health disparities as a result of gender, race, and socioeconomic status. And to mold nontraditional students in the image of what the academy expected them to be, “...medical theory and practice both reflected and reinforced gender norms, racial stereotypes, and social hierarchies” (p. 2).

The AIDS epidemic created an alliance between student affairs and student health services and the alliance persists to create a safer campus community for all students (Prescott, 2010).

**Nontraditional Students**

*October 2015*

My dad modeled being a nontraditional student for me. He began college when he was 18 and took one class a semester until he graduated at 40—it was an honor to watch him march down the aisle at graduation when I was 16. Some of my fondest childhood memories were sitting at the dining room or kitchen table doing our homework together. He always said school was fun and he loved learning. I never heard the stories of how tough it was to study alone in his hotel room (he traveled a lot), I never heard the stories of how he had to “fight” to adjust due dates when they interfered with work or family, I never heard about instructors who were unwilling to accommodate his inability to stay seated due to his physical discomfort through classes even though he had just driven 10 hours to get there...until I discussed my own trials as a nontraditional student.

Higher education has historically approached nontraditional students as a problem to be managed rather than as an asset (Fragoso et al., 2013). Nontraditional students have had a presence in higher education since its inception. Even in medieval times, students were accepted from the lower ranks of society to be trained as clergy so they could attend to the religious needs of a community (Haskins, 1965) and this tradition continued in the colonies of America (Rudolph, 1991). While the academy primarily catered to rich, white men, one of the purposes of higher education has
always been a means to advance the democratic vision of America (Thelin, 2011).

Republican Motherhood is one of the earliest motives for educating women, the idea was that women should be educated so they could raise their sons to be future leaders (Miller-Bernal, 2006). This notion paved the way for Academies and Normal Schools, primarily for women. The Morrill Acts were legislative endeavors that funded land-grant institutions, which focused on practical agricultural education for people in rural communities and the working class (Williams, 1991). The GI Bill was designed to educate returning soldiers so they could reenter civilian life with skills to succeed in the current economy (Thelin, 2011). The GI Bill and Affirmative Action opened the door of higher education to many minorities who would not have had the opportunity to go to college. The Americans with Disabilities Act legally required all institutions that accepted federal funds to make reasonable accommodations so people with disabilities could then access the academy (Drezner, 2008). However, with each new previously excluded group to enter higher education, the culture of the academy continued to privilege the schedule, priorities, and learning habits of the 18-22 year old, affluent, white male, which created a legacy of barriers to success for nontraditional students.

Navigating the system in academe is a challenge for nontraditional students, the path is not as clearly delineated as it is for traditional full-time students (Pelletier, 2010). Nontraditional students have less time with faculty and students, which affects the information that they have access to. The way information is disseminated and the support services available on campus are designed for traditional students. Nontraditional students—both undergraduate and graduate—are often unable to
access information and support they need to succeed. The combination of balancing personal obligations and institutional struggles can create stress, which can have a negative impact on health, which can lead to significant barriers for success (Fragoso, et al., 2013).

It is in the best interest of the academy to begin approaching nontraditional students as assets and develop resources to help improve persistence and retention rates for them because they need the revenue from this population. Nontraditional student enrollment in higher education represents a 190% increase from 1970-2007 (Heller, 2011). Nontraditional students constitute 71% of the undergraduate population and the percentage of nontraditional graduate students continues to rise (Brus, 2006; Casselman, 2013). State and federal funds for public institutions have been significantly reduced over the last 3 decades (Heller, 2011). Federal research grants and subsidies have also dried up for private institutions. Higher education institutions must adapt to the unique needs of nontraditional students because they rely on the tuition revenue from both traditional and nontraditional students.

Nontraditional students are at risk for stress related illnesses due to the culture of the academy and the stress of balancing multiple roles and nonacademic responsibilities (Maroney, 2010). Approximately 18 million people were classified as undergraduate students, during the 2011-2012 academic year and only 5 million were considered “traditional” (Casselman, 2013). “Traditional” students are students who are 18-22 years old, financially dependent on their parents, live on campus at a 4-year institution and do not have responsibilities other than school. That means 13 million
undergraduate students—a significant majority—are identified as nontraditional. Thus, nontraditional is the new norm. Sixty percent of undergraduate students have one or more nontraditional attributes (Casselman, 2013) and the culture of the academy, in most ways, continues to operate as if the majority of students are traditional. Table 1 provides a visual comparison of the most salient characteristics that differentiate traditional and nontraditional students.

<table>
<thead>
<tr>
<th>Traditional Student Attributes</th>
<th>Nontraditional Student Attributes</th>
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<tbody>
<tr>
<td><strong>Affluent White Male</strong></td>
<td>Low SES</td>
</tr>
<tr>
<td></td>
<td>Women</td>
</tr>
<tr>
<td></td>
<td>Minority</td>
</tr>
<tr>
<td><strong>18-22 years old</strong></td>
<td>25 years or older (undergraduate)</td>
</tr>
<tr>
<td></td>
<td>over 30 years old (graduate)</td>
</tr>
<tr>
<td><strong>Reside on campus at 4-year institution</strong></td>
<td>Commute or live in family housing</td>
</tr>
<tr>
<td><strong>Financially dependent on parents</strong></td>
<td>Financially independent</td>
</tr>
<tr>
<td><strong>School is primary responsibility</strong></td>
<td>Family obligations are primary responsibility</td>
</tr>
<tr>
<td></td>
<td>May be responsible for dependent minor or adult</td>
</tr>
<tr>
<td><strong>Do not work</strong></td>
<td>Employed</td>
</tr>
<tr>
<td><strong>Enter right after high school</strong></td>
<td>Delayed entry/may not have HS diploma</td>
</tr>
<tr>
<td><strong>Full-time</strong></td>
<td>Part-time</td>
</tr>
<tr>
<td><strong>Mid-high socioeconomic status</strong></td>
<td>Lower socioeconomic status</td>
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</table>

Table 2 Traditional and Nontraditional Student attributes

The demographics of graduate students are shifting as well. Women, minorities, people with disabilities, and people from low socioeconomic status have substantially increased enrollment in graduate programs over the last 4 decades (Brus, 2006). The number of women entering graduate school has outpaced the number of men enrolled since 1970. Minority students have doubled their matriculation rates. People with
disabilities represented 6% of the graduate student population in 2003. Many nontraditional students are at risk for stress related illnesses because of their membership in marginalized groups (Burke Harris, 2012), and nontraditional students are at greater risk for attrition than traditional students because their non-academic lives provide more external obstacles (Maroney, 2010). The average age of graduate students is also increasing. At the University of Iowa alone, 40% of doctoral students are over thirty and 10% are 40 or over. This age cohort has significant familial and financial responsibilities. Students over 40 are more likely to be in the Sandwich Generation, which means they care for dependent minors and dependent adults simultaneously (Schumacher, et al., 2012). The time constraints and emotional burden imposed on students who are caregivers can be crushing. Caregivers are also at risk for stress-related illnesses (Schumacher, et al., 2012). Stress related health issues can have a negative impact on academic performance and persistence for nontraditional students (Estevez, 2010) who are caregivers. Health has a significant impact on academic success.

**Caregivers**

1990-1999

I developed an interest in, and affection for caregivers, long before I became an informal caregiver. I worked my way through my undergraduate degree as an in-home nursing assistant. I cared for people with physical and developmental disabilities and for people in Hospice. The literature suggests that caregivers are at risk for stress related illnesses (Butcher, Holkup, & Buckwalter, 2001; Schumacher, et al., 2012) and I witnessed family members crumble under the pressure of their caregiving responsibilities and develop severe health issues. The family that I worked with the longest always comes to mind when I think of the tremendous health consequences of caregiving. The man I was hired to care for had a massive stroke when he was 18 years old, during his first semester at college. The stroke left him quadriplegic; it also stole his ability to speak but left his sharp mind intact. His mom tended to all of his physical and emotional needs.
She battled with the government to provide financial assistance to cover the significant medical costs so the whole family did not live in poverty; she struggled to maintain his network of high school friends so he did not live in isolation; she toiled to find activities that would stimulate his mind so he did not sink into despair. She was his primary caregiver for 16 years—until her last breath when cancer finally won. She died 17 years ago, and in that time I have watched many caregivers lose their own health along their caregiving journey.

**Overview of Caregiving.** Humans enter the world as completely dependent beings, and many people across the globe care for sick and disabled family and friends over extended periods of time (Abel, 2009; Isa et al., 2013; Kwok, 2006; Sternberg, 2000; Vellone, Piras, Talucci, & Cohen, 2008), therefore, caregiving is a universal experience. Anthropologists suggest “...the real beginning of civilization should not be gauged by tool use but by the evidence of healed bones. Healed fractures indicate that the person was cared for...” (Benner & Wrubel, 1989, p. 58). Dependency is inextricably linked with our humanity (Abel, 2009). Caring is embedded in our intimate relationships and we create an illusion of independence by denying that giving and receiving care can be understood apart from the human bonds on which we depend. “Time creates a story” (Benner & Wrubel, 1989, p. 64), the past affects how the present is experienced and the present affects how the past is interpreted, which shapes how the future is lived. It is essential to understand how caregiving was experienced in the past to grasp how it has influenced present caregiving dynamics.

Historically, women have been the primary caregivers in a community because they were believed to be natural nurturers and could emotionally and spiritually connect with the ill and disabled (Abel, 2009). Physicians endorsed the notion that the mind had an influence on physical health and that reassurance and empathy eased
psychic distress and promoted health. Women were adept at using their own experiences with suffering to deliver passionate care to facilitate health and healing, thus, it was the domain of women to provide nurturing care during the dependent cycles of human existence.

Abel (2009) provides an overview of female caregiving in the United States from 1850-1940. The significance of this particular time frame is that it allows us to see caregiving from multiple perspectives—in slave communities, in rural and poor communities, and in affluent communities—against the backdrop of major societal changes. In the 1850’s slavery was still legal, physicians did not have high professional status, and private insurance and public health initiatives were not yet part of the health care narrative. Slaves cared for their kin and community only after their onerous duties were complete; domestic slaves often had to perform caregiving tasks for sick people in the owner’s family while their family and friends were left unattended. At the beginning of the twentieth century, people of all races who lived in poverty were particularly subjected to strict regulation and surveillance to comply with public health programs, thereby losing most autonomy in caregiving. Meanwhile, middle class and affluent white women have consistently had the benefit of being able to afford assistance with caregiving duties, however, they were still expected to “…subordinate their own needs” (p. 43). Current literature addresses the combination of physical and emotional burdens for caregivers, which continue to vary among racial and socio-economic classes (Abel, 2009; Braun, Beyth, Ford, & McCullough, 2008; Wakabayashi & Donato, 2006).
Public health initiatives and charity organizations at the turn of the twentieth century deemed poor people and marginalized populations incapable of providing quality care, thus ill and disabled family members were forced into nursing care facilities. (Abel, 2009). The century also saw huge medical advances that prolonged life span and allowed people to survive that would never have survived in the 1800’s, creating the heaviest burden on individuals from low socio-economic backgrounds who care for a person with a disability or chronic illness. People who live in poverty are more likely to experience disabilities and chronic illnesses (Allensworth, 2011; Alvarez-Dardet & Ruiz, 2000; Brennan Ramirez & Metzler, 2008; Burke Harris, 2012; CDC, 2009, 2012; Porterfield & McBride, 2007). It is a vicious cycle.

**Gender and cultural disparities in caregiving.** Cultural norms and societal contexts affect who provides care and how caregiving responsibilities are divided within a family or community. Before medicine became a high-status and regulated profession, caregiving women were often viewed in the community as healers with an important role to play during births, illnesses, and deaths (Prescott, 2007). Knowledge about specific methods and remedies were passed down through generations from mother to daughter, where “…female caregivers employed many of the same diagnostic and therapeutic practices” (p. 3) used by physicians. As physicians sought more control over medical decisions and procedures, and the delivery of health care changed in the United States, caregiving became a “…relationship between power and knowledge” (Prescott, 2007, p. 3), thus, women without requisite credentials did not have the power to assert their knowledge.
Throughout history, the intimate bodily and psychological components of caregiving have fallen disproportionately on women, therefore, women endure the majority of physical, emotional, social and financial consequences of caregiving (Hooyman & Kiyak, 2005; Prescott, 2007; Wakabayashi & Donato, 2006). Even women with medical degrees were expected to assume nonmedical caregiving roles if a member of their family became ill and needed personal assistance. Personal assistance duties were typically associated with feminine roles such as tending to physical and emotional needs of the patient often at the expense of the woman who was caregiving. “…decisions women make about care are not simply private choices” (Prescott, 2007, p. 273), and societal expectations for women presume mothers, wives, and daughters will carry the brunt of caregiving obligations. Caregiving is trivialized because it is most often done by women.

Caregiving capacities are socially tied to femininity. Traditional religious and secular expectations of women are that they will be home to care for the full range of family needs. However, women’s entry into the labor force, delayed marriage and decreased fertility rates, and the search for individual autonomy have shifted socially constructed gender roles. Scott (2006) describes in a cross-national study about gender role attitudes, “…ideology is changing, and gender patterns of domestic behavior are also changing, albeit very slowly and with men changing less quickly and to a lesser extent than women” (p. 16). Men accept the role of hands-on parent and caregiver more often. Wolfson, Handfield-Jones, Glass, McClaran, and Keyserlingk (1993) investigated adult children’s perceptions about their responsibility to care for elderly
parents and found that sons had an equal sense of moral obligation to support aging parents with financial, physical, and emotional care as daughters. While men do assume caregiving responsibilities, the duties they choose often remain consistent with traditional masculinity, such as tasks associated with financial and legal decisions; they do not perform the physically demanding personal care that women do (Alliance, 2008; Kwok, 2006; Spillman & Pezzin, 2000). However, recent research indicates male caregivers are increasingly accepting caregiving tasks that were traditionally feminized but they often do not seek out or accept resources that improve their ability to cope (Giesbrecht, Williams, Duggleby, Ploeg, & Markele-Reid, 2016; Milligan & Morbey, 2016). Though men do not reach out for or accept help as readily as women, the men in this study drew on skillsets from previous education or jobs to incorporate pieces of their identity prior to caregiving, which helped them cope with the logistics of caregiving (Milligan & Morbey, 2016). Male caregivers are “…recreating new versions of masculinity that encompass both elements of the masculine and feminine” (Giesbrecht, et. al., 2016, p. 1595).

Just as males and females have different experiences as caregivers, people of various ethnic groups also experience caregiving differently. For example, studies have shown that African-American caregivers experience more internal satisfaction with less depression and anxiety than white caregivers (Family Caregiver Alliance, 2008). A narrative analysis by Dilworth-Anderson, Williams, and Gibson (2002) suggests that being White is one of the “…best predictors of caregiver depression…” (p. 243). However, a study by Haley et al. (1995) that compared Black and White caregivers to
Black and White non-caregivers found that White non-caregivers had higher rates of obsessive compulsive and anxiety disorders, thereby, suggesting that there are confounding variables affecting the conclusion that simply being a White caregiver increases the likelihood that one will develop anxiety or depression. Across the 20 year analysis, Hispanic caregivers, were also found to have a higher rate of depression and role strain than Black caregivers. American Indians and Asian Americans were less likely than Whites to experience psychological issues because of their cultural philosophy of collectivism and reciprocity. Given that the United States is a multicultural nation, it is necessary to understand the unique experiences of caregiving across race and ethnic cultures.

**Financial Consequences of Caregiving.** The economic, cultural and legal developments of the past 150 years have reshaped the structure of the family (Connell, 2003; Scott, 2006), which has pecuniary implications for caregivers. The Industrial Revolution created a sea change in America, we shifted from a rural economy to an urban economy, which changed the family unit into islands of small nuclear families instead of large extended families. When people lived within close proximity to the extended family network, caregiving was a shared experience, now it is more of an isolated experience and women, who fulfill most caregiving roles, are without the support networks they traditionally had with the financial burden generally left to one nuclear family (Connell, 2003).

A shift in cultural norms and legal rights that emanated from the Civil Rights Movement redefined the institution of marriage. Interracial and intercultural marriages
are legal; women have the right to be equal partners in marriage. Racial, ethnic, and social differences are reflected in family caregiving dynamics and expectations (Dilworth-Anderson et al., 2002). The significant societal transformations have resulted in women experiencing the heaviest financial burden for caregiving.

Caregiving has economic repercussions beyond the tenure of caregiving. The majority of informal caregivers are women (Albert, Schulz, & Colombi, 2010; Hooyman & Kiyak, 2005; Wakabayashi & Donato, 2006) and women are more likely to move to part-time work, decline promotions and retire early as a result of caregiving responsibilities (Gort et al. (2007). Research by Wakabayashi and Donato (2006) showed that work hours for middle aged women did not increase after caregiving responsibilities ceased, they experienced age discrimination and health problems—which were a by-product from the stress of caregiving. This has a negative impact on Social Security and retirement benefits, thereby increasing the risk that women who assumed caregiving roles will live in poverty in their senior years. Elders who live in poverty have a greater risk of acquiring physical and mental disabilities than elders who did not live in poverty (Vallas & Fremstad, 2014). Men have taken on more caregiving duties as gender roles have evolved over the last three decades. Albert et al. (2010) suggest that male caregivers also experience financial consequences due to caregiving but not to the same extent as women. Female caregivers are more economically dependent throughout their life course because they sacrifice employment opportunities to fulfill caregiving obligations.
Health Consequences and Benefits. An abundance of research shows that informal caregivers experience both objective and subjective burdens that affect their own health (Butcher, Holkup, & Buckwalter, 2001; Pickett Jr, Altmaier, & Paulsen, 2007; Schumacher et al., 2012). The burden of caregiving is experienced differently based on the illness or disability. Invisible illnesses and disabilities may create unique challenges for the caregiver. Invisible illnesses or disabilities are those which cannot be visibly detected by looking at a person, such as: dementia, learning disabilities, traumatic brain injury, cancer, mental illness, AIDS, Huntington’s Disease and chronic obstructive pulmonary disease. Some of these conditions carry a stigma and some increase emotional volatility of the care receiver. Since they are invisible the caregiver may choose to keep their role hidden, which may increase role captivity and isolation. Green (2004) suggests that finding a sense of control in uncontrollable situations may help caregivers, thus keeping their caregiving role concealed may allow them to feel a greater sense of escape when they are not physically with the care receiver. This idea is worthy of further investigation particularly because of the impact of role captivity on caregivers for someone with dementia.

People who care for someone with dementia experience role captivity and isolation at comparatively higher rates than other caregivers (Bertrand, Fredman, & Saczynski, 2006). Family and friends often stop coming around to offer support for dementia caregivers which in turn leads to a greater sense of role captivity and isolation. Dementia is a degenerative disease with no known cure (Alliance, 2008). “Caregivers to [people with dementia] must cope with the reality that their loved ones are facing a
deteriorative, irreversible disease that will increasingly rob the caregiver of the intellectual and emotional reciprocity that they once shared” (Bertrand et al., 2006, p. 547). The progression of the disease created much more inequality in the division of labor in the household and less reciprocity in the relationship (Quinn, Clare, Pearce, & van Dijkhuizen, 2008). Thereby, the caregiver loses social support, the reciprocal relationship with the care receiver, and time flexibility.

However, emerging literature suggests that caregivers for someone with dementia also gain benefits from the care they give (Butcher & Buckwalter, 2002; Cadell, Regehr, & Hemsworth, 2003; Kruse, 2006). They develop personal strength from the perseverance required in caregiving. Bergs’s (2002) study suggests that intimately knowing the care receiver and being able to satisfy their needs contributes to a sense of control and pleasure for the caregiver. Personal coping strategies and social support networks have an impact on how time constraints, emotions, and physical tasks of caregiving are interpreted. Thus, caregiving can vacillate between burden and benefits based on context and resources. Quinn et al. (2008) found that well-being changes over time and many factors contribute to well-being, with some factors being internal and others external to the caregiver. Caregiver coping strategies are internal factors and coping resources are external factors associated with well-being. Since a limited amount of research suggests that there are benefits associated with caregiving and caregiving can provide opportunities for personal growth; it is important for student affairs literature to investigate how the academy can provide coping resources that support coping strategies for student caregivers.
Student Caregivers.
August 2009 – December 2009

My water broke with Finn (9 weeks early) in the middle of the night of the first week of classes—one week after Jake started kindergarten. In the morning I called my advisor to let him know that I was on bed rest in the hospital until the baby was born. He told me not to worry and to take care of myself and my family. Well, I did have reason to worry. I learned that they did not calculate my time off according to the way I understood the union contract but I was too scared of losing the position that I did not fight it. So at the end of the third week in the hospital, without an indication of when we would be released, I was informed that I needed to return to work in two weeks. Finn was born August 31, 2009, at the beginning of the major recession and a swine flu epidemic. This specific type of flu severely compromised the lungs of anyone with a fragile immune system, like Finn’s. His preemie little lungs were not fully developed and were particularly vulnerable. And I was told that I had to go back to teaching while my son was still in the hospital and I would have to be exposed to college students in the middle of a flu epidemic that could literally kill my baby. As if I needed anything else to heighten my anxiety. I hopped into problem-solving mode. I suggested I conduct my classes virtually; that was denied. I begged my friends, colleagues, clients and professors to donate sick time to me—I was overwhelmed by their generosity, they all donated enough days to let me be home with Finn the whole semester. That was denied. A staff person told me that because I was a graduate student and not a “real” employee I was not entitled to use anyone else’s sick days no matter the circumstances. And I was quite condescendingly told, “You are certainly able to take unpaid leave.” My husband, who works in construction, lost a lot of hours because of fewer building projects due to the financial crisis and I was a graduate student. We did not have cash reserves. There was no way I could take unpaid leave or quit my TA position because we would not have been able to afford the health insurance that we critically needed. This occurred before the Affordable Care Act; if I lost my health insurance with the university, no insurance company would have accepted us because of Finn’s pre-existing condition. With my fragile little baby still in the hospital, I began to plan how I would manage teaching, taking care of Finn, and getting any time with Jake to help him to adjust to our new family dynamic—all while keeping us swine flu free.

October 2015

As I write this, I am angry. I had a premature infant in intensive care in the middle of a swine flu epidemic. I am certain that if I had reasonable accommodations to my particular circumstances and the social support I needed at the beginning of my journey as a student caregiver, I would have had the energy and personal resources to develop healthier coping strategies—and the whole process could have been healthier. This dissertation is allowing/forcing me to deal with a lot of painful memories, but now I have a support system on campus and a safe place to share my reflections about this journey. I told my current boss—the one who
taught me to try, adapt, and relax—that I wish I had this job during the early days of Finn. He shook his head and said, “Given that scenario, whereby you know a person’s situation and their previous work ethic, you make human adjustments to the policies. I wish you were here too, we would have supported you and figured out how to help you.” And I trust he and my “work family” would have.

A social support network and adaptable policies on campus are crucial for the health of student caregivers and their families because there are so many unforeseen circumstances, variables, and uncontrollable situation. Caregivers are at risk for stress-related illnesses as a result of role strain, caregiver burden, and time constraints (Butcher et al., 2001; Schumacher et al., 2012). Nontraditional students are also at risk for developing stress-related illnesses due to role strain, competing priorities, and time constraints (Brus, 2006; Calicchia & Graham, 2006; Estevez, 2010; Maroney; Pare, 2009; Stecker, 2004). Joshi et al. (2015) state "...in 2009, 51% of family caregivers ranged in age from 18-49 years...it will not be unusual for college-enrolled population to be involved in family caregiving" (p. 385-6). Embarking on a higher education degree as a caregiver is a stressful combination. Students who care for a person with a disability or chronic illness while pursuing a degree are considered nontraditional. Research on nontraditional students has focused on quantifying the population, access and retention rates (Compton et al., 2006), and learning outcomes (Hoyt, Howell, Touchet, Yound, & Wygant, 2010). Explicit roles nontraditional students assume while engaged in postsecondary education are not delineated in most of the literature. The number of student caregivers enrolled in higher education will continue to increase (Joshi, 2015) and they are not adequately represented in higher education literature. The continual decrease in state and federal funding for higher education (Heller, 2011) has raised the
dependence of colleges and universities on tuition revenues in order to pay their costs of providing education to their students. In order to sustain or increase the retention rates of—and ongoing tuition revenues from—the growing number of student caregivers enrolled, the academy must provide social and policy support for student caregivers who will contribute significant tuition revenue.

Nontraditional students have a diverse range of commitments beyond the academy (Brus, 2006; Estevez, 2010; Maroney, 2010) and student caregivers experience time constraints that exceed those of other nontraditional cohorts because of the unforeseen and uncontrollable demands inherent in caregiving. The rigorous academic requirements of higher education and the culture of the academy exacerbate a lack of perceived control for nontraditional students.

Regardless of the choice made, there is always something important that was not chosen. Students in such positions are acutely aware that the repercussions of each decision affects those around them...the difficulty... is in the accumulated weight of repeating the process several times a day, every day, often for years (Brus, 2006, p. 35)

A study by Schumacher et al. (2012) suggests that a sense of control is essential for caregiver well-being. The uncontrollable time pressures of the dual roles can take a tremendous toll on a student caregiver’s health, which has a negative effect on learning and success (Chambel & Curral, 2005; Goldrick-Rab & Cook, 2011; McKenzie & Richmond, 1998).

**Student Affairs: Living Learning Communities**

*August 2009 – August 2012*

Before I saw and touched Finn’s teeny tiny fuzzy body I never knew what it meant to feel completely helpless. I am a problem solver, I am self-reliant, I am a caregiver yet I had no idea what to do with that creature. When he was still in my belly he was a baby and he was my baby. When we shared my body, he was just
mine; I could cope with the hospital craziness—the intense lights, the loud hum of equipment, and the parade of people invading my sore anxious body to monitor Finn’s health and safety. But when I saw him and felt his heart beating outside my body, I couldn’t cope with the environment and my perceived inability to care for a being that looked more like a sci-fi creation than the baby I imagined I nurtured for seven months as a part of me.

After Finn’s birth, I could not summon the skills I honed as a hospital employee. As a recreational therapist, I spent years helping people cope with living in a hospital environment. I shared conversations with people in their rooms, I planned activities to help build social networks, and I taught people how to use leisure as a coping strategy for managing their illness. The fear and daunting responsibility of being Finn’s mom paralyzed me. My emotional and muscle memories of navigating as a competent being in a clinical environment were lost. I used to move confidently and effortlessly in the hospital but I had never lived there, I was just a visitor.

My recreational therapist in the hospital regularly visited me. After a couple of weeks of letting me remain isolated in our room she came in and said, “It’s time. You need to get out of here and take care of yourself.” I had said some variation of that statement to many family caregivers over the years and I knew she was right. As a formal caregiver I could suspend my own needs for a period of time and provide quality care; as an informal caregiver suspending my own needs diminished the quality of care I provided. I had to exit the cocoon I had spun for Finn and me. I had to find ways to cope in a larger space—with other people. My recreational therapist introduced me to Jennifer that day. We were each other’s support through the scariest parts of our journey as preemie moms. She knew what I meant when I said that the fear consumed me, the exhaustion hurt me, and the guilt overwhelmed me. She knew because we lived it together. Our bond continued as we transitioned from the hospital to our respective homes—200 miles apart. Out of desperation we taught each other how to cope, via phone calls, texts, and email. I have no idea how I would have survived the first three years of Finn’s life without Jennifer. Thank goodness my recreational therapist connected me with someone so that we could live and learn through our struggles together.

Student affairs professionals facilitate living learning communities in the academy. They create social support networks, foster skills and abilities that are important in and out of the academy (Brower & Inkelas, 2010) and encourage development through transitions. These programs benefit all students and seem to be
particularly helpful for historically underrepresented students. The residential environment is constructed to promote peer support. The communities have a common learning theme and are regarded as a “college within a college”. They foster student learning outcomes and student affairs professionals are often the primary managers of living learning programs. The longitudinal study conducted by Brower and Inkelas (2010) demonstrated that students experienced a smoother social and academic transition to college when they resided in a living learning community. A component of the community success is that they “...cut against institutional grain...” because they engage students in the dynamic contexts of their campus experiences, in and out of the classroom. They create safe places for students to actively develop personal resources. I contend that living learning communities on campuses are analogous to resource rich communities in society. They provide a strong network of resources. Figure 3 is from the Center for Disease Control and Prevention’s Social Determinants of Health workbook. The diagram creatively and vividly depicts how community resources affect health outcomes. The foundation of community health is directly and indirectly linked to the educational achievements, which affects the human, cultural, and social capital of their residents. Communities that are rich in resources, establish a deep root system of benefits that feed current residents and continue to nourish future residents. The root system includes a series of external benefits of higher education. Academic success and credentials ground a person with a web of resources that afford an individual with the opportunity to live in communities that provide access to positive social determinants of health. Nontraditional students enter higher education for a number of reasons and
generally the goal is to improve employment opportunities (Compton, Cox, Laanan, 2006) which then creates access to more societal resources. Like people who live in resource rich communities, students that reside in living learning communities are laying the groundwork for positive lifetime health outcomes.

Student caregivers are not likely to have the opportunity to reside in living learning communities on campus due to their family obligations, however, living learning communities can provide positive “second hand benefits” (Brower & Inkelas, 2010) for caregivers. The whole campus environment is affected by their presence.
These communities can create a climate that is more welcoming to student caregivers, which can create more opportunities for student caregivers to succeed and to have positive health outcomes. Again, I argue that living learning communities replicate the benefits in resource rich communities in society. Higher education promotes equity between populations (McMahon, 2009) by creating access to information that enhances health. Caregivers with educational resources experience better health (Quine & Pahl, 1991), healthy student caregivers have more energy to expend on developing coping strategies (Folkman, Schaefer, & Lazarus, 1979) and caregivers with healthy coping strategies generally have greater access to coping resources.

The five coping resources outlined in the Transactional Stress and Coping Model are: (1) utilitarian, (2) general and specific beliefs, (3) problem solving skills, (4) health/energy/morale, and (5) social networks. Utilitarian resources include socioeconomic status, access to information, and monetary resources. These resources are not equitably distributed throughout the population; they are concentrated in middle and upper class white student and societal populations. Utilitarian resources provide avenues to build positive coping strategies and are linked to all the other coping resources. General and specific beliefs pertain to an individual’s perceived control and self-efficacy. Student caregivers with significant utilitarian resources are conditioned to believe their effort will produce success, which is pivotal in building coping strategies. Problem solving skills are abstract skills that go beyond instinct, they include the ability to assess a situation, generate multiple solutions, and then choose the best course of action. Problem solving skills are crucial for the student caregiver to build coping strategies.
strategies because they must constantly navigate between choices that benefit the care receiver’s health or their own health. Health/energy/morale resources pertain to current physical and emotional health. Ethnic and racial minorities and people who live in poverty, both on and off campus, are more likely to experience chronic illnesses (CDC, 2014) and preexisting health conditions zap energy needed to develop coping strategies (Folkman et al., 1979). Social networks are imperative because they are the resources that connect people to support when they don’t know how or don’t have the energy to find the support they need. “Poverty is not deprivation. It is isolation” (Gladwell, 1999, p. 81). Personal connections, both on and off campus, are essential for developing coping strategies. The five coping resources outlined in the Transactional Stress and Coping Model lay the foundation for constructing coping strategies for student caregivers.

*June 2014–November 2015*

My coping strategies evolved as a student caregiver when I learned how to access coping resources. An hour after I turned down a tenure-track faculty position because the community did not have the resources I needed for my family, I received a call that my dad was in a serious accident. I lunged into caregiver mode: I attended to the logistics and postponed the emotions, a coping strategy I mastered throughout my years in graduate school.

Coping strategies refer to choices that are unique to each individual based on personal history, values, relationships, and accessible coping resources. When I focused on the logistics to deal with my dad’s accident, I used coping strategies I developed as a result of my access to coping resources (noted in italics): I called my mom’s friend to make sure she had emotional support (social networking), I emailed my boss to cover my shifts at work (utilitarian), I rearranged my kids’ activities (problem solving skills), I packed to leave for an undetermined amount of time (general & specific beliefs). I deliberately left my books on my desk because I finally learned that I could not concentrate on school in the middle of an acute crisis (health/energy/morale). My need to postpone the emotions that accompany an acute crisis is a coping strategy I developed to be an effective caregiver. Intense emotions once rendered me incapable of making decisions, but
I developed new coping strategies throughout my student caregiving trek and I trained myself to make decisions first and break down later (problem solving).

Along my student journey, I cared for my premature son, attended to my mom who suffered life-threatening complications after surgery, and monitored my dad’s recovery as I prepared for comprehensive exams. Finn, my parents, and I are all in good health now. I did not have the coping strategies I needed at the beginning of the journey to function in a healthy manner, but I developed them along the way as I discovered coping resources to support me.

**Conclusion**

Higher education institutions have an obligation and a convincing rationale to provide coping resources because the resources promote health and academic success, which increase retention rates of student caregivers and the tuition revenue they provide. Student affairs, historically, developed programs to meet this obligation in the academy. In the early 20th century, Dr. Paton compared student stress to shell shock and advised that colleges were not providing the kind of education that helped students cope with the stress and pressures of modern life, thereby creating disparities in health and academic outcomes (Prescott, 2007). Caregiving is a pressure of modern life and the prevalence of student caregivers in higher education will continue to grow.

While there is significant research that demonstrates a correlation between health and learning (Allensworth, 2011; Freudenberg & Ruglis, 2007; Marx & Wooley, 1998; Pascarella & Terenzini, 2005), there is a gap in student affairs literature that specifically describes the experience of students who care for a person with a disability or chronic illness. Student caregivers are a growing segment of the nontraditional student population (Joshi et al., 2015) and each role on its own carries substantial health consequences. Caregivers are at risk for stress-related health issues and nontraditional students are also at risk for stress-related health issues. (Maroney, 2010; Sansoni,
Vellone, & Piras, 2004). Combining the two roles multiplies the emotional strain, physical demands, and time pressure of each role. Coping resources and coping strategies have been shown to mitigate the deleterious effects on health for caregivers (Kelso et al., 2005; Kruse, 2006). Maroney (2010) suggests that effective coping strategies, which are influenced by coping resources, are positively correlated with persistence for nontraditional undergraduates. There is scant research in higher education literature that addresses student caregivers and I could not find any that specifically addressed how student caregivers cope with their multiple roles. More research is needed to describe the lived experience of students who care for a person with a disability or chronic illness and how they cope with two challenging roles.

This study addresses the important gap in the higher education and student affairs literature by describing the lived experience of student caregivers using a phenomenological approach. Individual interviews focused on the daily experiences student caregivers juggled to fulfill their responsibilities in both roles. The focus group, which occurred after all interviews were completed and I had begun data analysis, concentrated on themes that were emerging from personal interviews. The personal interviews and the focus group identified a set of primary themes and thematic elements that were grounded in the lived experiences of student caregivers. These findings have a number of important implications for theory, practice, policy and future research. Chapter three presents the methodological details of this study.
Chapter 3
Methodology

The purpose of this phenomenological study is to describe the lived experience of students who provide care for a person with a disability or chronic illness. Student caregivers are at risk for stress-related illnesses; how students cope with stress affects their health and health has significant implications for learning, development, and persistence. Since the particular circumstances of student caregivers’ time constraints and health consequences are not represented in higher education or student affairs literature it is important to fully understand their lived experience. Before appropriate policy and practice changes can be implemented to address student caregiver needs, there needs to be a comprehensive awareness of what being a student caregiver entails. I chose phenomenology as the central methodological approach for this study because the method specifically focuses on understanding the lived experience of a phenomenon. I used personal interviews and focus groups in order to provide rich and vivid descriptions of the day to day logistical struggles of organizing student and caregiving responsibilities, the identity challenges of juggling multiple roles, and the health consequences of managing two very demanding sets of responsibilities.

Hermeneutic phenomenology is a qualitative research method, and qualitative methods of inquiry stress that the researcher is the primary instrument for data collection and data analysis (van Manen, 1990). Interviews are the primary mode of data collection for a phenomenological study (Merriam, 2009; van Manen, 1990) and in this study I first conducted semi-structured interviews with participants who have
experience with the phenomenon of interest. I then facilitated a focus group to enrich the data by allowing student caregivers to connect and hear how their experiences are reflected in other student stories. Since my experience as both a formal and informal student caregiver shaped the conception, passion and execution of this study, I believe my narrative is inextricably linked with how I interpret the literature and the participants’ experiences. Hermeneutic phenomenology allowed me the freedom to critically weave my narrative and reflections throughout the research process to provide transparent reflexivity. van Manen (1990) states, “...phenomenological research projects require that we not simply raise a question...but rather that we ‘live’ this question, that we ‘become’ this question” (p. 43). This study was a culmination of the ways I have lived and become my question.

1990-1992
My phenomenological world view began long before I knew about Phenomenology. There are two moments that stand out as particularly significant that paved my path as a Phenomenologist. While I was an undergraduate student, I cared for a woman who was in her final stages of brain cancer. She was no longer able to speak, had limited motor ability, and had volatile emotional outbursts. She scared me. During one of my many shifts with her, I was unbelievably clumsy, I was afraid I hurt her and I started to cry. She put her hand on my arm and looked into my eyes with one of the most compassionate expressions I have ever experienced. I knew it had to take so much energy for her to coordinate her muscles to place her hand on my arm, it was an incredibly generous use of her energy. And when I looked into her eyes, I learned that no matter how much an awful diagnosis takes from a person it is only one part of who they are—even though it affects how others perceive you. One of the other people I cared for was a prominent veterinarian in a small town outside of Iowa City. He was part of the WWII generation and I was the first home health aide to come in and give him a shower in his own house. He had a stroke, had dominant side limitation, and aphasia. He resisted when I tried to help him undress and get him into the shower. I explained that I had done this many times. He struggled to hold up his index finger with a defeated look in his eye. I knew what he meant. It didn’t matter how many times I had done this task, it was the first time this strong independent man needed a stranger to help him take a shower in his own home. I think that was
the first time I understood that personal experience was essential for interpreting how you view life circumstances. The phenomenological world view “What is the lived experience” resonates with me more than other methodological world views.

Phenomenology is concurrently a philosophical approach and a research method (Connell, 2003; vanManen, 1990; Wojnar & Swanson, 2007). The Greek roots of phenomenology are “pheninoemn”, which means appearance, and “logos” which means reason (Gearing, 2004). Phenomenology, as a philosophy, seeks to understand the world as it is prior to social construction (Caelli, 2001); as a research method, it seeks to understand human experiences and consciousness through a systematic and rigorous approach (Koch, 1994; Wojnar & Swanson, 2007). Inductive research methods are utilized in phenomenology to comprehend universally-lived experiences (Connell, 2003; Merriam, 2009; Pehler, 2003; vanManen, 1990). Health is a universally lived experience. Hermeneutic phenomenology was chosen for this study because it allows the participants and the researcher to have a measure of freedom in how the experience is shared and interpreted.

The goal in phenomenology is to develop a rich vivid description of the phenomenon of interest to discover how the lived experience is represented for participants. Hence, objectivity in phenomenology “...means that the researcher remains true to the object” (vanManen, 1990, p. 20). The social sciences adopted phenomenology as a method to understand that there are components of human behavior that are not amenable to the quantification or cause/effect relationships (Merriam, 2009; Valle & Halling, 1989; vanManen, 1990; Wojnar & Swanson, 2007). Many studies have tried to find causal mechanisms to explicate the relationship
between health and educational achievement but found it to be fruitless (Pascarella & Terenzini, 2005). While causal mechanisms are important in many endeavors, cause is not a sine qua non for developing programs that promote better equity in education to reduce health disparities. There are many factors, such as race, ethnicity, selection bias, socioeconomic status and parental education that confound studies on the causal connections of health outcomes and education. Even without clear causal mechanisms, an abundance of research shows a significant positive correlation between health outcomes and higher education (Allensworth, 2011; Burke Harris, 2012; Stern, 2002; Sumowski, Wylie, DeLuca, & Chiaravalloti, 2010; Woolf, Johnson, Phillips Jr, & Philipsen, 2007). Thus, phenomenology as a philosophy and method is consistent with the content under study.

**Recruitment Procedures.** Participants were selected based on their experience as a student who was or is a caregiver for a person with a disability or chronic illness. This study used three types of purposive sampling: typical, snowball and maximum variation (Babbie, 2001; Merriam, 2009). Typical sampling focuses on recruiting participants based on their experience with the phenomenon. Snowball sampling focuses on asking current participants to help recruit family, friends or acquaintances that also experience the phenomenon of interest. Maximum variation of the sample focused on recruiting participants that had different demographic and caregiving experiences within the phenomenon of interest. My goal was to find participants that represented the spectrum of student caregiving experiences—past and present student caregivers, students who care(d) for dependent minors, elders and partners, and
students who care(d) for people with a variety of disabilities and illnesses. Maximum variation of the sample revealed how the lived experience of student caregivers echoed across different student identities and care receiver needs. Participants were selected using the following criteria: 1) post-secondary students in the midst of caring for a person with a disability or chronic illness; 2) previous post-secondary students who cared for a person with a disability or chronic illness; 3) the disability could be physical, emotional, or cognitive disability; 4) the chronic illness was identified by the Center for Disease Control and Prevention as a chronic illness; and 5) the care receiver was a dependent minor, dependent adult, or significant other.

Participants were recruited through multiple strategies. Information about the study was spread by “word of mouth” as I discussed my dissertation plans with peers and colleagues. I also sent an email to the entire university community to recruit participants. I anticipated that participants would also provide referrals via their social support networks and they did.

The rationale for the recruitment strategies I chose was because this Midwestern town is a university town with a nationally renowned teaching hospital. Nontraditional students may specifically have chosen this area because of its proximity to the hospital and the area resources. The assumptions and preconceptions that have influenced these choices were from my own experience as a student caregiver, as a recreational therapist, and as an instructor at the collegiate level.

**Sample.** van Manen (1990) does not specify a sample size for this method, however, saturation of the data is a common metric for determining sample size in
qualitative research (Creswell, 2007; Glesne, 2006; Merriam, 2009). Saturation of the data has occurred when “no new information” emerges in the data (Mason, 2010). How the researcher sees the data depends on the researcher’s positionality, epistemology and personal experience. Sunstein and Chiseri-Strater (2011, p. 165) state

...what we see depends on how we filter or select what we see. What we see also depends on how we look—how we open ourselves to the act of seeing. Just as we all read differently at different times in our lives, we also perceive differently.

Thus, the researcher is required to interpret what the concept “saturation of the data” means to her. I knew I reached saturation when codes were echoed in the majority of participants’ stories. Codes reflect data echoes when participants articulated their experiences in a manner that allowed the researcher to see, hear, and feel recurring elements of the phenomenon. The concept of echoing was important to me because it connoted both hearing and feeling the participants’ experiences. An echo allows a person to hear what has already been said in a new context; an echo is often accompanied by a sound vibration, thus a person is also feeling the information.

Sunstein & Chiseri-Strater’s (2011) description of seeing can be extended to hearing and feeling. What we hear and feel is filtered by what we choose to attend to, which affects the way we perceive information. This conceptualization of saturation of the data focused my attention on how I used multiple senses to filter perceptions in the coding process. Since my narrative was an inextricable component of this study, I inevitably saw, heard, and felt codes that resonated with my own experience. The echo metaphor served as an additional layer of reflexivity by allowing me to be transparent about how I reached saturation of the data.
Fifteen people were interviewed, however, only twelve people were included in the data analysis. The reason I decided not to include two people in the data analysis is because the person they each provided care for did not have an official medical diagnosis. Each of these two student caregivers created a diagnosis from their own research, which may or may not have aligned with a diagnosis from a physician, so I had no way of knowing if the diagnosis was accurate. I chose not to include the third person because there was more than thirty years between her interview and her caregiving experience, her memories were not clear enough to give me confidence in the data. I started finding data echoes in the codes at the sixth interview. However, they were all Caucasian doctoral or professional students so I kept collecting data to increase the diversity in this study, to determine if the data echoes were consistent across different degrees, race, and gender. I did not have the racial diversity that I had hoped for, but I did have three male participants which is more than I expected, and there were a variety of degree programs represented. There was also a wider range of disciplines than I anticipated. Demographic information about the twelve participants who were included in the data analysis is found in Table 3, a more comprehensive table regarding their experience and degree programs will be included in chapter five.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age at time of student caregiving</th>
<th>Age at time of interview</th>
<th>Race</th>
<th>College Going Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alex</td>
<td>32-36</td>
<td>39</td>
<td>Hispanic</td>
<td>Continuing generation student(^1)</td>
</tr>
</tbody>
</table>

\(^1\) Continuing education students are participants who have had at least one family member attend college before they did.
### Table 3 Demographic Information

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age at time of student caregiving</th>
<th>Age at time of interview</th>
<th>Race</th>
<th>College Going Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>43-45</td>
<td>47</td>
<td>Caucasian</td>
<td>1st generation student²</td>
</tr>
<tr>
<td>Anne</td>
<td>39-41</td>
<td>41</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Cassandra</td>
<td>39-44</td>
<td>44</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Ed</td>
<td>18-21</td>
<td>26</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>42</td>
<td>47</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Jenna</td>
<td>44-50</td>
<td>50</td>
<td>Caucasian</td>
<td>1st generation student</td>
</tr>
<tr>
<td>Jessica</td>
<td>19-25</td>
<td>30</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Natalia</td>
<td>28-30</td>
<td>30</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Orla</td>
<td>46-47</td>
<td>57</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Pooja</td>
<td>50-53</td>
<td>58</td>
<td>Caucasian</td>
<td>Continuing generation student</td>
</tr>
<tr>
<td>Waldo</td>
<td>18-22</td>
<td>30</td>
<td>Caucasian</td>
<td>1st generation student</td>
</tr>
</tbody>
</table>

\[²\] 1\textsuperscript{st} generation students are participants who did not have at least one family member attend college before they did.

### Data Collection and Methods

van Manen (1990) provided a guiding structure for conducting a phenomenological study but reminded researchers that the structure is malleable. "The methodology of phenomenology...tries to ward off any tendency toward constructing a predetermined set of fixed procedures" (p. 29). Table 4 gives a visual overview of the
### Table 4 Methodological Structure for Phenomenology
Adapted from “Doing” Phenomenological Research and Writing (van Manen, 1984, p. 5)

<table>
<thead>
<tr>
<th>Turning to the Nature of the Lived Experience</th>
<th>Existential Investigation</th>
<th>Phenomenological Reflection</th>
<th>Phenomenological Writing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Orienting to the phenomenon</strong></td>
<td><strong>Exploring the phenomenon: gathering data</strong></td>
<td><strong>Conducting thematic analysis</strong></td>
<td><strong>Attending to the speaking of language</strong></td>
</tr>
<tr>
<td><strong>Formulating the phenomenological question</strong></td>
<td>- Using personal experience as a starting point</td>
<td>- Uncovering thematic aspects in lifeworld descriptions</td>
<td><strong>Varying the examples</strong></td>
</tr>
<tr>
<td><strong>Explicating assumptions and pre-understandings</strong></td>
<td>- Tracing etymological sources</td>
<td>- Isolating thematic statements</td>
<td><strong>Writing</strong></td>
</tr>
<tr>
<td></td>
<td>- Searching idiomatic phrases</td>
<td>- Composing linguistic transformations</td>
<td><strong>Rewriting</strong></td>
</tr>
<tr>
<td></td>
<td>- Obtaining experiential descriptions from subjects</td>
<td>- Gleaning thematic descriptions from artistic sources</td>
<td><strong>Determining essential themes</strong></td>
</tr>
<tr>
<td></td>
<td>- Locating experiential descriptions in literature, art, etc.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

steps van Manen suggests, however this study did not lend itself to following all of the steps. The participants' and the researcher's experiences directed how this study unfolded. Before I could diverge from the structure, I needed to fully understand it. Below is my interpretation of van Manen's guiding methodological structure.

**Turning to the Nature of the Lived Experience.** Lived experience refers to the pre-reflected on experience that occurs in a person's lifeworld (van Manen, 1984; van
Manen, 1990). Before an individual can truly understand an experience, it needs to be named, interpreted and pondered. The phenomenological process required me to be as reflexive about the lived experience as the participants. I oriented to the phenomenon to formulate the phenomenological question and to explicate my assumptions and pre-understandings. My orientation to the phenomenon of interest emanated from my experiences as a recreational therapist, a student caregiver, and a scholar. I lived and became my question as I struggled through three years of graduate school as a parent of a child with health concerns. My assumptions and pre-understandings of the phenomenon of interest were based on my personal reflections of the benefits and challenges that accompanied my role as a student caregiver.

The phenomenological question evolved throughout my doctoral studies. I knew I wanted to continue my research with caregivers but did not know how to frame the question so it would fit within the context of higher education. My advisor urged me early on in the program to keep a notebook of all the ideas I had for my dissertation, which I did. I also reviewed all the papers I wrote for each class as I prepared for the comprehensive examination. I discovered that for every class I incorporated the intersection of health and education as a frame for my papers—classes such as Finance of Higher Education, Diversity and Equity in Higher Education and Higher Education Policy—that did not appear to have any connection with health based on name and syllabi content. My experience as a recreation therapist shaped how I absorbed and interpreted information. I saw parallels between recreation therapy and student affairs, thus I was able to commingle my previous knowledge and experience and reflect on
student affairs in the context of health. When I realized that I consistently focused on the intersection of health and education throughout my studies I began journaling on how to incorporate health into my dissertation. Each idea I journaled about was detached from my own experience because while I was a student caregiver, the struggle was too raw, I could not view it as a researcher. I noticed that once Finn was healthy and developmentally on target, I started journaling about student caregivers as my topic of study, yet my own experience as a student caregiver was noticeably absent. The phenomenological question that guides this study began to take shape on a family vacation three years ago. I watched Finn play on the beach with all the other kids and he was fine; he was healthy, and strong, and smart. It was the first time I viscerally knew I wasn’t the caregiver of a fragile child anymore. During a long peaceful walk on the beach it became clear that I would use my own experience as a student caregiver and the health consequences I endured to describe the lived experience of student caregivers and focus on how health may be woven into the journey.

Existential Investigation. van Manen (1990) states that there are four themes that are fundamental to all human experiences and he identifies them as “existentials”. He highlights the existentials as experiences that are “...productive categories for the process of phenomenological question posing, reflecting and writing” (p. 102). The categories are lived space, lived body, lived time, and lived other; the existentials intersect and are influenced by each other. The existentials are more easily understood with concrete examples, thus I will illustrate them using my experience as a student caregiver.
Lived space goes beyond physical space, it incorporates how a person feels within a particular context. As a student caregiver I was sensitive to lived space because I was hypervigilant about germs. For the first year of Finn’s life, I essentially isolated us in my home to keep him healthy. “Home is where we can be what we are” (van Manen, 1990, p. 102, italics in original document). There was one space in my house where I could just “be”, it was my office. I designed the space to make me feel like I was at the beach, beige carpet surrounded by blue walls to mimic sand meeting the water. The soothing space offered me a reprieve from caregiver anxiety.

Lived body focuses on how our physical selves move in the world and how the body affects and shapes awareness of internal and external influences. I am acutely attentive to lived body, I teach body awareness as the first line of defense for managing stress and improving health outcomes. As I reflect on my own student caregiving experience, I realize I did not follow my own instruction, I allowed myself to be numb because the physical and emotional pain were often overwhelming. I was recovering from a broken rib while writing a thesis and caring for a premature infant. There was no time or energy to tend to my sore body, making myself numb was the way I chose to live within myself so I could manage my responsibilities. The benefits of becoming numb were that I could cope with the pain and accomplish my goals, the consequences of my numbness were that I tuned out my body’s voice. I did not listen when it told me to stop being isolated, I did not listen when it told me to take a physical break so that I could heal properly, I did not listen when it told me I needed to attend to my emotions.
Lived time emphasizes subjective time rather than objective time. Subjective time encompasses the way memories help reinterpret past experiences, shape present perceptions, and mold future perspectives. Time seemed to move in slow motion for me, I felt like I was acting a scene in a movie that had been removed from the rest of the reel. Time had no context, I had no frame of reference. “Whatever I have encountered in my past...leave traces on my being—the way I carry myself...” (van Manen, 1990, p. 104). I did not know how to carry myself through time in isolated space with a numb body.

Lived other integrates how we develop and maintain relationships within our lived space, our lived body, and our lived time. Isolation, numbness, and warped time had a profound impact on how I related to other people. Duty was how I summoned the energy to care for my fragile baby; emotional separation was how I dealt with my husband’s struggles with our needy baby; and social isolation is how I coped with the anxiety of germs sending my baby back to the hospital. The only person I let into my anxious bubble was my oldest son, Jake. His laughter changed the feel of the space we shared, his hugs provided me with a connection to the physical world, and his activities kept me aware of objective time. Jake tethered me to a healthier self.

The existentials provided a guide for interviews because they allow the researcher to focus on the themes that are fundamental to all human experiences. It was important to structure research questions that incorporated each aspect of the lived experience-space, body, time, relationships. As I reflected on the existentials, I
have also used them as another method for reflexivity, I can write and reflect about how each influenced how I collected and analyzed the data.

Data Collection. Data was collected in two ways: individual semi-structured in-depth interviews, which is the “primary method of data collection” (Merriam, 2009, p. 25) in phenomenological inquiry and a focus group. The interview allowed the researcher and the participant to become partners in the process of discovery (Kvale, 1983; vanManen, 1990). The research questions provide the foundation for both the interview and focus group questions. The interviewer established a delicate balance of open-ended questions and silence to allow the participant to reflect on the story. The goal of the interview was to develop a comprehensive picture of the phenomenon of interest and the researcher must create a comfortable experience so the participant feels safe enough to share the details of their experience. Participants chose the location for the interview. At each interview, I asked participants if they were willing to join a focus group to talk with other student caregivers. Every person interviewed agreed to be involved in the focus group, however, due to schedule challenges only four people were able to participate. Three student caregivers were able to be physically present and one student caregiver joined the group through Skype.
Table 5 Questions to Guide the Interview

Guided Interview Questions that Answer Research Questions

What is the lived experience of students who care for a person with a disability or chronic illness?

1. Describe what your health was like before you began juggling both roles.  
a. Describe what your health is like since you became a caregiving student?

2. How has your body reacted? Think about your posture, how you breathe and how you sleep.

3. Tell me about times when you have felt healthy in your role as a student caregiver?  
a. What is happening?  
b. What type of control do you feel like you have over your life?

4. Tell me about times when you have felt unhealthy in your role as a student caregiver?  
a. What is happening?  
b. What type of control do you feel like you have over your life?

How do student caregivers cope with the role strain of juggling student and caregiving demands?

5. Suppose I could join you for a day. What would I see? Describe a typical day juggling both roles—student and caregiver.  
a. What types of things do you do to cope with the demands of both roles?  
b. How have your coping mechanisms changed with the demands of both roles?

6. Describe a time when you put the needs of the care receiver before your own.  
a. What did it feel like?

7. How have you grown as a person since you began your role as a student caregiver?  
a. If so, how has this growth had an impact on your health?

How do student caregivers develop coping strategies within the academy?

8. Can you identify a person or people, on campus, who make things better or worse?  
a. Describe what these relationships are like.

9. If your caregiving responsibilities conflicted with school responsibilities, describe the type of support, if any, you received from your department or the institution.  
a. How did the support or lack of support affect your health and academic success?
The research questions were written in academic language to uncover the essence of student caregiving, while the interview questions were written in lay language to delve into the personal experience of student caregiving (see Table 5).

- What is the lived experience of students who care for a person with a disability or chronic illness?
- How do student caregivers cope with the role strain of juggling student and caregiving demands?
- How do student caregivers develop coping strategies within the academy?

The semi-structured interview used a conversational style, thus the questions in the table merely provided a starting point. I actively listened to the participant and let her guide the conversation, thus I asked questions that are not listed or I omitted questions that did not naturally flow. I included a focus group as a source of triangulation. Participants were asked at the end of their interview if they would be willing to participate in a focus group. The guide to the interview questions provided a tentative structure for the focus group, the ebb and flow of the participants’ conversations will inevitably allow more questions to surface. I was able to analyze how participants’ reflections of their experiences within the context of other student caregivers shape their responses. Qualitative methods generally triangulate data by employing a variety of data-gathering techniques such as interviews, participant observations and documents to establish trustworthiness (Merriam, 2009; Glesne, 2011). Typically, the interview is the primary source of data collection in a phenomenological study, however, in this study the focus group is a method of triangulation.

**Phenomenological Reflection, Writing, and Data Analysis.** Although van Manen (1984, 1990) separates phenomenological reflection and writing, I will discuss them
together as a component of data analysis. “Writing is a magical and mysterious process that makes it possible to think differently” (Hunt, 2010). Writing is how I reflect, so I cannot view them as distinct entities. Thematic analysis and heuristic inquiry are methods of analysis used in phenomenology (Merriam, 2009; van Manen, 1990). Thematic analysis is mining the data for “themes and patterns” (Glesne, 2006; Merriam, 2009). Heuristic inquiry includes an analysis of the researcher’s experience with the phenomenon as a component of the data (Merriam, 2009). Since I have experience as a student caregiver, thematic analysis and heuristic inquiry are both necessary in the data analysis process. While van Manen (1990) does not specify a set of procedures for reflection and analysis, I had a very systematic method for coding.

Saldaña (2013) suggests coding is a “cyclical act” (p. 8) and it is rarely correct on the first several cycles. A code is a word or phrase that functions as a summative label that captures the essence of a particular element in the data. I had three methods of coding going simultaneously for each participant as modeled by Saldaña—in vivo codes, descriptive codes, and emotional codes. In vivo codes use words and phrases that come directly from the student caregiver, they “…keep the data rooted in the participant’s own language…” (Saldaña, 2013, p. 7). In vivo codes allowed me to concentrate specifically on the voice of each participant. Descriptive codes encompass experiences that are common among multiple participants (Saldaña, 2013) and relate to themes from previous research. Descriptive codes allowed me to view the data from a broader perspective and link current participant experiences with those found in the literature. It is impossible for me as a researcher to completely bracket my previous knowledge,
thus, I looked for the intersectionality between caregiving and nontraditional student experiences in prior studies as a component of the descriptive coding process. The method of emotional coding came after I had listened to all of the personal interviews and noticed a pattern emerging. I adapted Saldaña’s values coding—identifying subjective perspectives that can include a judgement—to code for emotions because there was not a specific model for emotional coding. Student caregivers expressed that the journey was like an emotional roller coaster. Emotions produce both a subjective reaction based on the mind’s cognitive ability to reflect and an objective reaction based on the body’s physiological response. Emotional codes allowed me to zero in on which emotions were most prevalent during the student caregiving experience and to find patterns in how emotions were experienced among participants.

I used all of the codes—in vivo, descriptive, and emotional—from each personal interview and the focus group as a starting point to uncover essential themes of the lived experience of student caregivers. Initially, I created documents for each code. As I found echoes in the data, I synthesized the codes into thematic elements. I then analyzed the thematic elements to find categories that represented the essential themes. The essential themes are the essence of the lived experience of student caregivers in this study. I presented the themes in a hierarchical structure, however, they are fluid and in motion. They can be examined in isolation, but can only be understood in the broader context of the experience as a whole. There are overlapping experiences in the thematic elements, but there is nuance in the way they were lived
depending on which theme they are located in. New challenges and personal
development affect how a particular theme is experienced.

The process of coding to find the essence of a phenomenon is unique to each researcher. My system relied on my individual learning preferences. Immediately after each interview, I handwrote my reflections on my tablet or recorded them on the voice recorder on my phone. The first time I listened to each interview, I had a chart open on my computer in which I had columns for In vivo codes, descriptive codes, and the time stamp for each code. In vivo codes were phrases that participants actually spoke in their interviews or the focus group that vividly described a particular aspect of their experience. The most important component of in vivo codes are that they were in the participants’ own words. Descriptive codes were how I interpreted a particular aspect of the student caregiving experience. The interpretation inevitably took into account my own experience as a student caregiver, information from my previous study on caregivers, and the knowledge I gained from my literature review. While I was entering codes, I simultaneously had a document open on my tablet to make handwritten reflections about the interview and to note how descriptive codes were affected by my personal experiences and scholarship: this was another layer of reflexivity. After listening to all of the interviews, I decided to add a column for the emotional codes. Upon subsequent reviews, I included emotional codes in the process. I then listened to each interview at least three or four more times to hone in on the essence of each persons’ student caregiving experience and wrote a narrative of their stories. I needed to listen to the interviews multiple times to understand each participant’s speech style.
and rhythm, emotional state at the time of the interview, and how they wove their story together. It was important for me to listen to each interview a number of times because each time allowed me to immerse myself in their story and I was able to reflect on how the way they told their story—and the parts they chose to include—broadened my perspective on the most salient points of a student caregivers’ journey. It was only upon multiple audio reviews of the data that I could truly hear and feel the essence of the lived experience of each student caregiver. When I had a deep understanding of the essence of each participants’ story, I was able to hear and feel the echoes in the data.

After I listened to each interview numerous times I felt I was then able to conduct the focus group because I had a sense of the most salient experiences for this group of student caregivers. I developed a set of questions for the focus group that highlighted the commonalities. In addition, I explained that in a phenomenological study the researcher and participants are partners and I needed assistance in understanding certain aspects of their experience that I felt I could not interpret accurately.

I set specific time each day to work on this study, but writing and reflections do not always come when summoned, so I had systems in place to allow me to record my reflections while I was away from my computer. I used my tablet as my first method for reflections and analyses. I always need to physically handwrite my initial thoughts for every paper I write— the majority of this dissertation was handwritten first. The tablet allows me to handwrite my thoughts and ideas and then save them in a very organized system. Since they were saved on an electronic device, I was able to take screen shots
of my notes for one participant, code, or theme, then paste them in other files so I could start to connect where there were echoes in the data. Another benefit of handwriting my reflections was that it allowed me to “draw” on my notes so I was able to visualize the data in concrete ways that made sense to me. An example of this level of analysis was when I had to decide on the order to present the themes and participants’ stories. I made a picture of trees with themes at different places on the trees, then placed the participants’ stories relative to the order of the themes on the trees. Each time I did this, I started to see a pattern of how each theme was portrayed in individual stories. The visual record, and physical component of drawing, gave me the ability to see, and feel, how the stories and themes were woven together. I always carry my phone and I discovered I could record voice memos if a connection/reflection/idea came to mind. Voice memos allowed me to speak freely without an internal writing critic. The information that I gained from stream of conscious recording gave me insight into how I made sense of how I connected individual participant experiences to other participants’, to my own experiences, and to the literature. The unfiltered nature of voice memos often provided revelations related to global ideas in my analysis. For example, it was in a voice memo that I began to uncover the nuances of how the multiple layers of timing—the academic phase, life experience, and care receiver health—are foundational for understanding the trajectory of a student caregiver’s journey. I also have a waterproof pad of paper and pencil in my shower so that I could record reflections if I had them. Generally, these notes emerged because I had a particular word or phrase stuck in my thoughts that I couldn’t make sense of, so I’d write the word
down and then let it go. As I let my thoughts drift from that specific word or phrase, ideas would surface about how that specific concept resonated more broadly in the analysis. An example of this was when I was trying to understand why the term “WIFI” seemed so significant. It was in my shower notes that I wrote “WIFI” and made the connection that technology had a huge impact for two participants, and then I made a note to review all the transcripts and look for references to technology. Samples of my handwritten reflections are included in Appendix E. These strategies are a method of triangulation to establish trustworthiness.

Standards for Evaluation
Establishing Trustworthiness. Trustworthiness is established using multiple data collection methods and using triangulation strategies to demonstrate credibility, consistence, and transferability. Trustworthiness is not synonymous with replicability, which is used as the metric for evaluation in quantitative research. The standards for evaluating qualitative data are substantively different than evaluating quantitative data but just as rigorous (Connell, 2003; Glesne, 2011; Merriam, 2009; van Manen, 1990). Horizontalization, imaginative variation, and reduction are triangulation techniques that are specific to phenomenology (Merriam, 2009). While credibility, consistency, and transferability are the criteria for establishing trustworthiness in qualitative research that are akin to internal validity, reliability, and external validity in quantitative research, though they are not direct translations (Connell, 2003; Koch, 1994; Merriam, 2009).

The establishment of trustworthiness provides the foundation for developing sound qualitative research (Koch, 1994). Credibility aligns with internal validity, it assesses if the findings of a study are congruent with reality (Connell, 2003; Koch, 1994;
Merriam, 2009). In phenomenology, the phenomenon of interest is interpreted through the lens of the participants’ and researcher’s personal and sensate experiences. Therefore a credible phenomenological study must attend to the notion that how you look shapes what you see (Chiseri-Strater & Sunstein, 2006; Merriam, 2009).

Consistency corresponds with reliability but it does not assume replicability as the metric for a successful study (Guba & Lincoln, 1994, 2005; Merriam, 2009; Sandelowski, 1986) “Reliability in a [traditional] research design is based on the assumption that there is a single reality and that studying it repeatedly will yield the same results” (Merriam, 2009, p. 220). Replicability is an unattainable goal for social science qualitative research because a person’s perception and interpretation of an experience is fluid, and it changes as a result of emotion, new information and social construction. This is true for both the researcher and the participants. Creating an audit trail for the reader develops consistency within a study (Lincoln & Guba, 1985). The audit trail has been compared to a log that a captain of a ship keeps with the details of the journey (Merriam, 2009). A qualitative researcher must provide the reader a detailed log of how every decision was made, how she interacted with the data, and how her interpretations were influenced by her own life experience throughout the journey of the study.

The audit trail for this study consisted of analytic and reflective memos for each participant, a preliminary code chart, reflections on preliminary codes, ongoing reflections that occurred outside of designated analysis time, and member checks. Appendix [E] includes a sample of each type of memo, reflection, and chart. Verbatim transcripts for each participant and the focus group were created, however, given the
time constraints of student caregivers, member checks were modified to fit their needs. Instead of having them review the entire verbatim transcript, I listened to each interview at least five times, made handwritten memos and voice memos while listening, and then wrote a narrative that captured the essence of their student caregiving journey. I sent the narratives to each participant to review and approve. There were four participants who asked that I make changes to their narratives, I did so and then they approved the revised version. All of the participants’ approvals are copied and included in Appendix [D]. A rigorous audit trail is essential in van Manen’s (1990) method of phenomenology and does not require an outside auditor.

Transferability is the counterpart for external validity (Koch, 1994; Lincoln & Guba, 1985; Merriam, 2009). External validity refers to the generalizability of a study. Traditional research extrapolates particular inferences from large random samples and the focus is on finding causal relationships. Qualitative research does not seek to find causal mechanisms but rather to discover universally lived experiences from rich, thick descriptions of individuals’ particular experiences. Since interviews are the primary method of data collection in a phenomenological study, there are unique strategies for triangulating the data to establish trustworthiness (Merriam, 2009). Imaginative variation, horizontalization, and reduction are strategies used in phenomenology that lay the groundwork to establish credibility, consistency, and transferability.

Since phenomenology uses the researcher’s personal experiences as a starting point, it affects how the triangulation techniques are interpreted within the trustworthiness criteria. My previous study about caregivers combined with my
personal experience as a caregiver impacted how I see the data; the following is my interpretation of imaginative variation, horizontalization, and reduction to establish trustworthiness. Imaginative variation focuses on holding up data to look at it from a variety of angles (Merriam, 2009). I used two methods of coding, descriptive and In Vivo, as described by Saldana (2013). I view this as developing credibility within the current study. Descriptive codes allowed me to contextualize the data based on the literature and my prior research, while InVivo codes pushed me to listen to the data in the participants’ own words. Demonstrating where the codes overlap provided evidence that the coding was based in the reality of this study and the analysis was credible. Horizontalization focused on initially viewing all data as if it had equal weight (Merriam, 2009). The methods I used to exhibit horizontalization were: I kept separate files for each participant because each person’s story evoked different musings about my own experience; I kept a detailed field journal with descriptive and analytic notes about how participants’ experiences aligned with the literature (Glesne, 2006; Koch, 1994; Merriam, 2009), I asked participants follow up questions to member check my analysis to ensure my interpretation of their experience reflected their intention. I viewed horizontalization as a means for establishing consistency because it created an audit trail for readers to examine. Phenomenological reduction focused on continually reducing the phenomenon to its essence (Merriam, 2009). The reader should be able to say, “I now have a better understanding of the lived experience of student caregivers”. This aligns with transferability because it allows the reader to decide if the information presented can transfer to other circumstances or populations. The processes in place to
uphold credibility, consistency, and transferability are developed through the triangulation methods of imaginative variation, horizontalization, and reduction.

**Ethical Considerations and Overview of Results**

I applied for and received approval for this study from IRB. The application was made in Spring of 2014 as an assignment in a qualitative methods course. This study qualified for exempt status so there is no expiration date for this application. I am aware of the time constraints student caregivers face, how difficult it is to talk about the challenges inherent in this role, and the fear of professional repercussions if faculty become privy to personal information. I made every effort to ensure confidentiality and each participant will have a pseudonym so they cannot be identified by the information they provide in the interview. If participants became distraught during the interview or focus group, I reminded them it was their right to stop the interview momentarily or permanently.

Chapter 4 presents the participants’ individual stories about their lived experience as a student caregiver. The essential themes and thematic elements are introduced. Chapter 5 examines the essential themes and thematic elements using data from personal interviews and the focus group. The results of this study are expressed in both the participants’ own words and my interpretations of the essence of the student caregiving experience.
Chapter 4
Participant Stories

The habits of wonder promoted by storytelling thus define the other person as spacious and deep, with qualitative differences from oneself and hidden places worthy of respect. (Nussbaum, 1997, p. 90)

Introduction
Stories have been passed down, throughout history, to highlight the interconnectedness of humankind and to describe how different cultures make meaning of their experiences. “Stories provide the necessary context for understanding, feeling, and interpreting” (Ladson-Billings, 2009, p. 15). In phenomenology, biographical stories are an important experiential resource for demonstrating how one person’s experience may possibly be the experience of others (van Manen, 1990). The goal of hermeneutic phenomenology is to uncover the essential meaning in lived experiences (van Manen, 1990; Connell, 2003; Wojnar & Swanson, 2007; Linseth & Norberg, 2004; Butcher, et al., 2001). In other words, give people an opportunity to share their stories, interpret their stories, and describe the essential meaning in their stories. The objective of the hermeneutic interview is not meant to be an intervention but research has shown that positive effects emerge from the interview process (Kvale, 1983). One of the positive effects is that while participants tell their stories they are able to reflect on their experience with the phenomenon and find meaning. Telling stories is one of the oldest methods used to find meaning in experiences. In this study, every participant expressed gratitude for the opportunity to tell their story.

Storytelling is also a method in qualitative research that gives voice to marginalized populations and enables the dominant culture to empathize with their
experience (Ladson-Billings, 2009). Many participants in this study articulated that they felt isolated or invisible at some point in their student caregiving journey, and they did not feel that their personal struggles as a caregiver would be recognized as legitimate in the academy. Cassandra stated:

...I think that's the choice of the caregiver...to be more public about those stories...I think that takes bravery. I think it takes being in a certain position of stability too...I do think that if enough of us choose that, then slowly those stories become not only visible, but also we create a place where they're accepted. That's part of the problem, I think. Because right now, you're not even allowed to have those stories. They run counter to the dominant narrative...the master narrative of academia needs to expand to include more experiences and more approaches...and make them legitimate.

This chapter is devoted to sharing each participant’s story as a way to introduce student caregivers’ voices into the narrative of academia. *Master narrative* refers to the cultural standards of a community. These standards are developed and enforced by people in authority (Thorne & Mclean, 2003). The master narrative of academia is based on the deficit model; thus, people without the requisite human, cultural, and social capital are not included with an equal voice. Nontraditional students are socialized, in the same way that traditional students are: to value the dominant cultural ideals as normative. Counter-narratives, or stories that focus on the lived experiences of marginalized populations and illustrate their successes, are both an act of resistance and a vehicle for demonstrating that alternative narratives are also credible (Espino, 2012).

I chose to dedicate an entire chapter to student caregivers’ stories because their alternative narratives need to be included in the literature. van Manen (1990) explains that biographies are sources of experiential material because their stories may be the
possible stories of others. I initially wrote the stories as a method to ensure that I truly understood the essence of the participants’ student caregiving experiences and to reduce the burden on participants by not requiring them to read their entire transcript. I expected that the stories would be edited and only small portions would be included as participant descriptions in the results chapter. However, throughout the process of member checking, participants also shared that they felt validated by seeing their story in print. It demonstrated that someone had listened to them, really understood their experience, and that their story could help other student caregivers. The stories reveal the essence of the lived experience of student caregiving, while illuminating the individual nature of the journey.

I strategically chose the order of the participants’ stories to align with the themes (table 6) and then adapted them based on individual nuances. As I explained in Chapter 3, I literally illustrated the themes in various orders and then added the participants’ stories within that framework. The process highlighted different patterns based on the order of the themes. However, participants did not tell their stories in a chronological tale. As I organized their experiences on a timeline that chronicled the sequence of events, I noticed that a common pattern in the relationship of themes in their stories suggested a hierarchical structure. The order of the themes—1) timing affects everything, 2) identities collide across contexts, 3) structure and flexibility enhance capacity, 4) coping facilitates health and growth, and 5) learning transforms the journey—is not rigid but the progressive dependence of subsequent themes on the prior ones was consistent enough in the stories to suggest a hierarchical relationship.
Themes emerged as the pattern within the individual stories when I organized their individual experiences in chronological order. My initial framework for participants’ stories was to reflect the chronology of the overall stories.

As I was trying to discern the order of the participants in relation to the themes, my son, Finn, brought me a dandelion. In my notes, I wrote about a dandelion at different stages of development—budding, blossoming, and seeds flying away to transform back into flowers in other places. I extended that into a metaphor of students budding, blossoming, and then spreading their ideas in new contexts. That metaphor guided the order in which I presented the participants’ stories. I began by looking at participants when they were “budding” into student caregivers. Then, I organized participants by their perceived identity changes throughout their student caregiving roles. I looked at how their identities “blossomed” over time relative to their own life experiences, the type of care they provided, and the resources available at their institutions. I considered how the structure they had in their caregiving roles was affected by the flexibility or inflexibility in their student roles. I analyzed how their coping strategies evolved over time and how personal and institutional resources impacted their health and ability to succeed in their student roles. Finally, I analyzed how their student caregiving experiences fostered their ability to “spread” their growth in other contexts. The order of participant stories represents my effort to clearly portray how participants began their journeys, coped with their dual roles, and how their student caregiving experiences transformed their personal and professional lives.
Pooja went back to school to earn credentials to improve her employment opportunities. At 50, she became the breadwinner in her family due to her husband’s severe mental illness; he lost his job and began collecting disability, which was not enough to support a family. All four of Pooja’s children live with mental health illnesses, and she cared for four out of five of her family members while she was a student. Pooja manages her own depression and diabetes as well. In 2008, after she was terminated from her position at a bank, Pooja decided to return to school through the vocational rehabilitation program at the local community college. She said that if her family was going to survive, she was the one who had to make a change. She reflected on how
much college changed her, “I’m a completely different person than when I started school”.

When Pooja began her program, she said that she had a difficult time looking people in the eye and she felt ashamed that at fifty years old she got fired and had to be in a vocational rehabilitation program. But she chose school because she knew it would give her family the most opportunities in the future. She wanted a career where she could hide in the basement of a hospital and do medical transcription without interacting with anyone. However, the instructors and her vocational counselor saw potential in her that she never saw in herself. Pooja revealed that no one ever encouraged her the way they had. For the first time in her life, she got As in school, her work study supervisor told her she was one of the best employees she ever had, and her vocational counselor said that she was his success story. The confidence they had in her allowed Pooja to have more confidence in herself.

One of Pooja’s instructors invited her to get a certificate in the medical assistant program because she thought she had a warm personality and the skills to succeed as a medical assistant. Pooja decided to complete an associate’s degree, and reach for an accomplishment that she did not think she was capable of at that point in her life. She said the way people treated her at school made her feel like she was getting “taller” and they helped her “blossom”.

The contrast at school and home was significant. The care she provided for her husband and children was draining because she was always needed for something. Her husband looked to her for his sole support and her daughter blamed her for her
husband’s illness. The stress took its toll. And when a school deadline prevented her from giving her family her undivided attention, she noted a peak in her husband’s flairs. During Pooja’s last semester, her husband was admitted to an inpatient psychiatric unit, which was hours away from her home because it was the only one that accepted his Medicaid insurance. Because of this incident, she was not able to attend a review session for a difficult class and subsequently failed the final. This class was one of the only Bs Pooja received throughout her college tenure. This disappointed Pooja but her mentor reminded her it was not the end of the world.

One of the things Pooja did to cope was to reconnect with a friend from her past. While she was a student caregiver she participated at the community theatre with her best friend from high school. She moved sets in between scenes and helped with costume changes. Pooja sat up straighter, her voice got higher, and her eyes lit up when she remembered this experience. There were also connections between the theatre and school. One of the instructors at the college was an actor in the theatre, she asked her to take attendance for a required class assignment. She appreciated bringing both of the worlds that made her happy together.

Pooja noted that she was healthier while she was in school; the structure and routine helped her eat better to manage the diabetes. Her mental health also improved because the success in classes allowed her to experience positive social interactions which did not let her depression “hold on so tight”. School was an escape from caregiving responsibilities. She often had to do homework in her husband’s line of vision to help him feel secure but that got to her sometimes so she enjoyed going to
school where people built her up. Pooja joined the Student Senate as a way to give back to her school. When she went ziplining for a teambuilding adventure with the Student Senate, she said she did it once for her son who was a paratrooper in Afghanistan but then she did it again for her own enjoyment. She gave herself permission to have fun while she worked hard to complete her goals. She finished two Associate degrees and then completed a third in a different semester. Pooja walked in one graduation ceremony and decided she deserved to walk in the next ceremony because she worked hard. And “graduating was so much fun”. Pooja asserts that school helped her find joy, health, and confidence.

Jessica

Jessica assumed the role of student caregiver when she was 19. She was an undergraduate and worked three part-time jobs. Her mom and sister both had severe mental illnesses that included suicidal tendencies. Jessica was hypervigilant about having her phone with her at all times so that she could answer it as soon as it rang. She never knew when she would receive a dramatic call from her mom, sister, or the in-patient psych unit at the hospital. At one point in time as an undergraduate, she made the decision to have her mom committed for her mother’s safety. Her grades plummeted during this time—not because of the scores on her academic work but because of her sporadic attendance. She expressed frustration that the professors were so rigid and did not exude compassion for her particular circumstances.

Even though she wanted to continue her education, she left college to care for her mom and sister in their family home. After a couple of years, she returned to a community college so that she could increase her GPA, with the intention of returning
to the university. During this student experience, her dad was in a motorcycle accident and remained in a coma until his death nine months later. She indicated that struggling through the grief of watching her dad was difficult, however, it was easier to tell her professors about him than it was to talk to them about her mom and sister’s invisible mental health conditions. She could say that he was in an accident and in a coma in the hospital, it was not sensitive information she felt she needed to keep confidential to maintain his dignity. She grappled with understanding how caregiving took a toll on her own emotional and physical health when she was not the one experiencing the illness or disability, thus it was difficult to articulate to professors her particular needs as a student. Jessica left higher education initially because she was unable to cope with the erratic nature of mental illness combined with the inflexibility of the institution. She developed healthier coping mechanisms while caring for her dad because it was structured and provided her with some schedule control. Part of coping with the trauma of her dad’s health status was that she did homework in the hospital while holding his hand.

**Waldo**

Waldo had been caring for his mom with Huntington’s Disease throughout high school. He was a first generation student who grew up in poverty, and at the age of 18, he chose to stay at home and commute to college so he could continue to help care for his mom and save money. He said that he “…got lost in the wash…” in the big classes, the instructors were detached, and he had no one in his family to help him understand how to negotiate college, so he floundered. He turned to alcohol and drugs to “self-medicate”.
He also cared for his dad who has bipolar disorder and was verbally and physically abusive throughout most of his life. This abuse peaked during the years Waldo’s mom was ill because his dad struggled to care for his mom. Part of Waldo’s stress was worrying about how his dad would treat his mom when he was not there. There were times when he came home and his dad was drunk or he had left his mom alone and she had fallen and hurt herself. Dealing with the physical and emotional burden of caregiving for his mom, enduring the erratic and violent nature of his dad’s mental illness, and navigating the inflexible culture at the university was compounded by his fear that he might develop Huntington’s Disease (HD). He had a 50 percent chance of inheriting HD, which he described as a combination of multiple sclerosis, Alzheimer’s, and Parkinson’s.

Waldo used athletics and his supportive rural community (he had many surrogate mothers) to survive while he was in high school, but he floundered in college because he felt like he was alone “on an island”. He was intimidated by the large classes, the unfamiliar campus culture, and the impersonal nature of the TA’s and instructors. During finals week of his freshman year, his mom fell and required brain surgery as a result of the fall. He explained the story to his statistics professor and the professor replied, “I had a student last year who had breast cancer and went through chemotherapy without ever missing a class. You can choose whether you come to the final or not”. He received several inhumane responses like that and quit trying to communicate with professors because he did not have the energy. With his family and the university offering little support, Waldo coped the only way he could: by turning to
drugs and alcohol. He always sobered up every couple days to go home and take care of his mom and “put the house back in order”.

Waldo says he reached rock bottom when he didn’t show up to volunteer with the middle school football team because of a 24-hour cocaine bender during his sophomore year. He viewed himself as a helper but he wasn’t helping anyone, least of all himself. He thought if he went any lower he would be in the ground, so he started pulling himself up. Realizing that he would not be able to do this on his own, Waldo began to talk to his grandma about his problem, returned to athletics to cope with his anger in healthy way and left the drug crowd behind him.

One of the final classes Waldo took before leaving the university was a death and dying course taught by a professor that “restored [his] faith in the university”. He went to office hours and discussed his life and the issues he faced with the instructor. The final project for this class asked the students to write about their own lives. Waldo wrote a 35-page paper entitled “Stranger than Fiction”. The paper was a healing experience that allowed his open wounds to become scars. Waldo realized in writing this paper that he didn’t have to carry the traumas of his life with him. He packed them up and left them in the paper.

Waldo began working as a nursing assistant in the psychiatric ward at the hospital, around the time his mom could no longer be cared for at home. It was familiar, it was like taking care of his parents but not personal. He had skills and empathy that nurse managers commented were beyond his current training. He is a great formal caregiver because of his student caregiving experience. This position led
him to become a registered nurse. Currently, Waldo is embarking on a Doctor of Nursing Practice degree. His mom has passed away but he still needs to care for his dad during difficult bipolar cycles. This student caregiving journey, he is better able to cope because he has learned how to analyze a situation and prioritize needs rather than getting overwhelmed and escaping with drugs and alcohol. He has also pursued genetic testing that confirmed he does not carry the gene for Huntington’s Disease. Waldo says he would not be a nurse or the person he is today if he hadn’t survived the challenges of student caregiving.

Amy

Amy began her student caregiver journey before she actually realized she was a student caregiver. Zack, her youngest child challenged her as a parent his whole life. Amy wondered why the parenting techniques she used with her other children were not effective with her youngest. Her husband suggested that she might be weary after staying home with all three kids. Zack entered first grade as Amy embarked on an art therapy certificate program. As she progressed in her classes, she learned information about a myriad of physical and mental illnesses that helped her understand Zack in a new way; he had cognitive and behavioral challenges consistent with Attention Deficit and Hyperactivity Disorder. Initially, the potential diagnosis gave her a sense of relief, it freed her from the guilt of being “a burnt out stay-at-home mom”. Relief was followed by dread and anxiety. Dread that her son would be labeled with the stigma of a mental health disorder; anxiety about how she would parent a child with special needs. Throughout her student caregiving journey, she struggled with juggling the demands of
doctor and therapy appointments, communicating with an authoritative advisor, and making sense of a new identity.

Amy reflected on her time in school and said that it was a time of self-exploration that paved the way to a healthier life. Two years after graduation, she still thinks about all the things she had to adapt to while she was a student caregiver. Amy had to figure out how to parent differently than she had in the past, she had to figure out how to be a mom who had more than “mom responsibilities”, and she had to figure out how to adjust her expectations of who she was as a nontraditional student. The contentious relationship with her advisor caused Amy to second guess herself a lot throughout the program. Currently, she wonders if the problems she had with her advisor were a manifestation of her own insecurities during that difficult time in her life because interactions with this professor post-graduation have been more congenial.

An unexpected gift of support came from Amy’s fellow classmates, who told her that she was their mom’s age. When she shared in a clinical class about her son’s ADHD diagnosis, students came up to her to share their own personal or family stories about coping with ADHD. And they asked about her son; the personal connection she craved. Amy said the peer support was very beneficial for her survival during the program.

Amy’s advisor knew about her son’s recent diagnosis but did not reach out to her in a personal way. She recounted a time when she was really struggling and ended up in tears in her advisor’s office. She asked Amy, “Every time you come to my office there are tears, what’s that about”? Amy wonders how she can call herself a therapist if she doesn’t even know how to respond to a crying student, the tears must mean that
something is not right. Tears welled up in the interview, and Amy questioned why her advisor never tried to get to know her as a person and look for her strengths rather than her perceived weaknesses. Due to this contentious relationship, she wanted to prove herself as a committed student and she did not ask for department support except for the semester her dad was diagnosed with cancer and she was also helping her mom care for him. Her advisor allowed her to drop a class and finish the requirements as an independent study.

Amy did not have the time or energy to exercise while she was a student caregiver, which was one of her ways of coping with stress. She went to her family doctor for help with anxiety and depression and was prescribed medication, though she did not like the way it made her feel. Instead, Amy chose therapy over drugs to cope with her son’s new diagnosis and not being a stay-at-home mom. She attributes her willingness to go to therapy to what she was learning in her classes; the literature indicated that the best therapists were people who had gone to therapy themselves and took time for self-reflection.

Amy blossomed during her internship. She had a supervisor that respected her personal philosophy about art therapy, appreciated her work, and valued her interactions with patients. She wishes she had the kind of support she had at her internship throughout her whole program.

Amy indicated that she felt she grew significantly as a person while she was a student caregiver. She believes studying art therapy “forced” her to engage in self-reflection. Student caregiving was a very difficult journey, but it gave her the
opportunity to learn how to develop self-esteem from the inside out rather than to rely on external affirmations. She noted the paradox of being silenced by her advisor while at the same time she required her to confront her own insecurities. Amy is glad that she modeled the importance of being a lifelong learner for her kids. She ended the interview with a chuckle and said she learned as much about herself in school as she did about the content.

Anne
Anne boldly accepted her student caregiver role. She began a master’s program as a mom with three children who have multiple disabilities, her husband has multiple disabilities, and she has multiple disabilities. Her fourth child was diagnosed with Attention Deficit and Hyperactivity Disorder (ADHD) while she was a student. Anne homeschooled her children for a number of years. Her decision to return to graduate school arose from conversations with her husband during marriage counseling, he revealed his angst about his ability to provide for his family and asked how she could help. Due to the combination of his disabilities, he knew he would always be stuck in a job that leaves their family in a constant state of financial instability. Anne disclosed that she is a very religious person and prayed about how to help ease her husband’s burden while being true to her calling. Anne had dreamed of getting her masters in teaching since she finished her undergraduate degree, nearly 20 years before. Leaving the cocoon of her house was a huge step for her because the isolation she experienced as a homeschooling mom exacerbated her anxiety and she claimed she was borderline agoraphobic. Thus, commuting almost an hour each way to go to school was a major accomplishment. She said her brain was happy to be woken up.
Anne thrived on the intellectual stimulation school offered. Homework “is always waiting” for her and the busyness helped distract her mind from “nonproductive worrying”. Anne says she does a lot of homework in the waiting rooms during her kids’ therapy appointments. Her husband is very supportive—he sees how her education will continue to benefit the family. She uses homework as an escape from household chores. An unexpected perk of Anne not being around all the time is that the family has learned to take care of themselves more because mom is occupied with school. Her youngest child was asked in school to draw a picture of his family relaxing and he drew a picture of his mom sitting in her chair doing homework. “Homework is sacred time,” Anne declared.

She worried that she would not be taken seriously, but is pleased that has not been the case. Anne feels she is able to speak in class and her voice is respected. Anne approached her advisor, even though she is intimidated by him, to help her find a teaching assistantship to help with tuition and insurance for her family. When he discouraged her from pursuing one, she did not question him. Upon reflection, Anne wonders what it is that she finds intimidating and allows her to be silenced. Overall, though, she is pleased with the positive model she is demonstrating for her children: teaching them that lifelong learning is the goal and showing them how to work hard to achieve that goal despite obstacles.

Even without a teaching assistantship, there are institutional resources that benefit Anne and her family. The institutional resources she says are most beneficial to her are assistive technology and health insurance. The assistive technology allows her
to help her family while the insurance allows her to take care of herself. She installed the assistive technology provided by the university on her personal computer, which helps her husband and children navigate ways to cope with their learning disabilities. She and her husband feel guilty that they have passed on their disabilities to their children but Anne is now able to reflect and tell her husband—who did not have the help he needed in school to succeed—that their children will get the resources they need because she is able to advocate for them. This helps her feel less guilty about going to school and leaving them. Though she thinks that “leaving them to fend for themselves” has helped them all grow. Because of the health insurance she was able to start going to counseling to cope with anxiety and depression, she is getting shots to manage her allergies, and she has replaced her old cracked orthotics to decrease her foot pain. An unforeseen advantage of school was the financial aid, which gave her the resources to take care of things such as purchasing orthotics and a computer. She said having access to money has taken a lot of pressure off the family, though she realizes she will have to pay it back someday and that adds some stress. But before school they did not have the financial reserves to weather a crisis.

School has helped her put life in perspective so that she can analyze whether a situation is actually a crisis. Anne strongly believes in the connection between mind and body. She says, “If my mind is relaxed, my body is more willing to be relaxed”. School has helped her mind relax so she can take better care of herself. She knows that she needs to sleep or she will get sick. So she is diligent about getting enough sleep. However, she is less able to let herself have downtime, which she knows she needs.
Anne gives herself permission to structure her driving time as “me time” because it is utilitarian—she has to drive to school so she is not “wasting time” if she does something for herself. Thus, Anne listens to music because she says she “feels through music”.

Anne uses the concepts, tools, and language she is learning in classes to advocate for her family. Now that her children are enrolled in public school again, she is less intimidated by the principal and teachers. Anne knows the language of education and has the confidence to demand services for her children in a way that she was not able to before she began graduate school. Anne has grown as a person during her student caregiving experience. She is able to think about thinking, have a broader world perspective, and understand herself better.

**Cassandra**

Cassandra’s student caregiving journey encompasses her time as a Master’s student in Social Work and her PhD in Education. She continually cares for her son, who has Attention Deficit and Hyperactivity Disorder (ADHD) and generalized anxiety disorder, and intermittently cares for her mom, sister, and ex-husband, all who have mental illnesses. Cassandra herself, was recently diagnosed with ADHD and has battled depression and anxiety for years. The complications from her own diagnoses compound the difficulties of juggling the demands of being a student caregiver.

At one point Cassandra decided to leave her master’s program for a while to attend to her son’s needs. It took her four years to complete a two-year degree, which bothers her. However, she has made peace with that decision because she says she can live with the long term consequences of failing as a student but she cannot live with the
long term consequences of failing as a mother. She is a single mom and this was her way of coping with the reality that she is solely responsible for her son’s well-being.

As a PhD student Cassandra grapples with the structure of the academy and how it leaves caregivers on the margins—they are invisible and left to find their own solutions. She compares caregivers to other subgroups in the academy: sexual assault survivors, students of color, and women, who are left to figure out how to fit into a system that blames them for not fitting in. Caregivers are left out of the master narrative in higher education. Cassandra consistently used the language of social work and education to explain her student caregiving experience. She considers one of her greatest strengths as a student and researcher is making personal connections with the content and then applying the content to her life. This, she believes, developed from her own intellectual ability, not what is being incubated in the academy.

Cassandra’s confidence in her intellectual ability is in stark contrast to her lack of confidence in her student and caregiving abilities. She repeatedly said that when juggling both roles she is consistently giving them both less than she would like. Despite her feelings of inadequacy as a student caregiver, she never doubts her intelligence which appears to act as a way to cope with her perceived failures in other areas of her life. Intellectual conversations about theory and research sustain her, she cited education and social work theories throughout her interview to explain why she made specific decisions for her son and how she chose personal coping strategies.

Cassandra became interested in self-care in the social work program, thus she integrated ideas from particular treatment methods in her own life. One technique is
finding areas where personal control is attainable. She asserts this control by deciding when and if she will hand in assignments or take exams. If there is an acute situation with her son when a paper is due or an exam is scheduled, she has often chosen to focus on her son’s needs. She has told professors that she will not complete the course requirements, they should review what she has completed, factor in her uncompleted work, and then compute her final grade accordingly. She is unapologetic for this course of action because she feels this is the best she can do given the constraints on her time.

Early in her doctoral program, her advisor told her that she should not share her personal struggles at school; she has rejected this advice and pays the price with her grades and how seriously she is taken as a scholar. She expressed that this is a liberating way of living within an inflexible system because it allows her to be in control of some component of her student caregiving experience. This is where the confidence in her own intelligence and ability to transform content into skills for personal well-being become indispensable coping mechanisms. She knows she is smart enough to make the grade if circumstances were different.

Orla

Orla began her PhD journey as a caregiver, and has cared for her son and both of her parents. Her son is gifted, he is on the autism spectrum and struggles with anxiety. Orla’s mother was diagnosed with Chronic Obstructive Pulmonary Disease (COPD) and Rheumatoid Arthritis and passed away three weeks into her first semester in the program. Within the first year of classes, she also became a long distance primary caregiver for her dad. Recently, he moved to a retirement community near Orla’s home. Despite the time and emotional burden these caregiving roles have created for
her, she wrestled with accepting that her burden “counted” since “many people have it much worse”. As she reflected on this in her personal interview and the focus group, she epiphonized that she was internalizing this comparison based on feedback she received from both professors and peers.

Orla has come to accept that her burden is real and she is entitled to it. The emotional strain of attending to another person’s well-being requires significant energy from the caregiver as the physical and emotional needs of the care receiver change. The caregiver must keep the care receiver safe, both physically and psychologically; the caregiver must diffuse situations to help decrease tension; the caregiver must listen to be able to provide the type of support the care receiver needs moment to moment. She uses the language of her discipline, human rights, to make sense of her situation. The fundamentals of caring transcend who she is caring for, she must allow each care receiver to preserve their dignity.

Orla said in various ways that her role of student or caregiver have routinely taken precedence over her own needs, which often infringes on her ability to maintain her dignity. In the focus group, she explained how a professor demeaned her choice of caring for her father’s needs instead of meeting the attendance requirements for class. Orla was visibly distraught. She said, “I am not a child”. Her final sentiment in her personal interview was that she would like for the institution to respect her dignity in the same manner that she respects the dignity of her care receivers.

Orla’s coping strategies and emotional resources have changed over time. Initially, she was excited by the intellectual stimulation of school, and academic work
was an escape. It was something that she could immerse herself into because it was just “hers”. As her caregiving tasks increased and the emotional fatigue of juggling both roles consumed her, she began counseling and medication to help her manage anxiety and depression. The institutional resource that motivates her to maintain her student status is the health insurance. She claims school is purely utilitarian at this point, though she does derive some pleasure from intermittent projects that feed her passion.

Due to Orla’s numerous outside responsibilities, her perception is that she is not taken seriously as an academic. Information to support her suspicion is that while peers in her cohort are engaging in research with faculty, she is often put in charge of managing the logistics of departmental events—i.e. making sure food and drinks are supplied. She grapples with this because she does not have the energy to do more academic work and she suspects that a professor (who knows about her caregiving responsibilities) is trying to respect her family obligations. She confessed that she often uses her studies to get out of caregiving tasks and her caregiving tasks to get out of school tasks. She is in the process of trying to establish a healthier balance so that Orla “the person” can come out, not just the caregiver or the student.

**Natalia**

Natalia embraced the role of caregiver for her mom shortly after she completed her comprehensive exam, in a doctoral program. Her mother was diagnosed with late stage ovarian cancer. Natalia returned to her parents’ home to help her mom recover from surgery and then commuted to care for her as she endured chemotherapy and radiation. When she returned to school, she lived and worked in a hospitality house for homeless people. At the time of Natalia’s personal interview, she had made
approximately 45 trips back and forth to school—an 8 hour drive—to juggle her student and caregiving responsibilities. Natalia’s personal history, research, and student caregiving experience fused objective and subjective realities that both helped and hindered her journey.

Natalia recognized and struggled with her family’s privilege in contrast to the people she was working with at the hospitality home. She was acutely aware of this because her research focuses on how people who experience structural inequalities cope with stress. There were people in the hospitality house who had cancer but did not have insurance and access to quality health care. However, her mom had the benefit of comprehensive insurance and state of the art medical care. She tried not to feel guilty because she believes guilt is not a productive emotion, but her privilege did add another layer of stress. She said it was “dizzying” sometimes to think about how her privilege buffered her in many ways, even though she still experienced much stress. Anxiety and exhaustion consumed her. Before Natalia became a student caregiver, she had struggled with anxiety and depression, but during her student caregiving journey, her anxiety specifically stemmed from: negotiating financial struggles, coping with the instability of commuting, and living in survival mode.

As Natalia identified maladaptive thought patterns and felt physical manifestations, she recognized that she needed distance from her caregiving responsibilities in order to focus on school and distance from school to focus on her caregiving responsibilities. Her advisor at Michigan allowed Natalia to maintain her funding while working remotely. She wanted to complete the work necessary to
maintain her funding and make progress on her dissertation proposal. Natalia felt compelled to prove that the flexibility and support her advisor was giving her was deserved. Since the cost of traveling back and forth to meet both student and caregiver obligations exceeded the stipend she received, her advisor also encouraged Natalia to apply for emergency funds instead of taking on an additional job. Her advisor’s flexibility and knowledge about available resources are examples of how Natalia’s privilege kept providing resources for her, which helped her employ healthy coping strategies. Natalia noted that she did not realize how important institutional resources were until she needed them—though she never anticipated needing them.

Natalia benefitted from significant institutional resources from two universities. She reflected on what institutional resources and personal connections were available to her in Iowa to help her cope with the instability of constant commuting. She recalled that she knew a professor at Iowa who used to be at Michigan. This professor told her that if she was ever back in Iowa to call if she needed anything. When Natalia realized she was going to be in Iowa for an extended time, she contacted the professor to see if there was “a corner” for her to work so she could “stay sane”. To Natalia’s surprise, the professor at Iowa helped her obtain visiting scholar status, which provided her with an office. The department offers her a stress-free environment to meet her professional goals, garner social support from colleagues, and establish a routine.

While the institutional resources allowed Natalia to continue functioning, she also needed some comfort. One day at the hospital early in her mom’s illness, Natalia and her brother met a therapy puppy in the elevator. The dog made them happy. She
thought the dog would be good therapy for the residents of the house where she lived as well as for her mom. Natalia adopted a dog almost immediately after that encounter. As she reflects back on that decision, she classifies it as a purely emotional decision. She can’t believe that her way of coping was to take on more responsibility while she was already overwhelmed. Natalia says the thing that she is most grateful for about the dog is that he provides “continuity between places”. Her dog knows her and can comfort her wherever she is.

Natalia says the dog is a blessing in the trauma of her mother’s illness. Finding blessings is a way to help her manage anxiety and depression. Building professional relationships at Iowa, meeting her fiancé, and reducing her aspirations are among the many blessings she attributes to her student caregiving experience. She says that life is about juggling family and work and student caregiving has given her a “crash course”. Natalia recognizes that when her mom is healthier she speeds up her work so that when her mom is ill she can slow down her work. This was not a conscious decision initially but it has become intentional. She’s proud that she made the decision to prioritize taking care of her mom and will never regret the time that she spent with her. She said that she now drinks less of the “academic kool-aid” because she sees how academic culture judges personal worth based on narrow types of accomplishments. The most valuable blessing Natalia attributes to her student caregiving experience is that it has helped her realize the kind of person she wants to be.

Elizabeth
Elizabeth is originally from Ireland and was a PhD student in Women’s Studies when she learned that her mother was diagnosed with late stage cancer. She noted
that she had the privilege of being able to leave the continent and temporarily abandon her own work because she was in the dissertation phase. When she received the news that her mom’s prognosis was grave, Elizabeth emphatically proclaimed that there was no question in her priorities, she would instantly leave to care for her mum. She made travel arrangements, organized to have someone cover her classes, and pulled her two youngest children out of school within two days. She left the Sunday before finals week, thus she was unable to proctor the exams for her students. The faculty were supportive but she said they weren’t tested very much because they just had to administer the tests and then sent them to Ireland for her to grade. Grading provided her a sense of normalcy amidst the grief and strain of caring for her terminally ill mother.

While being a PhD candidate provided Elizabeth with the flexibility to care for her mum, her previous life experience as a physical therapist gave her the intuition and language to address her mum’s symptoms with the physicians. When the family doctor did not communicate well with her parents, Elizabeth called his office directly and said, “Given my mum’s neurological symptoms, I am concerned that she has lung cancer and it has metastasized to her brain.” He condolingly replied he was afraid of that as well. She received a Trans-Atlantic call from a specialist on her cell phone. The call came while she was at home; she stepped outside so her children could not hear the conversation and she stayed outside until she stopped crying. He confirmed her worst fears, he estimated she had 6-12 weeks to live.

The news of her mum’s illness blindsided her; her dad had been chronically ill for years but she did not know how to cope the imminent death of her mother. Elizabeth
indicated that people perceive her as competent and she relied on that perception of competency as a way to cope with the trauma of her mum’s illness. She relayed medical information to her family, managed the logistics of care, and attended to her own health. Elizabeth often did not get the amount of sleep she needed; she stated stress and grief “propelled” her out of bed. Elizabeth understood that she did not have the time or energy to be sick, thus she took vitamins, ran, ate well-balanced meals, and slept as much as she was able to for self-care.

Physical therapy afforded Elizabeth the language to navigate the medical component of her mum’s illness and Women’s Studies gave her the language to identify the gendered expectations and privilege she had in her student caregiving experience. She was the only daughter out of five children and she returned to Ireland to care for her mum. She wanted to do it and was grateful for the time she had with her mum but she was acutely aware that she—the female—temporarily abandoned her dissertation, left her job, and forfeited income to be a caregiver. Her brothers made no such sacrifices, though they helped in their own ways. She had the privilege of being in the dissertation phase of her degree, had the financial resources to leave her position, and was able to have her own daughters with her as she endured the grief of watching her mum die.

After her mum’s death, Elizabeth returned to the states ready to finish her dissertation proposal and prepare it for defense. A month before she was to defend, her dad passed away. In the span of four months, Elizabeth lost both of her parents. She explained that the proposal defense was not her best work but she had a new
perspective on what was important. She shared how the “sick to your stomach anxiety” that seized her during her comprehensive exam defense was not present at her dissertation defense. The distance from the academy while she cared for her mum reminded her that the way academics become consumed with the tunnel vision of projects and hierarchy is not the end all be all that PhD students are indoctrinated to believe.

In an encounter outside of this interview, Elizabeth said, “That which you cannot change you must endure”. She endured the significant grief of being a student caregiver by taking time for self-care and prioritizing time with her mum over work and school.

**Ed**

Ed learned that his dad had brain cancer during the first weeks of his Freshman year of college. Three weeks after the tumors were discovered, he had a brain hemorrhage that lead to a severe stroke which affected his dad’s cognitive, emotional, physical, and social functions. Ed decided to return home and help care for his dad and commute to school. He chose caregiving over living on campus and getting a full residential student experience. He expressed pride that his dad never had to ask him or thank him for coming home. Caregiver was just an expected part of his familial role, and it had been since childhood.

Ed shared that he doesn’t think he would have ever “met” his dad if his illness had not occurred because he was a very busy lawyer and farmer. He essentially worked two full-time jobs. The stroke created a man who cherished being at home in the comfort of his family rather than working endlessly. Ed shared that even though his cognitive, emotional, physical, and social capabilities changed, his dad’s heart remained
unchanged. Thus, he worked hard to maintain his dad’s dignity as he became more dependent.

Ed indicated that school was an escape from the caregiving tasks, however, his caregiver identity always trumped his student identity. At the time, he was a student in the biomedical engineering department. He shared that his professors provided him with flexibility throughout the program even though they did not know his specific circumstances, nor did they ask. He was touched by how they just intuitively knew that his “brain was fried”. He appreciated the adaptability of his department without having to share the details of his caregiving experience. Ed also explained that he generally kept to himself but there was one older nontraditional male student who often checked up on him. He learned through conversations that he had had a similar experience of losing his own father at a young age. Ed shared that this social support was both a blessing and a curse. It did not allow him to fade in the background which he craved, however, he said that the support from this student pulled him through when he hit rock bottom after his dad passed away.

Ed’s student caregiving experience shaped him into the person he is today. He wouldn’t have chosen to be a physician, especially one who focuses on end of life care. He says, “I have a fight with medicine” and is determined to make the system better. Ed was dissatisfied with many of the medical choices and type of care his dad received early in his treatment. He believes the reason his dad had the stroke is because of medicine’s need to have a tissue sample despite the danger of the procedure. No difference in the course of treatment would have been made without the sample.
When they finally found an oncologist who had the type of bedside manner that respected his families’ needs, they were more comfortable with the difficult decisions they had to make. The oncologist’s philosophy complemented Ed’s natural caregiving style and he decided that he wanted to be that type of physician. He chose to focus on end of life care so that families like his could have a nurturing and realistic course of care as they transitioned into the last stage of life.

Ed maintained a level of efficiency he never experienced in his life while his caregiving identity was intact, as soon as his dad passed away he “hit rock bottom”. He could not escape any more, he had to process the last two and a half years of his life as a student caregiver. He chose to leave home and live on campus, which he now thinks was a mistake because he didn’t have his mom around to grieve with. When he reached his lowest point, he sought out help from Student Health. He believes the university resources were incredibly helpful and the flexibility his department provided helped him cope with his dual roles. Ed’s personal coping strategies along the way included exercise and burying himself in homework; he craved the escape he gained from keeping his mind occupied with problems that had a solution.

**Epilogue**
This epilogue is a departure from how I formatted all of the other participant stories. I included this piece in Ed’s story because of the physical and emotional state he was in at the time of his interview. He approved this addition, “I also appreciate the last paragraph or so, I feel like you had good insight into my mental state that week”. Ed shared before we started the interview that he had been very emotional all week due to extreme sleep deprivation and he was not sure how this interview would unfold. He
just finished the first week of his medical residency and was wrestling with being a
formal caregiver with the insight of his informal caregiving experience. Ed indicated that
he did not want to use a pseudonym because he felt so connected to his father’s name.
Since he is a scientist, he understood the necessity of a pseudonym and then chose one
that had some significance to his family. He became teary at multiple points in the
interview. His speech style vacillated from emotional to clinical. His affect, manner of
speech, and body language were sensory clues to his visceral struggle with his caregiver
identity in a clinical environment, in which he has very little control.

**Jenna**

Jenna cared for two people during her time as a doctoral student. Her husband,
Tom, was diagnosed with Guillain-Barré Syndrome when they first started dating in the
early stages of her degree. At that time, she was a full-time special education teacher
and was going to school part-time in the evenings. Jenna also cared for her teenage
son, Billy, who has Asperger’s, however, did not initially recognize that relationship as a
caregiver role. She didn’t think about including him in her caregiving responsibilities
because she is a mom and “that’s just what moms do”. Over the course of the
interview, as she told stories about how school affected her time with Billy, she began to
recognize herself as a caregiver, as well as mom.

Tom’s illness occurred in the last part of fall semester, and he was hospitalized
for 110 days. Since they had just begun dating, his family did not know her and Jenna
was not given any information about his condition. Guillain-Barré Syndrome initially left
him quadriplegic, which rendered him physically incapable of contacting her himself. It
was a painful time for Jenna. The professors that semester were empathetic as she explained what was happening in her life.

When Jenna finally was able to see Tom, she was extremely grateful that he was alive, even though his health status was critical. She researched Guillain-Barré Syndrome, as a doctoral student would, and dedicated an enormous of time and energy assisting with his rehabilitation. Jenna was scheduled for an elective surgery which she chose to follow through with while Tom was still in the hospital, expecting a quick recovery. However, she contracted MRSA (an infection which is resistant to antibiotics) in her incision site. MRSA complicated her own recovery while the stress, pain, and lack of sleep made it difficult to focus on school. Tom’s recovery took precedence over her health, her son, and school. While Jenna cared for Tom and nursed her own wounds, Billy struggled because he did not have a consistent routine. Jenna explained that he “explodes” when he can't take it anymore, and he exploded. Billy physically assaulted Tom and Jenna. The police removed Billy from the apartment and admitted him to a psychiatric ward. Jenna, who had been his sole caregiver for his whole life, was not permitted to see Billy for 7 days. Not being able to have any contact with her son was a trauma that exceeded all others.

Jenna managed her own anxiety, depression, and obsessive-compulsive disorder in addition to her caregiving responsibilities. She began medication for her anxiety while her husband was in the hospital. At that time, she also had difficulty sleeping so she was prescribed sleep medication. There is a history of alcoholism in her family and she recognized a dangerous pattern when she started to mix alcohol with her
prescriptions. She says she had enough life experience to know that if she continued doing what she was doing she’d end up as an alcoholic like her family. So she “monitored” herself and found other ways to cope. She chose “no-brainer” activities like Facebook and reading for pleasure to help her calm down in the evening. When Tom’s health became more stable she used him as her support again. She said that his type of support was what was missing in her life.

When Jenna attempted to tell her instructors what was happening in her life, her advisor discouraged her from revealing personal information in academia. She suffered in silence while she juggled recent traumas that were flung at her. Jenna ended up dropping a class that semester and received a D+ in her other class—even though she was normally an A and B student. The instructor actually wrote on her final paper “You need to think before you write”. As a teacher herself, she expected some level of humanity, however, many professors and her advisor, were rigid and unsympathetic about her personal struggles.

At the beginning of every semester when Jenna had night classes, she let each professor know that she had to keep her phone with her since Billy was staying at home by himself. If he called or texted she would quietly leave the room to answer the call or text. If Jenna did not respond immediately, he would think she was dead, which resulted from prior traumas. Most professors were respectful about this situation, however, there was one professor who yelled at her in front of the whole class and deemed her a rude, disrespectful person for getting up in his class to respond to a call. When she tried to explain the situation again, he continued to scold her like a child. This
kind of rigidity was not an isolated event. Jenna also sought flexibility from a professor when Billy, needed out-patient surgery and he could not be left alone for 24 hours. When she discussed this with her professor, he informed her that even under those circumstances her grade would be negatively affected because of his attendance policy. Knowing that, she chose to have her mom stay with her son while she attended class. Jenna said she could not afford another bad grade. She learned how to play the academic “game” and just did what they wanted.

The three years Jenna was a part-time student she felt like an outsider. She didn’t have any personal connections with faculty or peers. When Jenna quit her special education position and accepted a teaching assistantship so she could be a full-time student is when she finally began acclimating to the university culture. Jenna enjoyed being on campus so that she was able to go to workshops for personal development. Through these workshops and her assistantship, she met other students closer to her age who had similar life experiences that allowed her to reflect on how to navigate her student caregiver role. This ability to understand that she was not alone, provided her with a connection that she craved. Peers shared notes and gave her advice about classes which she claims was much better than the advice her advisor gave her.

Jenna’s experience as a special education teacher exposed her to people with physical, emotional, and learning disabilities which helped her negotiate Tom’s rehabilitation. She developed a teaching philosophy to model interdependence. Her students at the time of Tom’s disability, helped build ramps and railings for his apartment so that he could be as independent as possible. Thus, Jenna’s students who
had invisible disabilities helped her husband who had a visible disability. As a teacher
and caregiver who helps people maintain their dignity as they struggle with disabilities
and life challenges, she wishes she had been given the same courtesy by her teachers.

Jenna coped with the anger and frustration she had with the university by being
stubborn. “It’s amazing what the human mind can do and when someone tells you you
can’t [do something]. You try to prove them wrong”. She fought as long as she could to
achieve her goal, to not only be the first person in her family to graduate from college,
but also to earn a PhD. She finally decided after five years of playing the game, it was
best for her health and happiness to leave the program with the EdS degree instead of
the PhD. She moved out of state with her husband and she is healthier and happier.
Jenna is currently employed as a full-time special education teacher and an adjunct
faculty member at a university near her new home. She incorporates her life experience
as a student caregiver to create a supportive and flexible community for students so
they are able to achieve their goals.

Alex

Alex accepted the role of his mom’s caregiver at two different points in his
academic career. When he was working on his Master’s, he helped her through her
recovery with a knee replacement. The second occurred during his PhD journey. The
majority of this interview focused on the second caregiving experience when she had a
stroke while he was writing his dissertation. As Alex reflected, he shared that he was
quite lucky because the stroke occurred around Thanksgiving and while he was writing
his dissertation. He had both the fortune of the academic break and the fortune of only
having to negotiate with his dissertation chair while he was navigating his mom’s recovery.

Alex’s previous life experience as an event planner helped him deal with the stress of making quick decisions and prioritizing which decisions needed to be made immediately and which ones could wait. As a caregiver you often have no ability to plan for the situations that arise, which paralleled hosting an event itself. His identity as a researcher also informed his ability to understand the process of his mom’s recovery and negotiate the hierarchy within the hospital without being intimidated.

Alex said multiple times, and in various ways, that education helped him with everything. Education helped him understand the nature and limitations of his mom’s recovery; education helped him communicate with physicians, and education helped him interpret the nuances of working within the bureaucracy of health care and insurance companies. He noticed how his intellectual engagement with physicians affected the care his mom received. He witnessed how his advocacy provided his mom with interactive care by her physician. Alex observed, as a researcher does, how the doctor who cared for his mom interacted with him versus how he interacted and cared for the patient across the hall with the same diagnosis. The family did not have the confidence or verbal skills to ask informed questions and guide the type of care she received. Alex was intrigued by the difference. He recognized his privileged position in terms of education level.

Alex survived the initial trauma of the diagnosis by retreating into his student identity, he read and researched every piece of information the doctor gave him. He
said the wifi in the hospital was a life saver because he could access his university’s research database to find answers so he could feel competent in the way he advocated for his mom. Combining the PhD and caregiver processes ingrained in him an acute understanding that things were often beyond his control, thus, self-care was essential in making sure he was able to do what he needed to do when unpredictable demands arose. Alex coped with his student caregiver role by ensuring he got enough sleep and by maintaining boundaries with his family. Since childhood, he served as emotional manager for his family, and he chose to step back from his position for his own health. His role as emotional manager for his family was too much to bear at that time. He struggled with coming to terms with his own emotions about his new relationship with a mom who had a permanent disability because his dissertation focused on how people develop relationships with people with disabilities. Alex indicated that he could not continue analyzing the data from his dissertation because he could not view it from a researcher’s perspective.

Alex is currently an Assistant Professor and remains a primary caregiver for his mom and is a secondary caregiver for other members of his family. Alex said that caregiving has changed him both as a person and as a teacher. The joyful lighthearted side of himself got buried under the weight of caregiving, though it is slowly returning. His approach to teaching has shifted as well. Prior to his mom’s stroke he was stern about requiring documentation for student absences. But now he does not ask for verification because he worries that asking a student caregiver to do one more thing
may be the catalyst to push him/her over the edge. He is sure he will get burned at some point but chooses to err on the side of compassion.

**Summary**

The act of including student caregivers’ stories in this study illustrates that student caregivers are succeeding, and that their narratives are relevant to higher education. As I completed each participant’s story, I sent it to the participant to review to be sure I represented their experience accurately. Most people wrote a brief response that it was either acceptable or gave me suggestions for changes. There were three participants who offered how the process of participating in this study affected them. Pooja wrote, “Beautiful!! Thanks for letting me take part in your study. It was the first time in a very long time that I was able to talk about myself and my experiences!” This pleased me so much because I remember seeing how her face lit up in her interview as she recounted the growth and confidence she developed during her time as a student caregiver. Cassandra wrote, “It has been eye-opening for me to have to think about all of this for myself.” I was excited that Cassandra used the experience from this study to start to really process her student caregiving journey. Natalia wrote, “It is very validating to see that someone heard my story and took the time to reflect on it and make sense of it!” Natalia’s words made me feel as though I had succeeded as a phenomenologist. The foundation of hermeneutic phenomenology is that participant and researcher are partners in the process of discovery and meaning making. The importance of each student caregiver’s story “…is because it may be examined as the possible experience of other…” (van Manen, 1990, p. 73) student caregivers. The
participants’ stories, and their affirmation that I understood their experience, laid the foundation for thematic analysis in chapter five.
Chapter 5
Results

Overview of Chapter
The participant stories in chapter four provided context for the individual lived experiences of student caregivers, and this chapter illuminates the essence of the student caregiver experience based on the participants in this study. Twelve people participated in this study, and they were either a current student caregiver at the time of the interview or were reflecting on their student caregiving experience from the past. Five participants were actively engaged in student caregiving at the time of their interviews and provided real time illustrations of their struggles and achievements. The seven participants who reflected on their student caregiving journey emphasized that their lives were forever changed by the experience. The goal of this chapter is to explicate the essence of the student caregiving experience that is common to all participants.

Table 7 provides a guide to refer to as you read the results, it provides each participant’s self-reported life experience, their academic program and degree process at the time of caregiving, their relationship to the care receiver, and the care receiver’s diagnosis. The chart may help remind you of the participant’s personal journey. It is important to understand both the individual and collective nature of the student caregiver’s lived experience to get a comprehensive view of how the themes unfold in unique scenarios.
### Participant Descriptions

<table>
<thead>
<tr>
<th>Participant</th>
<th>Self-reported life &amp; student caregiving experiences</th>
<th>Academic program &amp; degree progress at time of caregiving</th>
<th>Care Receiver’s relationship &amp; diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alex</td>
<td>Used his life experience from a previous career to navigate student caregiving.</td>
<td>PhD in Recreation Dissertation—in data analysis phase</td>
<td>Mom had a stroke</td>
</tr>
<tr>
<td>Amy</td>
<td>Was frustrated that her life experience was dismissed while she was a student caregiver.</td>
<td>Post-baccalaureate certificate in rehabilitation counseling</td>
<td>Son has Attention Deficit &amp; Hyperactivity Disorder</td>
</tr>
<tr>
<td>Anne</td>
<td>Used life experience as a mom of kids with special needs to inform her academic work and vice versa.</td>
<td>Entered Masters in Education program as a caregiver</td>
<td>All four of her children have learning disabilities and/or mental health illnesses</td>
</tr>
<tr>
<td>Cassandra*</td>
<td>Combined life experience &amp; previous educational experience to navigate logistics &amp; ethics while she is a student caregiver.</td>
<td>Entered PhD in Education program as a caregiver</td>
<td>Son has Attention Deficit &amp; Hyperactivity Disorder &amp; Generalized Anxiety Disorder</td>
</tr>
<tr>
<td>Ed</td>
<td>Continues to reflect on how his student caregiving experience influences his medical practice.</td>
<td>Bio-Medical Engineering Freshmen to Junior year</td>
<td>Dad had terminal cancer and a debilitating stroke</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>Used her previous medical background to negotiate student caregiving while she also used her dissertation research to inform how she processed the whole experience.</td>
<td>PhD in Women’s Studies Dissertation — developing proposal phase</td>
<td>Mother had lung and brain cancer</td>
</tr>
<tr>
<td>Jenna*</td>
<td>Used her experience as a special education teacher to navigate her husband’s rehabilitation and was frustrated that her life experience was dismissed as irrelevant in her PhD work.</td>
<td>Entered PhD in Education program as a caregiver</td>
<td>Son had autism &amp; husband had Guillain-Barré Syndrome</td>
</tr>
</tbody>
</table>

3 (*)denotes that participant was an active student caregiver at the time of the interview
<table>
<thead>
<tr>
<th>Participant</th>
<th>Self-reported life &amp; student caregiving experiences</th>
<th>Academic program &amp; degree progress at time of caregiving</th>
<th>Care Receiver’s relationship &amp; diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jessica</td>
<td>Indicated that she had no prior traumatic life experience that equipped her with the skills she needed to endure the trauma of being a student caregiver.</td>
<td>Psychology Sophomore – Senior (with break between)</td>
<td>Mother and sister had mental health illnesses; Dad was in a coma for 9 months before he passed away</td>
</tr>
<tr>
<td>Natalia*</td>
<td>Uses her previous life experience of struggling with anxiety and depression to negotiate the anxiety and depression that re-emerged during her student caregiving journey.</td>
<td>PhD in Epidemiology Dissertation — developing proposal phase</td>
<td>Mom has ovarian cancer</td>
</tr>
<tr>
<td>Orla*</td>
<td>Uses her previous life experience as a teacher, mother, &amp; human rights activist to ensure she maintained her father’s dignity while she cared for him as a student caregiver.</td>
<td>Entered MA and PhD in Social Studies programs as a caregiver</td>
<td>Son has anxiety and father has age related cognitive and physical manifestations</td>
</tr>
<tr>
<td>Pooja</td>
<td>Diminished her lifelong experience with self-doubt to achieve goals she did not think she was capable of prior to her student caregiving journey.</td>
<td>Entered Associates Degree program as a caregiver</td>
<td>Husband and children had mental health illnesses</td>
</tr>
<tr>
<td>Waldo</td>
<td>Entered college with a significant history as a caregiver but did not have life experience with college going behaviors to prepare him to negotiate for his own needs as a student caregiver.</td>
<td>Entered Freshman year as an undeclared major as a caregiver</td>
<td>Mom had Huntington’s Disease Dad had bipolar alcoholism</td>
</tr>
</tbody>
</table>

Table 7 Participant Descriptions

There were five essential themes and seventeen thematic elements that emerged from the data. They will be discussed in detail in this chapter. The themes and thematic elements are delineated in table 8.
Timing affects everything

<table>
<thead>
<tr>
<th>Essential Themes and Thematic Elements</th>
</tr>
</thead>
</table>
| Timing played a central role in the student caregiving experience and it affected every aspect in the journey; it is one of five essential themes and the one I address first in this chapter. In this study, timing refers to the specific chronological points at which student and caregiving roles emerged and evolved. The three thematic elements within the essential theme are: (1) academic phase is crucial, (2) life experience helps, and (3) health affects progress. Each element of timing is interconnected and affects not only how the other elements unfold but also how the other essential themes weave together.

| Academic phase is crucial |
| Life experience helps |
| Health affects progress |

Identities collide across contexts

| Roles between places |
| Caregiver, it’s who I am |
| Students learn the master narrative |

Structure and flexibility enhance capacity

| Uncertainty causes problems |
| Flexibility takes the pressure off |
| Technology offers freedom |
| Caring, learning, and teaching with dignity |

Coping facilitates health and growth

| Coping with trauma |
| Self-care is necessary |
| Boundaries give me control |
| School is an ally |

Learning transforms the journey

| Academic language and content are tools for reflection |
| Education helps everything |
| I have options |

**Essential themes and thematic elements.** Timing played a central role in the student caregiving experience and it affected every aspect in the journey; it is one of five essential themes and the one I address first in this chapter. In this study, timing refers to the specific chronological points at which student and caregiving roles emerged and evolved. The three thematic elements within the essential theme are: (1) academic phase is crucial, (2) life experience helps, and (3) health affects progress. Each element of timing is interconnected and affects not only how the other elements unfold but also how the other essential themes weave together.

**Academic phase is crucial.** Academic phase is crucial to a student caregiver because it sets the stage for the whole journey. Academic phase refers to both the
progress in a degree program and the point in the academic calendar where caregiving tasks are required. The gift of qualitative research is the partnership between the researcher and the participants in the journey of discovery. Natalia’s perspective as a researcher gave me insight into the critical importance of how academic phase impacts a student caregiver’s journey.

_Natalia_
When I was reading your call for participants, I was thinking about the diversity of situations that a call like that is going to invite which is super cool but I think about people who have kids with chronic disabilities and are trying to do a BA. That would be really, really, really hard ...It’s not just an advisor like I have or someone who knows you well and knows your record but you’re just going to have [multiple] professors and for each professor you have to build a relationship and explain what you’re facing...that’s a lot. That’s a full-time job...

Before Natalia said this in her interview (and hers was the sixth interview), I had not truly reflected on how crucial the chance of timing in the degree progress was to academic success and persistence for student caregivers. The point where caregiving began in their academic program affected how students experienced faculty and institutional support. Students who began caregiving early in their academic programs or who entered their programs as caregivers had the challenge of consulting with multiple teaching assistants, instructors, or professors if they needed an accommodation for caregiving, and most did not know how or where to access institutional resources.

Jessica began caring for her mom and sister during her Sophomore year in college. Each family member had severe mental health illnesses which resulted in suicidal attempts, her quote below demonstrates the difficult life and death decisions she was forced to make and how those decisions negatively impacted her grades.
Jessica
...she [mom] had 3 suicide attempts at which point I then had her committed. And did all of those proceedings for her safety... I went from being...in the 3.0 GPA range--and those are my worst grades actually--and when I became a caregiver...I would I would be getting A's and B's on exams I’d be doing so poorly in the course by the end of it because of attendance alone...it was either you're here or you’re not and there weren't accommodations made...I didn't find any professor that was particularly compassionate... I reached out to the student health here to get some counseling myself, to have somebody to talk it through. At the time ... they gave me like two free sessions and then said "best of luck to you"...they didn’t recommend aftercare or ongoing care...I was left to my own devices...

Whereas, students in the dissertation phase of a doctoral degree had the benefit of communicating primarily with their dissertation advisor(s), they also had cultural capital and research skills to find institutional resources as they needed them, and they had flexibility in their schedules.

Natalia
The most important thing is that I had really supportive advisors and to some extent that’s because they trusted me and we had built a good relationship. I have friends whose parents had cancer diagnosis and they did not get as much support with spending time away from the university to care for family. And mine...just said, “Yeah. Go do what you need to do. You’re fine.” I was still able to get my funding. I was on...a training grant and I was supposed to do 12 hours a week of work which...they just let me do that [remotely]...

As I thought about the role chance played in where the student caregiver was in their degree progress, I started to look at where acute caregiving responsibilities fell in the academic calendar. Student caregivers who had the fortune of having acute care occur near a holiday or break were able to fully attend to the care receiver, as Alex demonstrates.

Alex
Her stroke, as awkward as it sounds, happened shortly before Thanksgiving, so there was a Thanksgiving break. I was able to be home...Over the winter holiday...I was home the entire time providing care, doing everything that I needed to do.... All of that was taken care of by the time I went back to school in order to teach
classes. Then I just went home on the weekends in order to make sure that everything was being done that needed to be done.

Student caregivers who had the misfortune of having acute care near deadlines or during exams often lost concentration, struggled to communicate effectively with professors, and had to make ethical decisions about meeting academic goals or choosing to care for a human being.

_Waldo_

I had a statistics course here at the [university] and asked a professor, "Hey, my mother's in the midst of surgery. Can I push this back? I'm stressed out here. It's finals." He told me that the previous semester he had a student who was dealing with breast cancer and going through chemo and she didn't miss a class. He said, "The final's on Friday, you can be there if you want."

The interplay between phase in academic program and academic calendar is highlighted in this quote from Alex who was in the dissertation phase. As we saw above, he noted that it was fortunate that his mom’s stroke happened over Thanksgiving break but the last weeks of the semester after Thanksgiving are intense in terms of teaching. He had already proven himself to his department and had developed relationships with faculty who stepped in to help him.

_Alex_

...[after Thanksgiving break] I went back to school in order to teach basically two classes that I couldn't get someone else to cover, but then...faculty stepped in and taught some classes for me, and then it was finals...

There was one participant who was an outlier. Ed was a biomedical engineering undergraduate student and he claimed his department was accommodating without much effort on his part.
Ed
Thanksgiving to December is when we all have our finals. Thanksgiving, he stopped eating. December 18, he passed away... That screwed up all of the finals so I had to take them after... I took all my finals but one, it was an organic chem final...that wasn’t bad. I loved the class actually. It was one of those ones I felt really good about. I just could not be there. They were very understanding. They never gave me a hard time. In fact, they lowered a lot of barriers to me that would have been a real pain.

Ed’s experience confounded me. My personal bias was that a highly selective and competitive program like biomedical engineering would have been less accommodating than the liberal arts, however, that was not evident for this participant. I reached out to an engineer that graduated from this program to inquire about the culture of the department. She indicated that it is extremely difficult to get in, ie. highly selective, but once you are in they do everything possible to help you succeed. Ed’s experience in terms of timing and flexibility more closely align with the experience of advanced graduate students in this study.

Academic phase is crucial to student caregiver personal development, success, and persistence because the faculty support and institutional resources available to students are different at each stage in the academic program and academic calendar. The data in this study suggests that doctoral students in their dissertation phase had access to the most faculty support, institutional resources, and cultural capital to persist successfully. Many student caregivers who were undergraduates or began their journey as a caregiver, struggled to find the support and resources they needed to negotiate in a system that ignored their non-academic lives. One participant’s experience, in the undergraduate biomedical engineering program, did not align with the majority of participant’s experiences and that will be further discussed in chapter six. Generally,
participants in this study experienced advantages and disadvantages to success based on the chance occurrence of where student caregiving fell in their academic path.

**Life experience helps.** Life experience helps student caregivers negotiate the logistical and emotional components of juggling student and caregiving roles. Participants in this study had significantly different life experiences prior to becoming student caregivers. Life experience that prepared them for juggling multiple tasks, coping with extremely emotional circumstances, and advocating for themselves and the care receiver provided a foundation for success. Student caregivers who did not have life experience that helped them develop the skills they needed to withstand the pressure of both roles struggled and it affected their own health, learning, and persistence.

Young adult student caregivers often did not have previous life experiences that could help them develop healthy coping mechanisms to manage the stress of both roles.  

*Jessica*  
...and being new to adulthood really this is the first tragedy or any sort of difficulty...I wasn't set up to handle it without that experience and knowledge and expertise. There are things I could have done differently but I did not know how to handle it...

Young adult student caregivers sometimes did not have the cultural capital to negotiate for their specific needs. Waldo was a first-generation student and had no college going knowledge. He also bore the burdens of: growing up in poverty, having an abusive father, and providing care for his mom since he was twelve years old. His life experience impacted his ability to assimilate to college culture and expectations which was complicated by his acute awareness that he had a fifty percent chance of inheriting
Huntington’s Disease, his mother’s illness. The impersonal nature of general education classes and lack of “warmth” he received from his professors combined with his personal struggles left him unengaged and wondering why he was even going to college.

Waldo
...I was 18, I was 19, I was 20 years old and my mother was diagnosed at 34.... people define it [Huntington’s Disease] is if you take Parkinson’s, Alzheimer’s, and Multiple Sclerosis and mush them into one...It's pretty nasty...I was really bummed out when I walked into a room with 450 people. I became inattentive ... I felt like a number...I've known about Huntington's disease for almost half my life at that point...I had seen my mother basically disintegrate...am I going to get sick? Why am I going to school?

Older students who had life experience negotiating difficult situations had developed skills and personal resources to manage the tasks at hand, cope, and understand what lies ahead. Alex navigated the trauma of his mom’s stroke using the skills he honed as an event director.

Alex
...part of that is I was an event director for the majority of my adult life, so handling crisis moments, I have that skill set of being able to go, okay, emotively removing those kinds of things in order to do what has to be done.

Jenna summoned life experience and experience she gained from teaching students with disabilities to help her cope with her anxiety and depression while she was a student caregiver.

Jenna
My life experience allowed me to cope in a more positive way than a self-destructive way... just kinda like slapping myself in the head and saying “snap out of it...that’s not right....you shouldn’t be thinking this way”...I don’t know if that’s based on my [own] experience or just teaching students with disabilities and getting them thru those things I had to start doing the same things myself...
Jenna’s experience as a special education teacher also helped her adjust to her husband’s rehabilitation because she was familiar with the equipment.

And plus my background in teaching—I taught severe and profound kids—so wheelchair stuff and handicap equipment...I knew what it all was...When he [husband] got out of the hospital, he was confined to a wheelchair...he had all the handicap accessible tools.

Elizabeth employed knowledge she acquired from her previous career in health care to glean important information that was not readily available to the average patient and family.

Elizabeth
The lung guy had looked in her chest and came to see her after and said, "Look, I couldn't see anything nasty down there." She felt all relieved that there was nothing to worry about. I, however, was less convinced because I could see what had not been said...As somebody who worked in healthcare I could see just how bad things could get.

Life experience helps student caregivers understand how to absorb and organize information needed to attend to multiple responsibilities. Student caregivers who began as young adults lacked the personal experience to navigate the significant logistical and emotional burdens of both roles. Student caregivers who had life experience as professionals, either in leadership positions or as practitioners, were better able to organize and manage the complexities of being a student and a caregiver simultaneously.

Health affects progress. Health affects progress for student caregivers, both the health of the care receiver and their own health in processing the demands of both roles. The health of the person that was cared for impacted the student’s ability to attend classes and attend to assignments. Every participant stated that if there was a
negative change in the care receiver’s health, their ability to concentrate and complete work was impaired. The health of the student caregiver also influenced their ability to participate in class and complete assignments, it had a profound effect on their energy and perspective to perform the work necessary to persist. While the majority of student caregivers experienced anxiety and depression during their journey, many also found resources that helped promoted better health. Thus, in this thematic element, health of the student caregiver can both negatively and positively affect progress. Student caregivers had to balance the health shifts of the person they cared for and the changes in their own health during their student caregiving role. The timing of these health shifts, which were influenced by academic phase and life experience, shaped how student caregivers progressed.

This passage from Jessica highlights how her sister’s acute mental health crisis affected her perceived ability to attend class which negatively affected her grades. She felt it was her obligation to care for her mom and sister—both of whom had suicidal ideations. As was demonstrated in the thematic elements “academic phase is crucial” and “life experience helps”, Jessica had the misfortune of becoming a student caregiver early in her academic path and early in her adult life. By her own admission, she did not have the skills to handle the stress and she did not know how to separate herself from the overwhelming responsibility she felt for their safety. Jessica’s experience emphasizes how the three elements of “timing affects everything” are interconnected, she began her student caregiving journey near the beginning of college as a first-
generation student and she was a young adult without skills to negotiate for her needs at the university. The combination of variables left her unable to persist to graduation.

Jessica

...I was in school full time and had 3 part-time jobs ...I was walking between jobs and walking to class...taking calls and fielding them. My sister was calling from an in-patient center...she's having troubles...and called me 30 times a day...I couldn't go to classes because I couldn't avoid these calls because my sister kept threatening she's going to...slit her wrists...I was 20...It's not that I wasn't participating, I wasn't not doing the work, I just hadn't slept...felt utterly hopeless just needed some accommodation...some compassion...and there wasn't any...so I actually left college at that time to come back and take care of them.

Pooja enjoyed consistently getting A’s for the first time in her academic life, it helped her gain confidence. It was disappointing for her to fail a final and receive her only B because she missed class time at the end of a semester due to one of her husband’s hospitalizations.

Pooja

Once it [interfered with school] because he was brought down here [to the hospital]. It was the end of the semester, it was my hardest class and I spent a week down here [at the hospital]...the stress of going through everything...I missed so much [at] the end of the class...I failed my final...That was the class I got a B in...I survived.

Alex understood that the trauma he experienced as a result of his mom’s stroke and permanent disability affected his perspective. As a researcher, he realized it could have had an impact on his data analysis because one aspect of his dissertation included how relationships function with people who have a disability. Even though he was on track to graduate in four years, he chose to slow down to care for his mom, give himself time to adjust to her disability, and bracket his personal experience so he could look at his data objectively.
Alex
They [dissertation committee] were extremely understanding, because originally I had been on time to graduate in four years. I explained to my lead professor, my chair, man there's no way. I'm sure there are people...that they could have analyzed data during this time, but I couldn't. Especially because my dissertation looked at friendships and the ways that relationships work between a whole gamut of people, but included in my studies were individuals with disabilities. Reading their stories and thinking through their stories at the same time that I was dealing with the fact that now my parent was going to be permanently disabled was just too much for me...I couldn't go there. There was no point in me analyzing data at that point, because I would have gotten it wrong...I was so skewed at that point, that I wouldn't be able to do it. I said I'm just going to put this on hold until I'm in a better mental space.

The stress of student caregiving can induce anxiety and depression because they are considered stress-related illnesses. Participants who had a history of anxiety and/or depression prior to student caregiver, did not have consistent reactions to the pressure of their dual roles.

Natalia’s experience with anxiety and depression prior to her student caregiving journey reemerged under the stress of the dual roles. She not only battled the roller coaster of her mom’s health but also the shifts in her own health that affected her academic progress.

Natalia
If you mapped out my progress it would pretty match perfectly with how she was doing...that’s why I finished my proposal, she was doing well...It was like the end of the 1st round of chemo so she was in better shape... I have been very good at speeding my work up when she’s doing well...I remember last fall we knew it had recurred but the symptoms weren’t back yet...I was...trying to make progress...but I also was a mess. I just watched a lot of television and I slept a lot and I would try to do work but didn’t get a lot done...I have a history of anxiety and depression and it felt like that but at a time when it was like the worst possible time for those things to be recurring because I had a lot of things that I was supposed to be getting done. I remember mostly just being really tired.
Cassandra has struggled with depression throughout her life and she recently was
diagnosed with Attention Deficit and Hyperactivity Disorder as well. The combination of
her illnesses and her son’s illnesses significantly affected her progress, in terms of
academic success and persistence. She has been eligible to take her comprehensive
exams more than a year ago and she has not done it. She enrolled with Disability
Services to get accommodations, but that has not yet helped her to complete them.

Cassandra
My person is my 12 year old son…I've thrown plenty of grades under the bus for
my kid. I've not handed in final papers...I just got diagnosed [with ADHD] late in
life...I just barely got myself registered [at Disability Services]...I got enrolled
hoping that I might be able to use something for comps, like extended time,
maybe a couple extra days, but we'll see. Not yet... I'm in stalled mode. I could've
comped a year ago and should have this fall and now it's January...

Anne and Pooja experienced improved health when they embarked on their student
caregiver journey. Both had been caregivers for a long time before they started school.
Each stated that school offered a much needed break from caregiving. Anne claims her
interest in what she was learning at school helped decrease her anxiety. But given her
own multiple disabilities, she needed to be sure to find balance.

Anne
Whereas before I was a student...I had a lot more anxiety...I was very
insular...Didn't get out and meet people and do much. I think I was getting
borderline agoraphobic. I didn't want to be away from home too long and now I
have to be. But I am so interested that it doesn't bother me as much now that I
have something to think about... But I do find that I need to check to make sure
I'm not hyper-focusing on schoolwork, and ignoring the needs of my family. When
I was working on my MA Seminar research, I think my family forgot who I was. I
needed to step back and readjust my priorities a little. With having ADHD myself,
it’s hard sometimes.
Pooja has diabetes and depression and found that having a routine and being successful at school helped her manage both illnesses.

*Pooja*
My diabetes did pretty well... I would try to... eat the hundred calorie snacks or something like that... I felt like it was easier because I knew I was just going to take these and that’s all I was going to eat even if I ate two packages, it’s still way less than a bag of chips or something else... Then with my own depression... I was doing the best that I could... Sometimes I was okay, sometimes everything would get me down, but it wasn’t holding on as tight as some other times... It just makes me feel better... because I’ve been through that and survived getting through school. To me, that feels like a super huge accomplishment.

Health affects progress for student caregivers as they weathered the shifts in the care receiver’s health and their own health changes as a result of caregiving. Health and progress were entwined with academic phase and life experience. Generally, students who were in advanced graduate work and who had life experience that prepared them for coordinating competing pressures were able to progress, even if it was slower than anticipated, despite health fluctuations. However, two participants who entered school as a caregiver, did note that their own health improved once they became students. They appreciated the break from caregiving, they both said that school opened their world. Health affected progress for students in various ways.

**Summary**
Timing affects everything in the course of a student caregiver’s journey. While all participants chose to provide care, none of them chose when the caregiving started, the need arose and they answered “the call of duty”. A significant portion of timing effects were beyond a student’s control, even if the student entered college as a caregiver. Academic phase, life experience, and health created benefits and obstacles depending on where they occurred in a student caregiver’s experience. Timing also
affects how every subsequent theme unfolds; it is an undercurrent for how identity evolves, flexibility enhances capacity, coping empowers, and learning transforms.

**Identities Collide Across Contexts**

Student caregivers’ identities—i.e., their internal and external perceptions of who they are as people—evolved in myriad and complex ways throughout the course of their individual journeys, a process that was influenced by when their dual roles emerged and their own changing self-conceptions: *Identities collide across contexts* is an essential theme. Students who entered school as caregivers, and those who established independent identities as students before becoming caregivers, expressed that their roles as caregivers informed internal and external perceptions of their identity. The three thematic elements within the essential theme are: (1) Roles between places, (2) Caregiver, it’s who I am (3) Students learn the master narrative. The elements of *Identities collide across contexts* are fluid, and are not only shaped by the theme *Timing affects everything* but also provide a framework for subsequent themes to compose a narrative that describes the lived experience of student caregivers.

**Roles between places.** Roles between places emphasizes how student caregivers balance role strain. The constant need to adjust to different people, environments, and expectations was draining. Participants spoke in various ways about how managing thoughts, feelings, and actions to adapt to the identity in the moment contributed to role strain.

This thematic element evolved from Natalia’s comment that her dog provided comfort for her because he gave her “continuity between places”. She was constantly traveling back and forth from home to school, it was lonely and exhausting to keep
switching roles, and the dog gave her consistency. Natalia was the only participant who gave a tangible example of something that helped connect her identities.

During the focus group Cassandra, Anne, and Natalia discussed that they essentially let go of the social support network they had before becoming a student caregiver. Straddling two roles was tiring enough, they simply did not have the energy to “police the identity” they were presenting to anyone else.

*Cassandra*
I think I would feel isolated anyway, but I self-isolate because it's hard to find someone I can interact with where I'm going to feel comfortable in both of those roles...makes me more tense because I'm having to police the identity that I'm presenting, so self-isolating is easier. I can be comfortable by myself.

*Anne*
I'm not comfortable in the group of friends I had before I came to school. The things they talk about are boring now and petty, but I can't fully commit myself to the world of education, either, because I have that strong pull from home and from my family that I need to stay with.

*Natalia*
That's interesting. I had a different experience where I was living normal student, youngish grad student life and then I left and I remember when I came back, I didn't want to go into my lab and I didn't want to see people and I didn't want them to ask me how things were going. I didn't want any of that and I also avoided my old friends when I came back. I was coming back for two weeks and then I was going to go back again to do more caregiving. I just figured I was tired, but what you are saying, maybe that was part of it, too. I just didn't want to have to shift gears again.

Cassandra, Anne, and Natalia were active caregivers during the focus group. Their conversation took place in the midst of juggling student and caregiver tasks, their fatigue was palpable.
Ed was not an active caregiver at the time of his interview, his dad had passed away six years earlier. Ed reflected on his journey of self-isolation at school while he was a student caregiver.

*Ed*

The thing I liked about the university was how impersonal it was. It let me hide...I could escape. This was my solace...Then when I lost my role as a caregiver I couldn't escape it...It was like, "Oh God, now I have to feel all the stuff I hadn't been feeling." It was hard. I really wish I had known at the time that I should have been dealing with all this stuff as I was going through it. I think it would have really changed the quality of care that he had and the quality of time that I spent with my father. When you have that social support where you have people around you. They give you perspective. They help you realize maybe your thoughts aren't the most accurate description. They give you these other voices that you trust that you can bounce your thoughts off of. There were times I would be really frustrated with my dad. Once I was able to open up to people and say how I was feeling about stuff. I'd look back on that and say, "Wow I was a lot harsher than I wanted to be." Why did I put peanut butter on top of the shelf. Why did I get mad at him for just asking me how my day was? He would ask me what was for dinner 20 times a day, which was frustrating. I think that was something he really looked forward to because we would all sit down and eat with him...I think if you deal with those emotions at the time, they don't seep out in other ways.

He learned that the social support he chose to forgo would have helped him while he was a caregiver and during his despair when he lost his caregiver identity.

Cassandra, Anne, Natalia, and Ed were all continuing generation students, which means they were not the first person in their family of origin to attend college. Thus, they had college going knowledge and an understanding of the long-term benefits college offered. Even though they struggled balancing their student and caregiver identities, they knew the master narrative—language, behavior, and culture—of a student identity. Waldo was a first-generation student who grew up in poverty in a rural community. He came to college “to make a better life” for himself but he had never seen what life looked like on the other side of college and he did not know what
to expect along the way. He described how he felt caring for his mom, navigating college, and watching his student debt rise on the backdrop of his family's poverty.

_Waldo_

I felt guilty. I don't know, it was kind of a weird thing. I knew my mom and dad basically didn't have any money. My dad would try to go work and my mom would be at home and I'd find out that mom fell at home and was all bruised up or split her head open and needed to go get stitches. If I was away for an extended period of time, I would feel guilty... I think with my undergrad, I didn't see any light at the end of the tunnel. I didn't feel like I was doing anything. When you first start school, I feel like it's such a steep mountain that you're like, "This is going to take forever." You're still a kid basically. They're like, "Oh, yeah. Now you need to go to school for four years and be a grown up." It's like, "Uh." I wasn't seeing any progress... You're an 18 year old kid, you're scared to death because here's this PhD professor...up there talking about things that you've never heard about...The fact that my family had no money and the fact that my student debt was going up, it made me feel even more guilty.

The stress of living in poverty combined with the stress of caregiving created significant role strain, which had an impact on Waldo’s ability to identify as a competent student when he arrived at college.

Throughout this thematic element, I have discussed how student and caregiver identities intersect to intensify role strain. Elizabeth and Pooja also experienced role strain, but they provide examples of how other people’s positive perceptions of their identity helped them. Elizabeth relied on her identity of competence during her time as a student caregiver.

_Elizabeth_

In terms of how was I managing, we all have our persona and how we're perceived by other people. I'm perceived as quite competent, which comes in handy in emergency situations because that is the persona that takes over—competence. What are the steps I need to take? I will take them.
Pooja spoke many times about how the encouragement and praise she received from her supervisor made her physically and emotionally healthier. This passage provides a wonderful image of that process.

*Pooja*

I mean like when she [work study supervisor] said I was better than the ones who are in the secretarial program, I was like really? I’d feel like I was getting taller...Because I could stand up better...Well I hunched some and sometimes I’d just feel...uncomfortable being around other people but when I felt good, it was like I actually could stand up taller and feel better about myself.

I actually witnessed Pooja’s presence shift in a positive way as she spoke about this memory. She sat taller and straighter, she smiled, and her tone became lighter. It is incredibly important for faculty and student affairs professionals to remember that we are mirrors that reflect a student’s identity back to them.

Roles between places illustrates how student and caregiving identities converge to create role strain. Most participants experienced fatigue when switching from caregiver to student roles. Each identity carried different physical and emotional expectations and generally participants attempted to compartmentalize them.

Caregiver, it’s who I am. “Caregiver, it’s who I am” was articulated by each participant in some way during their interview. Many participants identified as a caregiver before becoming a student caregiver and indicated that taking care of people was the role they served in their family. Alex called himself the family’s “emotional manager” and “peacekeeper”. Waldo claimed that he was “the glue that held the family together”. Ed took pride in the fact that no one in his family had to ask him to move home from college to care for his dad, “That meant a lot to me too. Being the child that was expected to come home. I was always the one who was taking care of people before
that”. Both Amy and Orla shared that they had been taking care of people in their families since they were children. Jenna’s comment was the inspiration for the name of this thematic element, “...it just comes naturally to me to be a caretaker...I took care of my grandparents when I was a teenager...it’s just who I am”.

Caregiving took precedence over school for every student at some point in their journey. Alex and Elizabeth, who were in the dissertation phase of their programs when their mothers needed critical care, let go of their own projects to provide care. Alex explained, “During this time [when mom was in the hospital]...school was nothing to me...” Elizabeth reflected, “Whatever I was doing in terms of my own stuff was just immediately abandoned”. They both were at a place in their degree that they had the flexibility in their schedules and the support of faculty that could devote all of their time and energy to the person they cared for. Progress in their degree slowed but it was not derailed. I chose the quotes below to highlight how other areas of their lives outside of school were affected more acutely than school because they had flexibility and support at school. However, as I was writing, I realized that the parts of their lives that they described as being affected by caregiving reflected their topics of study.

Alex earned his PhD in Recreation, Sport and Tourism and he described how aspects of his life related to leisure changed through the lens of caregiving.

_Alex_

...I think through this I lost some of my sense of humor...I laugh a lot less and...being able to willy nilly do things, I don't do anymore. Things that I just would have done...I would never try a weird drug now. Not to say that I did a lot of drugs when I was younger, but I would have tried, or you know like skydiving. Which I used to, not a lot, but I've not gone skydiving or do dangerous activities, now I have to think about it. Because... now I think, "Okay, but if I die, who's going to take care of my parents?"
Elizabeth earned a PhD in the Department of Gender, Women, and Sexuality Studies and she described what she forfeited as a result of caregiving from the lens of gender.

*Elizabeth*
There was no doubt in anybody's mind, including my own, that I would be the one to do it [caregive]...I was fully aware that this was a gendered presumption on everybody's part. I was fully aware that my career and my finances were being affected in a way that my brothers' weren't. My brothers, they had all the same worry and all of the same stress as I did, and we became very, very close over that period of time and we get on great. They didn't lose much income whereas I gave up a job for the semester. My semester job was gone. I had no way of earning any income over the summer. Totally gendered.

The influence of disciplines will be discussed more fully in *Tools of the trade*, a thematic element within the theme *Learning transforms the journey*. However, the way Alex and Elizabeth describe the lived experience of student caregiving in ways that relate to their discipline magnifies how the discipline a student studied affect their world view. It is important to remember that while themes are presented in a particular order, they are fluid and overlap with each other.

The caregiver identity sometimes overshadowed a participant’s life and exacerbated anxiety and/or depression. Orla asserted, “...me as a person doesn't really exist. It's me as a caregiver mother and a caregiver daughter... I've been in therapy and on antidepressants myself. It just got to be too much.” Jessica professed, “...I wasn't existing as myself I was existing to serve a purpose...I didn't exist as an individual because I was just there for everybody else...that was the priority at the time” and she noticed that symptoms of anxiety and depression would surface when she did not take time for herself. While Ed explained how caring for his dad gave him structure and
purpose but when his dad passed away is when the symptoms of his depression became unmanageable for him to deal with on his own.

*Ed*

I defined myself by caring for my father. That was my role. I had a mission. I had a clear objective. I knew what I was doing. I could pretty much do anything as long as knew that I was caring for my father this was what I was supposed to be doing...It's the weirdest experience I've ever had. You would think that your mind wouldn’t work well when you're under so much outside pressure...Then when you lose the structure of having identity as a caregiver a lot of stuff evaporates, a lot of the courage a lot of the spine that was holding [me] together. In a way you lose your purpose... I would say after my dad passed away I crashed. I got back in spring and I kept on going down, and down, and down this rabbit hole. I think one day toward the end of the term I just decided I was going to walk over to student health and ask them for help because I was not feeling anything. I did not want to continue.

Orla accepted medication as a way to cope with how her caregiver identity impacted her life; Jessica practiced self-awareness to learn how her caregiver identity pre-empted self-care. Ed sought out institutional resources to help him cope with his depression and deep grief. The way trauma affects a person's identity and ability to cope will be discussed further in the thematic element *Coping with trauma* within the theme *Coping facilitates health and growth*.

Every single student caregiver prioritized their caregiver identity over their student identity at least once during their student caregiver journey, the consequences of that choice were influenced by the point in their academic phase, the type of faculty support they received, and how they chose to cope. Since the participants articulated that their caregiver identity generally trumped their student identity, it sets the stage for examining how other identities, such as socioeconomic status, gender, age, and disability impacted how they interpreted the master narrative within the academy.
Students learn the master narrative. When students learn the master narrative—i.e. the language, behavior, and culture—of the academy they take notice of how their intersecting identities shape their experience as a student caregiver. This thematic element grew from Cassandra’s discussion about how the “master narrative” in academia impacted her perceived identity as a competent student when she returned to college as a student with multiple disabilities and as a caregiver for a person with a disability.

Cassandra
I underestimated how hard it was going to be to come back as a single parent and then have a kid with all kinds of issues...I spent a lot of time attributing my struggles to... my own shortcomings [depression and ADHD], which was really frustrating because, before I came back, school was the thing that I did with one hand behind my back and that was my identity... I can knock this out and then suddenly I can't knock anything out...Huge identity crisis that I'm still not over. There is a master narrative for how you do grad school, right? I believe that a lot of us don't understand that that can be ever questioned. We try to fit ourselves and our lives into that master narrative. We try to mold ourselves and bend ourselves, and shape ourselves into that narrative because we think that's the only way to be successful and make it through grad school...I'm sure that a lot of people don't make it in part because they can't figure out how to play by whatever they think the rules of the system are, and meet their...responsibilities or personal needs...

Waldo and Orla articulated that the overall feeling they received from the institution was that it did not care about their personal circumstances. Waldo even compared the university to a “machine”.

Waldo
I went in to speak to her [academic advisor] a couple of times and basically she was like, "Well, here's your next set of classes." It was never warm to like, "How are things? How are you doing?" I explained to her my family situation...I felt like it was always so cold. Anybody that I would talk to, it was like this place is a machine.
Orla highlighted that every degree operates with the expectation that there is a prescribed path and serious students know not to stray from that path. Serious students also know that there is a quid pro quo with the institution, they will use the skills they developed as a marketing tool for the college. Orla chose to come back to school in her mid-fifties for personal fulfillment. Because her goals did not align with the university’s, she perceived that she was not identified as a serious student.

**Orla**

...it is tied to is this notion of everybody, no matter what program you are in -- whether it’s a BA an MA or a PhD you’re following this trajectory that everybody else is following and you’re not supposed to...stray from the path... I'm at the age where there isn't a career in this for me. There comes a point...if I'm doing this, it has to be for me...but the expectation from the university is you're going to do something with this so that we can be proud of you and that we can put you into our advertising ...If you're young enough, it's okay, but if...you’re an older student...you have all these other things going on in your life. You're to some degree not worth us investing too much into you...I think people think I'm smart...but it's not enough to get me taken seriously.

Serious students have access to resources and opportunities that students who are perceived as non-serious do not. Orla has not been invited to participate in research, while the students in her department who are identified as serious are engaging in research with faculty.

**Jenna and Amy** explained how their experiences with individuals in their departments reinforced the institutional master narrative at the discipline level. Jenna expressed that the constant message she received from her advisor was that the only identity that mattered to professors in her department was her student identity. Her physical and emotional illnesses and the disabilities of the people she was caring for should remain private.
Jenna
When he was discharged and [I was dealing with] my health [issues]….She [advisor] said, “well don’t even tell that professor because that professor doesn’t care about your personal life and it won’t matter so don’t even share anything personal”…there is NO support system here for anything that is life related. You are a student, you are a student first… you will read, you will breathe, and you will live for the [institution] we don’t care about your life.

Jenna suspected that her personal struggles affected the support her advisor was willing to give her.

Jenna
It was clear from the start that I was not one of the “favorites” and my contact and support was minimal. I always felt like I had to find things out on my own and I would see the others in my program getting full support. Things like registration help, help with editing papers, help finding TA jobs. The favorites were invited to group studies, group lunches, writing workshops, etc. I was NEVER included in those. I went one full year in the program before I was even added to the mass emails for [the department]. I had to ask the secretary for that. I always had the feeling that my advisor wanted me to fail and was just waiting for that to happen.

Amy returned to school to help her re-enter the workforce after being a stay-at-home mom for eleven years. She assumed that she would not be taken seriously because she was a stay-at-home mom for so long which had a negative impact on her self-identity and self-worth. She was excited to return to her student identity, which in the past had been a positive experience. But she was challenged with discovering her youngest son had a disability as a result of what she was learning in school, she was navigating her own depression, and she was negotiating with an advisor that identified her as a non-serious student.

Amy
I decided to go back to school…I thought, okay, my kids are all in school, now there’s a time in my life for me to go explore what I want to do. Suddenly this [Zach’s diagnosis] meant meetings with therapists, meetings with counselors. It complicated life. I needed to juggle not only being a parent and being a student…[and] a caregiver…while I was in school…School had always been easy for
me. I've been a well-liked student by my teachers...it was flat out confusing to suddenly be perceived as a difficult student...so I was also having to wrestle with some issues in the program of...self-esteem, self-identity. Who do I think I am if...I think I'm called or interested in being... a rehabilitation counselor but my advisor is challenging me on that...I thought she was trying to evaluate my committedness or my interest or whatever...

Amy connected how her experience at the institution where she was a student caregiver differed greatly from the university where she did her undergraduate degree. The master narrative espoused at the large institution is not what she wants for her children. This is important for administrators to understand, the way the master narrative is experienced by student caregivers may have an impact on legacy students.

Amy

Maybe it was the difference of going to a small college like where I went for undergraduate...they got to know us as people...we called each other by first name so all of a sudden switching to Dr. ____ was weird...I experienced the [institution] as much less personal. If anything, that experience has solidified in my mind that the experience I want for my kids...is a small private college experience where...they will learn to know their professors as people and they will...The professors will learn to know them as people.

Sometimes a student caregiver’s family of origin intersects with the master narrative in the academy. Anne, had multiple emotional and learning disabilities, struggled with poverty, and re-entered school at forty years old as a caregiver, she was raised to work hard and not ask for help, so at school she works hard and does not ask for help.

Anne

...I was raised you just did what needed to be done. You weren't lazy you just worked really hard. That's how you were a person of worth. You just worked hard and you dealt with what you were given. I feel like if I whined about "It's so hard" that's whining, that's not what I do. So I don't really ask for help I feel like this is what I had to deal with. That mindset works pretty well most of the time, but sometimes I just get exhausted or depressed...I don't see my nonverbal learning
disability causing a problem for me in school. But with my ADHD, I do have to be very careful blurting out answers in class. I’ve been gently reprimanded a few times for it. I do try to tell my teachers in private that I know that’s a weakness of mine and that I’m working on it. I find that if I knit or color in class, I can stay more appropriately quiet...I do feel better about myself now that I’m a student and I’m not just a drain on society...Maybe not drain a society but drain on the family maybe...

The irony is that she makes sure each of her children has a diagnosis so they get the services they need to be successful in school, which will be discussed more in the

*Flexibility and structure enhance capacity theme*. The master narrative in academia can also interact with the master narrative with which they were raised to further complicate intersecting identities.

Elizabeth reflected on how her privileged identities—eg. being white, middle class, having advanced degrees, as explained below—gave her an advantage in her department. She compared her experience with other students who did not share one of her privileged identities and she noted that they did not benefit from the same type of support she had. I connect that with Orla’s perspective that if she was a younger nontraditional student she might have been taken more seriously, you can be nontraditional as long as it is within the margin of acceptability in the academic master narrative.

*Elizabeth*

My general impression of the department is that they’re pretty supportive of graduate students...Having said that, I’m a pretty traditional student in the sense that I am white and I am middle class and I speak their language and except for the fact that I was older and had children, I’m not particularly non-traditional. Our department...also attracts students who are transgender or transsexual or in other ways non-traditional and experimenting with various ways of living. That hasn't, to my surprise, always gone over quite as easily...
Alex’s identity as a competent student was his most salient identity which made the institution a place where he felt more confident in his caregiver identity. He had enormous support from his advisor and his dissertation committee, which will be highlighted in the next theme about flexibility.

Alex
Even though by the time I left I knew my way around the hospital very well, I was not part of it. Whereas, at the university, especially as a PhD student, I knew my way around. I felt very competent at school in a way that I did not at the hospital. In that way, there was a piece of my being at the university that wasn’t institution - the institution wasn’t actively doing anything in order to assist me in regard to caregiving or anything, but my own feelings of efficacy were much higher being at the university, so I felt more able to handle things...there wasn’t as much of an emotive drain when I was at the university dealing with things than there had been while I was at home.

Most participants had at least one of protected identity in addition to student and caregiver that affected how they internalized the master narrative from the institution. Disability, low socioeconomic status, age, and gender were the predominant protected identities that intersected for participants in this study. The majority of participants had anxiety and/or depression, mental illness comes with a significant stigma. Three participants experienced poverty during their student caregiver journey, and low socioeconomic status also carries a stigma. Stigmatized identities have a profound affect on the way people are treated and the resources available to them. Age and gender also influenced how student caregivers experienced the master narrative in multiple ways.

Summary
Identity collides across contexts show how role strain has an impact on identity development. Caregiver and student identities intersected in ways that affected how
participants saw themselves and how they were perceived by others. The identities they carried beyond student and caregiver also had an impact on their journey. Active student caregivers often did not have the perspective to see beyond their own fatigue and their role strain. Participants who were no longer student caregivers reflected on how their own perception of their identities helped or hindered them along the way.

**Structure and Flexibility Enhance Capacity**

Structure and flexibility are critical components that enhance capacity for student caregivers: *Structure and flexibility enhance capacity* is an essential theme. When institutional structures allowed for flexibility to buffer the uncertainties of caregiving, it created an environment that nurtured students, which made it more likely that they could succeed within the system. Flexibility was influenced by the timing of when caregiving emerged in their student experience. Advanced graduate students had the benefit of more flexibility than graduate students in earlier stages of their programs and undergraduate students. Doctoral students in the dissertation phase of their programs shared that the following factors created an atmosphere that allowed them to adjust their work to meet their specific needs: established cultural capital; knowledge of their disciplines’ languages; and well-developed relationships with their advisors (the primary people with whom they communicated). On the other hand, graduate students in the early stages of their programs and undergraduate students focused their frustration on the rigidity of the system; they had not yet fully established cultural capital, were learning the languages of their disciplines, and had multiple professors with whom they had to communicate, which required more energy than they had. Thus, students who were privileged with flexibility were able to adapt to the
unpredictable demands of caregiving. The type of illness or disability that care receivers had influenced the potential for chaos in the lives of student caregivers. Students who cared for people who had disabilities that were erratic in nature, or illnesses that had unforeseen acute episodes, often lacked the structure they needed to organize their time to complete academic tasks. Hence, flexibility in institutional structure was essential for student success. Identity also played a role in access to flexibility; caregivers who were perceived as competent, and felt competent, in their student identities were able to use their academic and cultural capital to further enhance their capacity. The four thematic elements within the essential theme are: (1) Uncertainty causes problems, (2) Flexibility takes the pressure off, (3) Technology offers freedom, (4) Caring, learning, and teaching with dignity. The elements in *Structure and flexibility enhance capacity* build on the previous themes and create a tapestry of how coping empowers and learning transforms their experience.

Every participant addressed the need for flexibility as a student caregiver, but Alex made me think about how important structure was as well. Alex reiterated, many times and in various ways in his interview, “…you can’t separate education from anything” and the quote below demonstrated how he used the critical awareness he gained from balancing both student and caregiving responsibilities. He learned the rules of navigating within a bureaucracy, learned how to recognize the limitations of the structure, and learned to be flexible with how he approached policies that did not make sense.
Alex
In order to get a PhD, you learn how to jump through hoops. In order to navigate a hospital, you learn how to jump through hoops. You learn, "Nope, this policy does not make sense," but spending hours railing against the policy accomplishes nothing. Instead, what you do is, you figure out what is the best way to work within the structure that you have...

The previous quote made me look at the data in terms of how structure and flexibility interact. I started looking at what types of structure were in place in student caregivers’ lives that supported or hindered flexibility.

**Uncertainty causes problems.** Uncertainty causes problems for student caregivers because it does not provide the structure and flexibility necessary to organize and adapt to competing demands. The dichotomy of unpredictability of caregiving and rigid requirements at school create a perfect storm for caregivers to experience role strain. Uncertainty takes many forms. The type of illness or disability the care receiver has can exacerbate uncertainty. Participants who cared for someone with a mental illness expressed how difficult it was to deal with the erratic nature of mental illness because they never knew what or when chaos would ensue. Students who cared for a person with a terminal illness also had to negotiate the uncertainty of when and how the disease would progress. And students who had to navigate their own illness or disability in addition to juggling caregiving often had to choose whose health needs would take priority. While they were balancing health concerns, they also had to bow to the requirements of school. Where they were in their degree program and faculty willingness to be flexible with accommodations with nonacademic conflicts made a difference in a student caregivers ability to be successful.
Orla clearly articulated what every participant expressed in some variation: the student caregiver is “at the mercy” of the care receiver—you cannot plan when they will need you. You cannot organize your time to accommodate a crisis. You cannot brace yourself for the emotional toll it may take. And sometimes the emotional toll renders the student caregiver incapable of completing their academic tasks once the crisis has passed.

*Orla*

...when you're a caregiver you are at the mercy of the [care receiver] in this case my father...when he decides to intrude on my life with something...it's not something I can organize for. He can call at 10:00 AM or midnight...telling me the same thing or asking me the same thing. So I guess my coping mechanism is whatever time I have I will use knowing full well that I may have to drop everything...deal with that issue. There are times when the issue I have to deal with has an emotional toll on me. And then I can't do any work after.

Jenna had to cope with uncertainty related to the health and well-being of the people she cared for. Her husband’s illness began when they first started dating and she had not yet met his family. She was not allowed to get access to his health status. She did not even know if he was alive, which made concentrating on school difficult.

*Jenna*

...the man I was dating has Guillain–Barré syndrome...he went into respiratory failure and had to be intubated. They crash carted him—the whole 9 yards. He was in a coma for two weeks...and woke up quadriplegic... Because his family didn’t know me and they put a block—nobody from the outside could get information—they didn’t know he was dating me...I went 5 weeks without knowing whether he was alive or dead. I was still a student...And so that 5 weeks was very very hard to even to focus on school...That first semester it was it was really hard. And once I knew that he was ok and alive it got easier.

Jenna also cared for her son, who has Asperger’s, while she was a student. Routine and consistency is essential for people with Asperger’s. While Jenna was caring for her boyfriend, she had to explain to her son that he was in a wheelchair and was recovering
after a serious illness. Jenna was juggling the uncertainty of her boyfriend’s recovery on top of trying to explain this uncertainty to a kid who needs certainty. It did not go well.

Jenna
...my son has a disability and part of Aspergers is they don’t deal well with change...when he [boyfriend] came out of the hospital my son had known him before as a healthy human. And to see him in a wheelchair and to see that he almost died and all that. My son really really took it hard. And I slowly introduced him...he’s gonna be in a wheelchair, you’re gonna see this, your gonna see that. With my son’s disability it all builds up and then it explodes in a physically aggressive meltdown...that happened about mid-march and we were in my apartment and he was making reference to him being a stupid cripple and we can’t do anything because he’s a cripple....and da da da. And it was all coming out. And he was crying and he says that he was gonna go down there and hurt him so he took off and walked towards his apartment. I was concerned because he [boyfriend] couldn’t stand by himself at the time...and it was warm enough outside and I knew he sat with the door open. And I got in my car and drove down there to warn him that my son—big kid—was on his way to come to hurt him...my son attacked him and physically assaulted me...The cops were involved and my son was admitted to the hospital, he spent a week in the adolescent unit...that was a huge reason why I got that D+ that semester.

Cassandra’s battle with uncertainty stems from her own disability. She has ADHD and struggles with time management skills. This creates problems for her son who needs consistency to cope with his disability and it diminishes her success in graduate school.

Cassandra
Unpredictability has really just governed my life on every level, and his [son] life as well. That’s been huge, especially if you think about what it would be like to be a mother with ADHD who is almost unable to maintain any routine or create consistency, and my child is a kid who needs routine and consistency far more than the average bear. It’s a real challenge. I almost can’t give him something he really needs.... I have no time management skills. I have zero executive functioning skills....Once you get to the graduate level, if you aren’t able to manage your time and prioritize and figure out how to multitask, good luck.
Waldo had a layer of uncertainty that no other participant in this study had to endure. He did not know if he carried the gene for Huntington’s Disease, because his mom had the illness he had a fifty percent chance of carrying it.

_Waldo_

I kind of lived this reckless lifestyle where it was like if I died tomorrow, I’m living for right now and I’m going to have as much fun as I want…I wasn’t planning anything...To compound that...My dad was very fragile...bipolar who’s had many of hospitalizations and things like that...so I was the guardian that was behind him to make sure he would stay on the straight path...

The stress of that uncertainty affected his motivation and success in college because he wondered what was the purpose of going to school if he would get this devastating disease in the prime of his life like his mom did. The fear that came with this type of uncertainty combined with the unpredictability of his dad’s bipolar made it unbearable when he was not given any flexibility at school.

Jessica described the difference of caring for a parent who has a mental illness and a parent who has a physical disability. Her mom’s mental illness flair ups often coincided with her own stressful times in school and Jessica could not predict when they would happen or how serious they might be: “…my mom is being really dramatic and she keeps saying that she is going to kill herself, she probably won’t tonight but I don’t really know…” On the other hand, even though her dad’s motorcycle accident that left him in a coma for nine months until he passed away was traumatic, caring for him was predictable and structured so she could organize her time and find ways to cope.

_Jessica_

…my mom with her invisible illness…the maze that is mental illness…which is erratic and very unpredictable…was having most of her episodes at moments that were most crucial for me…I can’t choose what my mom will do, "Hey, you know what, actually I don't have an exam for the next two weeks so it would be really
convenient if you get all of your craziness out in these two weeks”. It doesn’t happen.

I don’t think I ever needed any flexibility with him [dad] because it [coma] was pretty predictable…that was actually one of my best semesters I had [when dad was in hospital]...things jumped dramatically for me just because things are more structured so it’s interesting,... even though this is by far the worst thing I’ve ever been experiencing it was still very structured so I was able to appear extremely successful [at school].

Ed used the certainty of his engineering homework, which came with an answer set, to balance the uncertainty of constantly worrying about his dad.

Ed

...I would spend a lot of time doing work. I got most of my degree down to muscle memory...Engineering is not that bad. We play it up to make everyone else feel bad. The first few classes, those are hard. What you realize later is that everyone's getting an answer key to all of the problem sets. I just did every problem I could. That was really cathartic, because then I was focused on engineering I wasn't worried about my dad...I would go to a different room of the house, and I'd hear him in another room. I'd have kind of like a third ear always listening for something going on. Then, I'd work away on problems, and if I heard anything, I'd go get up and check him...His care always trumped everything else...Otherwise, I'd just be working away.

Pooja described how her presence provided certainty and a sense of comfort for her husband, who has anxiety and multiple other disabilities. But sometimes his comfort and security came at the price of her work.

Pooja

Our desk was in the corner of the dining room. It was a very, very small house. It was less than 1000 ft.². We had a desk in the dining room which had an open area to go into the living room, and I was there. He could be watching TV or doing whatever needed to be done but I was there and if he needed me, he knew where I was, he just liked to have me around. I mean sometimes it was for no reason, he didn’t need anything and sometimes he did. As long as he knew I was there, he was okay...It was difficult sometimes I would have to remind him if I was doing an online quiz test or anything because a couple of my classes were online, I’d have to tell him okay I have to take this test. It’s timed... sometimes it was just like I
either had to tell him you have to wait until I get this part done to where I can stop or I would just have to stop and take care of whatever needed taking care of.

Anne experienced financial strain as an additional stressor while student caregiving, which created more uncertainty. Every single person in her family has at least one disability. They need health insurance. They are using Medicaid, which is complicated and full of glitches since it is transitioning to private companies. Anne is juggling her own disabilities, parenting four children with disabilities, while working on a Master’s degree—she does not have time to constantly attend to the mistakes Medicaid makes which affect her family’s medication, but she must. And she states that she is grateful that she has the technology, language, and tenacity to do it.

Anne
And he's [husband] very concerned about being able to provide for the family financially because of his disability he can't finish college he can't read and write on a level well enough to complete college. So he's at cap as far as what he can earn and that's a major concern of his...He actually recently lost his job, and had to take one that pays even less. So we have more money worries than before! Getting medical care for the kids has been frustrating, to say the least. We used to be on Hawk-i, but now with the lowered income, we are all on Medicaid. Medicaid recently transitioned to using private companies to administer their programs, and for a long time I had to make numerous phone calls to even get basic things, like prescription refills. For a few months, the kids weren't even listed as being active on the insurance company's lists, despite Medicaid saying they were. Stuff like that. I keep thinking that I'm really lucky that I have access to a phone, good English skills, and the tenacity and confidence to keep calling customer service again and again, demanding what we need. I bet a lot of people on Medicaid whose records were messed up have just given up. It’s so not fair!

Natalia and Elizabeth highlight how stressful it is to cope with the uncertainty of a terminal illness. The uncertainty of waiting for the next relapse was emotionally difficult, but the flexibility Natalia had with her academic schedule was important to her success.
Natalia
...realizing that I should try to finish my dissertation soon because mom’s chemo is going well. Ovarian cancer is awful. We don’t really talk about this as a family but my understanding is that you don’t usually cure it so the chemo is more of just a long journey of delaying. If last year is any indication...she’s finishing chemo in June or July, I probably have a few months where for sure she’ll be doing fine and then who knows after that. It’s very possible that it will recur so my thinking was, “I should just go ahead and try to finish during that time when she’s doing well because who knows what’s coming later.”

Elizabeth had completely abandoned her dissertation work to attend to her mom. She painted a vivid picture of the tension.

Elizabeth
The tension of that whole period was just enormous. You feel like you’re wound really tightly constantly waiting. Then part of the problem I think for me was that I was...somebody who worked in healthcare I could see just how bad things could get. There were nights where I would just hope for her that she would die in her sleep rather than go slowly in a difficult, in a painfully, or just increasingly disabled [state], which is how it went. There was just that constant pressure, that tension... The day she died was almost a relief. I literally felt a huge burden of weight lift off my shoulders. For her, because she no longer had to suffer this, and just that we didn't have to worry about her anymore. That lasted a couple of days and then the grief set in... My own stuff [dissertation proposal] just got completely abandoned. I don’t remember that being a problem...

Both Natalia and Elizabeth had the benefit of being able to postpone their dissertation work because of the timing of when their mothers’ illness occurred in their degree programs, the dissertation phase has flexibility built into the structure. It is important for faculty and administrators to remember that student caregivers can face this scenario at any point in their degree program.

Uncertainty causes problems for student caregivers because they are not able to develop a systematic way of managing the responsibilities of both roles. When students care for a person with an illness that is inherently unpredictable they are at the mercy of
the care receiver’s health fluctuations. The pressure of uncertainty in the caregiving role is compounded when students are required to meet inflexible expectations in their student role.

**Flexibility takes the pressure off.** Flexibility takes the pressure off student caregivers by allowing them to prioritize their immediate needs. Flexibility presented itself in many ways, however, it was discussed primarily in two ways: flexibility from faculty and flexibility with self. Flexibility from faculty was different based on phase in the degree program, relationship with professors, and institution type. Flexibility with self came with time, experience, and confidence.

Jenna reflected on a time when her son had to have outpatient surgery and she told her professor that he could not be left alone for twenty-four hours and she was a single mom; she requested an excused absence. He had a strict attendance policy and said that her grade would be affected if she missed class for any reason. She struggled knowing that she had to choose between being with her son and attending a class.

*Jenna*

...there was one class I had to go to...and my son was having outpatient surgery, I was there...but you can’t leave them alone for 24 hours, I had to rely on my mom...and that feeling like “my son just had surgery and I have to go to class”...my professor will fail me if I don’t go to class....because I did ask....I told him what was going on and asked if it was ok to miss class...“well your grade will be affected”...ok I might be a few minutes late, I made it there on time and I liked the class otherwise...but that’s the feeling I had is you’re forced to choose...

Pooja and Waldo attended community colleges. They both indicated that they had a very positive experience. Pooja had only attended a community college, she did not have any other institutional experience to compare it to.
Pooja
Oh they were really good if I needed to deal with something...Most of them knew that my son was in Afghanistan and that if I got a call, I needed to take it so if I got a call about [husband], I needed to take that too...they were all really good and understanding...most of them had been teaching for years and they were just wonderful.

Waldo returned to nursing school at the community college after he finished his bachelor’s degree at a large university. He was able to compare both academic experiences and really appreciated the flexibility and warmth he received at the community college.

Waldo
The community college level has been super flexible...And it's personal, too. To be honest, if I would have done this all over again, I would have gone to the community college level first and finished all my prerequisites. The upper levels at [university], they are a little more personal.

Amy expressed many times in her interview that she had a somewhat antagonist relationship with her advisor, but when she really needed her to be flexible her advisor came through for her. Shortly after her son was diagnosed with ADHD, her dad was diagnosed with colon cancer. She decided that she needed to drop a class in the middle of the semester for her own health and her advisor offered her the opportunity to complete it as an independent study rather than losing the credits.

Amy
My first semester I took a full load like I always used to take when I was a student without anybody that I was responsible for and went, "Dear, I can't do that again."...Then I don't remember which semester it was but one of the semesters I had again taken a fairly full load and my father was diagnosed with colon cancer...and [son] was diagnosed with ADHD. Then I went back and said, "I need to drop a class." I dropped a class at that point. She [advisor] did let me do an independent study on that class...I think I was halfway through the class...I had taken a good deal of it... she said, "If you complete this this way we will count that towards your [degree]"
Anne commuted approximately forty-five minutes to campus, which is also where the hospital is that serves her family. One day her daughter had an appointment on the same day Anne had class. She did not want to make two trips, so she asked her professor if she could bring her daughter to class with her.

Anne
...we were down here at the [clinic for people with disabilities] because she [daughter] needed to get updated educational testing so that we could get her 504 written and we had to be there all morning and I thought I'm not going to drive up to town and then all the way back to get her. So I asked the professor if I could bring her to class and she was very willing to do that, she thought it that was great...

She was very grateful for the flexibility that the professor granted her and for the opportunity to have her daughter experience college. “...a lot of times for kids with disabilities the transitions are really hard and they need to know what to expect before it happens. And the more exposure they have to it the better”.

Alex and Natalia stated that the flexibility their faculty advisors gave them was invaluable. They also discussed how over time they were more flexible with their own expectations. Alex said, “They [committee] gave me a lot of flexibility. That took a lot of pressure off...I gave myself more time to get school deadlines done.”

Natalia
...my advisors were supportive and I did finish my proposal largely from [home] and I came back to defend it. The fact that I kept making progress made them feel like they could continue to be supportive.

I felt a lot of pressure to always be putting energy out either into my mom [or school]...it wasn’t really acceptable to put energy into me or if I did do that I would judge myself or think other people were judging me. I have gotten a lot more gentle with myself. Most recently I was just back to blitz out some dissertation stuff back in [state] and there were a lot of evenings where like around 8:00pm I just would just be like, “I’m done”...I can’t get any more work done... My body will
let me know when I can’t do any more...I used to have illusions that I could just crank it out until 11:00 or 12:00 at night. I give myself a night off...

Ed explained that the faculty in his department was very responsive to his situation.

*Ed*

I would say the university is very understanding. It's made up of individuals that have the flexibility, at least in the bio-medical group, the agency to adapt... didn't have the feeling that I was hitting a wall of stupid rules... that no one could change... There's people behind those rules that you could go talk to. They're incredibly responsive. I really respected that... I was missing one credit for my engineering degree. It was in something very easy. Whereas I had these advanced organic chemistry classes that no one wanted to take. I had gone and taken a bunch of bio-chem that I didn't need. They just let it go. “We realize that you’re not fully accredited. We think you’re up to the snuff of being credited. You’ve already gotten into med school. We’re not going to stop you. We understand that your brain is probably fried from most of this”... I really appreciated it.

The flexibility Ed experienced in the engineering department was incredible. While I was analyzing the data, I kept reaching out to people to try to understand how an undergraduate student in engineering could receive so much support when undergraduate students in psychology were not receiving half the support and flexibility. A dean at the university suggested that the size of the program matters. A small department functions more like a community than large departments. The flexibility Ed encountered definitely helped him succeed.

The contrast between Ed and Jessica’s experience is stark. Jessica did not receive the faculty support that Ed did. And she reflected on how if she had the personal resources she could have helped herself more.

*Jessica*

I failed myself by not continually asking for help... you can only get shut down so many times before you internally shut down... I think the institution failed me in a lot of ways by... not being flexible... but I think the environment has definitely
changed, there’s online courses and things like that...maybe they [the institution] has already adapted to the things that allowed me to be lost and forgotten about...

Jessica’s reflections about how online classes would have helped her, combined with Alex’s reliance on WIFI in the hospital, inspired me to look at the data again and see how technology was experienced by other participants.

**Technology offers freedom.** Technology offers freedom to student caregivers in multiple ways: flexibility in location, off campus access to institutional resources, and time flexibility. Alex’s reference to WiFi was “lifesaver” instigated my search for how technology impacted the student caregiving experience for other participants. He indicated that he utilized the WiFi I at the hospital and nursing home to help him stay organized and caught up with his own work.

*Alex*

The lifesaver was the skilled nursing unit she was in had WiFi. The hospital had WiFi, so I was able to keep up thanks to technology...I was able to do all of the things that I had to do, and I didn’t get behind because of that.

Alex’s reliance on technology in the hospital sparked a follow up question during his interview. He revealed that he “read and read” to gain information about her mom’s stroke. He asked the doctor to give him homework so he could understand the medical terms and treatments when the physician came for rounds and to know to explain his mom’s treatment plan to his family. I wondered if he used the university’s databases to do research about his mom’s health. He said, “Sometimes I use my resources for their advantage...when I wanted actual journal articles, yeah, I definitely used the university system”. Technology offered him access to university resources even when he was not
on campus. The majority of participants expressed that technology made some part of their student caregiving journey easier.

Elizabeth flew to Ireland to care for her mom the week before finals. A colleague in her department proctored the exams for her and then sent them to Ireland for her to grade. She reflected on how being able to submit the grades online was a relief, it offered her the freedom to be in Ireland with her mom and still complete her work.

*Elizabeth*
I remember staying up late to finish it [grading] one night because the deadline was coming...I remember being very relieved that it was so easy to submit grades online these days. Everything is online, because I can remember back to the days where this would all have been much more difficult.

As was noted in the previous theme, Elizabeth gave up her teaching assistant position to care for her mom, in Ireland, so she forfeited her income and was required to pay full tuition for her dissertation hours. Technology gave her the freedom to continue working as an online writing tutor with the university writing center. “I was also doing a few hours at the writing center, and they were great because they said, ‘Don't worry about it. If you want to do online work, you can do it from Ireland’”. This gave her much needed income.

Anne learned about assistive technology in a class and discovered that, as a student, she could download software on her personal computers. She chose to put Snap and Read on her husband’s computer as a resource to help him cope with his dyslexia.
Anne
He [husband] hates having dyslexia. He said, "I would give up my right arm if I could just spell" and he means it. It is so hard for him to send work emails because they come out with them looking like he is not smart, which he is. So that's why Snap and Read is nice, he's been using it. I learned about assistive technology from a class—that's helping my family. I said bring home your laptop, I want to download something for you...he loves it. He uses a lot.

During the focus group Anne said that it was really important for her to use what she was learning in school to help her family. “…it takes care of my guilt for doing something I want to do, going to school. If I can use what I'm learning to help my family, then it somehow makes it okay.” Assistive technology was not only something that she learned about in school that could help her husband, it was an institutional resource that she had access to on and off campus.

Alex, Elizabeth, and Anne attended large universities with a lot of resources. As I reviewed the data looking specifically for technology references, I found Pooja’s reference to Microsoft Office. Pooja attended a community college and students were required to purchase the software themselves. Her parents gave her the money to buy it. The software gave her the equipment she needed to succeed in classes and it gave her the freedom to work from home.

Pooja
My parents had never been very positive. They really didn't do anything to help me with school but they kept telling me how they were proud of me...There was actually one time for one of the classes I had to have the [Microsoft] office suite. It’s like 100 and some odd dollars to buy it. I didn’t have the money and sometimes I worked with my parents. They had a couple rentals and I help them out a bit...they handed me a check so I could go buy it.
I had to reread that several times because I could not believe I did not process this information during her interview or the multiple times I listened to her audio recording to write her personal story, I just took for granted that Microsoft Word was provided by the school because of my experience. This was a very good reminder that not all institutions have comparable resources for students. Natalia “could remote in to my computer at [university]” three states away and Pooja did not have free access to Microsoft Word.

Online classes gave Jenna and Waldo freedom in two different ways; Jenna did not have to commute and Waldo could complete his degree around his work schedule. Jenna took an online class “…through adobe connect where you watch the professor. So that helped that I was home and I didn’t have to drive down [to campus]…”. Waldo completed his third degree entirely online, “My RN to BSN program, the entire thing was online, for students who have to work and for students who have families…”.

Online classes were a good resource for Jenna and Waldo.

Online classes, however, are difficult for some students who need personal assistance to learn the material. Pooja struggled with her online math class.

_Pooja_

Online classes are hard. I had a couple of them and they were hard because you’re teaching yourself, you’re not getting the benefit of an instructor up there...There was one thing that I needed to do. It wasn’t in my book, it wasn’t in my math lab. There were two of us trying to get through the online math so they offered us a tutor. All that tutor had to do was say one thing and everything clicked for me.
The institution’s response to Pooja and her classmate was wonderful, they offered them a tutor so that they could be successful in the class. It is a great model for how to adapt to the individual learning needs of students.

**Caring, learning, and teaching with dignity.** Caring, learning, and teaching with dignity developed from Orla’s interview and contributions during the focus group.

Orla’s world view is always positioned from a human rights perspective, maintaining human dignity is consistently her primary objective no matter what she is doing. She spoke about dignity from the caring perspective, the learning perspective, and the teaching perspective.

*Orla*

That human rights perspective was ingrained from the time I was five and went to the United Nations International School in New York. That's part of my DNA. Where did the dignity come from? Well part of it was the way my brother handled my parents which was not dignified...I also think that it just as part of looking at the world and being in that human rights...mindset and I see when dignity is lacking...

I'm taking two courses this semester and I'm caring for my father and he wants to go to a reunion in Amsterdam and I can't let him go alone, so I'm going with him...He established a student fraternity... they're celebrating 75 years... He's the founder, so he's going and I'm going. I sent my two professors an email saying I will be away. It means I'm missing a second class. I'm also missing at the end of the semester for a conference. I said, "If there's something extra you want me to do, just let me know." One answer was, "Look at the syllabus and see what's due that week." The other one was, "As a graduate student, the maximum number of classes that you can really miss is two"...I'm like, "I'm not an idiot." I found it at the time very patronizing and I thought, "This is what you say to a ... Well, this is not even what you say to an elementary or a high school student...”.

Orla is a caregiver, a student, and a teacher, she indicated that she would not treat anyone in any of her roles in such an undignified way. She defiantly stated, “The institution owes us dignity”.
Jenna and Amy reflected on their experiences as student caregivers and highlighted moments when they felt that they were not treated with dignity. Jenna had to leave her son home alone to attend night classes. He has Asperger’s and went through a very traumatic experience shortly before Jenna started the PhD program. Her son needed to be able to reach her immediately to calm his anxiety about being left alone. She explained the reason that she needed to keep her phone with her during class and would have to leave class to respond to a call or text.

Jenna
...when I first started here, I’d email profs at the beginning of the semester and I said “my child’s home alone, he’s been through this traumatic thing and he may text me and I will leave the room to answer the text ...but if I don’t answer that text...he thinks I’m dead...I’d explain the whole process because of the Aspergers....9 out of 10 [professors] were ok w that until I had one and a text came in class and I was just starting to walk out of the room at the same time and he started yelling at me and he yelled at me for 15 minutes that texting was rude and I needed to listen to the professor. I was totally totally thrown back by it...You DON’T do that...you DON’T do that to people! Whether I’m a student and you’re a professor or not...if you have an issue w me that’s confidential you talk to me later...

Jenna is a special education teacher; she was appalled by the lack of dignity her professor showed her. Amy had a similar response about her advisor, who was supposed to be modeling how to be an effective counselor.

Amy
...as I look back, I wish when I started swirling as a student, I wished my advisor had pulled me in and said, tell me what’s going on instead of [saying] “Every time you come talk to me, Amy, there's tears. What's that about?” I remember that just burned because I thought you call yourself a counselor...The tears must mean something is going on. Can you ask me a little bit more about that? I think if she got to know me as a person and maybe even said, okay, this is a person coming in who has all these life experiences but she never asked me...What have you done? Who have you been? Tell me who you are.
Amy needed to be treated with the type of dignity she was expected to convey in her practice.

Cassandra chose to approach school on her own terms, it was her way of preserving her dignity while meeting her needs as a learner with disabilities, while caring for a person with disabilities.

_Cassandra_

... education...completely up to me... and as I went back to grad school. I just thought, "You know what? It's none of your business because I'm an adult, I'm taking the consequences. Therefore, I get to make my own choices. If I need to tell you I'm not handing in a final paper, well, you just grade me as you see fit..."it's liberating because it's like, "Well, you know what? I'm doing the best I can.

As was highlighted in her personal story, Cassandra has ADHD, depression, and anxiety. One of her most effective coping strategies is finding moments where she can assert personal control and when and if she hands in assignments are the moments where she asserts her control.

Anne uses her position as an education student and a parent of children with disabilities to facilitate discussions about disability in the classroom.

_Anne_

...it usually comes out in class discussions... I have a disabled child... a lot of times I use it as a way to open other people's eyes. I say maybe that student can't comprehend what they are reading because of a learning disability not because they can't read.

As a teacher, I see this as Anne enlightening future teachers about how to treat students with disabilities with dignity. Thus, she is in both the student and teacher role in her degree classes.

Jessica had two unique experiences with how to maintain dignity for her parents while she was a student caregiver, her mom had a mental illness and her dad was in a
coma. The sensitivity of her mother’s illness was challenging. She did not know how to reveal information that could give professors insight into the severity of her situation while preserving her mother’s dignity—and her own.

Jessica
...it was such a sensitive thing, especially with mental illness I didn't want to bring up everybody else's story. It's not my story to tell. I was assisting in their care and dealing with the responsibilities of the family but I didn't want to disclose the details...From some shame and embarrassment...But I definitely left them [professors] bread crumbs but nobody was proactively looking into the situation.

The challenge with caring for her dad was that she felt she needed to make sure that the people who cared for him knew who he was before he lost the ability to communicate that for himself, to maintain the dignity of the dad she knew and loved.

Jessica
...to remind the nurses who he was...I made a board with his [dad’s] narrative....I made a board with ....pictures of my dad and ...I would...put that in his room so that they can go in there and they can see who my dad was...

Ed illustrated how important it was to him, as a caregiver, to help his dad keep his dignity as the disease progressed.

Ed
He'd [dad] walk down the halls and he'd lose his bowel function. He'd be incredibly ashamed...It was this code between us that we'll keep this on the down low because it was already embarrassing enough...I wasn't going to stress him out by reacting badly to it. I was just going to accept it as part of what's going on...

As physician, he applies that skill and perspective to how he treats his patients.

Ed
Patients, so many patients when they're dying they're at Hospice or something similar... they know they're dying. You have to tell them, "You can't smoke." There's people that just hate them for smoking. What the hell, who cares? They've already smoked this much. It's not going to matter...This is something that gives them relief. Their social structure has always been the Smoking Shack. That's the only part of the day where they're not a patient. They're just enjoying some relief, or the people who...people who don't have legs. They still insist upon standing
while urinating because it's a point of pride. When you start thinking you know best. You know how they should be feeling. Those are red flags for me. I think medicine is full of that. You're so overwhelmed with other stuff. It's kind of like caregiving. You're so overwhelmed that you don't see, you don't have the perspective.

Ed is frustrated because he believes the culture of medicine often lacks the perspective to treat patients with dignity.

Waldo also brings his caregiving experience to nursing.

Waldo
...every nurse manager I've ever had said, "You are leaps and bounds ahead ..." I feel so empathetic when families come in...There's a saying at the hospital that our everyday is somebody's worst day because they come in, they've never dealt with this. It's bad enough trying to find a place to park and get through there [at the hospital]. This patient comes in, 95% of their body's burnt and their family is just complete train wrecks, but it's our everyday. Being able to talk to families, I think a lot of that was molded from my experience growing up [as a caregiver].

Ed and Waldo understand that their greatest assets as a physician and a nurse are that they know what it feels like to be a caregiver from a personal and professional standpoint. Their informal caregiving experience informs their professional caregiving experience; maintaining personal dignity is essential for providing quality care.

Natalia and Alex reflected on how they bring their caregiving experience to education. Natalia muses, “...so I want to teach someday. It’s making me think a lot more concretely about how I would build an accommodating classroom or an accessible classroom”. Alex explains that his teaching style has empirically changed as a result of caregiving, “If a student says to me, "I'm having family problems, "...I used to demand documentation. Now I don't, and it's directly related to my experience”. Student caregivers bring care to the classroom when they teach.
Coping Facilitates Health and Growth

Coping is an essential process in the student caregiver journey, the specific coping strategies that students used to process the stress of dual roles facilitated health and growth for student caregivers in unique ways: *Coping facilitates health and growth* is an essential theme. When participants learned how to access institutional or personal resources to employ coping strategies they became empowered to seek out more resources and strategies when they needed them in future crisis moments. However, when students were too overwhelmed by trauma, some students stated that they were “paralyzed” and incapable of coping in a healthy manner, which affected the care they gave, the quality of work they completed, and the health they experienced. Students who employed healthy coping strategies often had the benefit of fortuitous timing, secure identities, and sufficient flexibility. Students who had previous life experiences that prepared them for traumatic events had a set of coping tools to utilize; students who were secure in their identity as either student or caregiver had strong cores to sustain them during uncertain times; students who experienced flexible expectations from mentors had a supportive structure to enhance their capacities. Coping strategies were fluid and changed over time. Thus, most student caregivers in this study who did not have healthy coping strategies early in their journeys were able to learn coping strategies that facilitated growth and allowed them to attend to their own health, as well as manage the logistics of being a student and a caregiver. The four thematic elements within the essential theme are: (1) coping with trauma, (2) self-care is necessary, (3) boundaries give me control, (4) school is your friend. Jessica provided the perfect image for *Coping facilitates health and growth:*
Jessica
I imagine myself as this baby bird just...starting to stretch out her wings and somebody knocks the nest out and on the descent you're having to learn to survive and fly otherwise you will hit the pavement and that's it... that's how I felt... that my wings had just barely come in and I didn't know how to use them yet and I'm learning how to fly and right before I hit the pavement, I take off...I didn't get very far but eventually I learned to use my wings.

Coping with trauma. Coping with trauma is a physical, as well as emotional, experience for student caregivers. This thematic element sprouted from Alex’s comment, “I think anybody that provides long-term care or even really severe short-term care, they are fundamentally changed by it...with that kind of trauma...Your life is never going back to the same”. I began to look at the data for how student caregivers’ lives were changed by the trauma. The data showed two significant ways that trauma touched student caregivers: physical symptoms and personal growth. This thematic element will focus on the physicality of trauma.

The majority of participants noted some physical or emotional symptom that they attributed to the stress of student caregiving. Cassandra illustrates a vivid picture of how the body responds to emotion, even if it tries to be ignored. “My body is usually something I ignore...it gets my head places. I carry lots of tension in my body...everything is tense, tight tendons... so I ignore it, but it does a lot of heavy lifting for me emotionally”. Ed, Elizabeth, Jessica, Orla, and Natalia discussed how trauma affected them physically. Ed said, “I would say I was completely numb. I did not feel my body”. Even though Elizabeth indicated that she never got sick while she was caring for her mom, she recalls feeling like “…there was something on the back of my neck. It's like when you're getting the flu or something, there’s this icky feeling of tension and nausea...
at the back of your neck”. Jessica described that she felt like she was comatose while she was caring for her dad who was in a coma.

Jessica
...my dad was in a coma for nine months but I was myself very comatose, I was paralyzed with anxiety...I wasn't sleeping, I was just numb... when I lay down at night...I couldn't feel my limbs...I didn't have the energy to exist.

Jenna used prescription drugs combined with alcohol to help her cope with trauma induced anxiety and insomnia.

Jenna
I think the anxiety went into high gear and it was also like I was hyper and couldn’t shut off my brain...I used [prescribed] anxiety meds and sleeping meds...I started drinking and then I quit doing that because I had a biological father who died of that and a step father who eventually died of alcoholism and I didn’t want to do that...saw the pattern and I said you just don’t need a drink and take prescriptions drugs to go to sleep every night that’s not healthy...

Thankfully, she was able to reflect on her familial experience with alcohol abuse and chose to find healthier ways of coping.

Orla was able to attribute her physical experience to stress because of a prior life experience, “I got this pain in my neck and it hasn't gone away... and I had a similar experience...when my son was a baby which is why I made the connection that it's stress related”. Natalia also understood that feeling dizzy and feverish were stress manifestations for her but the information didn’t help because she could not change the cause of the stress. Natalia’s research interest is stress and her father is a physician.

She had the knowledge and insight to understand what was causing her to feel this way.

Natalia
I felt...dizzy...That also seems to go with stress for me...feeling a like I had a fever or something and just everything was a little tingly and not totally there... The whole time I figured all this stuff was stress related...It’s not especially helpful because you can’t fix the stressors...I take medication for anxiety depression and
I changed my dose. That was coping... Moderate amount of work is good. Exercise and then seeing friends the right amount...”

Even though she could not change it, the knowledge itself helped her employ healthy coping strategies.

Waldo, however, did not have the benefit of familial support, life experience, or academic knowledge to figure out how to cope with the devastating trauma in his life.

Waldo
There were times that I'd find out that he [dad] was drunk and I would put off my school stuff and get home...It would come in waves, I would see my mom having a bad day or being around mom two or three days in which she couldn't talk to me and she'd freak out and start to scream because she couldn't vocalize what she needed. As the disease progressed, she lost the ability to talk. You would really have to focus in and hopefully get a good word or two out of it and understand what she wanted. To see her get to the point where she couldn't walk on her own and it's like is that going to be me? To be a 16, 18, 20 year old kid and have to change your mom's diapers and give her a bath...Taking care of her for a couple days, I'd leave and I'd be like, "You know what? Fuck it. I'm going to go get smashed."

He turned to drugs and alcohol to numb the pain early in his student caregiver journey.

As he grew he chose healthier ways of dealing with not only the trauma of his mom’s illness but also the repercussions of the physical abuse he experienced at the hands of his dad.

I started working out again, and getting into kickboxing, and getting back into wrestling, and things like that...Ironically, what got me to feel like I could do kickboxing and things like that was I got into a fight at a bar and I got punched and I didn't fall over, or get hurt, or anything. It's like, "Hey, that was actually kind of fun."...I was like, "You know what, maybe I should go do this in a organized setting." I started doing that and it was fun....That got me away from that bad crowd...I found a new outlet to cope with all these things...In the process, still caring for my mom...

His training allowed him to be part of a different social group and defend himself against his dad when he attacked him.
Student caregivers coped with trauma in various ways. It generally had a physical component that accompanied the emotional angst. Coping with trauma was the initial step for student caregivers to develop ways to engage in self-care.

**Self-care is necessary.** Self-care is necessary for student caregivers to cope with the demands of being a student and a caregiver. Self-care allows a person to renew their energy in order to focus on and organize for the requirements of both roles. The way Alex teaches his students about self-care based on his experience as a student caregiver helped me frame this thematic element.

*Alex*

...if you don't take a little bit of time for yourself you become worthless to everybody...I did learn this...going through everything with my mom...A person can only do so much, so I teach them [my students] bucket theory. Your life is a bucket. Here are the things that are in it. If the water that's in the bucket is you, how much shit can you put in there before you start spilling out? Once you start spilling out, you're just a wreck. You're worthless to everybody else. You can't put your own water back in...What you've got to do is you've got to take things out, to where your water level, the water that you still have, works. I think that's part of my water...that got away was being less serious. Some of my humor and ability to just laugh things off, over flowed out of my bucket, and I don't get it back.

Student caregivers are under an inordinate amount of pressure, Cassandra succinctly stated, “We can't ride ourselves that hard. We're going to break”. Jessica asserted, “...a person needs to take care of themselves...it may look different, someone may need to take a day off and someone may need to go to yoga...maybe somebody just needs an extension...it takes a lot of different forms...”. The participants in this study took care of themselves in varied ways.

Amy expressed that it was very important for her to maintain doing something that was familiar to her. “I continued to make homemade bread and granola
throughout school because it is a centering thing for me to engage in.” Making bread and granola was something Amy did every single week before she started school and consistently did during school, it nourished her physical and spiritually.

Pooja needed a complete break from school and caregiving.

*Pooja*
Working at the theater was just for me. I didn’t have to think about school. I didn’t have to think about [husband]. I didn’t have to think about anything else. It was very much an escape. My best friend from high school was there all the time, too.

Working at the theater gave her brain a break from thinking about any of her obligations. It also provided a social outlet with one of her oldest friends.

Jessica and Anne combined tasks they had to do for school with activities they did to take care of themselves. Jessica shared, “I would go to the hospital do my homework, sit next to my dad and hold his hand while I did my homework...”. The physical contact with her dad along with the focus of a school project helped her cope in the moment.

Anne used the commute to take time for herself. And she chose to listen to music which facilitated an emotional release.

*Anne*
Spending time in the car has been fun...I have to do it. I have to get to school...It's actually kind of nice because I can listen to music or whatever I want to do because it's my "me" time...I feel through music. So it feels good just to sit there and feel.

Elizabeth used her knowledge of how stress affects immunity to take care of herself.

*Elizabeth*
I remember thinking that it [not getting sick] was a pure act of will... I was aware that I was under stress and that this was a prime time to get ill. I exercised as much
as possible. I always ran, but I made a point of trying to make time to run every
day while at my parents' house. This was easier actually once my mother was in
hospice because I didn't like to leave her alone at all in case she fell or something.
She fell a couple times when she was at home, so I would have to time it, get out
for a quick 20-minute run when I knew she had just gone to bed. Eating carefully,
taking a multi-vitamin, taking cod liver oil, those kinds of things.

She demonstrates how calculated she had to be in order to do the things she knew she
had to do to keep herself healthy.

Jenna demonstrated how coping strategies changed over time to meet current
needs. She chose passive activities that helped her anxious brain relax during acute
stress.

Jenna
I tried to do no brainer activities...and for me that's reading something that’s not
for my classes...something as silly as the Readers Digest...something you’re
focusing on nothing...the internet...I’d allow myself an hour on the internet... I’d
look at CNN...I allowed myself time to catch up with the world...and to me that’s a
coping thing to me...reading something for pleasure instead of something that I
have to. Eventually...about 5 or 6 months after he got out of the hosp
ital we got
to the point where we started going to the gym...So that was a coping thing...that
was like a stress reliever...

During times of stability when she had the energy, she began working out with her
husband at the gym, which combined rehabilitation for him and a stress release for her.

Self-care is necessary for student caregivers to cope with the significant
responsibilities of both roles. Self-care allows the body and mind to rest, which is
essential for health and success.

Boundaries give me control. Boundaries give student caregivers a way to
organize their priorities to give them perceived control. Jessica’s planted the seed for
this thematic element, “…another thing about being a caregiver also is knowing how to
set boundaries...because boundaries have become my saving grace”. Student caregivers
had to set boundaries with other family members, with the care receiver, and with friends. The ability to develop and maintain boundaries is a process that occurred when participants coped with the trauma they experienced and took time to care for themselves in a healthy manner.

The onerous time constraints of being a student caregiver often led to changes in socialization. Participants just did not have time to commit to friends who did not understand or respect their obligations, thus boundaries with friends often occurred earlier in the journey than boundaries with family members and care receivers. Cassandra and Natalia explained that it felt healthier when they were able to say what they needed.

*Cassandra*
I was thinking about being a caregiver and going back to school ...I got to that place and with my friends saying, "Listen, I've got this much time and I'm going to disappear sometimes," and the friends that stick with you, stick with you...

Cassandra appreciated the friends that stuck with her because they helped her, they didn’t cause her more stress.

*Natalia*
...I've also gotten a little tougher. I used to be much more socially anxious and easily guilted by other people...I just don't have the patience for it anymore. Someone tried to make me feel guilty about not keeping in touch this past year and I was like, "You're fine." I was sorry for them, but just also confident that I was doing the best I could do and that's all I got...I didn't have social energy at that time. It's a relief...I used to waste a lot of time worrying about those things. Now it's just the way it is.

Natalia reflected on her personal growth, she grew tougher and *less* anxious in one realm of her life. She was able to stand up for what was best for her and be confident in that decision.
Setting boundaries with family members often occurred when their actions increased the student caregiver’s stress level. Ed and Alex had two very different experiences, but the common thread was that they set the boundaries that allowed them to provide the type and quality of care that they needed to give.

**Ed**
I would say she [mom] is a very high functioning alcoholic sometimes. It would be 11:30 at night and I’m freaking out because...I had to call the home health nurse and try to triage how to take this stupid catheter out. That was one of the worst times ever...My mom would be cheerfully...toasted....her response to how serious this situation was would be off. I don't blame her at all...it was really, really hard on her...At the time I was really pissed. For a long time I made her stop drinking because I was so pissed. I was very angry at her and I let her know that... was not acceptable.

Ed recognized that his mom was going through a difficult time watching her husband die, but the way she coped made it more difficult for Ed to provide quality care for his dad. The boundary he created with his mom helped him focus on his dad without diverting any of his limited energy on anger toward his mom.

Alex’s anger was directed at his sisters. They came to the hospital well after the acute crisis had passed.

**Alex**
...my sisters lectured me about not being a proper caregiver. I brought all of the functional things that she [mom] needed at the hospital... Looking back, there was probably the awkwardness of dudes figuring out which bra to take. We just didn't do it. My sisters are just going off about this, and it was one of the few times that I would say I actually got angry. Where I just went, "You know what? This is what I've done this week. I give 2 shits if Mom looks attractive right now. I could care less." They're like, "Well, it'll make her feel a lot better." "Don't care." To this day, we've still talked about the fact that if an emergency happens in my family, if anybody wants the person to look good, they better bring it because I'm not going to. I'm going to take functional care. Aesthetic care is on my siblings, or it's on my dad... I didn't give a shit. I just did not care if Mom had the right shade of lipstick, or if Mom was wearing a bra, or if any of these things were happening. Didn't care.
Alex articulated the type of care he was willing to give and not willing to give. Setting boundaries entails both parameters.

Setting boundaries with the care receiver depended on their health status in the moment and the competing priorities for the caregiver. Alex, Orla, and Waldo shared how they processed when they were able to say that their needs came first this time. Alex accepted a position as an assistant professor while he was still completing his dissertation. His mom’s health was stable so he made it clear that he had to focus on his professional and school work.

*Alex*

I was still in school... I had started the new job and was working and my mom was wanting immediate responses to her text messages. She went through this...phase of being highly demanding, and I had to explain, "You don't win right now. You are functionally capable of surviving. I have got to get these things done."

Orla indicated that she got better over time setting boundaries with her dad. She did note that she could let go of guilt when she was “in sync with the world”, that didn’t always happen.

*Orla*

...I think I’m better in setting those limits and boundaries...when you're in sync with the world then you're able to say to people leave me alone...It wasn't that long ago that I was able to say to my father, can't do that, got to write this paper. Without feeling guilty that I am neglecting him...

Waldo never indicated that he set boundaries with his mom because of the severity of her illness. He did discuss how he is able to analyze the situation with his dad now and prioritize what he needs to do rather than just react.
Waldo

Let's say if he went to jail for example and I had an exam the next day, I get a phone call at 3am and he's in jail. I'll say, not to sound cold...they got a cot there. He can take a nap, I'll take my exam, we'll figure it out when it's over. I've learned to put my stuff ahead. Not necessarily ahead because it's dependent on how bad it is. If it's a situation in which I can analyze the situation, I'm not impulsive to like, "Oh my god, I need to go take care of this." If it's not a life or death situation or if there's a possibility of something really bad happening, it can wait. I've learned that. I've learned to cope with that. I guess it does bother me to a point but it's not where it's going to break me down. I can take a step back now and I can analyze things and say it is what it is.

His ability to analyze and prioritize the demands of an emergent situation developed from his training as a nurse. His ability to set boundaries with his dad improved over a very long time of juggling being a student and his caregiver.

Boundaries allowed student caregivers to prioritize their needs and gave them control. Boundaries had to be set with multiple people: friends, family, and the care receiver. They were not static, they developed over time as the student caregiver learned how to cope with trauma and developed self-care strategies.

School is an ally. School is an ally emerged from a conversation that occurred during the focus group. I asked the group to help me understand how they used the language of their discipline to cope with student caregiving, because it consistently came through in the interviews. Natalia said, “...maybe, it relates to that idea of isolation that came up earlier...Your friends want to be supportive or sympathetic...they don't get it, so you end up using other things to make sense of it, the theory is your friend”. I gave each participant a notebook to write down notes so they did not forget what they wanted to say. Near the end of the conversation, Cassandra pulled out her notebook and told the group what she wrote.
Cassandra
That whole conversation we were having earlier about using your disciplinary language to help get through, so I wrote maybe our disciplines are our imaginary friends.

Anne
I love that.

Cassandra
I don't want to talk to my other friends or family members. Nobody understands me, but I can use that disciplinary language to get myself through. They're like my friend that I talk to...

Anne
I have at least one friend, education.

Cassandra
That's nice...Good friend to have.

Anne
A little demanding, but in ways that we can handle, right?

I broadened “education” to school to encompass the physical and social components of the academy as well.

School offered student caregivers an escape from their caregiving responsibilities when there was not an acute situation. Alex illustrated this well, “For me the best distraction from everything that was going on was to work on my dissertation. I mean not initially I was incapable. I could not have worked on it...”. School offered a diversion from caregiving.

Pooja had been a caregiver for a long time before she started school. She struggled with her own depression.

Pooja
It [school] gave me a kind of break from what was going on at home... Sometimes staying at home with [husband], it’s just like I don’t have to deal with anything else out there. It’s just I have to take care of him. Our daughter was living with us at
the time...I had to deal with her and I just didn’t want to associate with anything else just take care of right here right now what has to be done but by going to school I felt like it just kind of made my whole world a little more open. I wasn’t just closed into this little tiny space.

A symptom of depression can be self-isolation, for Pooja’s own health she needed her world to be broadened. As was discussed in her personal story, she thrived when she succeeded in her coursework and enjoyed the socialization of school.

Jessica and Jenna also noted that they appreciated the social aspect school offered. Jessica said, “...school preoccupied me...and it was nice to have conversations with people”. Jenna reflected on the difference in her experience at school when she was commuting and attending part-time versus when she left her teaching position and started as a full-time student.

Jenna
...it did help for me to be down here full time, to be in the loop to know what’s going on....to know what classes I should be taking....to know what the requirements are.... I felt like I had more people to get to know and more people as they got to know me could help me out more...classmates would be helpful “oh, I’ve taken that class, here’s my notes” or take this class, don’t take this one...I just get to know more people in the program...

Ed literally tried to escape his grief by moving to campus.

Ed
I cut myself off from my mom who was also coping right at the same time...it's really hard to drive an hour and a half everyday just to get to school. It saved me time to study and get ready for med school. Then I was reading everything I could about grief and coping. It just was not helping at all...kept on talking about resilience that’s frustrating...I was thinking, ”This is way too late. Now I know what I don't have”...doesn't tell me how to get to the point where I get resilience back. What was instrumental about the counseling at [university] was that it helped me realize that I had to reset. After that I really started reaching out to the people that were already around me, that had been friendly to me. I had just been closed off. I started a really supportive community at the engineering department. A lot of great people that I'm still proud to be friends with.
He could not escape the grief, but he did find the university counseling center which helped him cope with his grief. And he developed a social support system that helped him develop resilience.

Amy experienced intergenerational support when she disclosed her son’s recent diagnosis during a class discussion.

Amy
I’m surrounded by 20 somethings...I didn’t expect to get support for my role as a parent from 20 somethings.... they would even be like, Amy, you’re the same age as my mom...but they were reaching out to me because they either have a sibling with ADHD or they themselves were diagnosed with ADHD...

The encouragement she received from classmates who were young enough to be her children, helped buoy her through the early days of her son’s diagnosis.

School is an ally encompassed how student caregivers viewed the intellectual and social aspects of college as support in their journey. Sometimes it was the discipline itself that offered them a way to make meaning of their experience, sometimes it was an institutional resource that gave them assistance, and sometimes it was their peers that provided them support. The majority of participants indicated that at some point in their time as a student caregiver they experience school as an ally.

Summary
Coping is fundamental for student caregivers to develop strategies that will build resilience. It is a process that changes throughout the course of the whole journey, due to shifts in identity, support from faculty, and social support. New and modified coping strategies are cultivated as student caregivers develop and utilize personal and institutional resources. The theme *Coping facilitates health and growth* represents the
nexus of a healthy caregiver, a healthy student, and an educational experience where learning transforms.

**Learning Transforms the Journey**

Learning transforms the student caregiving journey for each participant as they used their education to reflect on and make meaning of their experience; it is an essential theme. In this study, learning transforms the journey refers to concept of transformative learning which is the process of adapting perspectives about self that result in emotional, ethical, and developmental changes, all of which emerged from the concomitant roles of student and caregiver. The critical awareness that came as a result of the crossroad between student and caregiver allowed participants to reflect on how the trauma fundamentally transformed who they were as a person.

*Alex*

I think anybody that provides long-term care or even really severe short-term care, they are fundamentally changed by it. When you deal with that kind of trauma...your life is never going back to the same.

*Interviewer*

You've changed, and the PhD process changes you too.

*Alex*

Oh, absolutely. Absolutely. You overthink everything....You just see the depth of life in a very different way. PhD teaches you to be critical and question everything.

Personal growth was fostered through transformative learning. The thematic elements in “Learning transforms the journey” demonstrated the progression of how the knowledge gained from their student caregiver role lead to personal reflection, which resulted in a shift in participants’ perceptions of self, ethics, and place in the world. The thematic elements within the essential theme “Learning transforms the journey” are: (1)
Academic language and content are tools for reflection, (2) education helps everything, (3) I have options.

**Academic language and content are tools for reflection.** The majority of participants used the language of their discipline to help make meaning of their experience. Student caregivers used their experience as a caregiver to make meaning in their academic work and used the language and content of their discipline to make meaning in their lives. Transformative learning allowed students to glean new meaning from a previous experience, as Amy expressed:

*Amy*

Before I went to school I was not aware that my own child had special needs...I was taking a class in rehabilitation counseling about special education and there was a whole section on working with children with ADHD. I remember one evening reading through that chapter and having this awareness of they are describing many of the attributes I see in my son, how interesting, I've never thought that might be a part of who [son] is...I was already...reflecting about what that might mean when his first grade teacher pulled me aside and said, "Have you ever considered testing [son] for ADHD?"...I kept thinking all of this is about me and yet when I looked at the possibility...dealing with someone who is wired differently, it was a bit of a relief of maybe it's not mommy burnout but that he's wired differently and is going to require different ways to engage him...There was relief initially and then dread and then crap, what does this mean? It's very interesting as I look back...I went through a lot of emotions and thoughts about what this would mean.

During the focus group, I shared that most participants used their discipline to explain some component of their student caregiving experience. I asked them to help me understand why their specific discipline helped them make meaning of their personal story.

*Anne*

I have to make it make sense in my head and through my experience. And my experience is being a student caregiver, so these things that I learn in class, they
naturally filter through my learned experiences—more education terms here—and that's how I make sense of it all. I fit it into what I know.

_Natalia_
You're just stewing in this world of your studies and the caregiving and you can't help but draw on all these tools that you're swimming in to make sense of the whole mess...it all gets so intertwined. What else would you turn to but this set of ideas that you're trying to use to explain the world and then it ends up explaining your life, too.

Cassandra proposed that perhaps the discipline itself was not the key to understanding but that the language the discipline provided was the tool they used to help make meaning of their lives.

_Cassandra_
Maybe it's less important the disciplines that we're [studying] and maybe it's more important that we're all falling back on the language that we're learning here as a tool to help us...It's a tool we're using. We're borrowing whatever discourse that's available to us to help us make sense of those pieces of our lives.

The thematic element “language and discipline are tools for reflection” emphasizes the intersection of academic discipline and personal reflection as factors in transformative learning. Participants in this study reflected on how they used the tools their discipline provided to make meaning of their student caregiving experience. Sometimes self-reflection itself was a tool of the discipline that allowed participants to make meaning of their student caregiving experience, such as in Amy’s program. Whereas, students in other disciplines created tools from their training to make sense of their student caregiving journey. The majority of participants came to use their discipline as a tool for meaning making which enhanced transformative learning.

_Education helps everything._ Each participant used some component of their academic work to explain how the meaning they derived from their student caregiver
role supported transformations in confidence, advocacy, and purpose. Building positive relationships with faculty who encouraged them to acknowledge their skill set, learning content that helped them advocate better for the care receiver, and discovering how to use personal skills and academic content to make healthy life choices were factors in the educational context that assisted student caregivers throughout the journey.

Participants in this study illustrated the connection education, identity, and coping skills had on their self and global perceptions.

Pooja demonstrated that the affirmations she received from her supervisor combined with the grades produced by her own effort, helped change her perception of herself.

_Pooja_
...she [supervisor] saw in me what I was capable of that nobody else had shown me in years. I mean for most of my life, I didn’t think I was capable of anything worthwhile and she was the one who showed me that I really was... I started getting As...I think about the person I was before school and the person I am after. I am a completely different person than I was before. I have more confidence in myself.

The confidence Anne gained from the discipline she studied translated into confidence about her ability to advocate for her son.

_Anne_
I was just dealing with my youngest. He's in first grade, first time at public school...He's having a lot of trouble. His teacher is like, "He won't stay in his seat. He won't answer when I call his name and he's always standing on his head and he wanders away." He has ADHD. That's what you're going to see. She doesn't know anything about it. She's very, very ill informed about ADHD...This is what you're seeing, this is why." I might have known that as a mom, but as an educator, then I feel very confident that I know this is what is going on and I know this is what he needs and I don't even question myself and I'm not going to sit there and let the teacher muddle through or put me off.

Elizabeth shared that she reconstructed her identity when she lost her mother.
which affected how she viewed the world and her place in it. She used the concept of privilege, which is the foundation of her research, to understand this personal and global shift in perception.

_Elizabeth_

Yeah, I'm looking death in the face literally. It changes your perspective on everything else. I thought I was grown up when I left my parents' house ... I thought I was a grown up now that I had children...Then when my mother died...no, no, no, I was never grown up...Now I know what it means to be an adult when you no longer have that protective shelter of your parents, when you grow up in a privileged [family], even though you're an adult, just knowing your parents are there, even if they can't fork out money for you, even if they're not housing you or feeding you, just the emotional support of having your parents there is something that shelters you. The world changed for me when my mother died. It was not a safe place anymore.

Alex was secure in his identity as a competent learner and used his education to cope and advocate for his mom. The awareness of his educational privilege compelled him to observe how another patient advocate without his privilege engaged with the physician.

_Alex_

The doctor came in and started using very medical terms. I just looked at him and went, "I don't know what you're telling me. I don't understand these words. If you give me an idea of the words that I need to know, the concepts I need to have, I will prepare and be much more ready when you come back in tomorrow morning...He did. He told me what type of stroke my mom had. He told me what tests she was undergoing. He basically gave me an assignment...I read and read. The doctor came in the next morning. I said, "Okay. I understand this."... We had a good laugh, because he goes, "What do you do?" I said, "Well, I'm finishing my PhD. I'm going to be a professor." He went, "Ah." Just the tone, the pace of everything, was very different. I feel okay saying that, because I watched the same doctor with the other family. He would go in and assess the lady across the hall, didn't really meet with the family. He changed orders, did everything. He didn't change any of my mom's orders without talking to me.
Jessica illustrated the progression of her ethical struggle while she was a student caregiver. She has chosen to use her experience to help other students who grapple with personal challenges.

Jessica
...she [mom] had 3 suicide attempts at which point I then had her committed. And did all of those proceedings for her safety...I could not have lived with myself...there wasn't anyway...to avoid those responsibilities...my family comes first whether I like it or not. I didn't know how to not answer that call to duty. I came secondary...it has been six years since my dad passed...[now] I am advocating [as a sorority supervisor] for others who may not have a voice and may not be able to speak... and I evaluate girls in similar situations check in on them proactively...then I share my story and let them know what the resources are, that's what I spent my whole life trying to understand is how do I be there for myself and have my goals while managing what's going on...

Cassandra summoned her own battles with her anxiety, depression, and ADHD to find purpose in her practice and research. She highlights that her ability to engage in self-care now extends to promoting self-care.

Cassandra
It started back in the social work program. I was already attracted to self-care, but I'm doing a lot of things, looking at people with invisible disabilities that don't make it or struggle in university, even though they clearly need to be here because their brains are coming up with fantastic things and they're going to be advancing the discourse, but if we kick them out because they're a square peg ... I think I've moved into this political realm where these things are now bigger than I am.

The thematic element “education helps everything” emphasizes how student caregivers employ their educational experiences to build confidence and inform their advocacy, and purpose in life. Their personal stories highlighted that growth and development is fluid.

I have options. Every participant indicated that they had grown during their time as a student caregiver and part of the transformation stemmed from their
educational experience which lead to self-authorship. The crossroads that created shifts in confidence, advocacy, and purpose for student caregivers paved the path for emotional, ethical, and developmental changes necessary for transformative learning and self-authorship.

Orla explained that the principles she learned from her education in human rights about allowing people to maintain their dignity always guided the way she advocates for the people she cares for and it helped her grow in the process.

...the way that my mother was treated in the hospital...was so utterly and completely undignified. I became very vocal about making sure they treated her with dignity...I can say that standing up for my mother in the hospital that I grew by not being afraid of doctors who think they're God

The burden she feels taking care of her dad makes her reflect on how she wants to be as she grows older so she is not a burden for her son.

...aging isn't fun and I decided to make sure that our son is spared this [burden] to some degree...I'll be a little less adamant about wanting to be independent for so long. Because I think in my case, that stubbornness, that my father just didn't want to give up his work in New York made it very difficult...There comes a point when you have to recognize that it's time to move on. Now having said that it's got to be with dignity...

Waldo illustrated how personal care and attention by a professor lead to the trust to be able to tell his story. His story lead to questions about “who” he wants to be in the world.

Waldo
It was the first time I felt like somebody had listened. I would go into his [professor’s] office and I would just chat and he would listen. Ironically, at the end of the class, this was actually the only A I got in my undergrad...we wrote a story. He said write a story about your life or a situation. I wrote my entire story and it was like a 35 page paper... It was after I had come to terms I had a problem.... It kind of brought everything into full circle. It was an opportunity to look back in the
mirror and look at that person in class and say what kind of person do I want to be?

Ed described how his student caregiving experience affected his career path. He chose palliative care because it is what he values even though it is not valued in our culture.

*Ed*

I think as a student caregiver...it shaped my career...I grew to really value caregiving. I would not be where I am... I've got a fight to pick with medicine...I can't do that from the outside...I think this really focused me on something that I just really wanted to change...For a long time I wanted to become an oncologist. Then once my dad started to get really sick I thought maybe I don't want to be in medicine at all...Now I want to do the end of life care...I really want to be in palliative care...It's hard because palliative care has a really bad rep in America.

Natalia shared how her student caregiving journey gave her insight into her priorities, how she will negotiate work life balance, and how she will use the skills of her degree to author her life.

*Natalia*

I feel a lot more mature now than before. I’m more honest with myself about my limits than I was before. I’ve also gained some confidence even at the same time as coming up against my failures. I’ve seen what I have been able to do and I’m proud that I was able to make the decision I made to spend time at home...Your whole life is going to be juggling family and work and I’ve got this crash course in it now...I’m in this very competitive environment and I feel like so much of graduate school is just absorbing these set of priorities and hierarchies that all the people around you have about valuing certain types of achievement over others and really judging people’s worth based on particular types of productivity that they do and don’t achieve...you’re just swimming in it for years and it’s so easy to absorb it and I know I have. I have to actively resist it...It’s made me be more open...there’s a lot of ways that I could use the tools that this degree has given me and maybe I want to teach and work in a certain kind of setting but there’s a lot of other ways that I could use these skills and be the kind of person I want to be.

Alex reflected on the multiple ways his student caregiving affects his personal life, the way he mentors graduate students, and the way he designs his syllabus. He is
very clear that the changes he has made are directly related to his student caregiving experience.

I learned that from all of the caregiving...and school...just because a person says [or does] something...like my mom says crazy shit all the time...and much of the PhD is hazing...doesn't mean that I have to...be miserable...I have options...I actively reject some family behaviors...and I go out of my way not to haze.

I'm not asking students for documentation if they're having a family situation, which logically I know I'm going to get burnt at some point by a student that's going to take advantage of this. I am willing to get burnt that time rather than have the moment when I ask a student to get me documentation when they already have enough on their plate that that little piece of paper is what stresses them out. I look at my syllabi policies from when I was TAing versus when I'm an assistant professor...I used to demand documentation. Now I don't, and it's directly related to my experience.

The thematic element “I have options” emphasizes the role student caregiving played in the development of self-authorship. Each student reflected on the importance of how the role convergence of student and caregiving created the opportunity for growth in confidence, advocacy, and purpose. The personal and institutional resources available when they encountered the crossroads offered them the agency to shape their own path.

Summary

Learning transforms illuminated the role student caregiving played in transformative learning which created a path to self-authorship. Transformative learning entailed becoming critically aware of how institutional and personal resources constructed shifts in self perceptions that resulted in emotional, ethical, and developmental changes. Self-authorship is a process that continues beyond the student caregiving experience, it affects every aspect of a person’s life.
Summary
The participants in this study provided rich and vivid descriptions of their student caregiver journeys. The lived experience of student caregivers was articulated in participants’ stories and interpreted by me through the essential themes: *Timing affects everything, Identities collide across contexts, Structure and flexibility enhance capacity, Coping facilitates health and growth, and Learning transforms the journey.* Chapter six will connect the findings in this study to prior research in education, health care, and psychology.
Chapter 6
Discussion and Implications

“...I don't think you can separate education from anything... it's through our education that we learn how to access information. It's how we learn to judge situations. It's how we learn to negotiate policies and procedures.” (Alex)

Introduction

November 2016-January 2017

“Context matters,” Dr. Morphew (2013) said in almost every lecture in Introduction to Public Policymaking. I was writing the results section of this dissertation when Donald Trump was elected president of the United States. A man who publicly mocked a person with a disability, who boasted of sexually assaulting women, and who was enthusiastically endorsed by the Ku Klux Klan. As a teacher, a recreational therapist and a researcher, I know the socially constructed barriers society already has in place to marginalize people with disabilities. I understand that people who experience sexual and racial violence are at increased risk of developing physical and emotional disabilities. I cried for three days because I have spent 30 years of my life working with and advocating for people with disabilities; I know how this rhetoric and behavior will affect the people I have spent my life serving. My boss—the one who has guided me many times throughout this journey—gently told me to pull it together and get back to thinking like a researcher. He said to look at the argument for Trump. I had no energy to do that, so I immersed myself in my research. However, as I looked at my data through the lens of this new political context, Waldo’s experience gave me a window into the life of the disenfranchised, white male, living in poverty, in a rural community—the demographic that seems to be Trump’s base. I was grateful for these moments of empathy because empathy broadens one’s perspective. Thus, began the journey of conceptualizing this chapter, grounded in empathy.

Context matters. As I reread Waldo’s story, I was reminded how much trauma he endured. Trauma touches every race, class, gender, and ability level. Surviving and coping with trauma was an integral part of this study. One of my former students sent me an email on Christmas Eve that tied my vision of this chapter together. Even though she was not a student caregiver, she demonstrated how she utilized skills she learned in college to help her survive and cope with a trauma she experienced after she graduated—transformative learning at its best. She gave me permission to share excerpts from her email.

Merry Christmas Eve Lisa,
I have been thinking about you...I just have really been wanting to thank you again for all that you have taught me in the short amount of time
that I have known you. You explained subjects in a way that made so much sense to me. The love for your career [recreational therapy] really shines through in the way you teach.

I have recently been involved in a very traumatic situation and I cannot help but think that you came to [university] to teach at the perfect time in my life. I am currently going to counseling once a week and everything we speak about and all of the skills she uses to guide me are things that I have learned from you and I am very familiar with. This makes me feel more relaxed and comfortable when I attend sessions...This has also made me reevaluate my career path...so that I can help others that have been in my situation.

Thank you so much for your passion of teaching and helping others... Also thank you from the bottom of my heart for quite possibly saving my life!

I am still processing this email nearly a month later. I have read it many times. It is saved on my desktop as a reminder that my responsibility as a teacher, recreational therapist, and student affairs professional demands I keep teaching personal coping skills that build resilience.

Context does matter. Today, Trump was inaugurated. Thus, this chapter has inevitably been influenced by this context. I, and many in academia, are bracing for the worst during his administration. We worry about what will happen to our marginalized students: students with disabilities, students of color, international and immigrant students, and students who have been sexually assaulted. We can’t prevent the traumas that may occur to our students because of the policies of his administration. But we are obligated to create an environment—that teaches students how to build resiliency skills so they can cope with the traumas they endure. This passion has helped me cope with my final chapter as a student and transformed my mission as a professional.

Overview of the Study
The purpose of this phenomenological study was to describe the lived experience of students who provide care for a person with a disability or chronic illness.

A phenomenological approach was used to gain a better understanding of how student caregivers cope with the demands of both roles. The strategies students use to cope with stress has an impact on health, and health has an impact on development, learning, and success. The participants for this study were people who were enrolled in a college
degree program while they simultaneously cared for a person with a chronic illness or disability. Fifteen people participated in individual interviews, however, only twelve participants were included in the data analysis. Four of the twelve participants joined a focus group after their personal interview to further reflect on their own personal journeys with others who share their experiences. Student caregivers are a subset of nontraditional students with unique challenges and needs and they are not adequately represented in higher education or student affairs literature. This study is one small step in giving voice to student caregivers by describing their lived experiences.

The research questions that guided this study are: What is the lived experience of students who care for a person with a disability or chronic illness? How do student caregivers cope with the role strain of juggling student and caregiving demands? How do student caregivers develop coping strategies within the academy? Student caregivers are nontraditional students who experience challenges that often result in stress-related illnesses, which have a significant impact on learning, development, and retention. Nine out of the twelve participants indicated that they experienced anxiety and or depression at some point in their student caregiving role. The three participants who did not state that they experienced anxiety or depression per se, explained behaviors, feelings, or physical manifestations that are consistent with situational anxiety and depression. Prior studies suggest that anxiety and depression are common stress-related illnesses associated with caregiving (Isa, Aziz, Rahman, Ibrahim, Ibrahim, et al., 2013; Sansoni, Vellone, & Piras, 2004; Schumacher, et al., 2012). Students who were established in their program and confident in their student identity prior to
becoming a caregiver were able to employ personal and institutional resources to help them develop healthy coping strategies. Direct institutional resources such as faculty support, health insurance, and student health/counseling services were instrumental in the development of healthy coping strategies. Indirect institutional resources that promoted healthy coping strategies were flexibility in the academic schedule, peer support, and learning multiple perspectives through class content that enriched personal reflection. The discussion of the findings and how they connect to prior research are organized by how the themes answered the research questions.

Discussion of the Findings
There were five essential themes that emerged from the data: (1) Timing affects everything, (2) Identities collide across contexts, (3) Structure and flexibility enhance capacity, (4) Coping facilitates health and growth, (5) Learning transforms the journey. The themes were synthesized to create this hermeneutic summary: Timing affects everything in the student caregiver journey; timing in terms of personal development, academic program phase, and point in the academic calendar where the dual roles merged. Identities collide across contexts as students negotiate role strain in their home, academic, and social environments. Structure and flexibility enhance capacity when students balance the needs of the person they care for with institutional expectations. Coping facilitates health and growth when students use personal and institutional resources to develop strategies that promote health and personal development. Learning transforms the journey as students reflect on how they can utilize the insights, lessons, and skills they learned from their dual roles to foster lifelong
growth. This study’s answers to the research questions are embedded in the themes. I have used the research questions to organize the findings in relation to prior research.

**What is the lived experience of student caregivers?**

**Timing affects everything.** The majority of participants either indicated that some part of their student caregiving experience was traumatic or they spoke about it in ways that were consistent with people who experienced trauma. The point in the academic program where trauma occurred has implications for the whole journey. Trauma has cognitive, physical, emotional, and social consequences (Van Der Kolk, 2014). Trauma changes the way the brain functions. Two significant cognitive brain changes that impact student caregivers are the way that trauma affects communication. Trauma deactivates the Broca’s area and the left hemisphere of the brain. The Broca’s area is one of the centers of the brain for speech. When a person experiences trauma the loss of function in the Broca’s area results in the inability to express their thoughts and emotions. The memory of trauma deactivates the left hemisphere of the brain, which also negatively impacts the ability to logically organize experiences and translate them into words. If student caregivers experience trauma during finals week in their first semester of college—like Waldo—the combination of communication barriers they face may impact their ability to succeed. When students do not have the cultural capital to communicate in a way that is respected in higher education, their ability to organize, construct, and translate thoughts and emotions is compromised due to trauma. And if a professor with whom they are communicating does not understand the effect trauma has on speech, this combination of variables may compromise their academic outcomes.
Students who had prior life experience with trauma had a repertoire of coping mechanisms that allowed them to navigate through the stress of student caregiving; whereas, emerging adults who did not have life experience that established healthy coping skills retreated into maladaptive strategies. Kelso, et al (2005) suggest that life experience and intelligence are components that helped people develop coping skills. Both life experience and intelligence are correlated with education levels. Every participant stated that caregiving responsibilities trumped school at some point in their journey because it was the ethical decision for them. This is consistent with prior literature, nontraditional students generally choose non-academic obligations over academic obligations (Pelletier, 2010). Students who had previous experience dealing with trauma were able to stay true to their ethical obligations in a way that didn’t negatively affect their long-term academic goals. Students who had the fortune of having an acute crisis happen near or during an academic break had time to physically attend to the demands of the situation and the emotional space to process the event without the added pressures of completing academic tasks. In contrast, students who had the misfortune of having an acute crisis occur during midterms, finals, or a project deadline had to choose to complete the academic task or care for a human being. This stress contributed to the anxiety or depression that developed for almost all participants. A study by Chappell (2016) explains caregivers experience anxiety more than non-caregivers and anxiety and depression often occur together. Stress and health have an impact on educational outcomes (Goldrick-Rab & Cook, 2011).
Structure and flexibility enhance capacity. Both structure and flexibility are essential components for student caregivers’ health and success throughout their journey. They seem to be the antithesis of each other but they complement each other to either exacerbate or mitigate the stress of being a student caregiver. Structure pertains to the caregiving side of the equation and flexibility pertains to the student side of the equation. When students care for a person who has predictable needs, they are able to develop a routine and can organize their time—and energy—to balance both roles. However, when students care for a person with an invisible illness that is erratic in nature—like mental illness, dementia, Huntington’s Disease, or Attention Deficit and Hyperactivity Disorder—they are less able to organize their time and balance their own needs. This finding is consistent with other studies (Pickett, et al., 2007; Quine & Pahl, 1991; Quinn, et al., 2008). Thus, if students care for a person with an unpredictable illness or disability and they experience inflexibility at school, their stress level increases.

Many student caregivers in this study felt the institution was not responsive or respectful of their personal commitments beyond academics. Quine & Pahl (1991) indicated that the way the community responds to your situation can be a source of stress. Students who attended community colleges and graduate students who were in the dissertation phase, experienced the most flexibility from faculty in this sample. Professors at the community college are used to working with nontraditional students with competing personal demands, thus flexibility is part of the culture (Rose, 2012). Pedagogical philosophy also contributes to an instructor’s willingness to be flexible at all institution types. Classroom environments that promote competition over collaboration
are inherently less flexible (Weimer, 2002). Students in the dissertation phase had the benefit of communicating mostly with their advisor, with whom they already had an established relationship. In addition, flexibility is built into the structure of the dissertation, it depends on autonomy—both in content and in execution. The majority of students in this sample had advisors who were supportive, however, one doctoral student did have a contentious relationship with her advisor, which she contends affected her ability to persist. One of the ways that advisors provided flexibility is through the use of technology. Technology allowed students to attend classes virtually, submit assignments and conduct research online, and access assistive technology. Struckmeyer (2013) suggests that caregivers who are comfortable using technology and the internet are able to access information and resources more easily than caregivers who were not confident with technology. The freedom technology offered student caregivers was a significant resource because of the onerous time constraints they faced.

Flexibility in the system gave students a sense that there was a purpose for the academic structure but when the academic structure was not serving the students’ needs it could be modified. Multiple studies identified the need for higher education to meet the needs of students where they are (Keeling, 2004; Tett, 2004; Pelletier, 2010; Ramos, 2011). Flexibility gave students the perception that they were being treated with dignity. Treating the care receiver with dignity was always a priority from their caregiving perspective. When they were treating someone with dignity, and they were
treated with dignity, they were able to treat themselves with dignity. We learn to care for ourselves by the way we are cared for (Van Der Kolk, 2014).

**How do student caregivers cope with the role strain of juggling student and caregiving demands?**

**Identities collide across contexts.** Conflicting student and caregiver identities are linked with role strain. Student caregivers experienced fatigue switching between roles. Role is not synonymous with identity. Role involves action, it refers to the responsibilities that are required in a particular context. Identity refers to the process of developing a “...sense of self in a context shaped by historical events and social and cultural conditions and by issues emanating from family and ethnic heritage” (Pascarella & Terenzini, 2005, p. 22). Student caregivers must balance both their student and caregiver identities. Erickson describes a sense of identity as “being at home in one’s body...and knowing where one is going...it is constantly lost and regained...” (Erickson, 1959, pp. 92-118). The physical and emotional stress of juggling both roles affects: how comfortable a student caregiver is in his/her body, how confident a student caregiver is in pursuing educational goals, and how adaptable a student caregiver is to the unpredictability of the journey. Student and caregiving identities intersect and are altered through personal development, knowledge acquisition, and social engagement. Role conflict is a common stressor for traditional college students as they negotiate independence for the first time and learn to balance the personal, school, and friendship demands (Hudd, et al., 2000). It is even more significant for student caregivers.
The constant moving between roles affects developing a consistent personal identity. While Goldrick-Rab & Cook (2011) argue that college is no longer the place for most students to explore their identity because the credential is about social mobility, student caregivers are almost forced to do identity exploration because of the conflicts in their multiple identities. Every participant indicated that their caregiver role always superseded their student role during an acute health crisis, which impacted their student identity.

Lee, Datillo, Kleiber, & Caldwell (1996) found that leisure helped patients provide continuity between their identities before a traumatic experience and while they were adapting to their new identity. Natalia and Waldo provided examples of how leisure experiences helped them navigate their shifting identities. Natalia shared that her dog provided a sense of continuity between her identities. She relied on him to provide comfort everywhere she went; he was great with her mom when she was caregiving and he was a companion when she traveled back to school. She indicated that he knew her in every place she went. Waldo began to cope better when he started mixed martial arts because it helped him reconnect to his previous identity as an athlete. Most other participants discussed how they compartmentalized each identity, either because it offered them an escape from the other role or because it was too exhausting to reveal who they were in the other context. This lead to feelings of isolation, which has been noted in numerous caregiver studies (Isa, et al., 2013; Kelso, et al., 2005; McGillick & Murphy-White, 2016). Ed used exercise, his leisure, to cope while he was a caregiver but reflected that after his caregiving identity ceased that he would have been healthier.
and provided better care if he had gotten the perspective he needed through social support systems, instead of just exercise that was a solitary activity.

A study conducted by Struckmeyer (2013) about student caregivers who are emerging adults found that identity development was not negatively impacted by their student caregiving role which is inconsistent with this study. I suggest that the difference in results is due to the difference in the type of caregivers our studies focused on. The student caregivers in his study were secondary or tertiary caregivers, which means they were not responsible for the bulk of the caregiving responsibilities. The participants in this study all identified as primary caregivers, which means they were, or felt, responsible for the majority of caregiving tasks.

The point students were at in their academic program had an impact on how prioritizing their caregiver identity affected the faculty’s perception of them as a serious student. The culture of higher education dictates that students should prioritize their student identity over all other identities (Brus, 2006). Student caregivers internalized the master narrative—the language, behaviors, and culture that promotes success in higher education—through direct and indirect messages from faculty. Participants who were continuing generation students understood the cultural expectations early in their journey. However, first generation students had to learn the language, the expectations, and the cultural cues within the institution to navigate through the system. Fragoso, et al., 2013 suggest that early faculty contact with nontraditional students to help them transition is necessary to mitigate the stress of uncertainty. Quinn, et al. (2008) offer a similar suggestion for caregivers, early education for
caregivers will assist them in navigating the illness. Several student caregivers in this study expressed that they would have liked to have been aware of the support services available through the institution and have those services available outside normal business hours to accommodate their schedules.

Student and caregiving identities were fluid, they changed depending on the context. Shifting identities exacerbated role strain, particularly when an acute health crisis and a school responsibility overlapped. However, feelings of competence with one identity had positive implications for other identities, which has been found in other studies about nontraditional students (Taylor, 2010; Tett, 2004). Higher education is a safe space for nontraditional students to develop evolving identities. “For nontraditional students already engaged in other social roles, combining studying with other commitments (parenting, work, taking care of elderly parents or siblings, etc.) is challenging, but often highly motivational, the boost it gives to changes in one’s life should not be underestimated” (Kurantowicz & Nizinska, 2013, p. 138). Each participant in this study did note that being a student caregiver shifted how they saw themselves in some significant, mostly positive, way.

**How do student caregivers develop coping strategies within the academy?**

*Coping facilitates health and growth.* Coping is a process student caregivers engage in which facilitates health and growth. Several participants in this study expressed that they engaged in both adaptive and maladaptive coping strategies. When they felt that they had no perceived control over their circumstances, they were more likely to make choices that did not promote health or growth. Perceived control is cited in both caregiver and education literature as a means of improving health and learning
outcomes (Green, 2004; Weimer, 2002). Perceived control increases with access to personal, community, and social resources.

Coping takes into account life experiences and personal resources which are influenced by human, cultural, and social capital. Human capital develops from the knowledge and skills that are learned in higher education which have a positive impact on health awareness (McMahon, 2009). Cultural capital is fostered through educational attainment which promotes an understanding of the dominant communication style, and provides access to networks that have resources and power (Paulsen & Smart, 2001). Cultural capital is often passed down from parents, however, nontraditional students see higher education as a way to gain cultural capital (Flacks & Thomas, 2007). Student caregivers who have cultural capital are able to access the communication style they need to articulate their particular circumstances to professors that will allow them to be heard. Social capital gives student caregivers access to social networks that can connect them with expert information and social support (Glover & Hemingway, 2005). Historically, higher education has been viewed as a means to make social connections that were deemed essential for success throughout life (Vine, 1979). Social capital for student caregivers provides access to social support.

Human capital, cultural capital, and social capital align with the five coping resources in the Transactional Stress and Coping Model: (1) utilitarian, (2) problem solving skills, (3) health/energy/morale, (4) general and specific beliefs and (5) social networks (Folkman, Schaefer, & Lazarus, 1979). The way I conceptualized their connections is in Table 8. I envision human capital encompassing utilitarian, problem
solving skills, and health/energy/morale; cultural capital encompassing general and specific beliefs; and social capital encompassing social networks. Utilitarian resources comprise socioeconomic status, educational attainment, and financial security; they are the link to all other resources. In a study by Quine & Pahl (1991), caregivers who had access to utilitarian resources experienced better health than caregivers who did not have access to them, which affected access to other resources. Problem solving skills are the ability to think abstractly to assess a situation and decide on the best course of action. Health/energy/morale pertains to one’s current physical and mental health, individuals who are healthy have energy and motivation to set and achieve goals. General and specific beliefs correspond with a person’s sense of perceived control and self-efficacy. Social networks are established social connections to support individuals even when they may not have the energy to find the support they need.

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<tr>
<th>Transactional Stress &amp; Coping Model Resources</th>
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<td>Utilitarian</td>
<td>Human capital</td>
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<td>Problem solving skills</td>
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<td>Health/energy/morale</td>
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<td>General and Specific Beliefs</td>
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<td>Social Networks</td>
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Table 8 Coping Resources and Capital Correlations

Cultivating perceived control and self-efficacy, which are components of general and specific beliefs resources, and garnering social support, which is integral in the social networks resource, are the foundation for recreational therapy. Recreational therapy is a field within human services that uses leisure to promote healthy lifestyle
choices. Leisure was one means student caregivers used to reestablish some control in their lives and to connect with people.

Leisure is a tool for developing coping strategies (Iwasaki, et al., 2005). Every student caregiver in this study expressed that they “took time” for themselves when they could or when they did not have the energy to do anything else. I deliberately chose to use the phrase “time for yourself” instead of leisure. People who are guided by the ethic of care, may experience leisure as selfish and feel guilty about choosing leisure as self-care (Bedini & Phoenix, 2004; Henderson & Alian, 1991). Although, the participants in this study articulated leisure as “time for myself,” “stress relievers,” “self-care,” and “ways to stay healthy,” for simplicity I will refer to this concept as leisure. Leisure provides a safe place to regroup when life is stressful, the choice of the leisure activity depends on the type of stress, and the most important part of leisure is that it is your choice to participate (Iwasaki, et al., 2005). Some student caregivers needed leisure to be solitary and some student caregivers needed leisure to build social support. The types of leisure participants in this study identified were exercise, reading for fun, going out with friends, music, participating in community theatre, physical contact, and eating healthy. Pooja shared how being in school helped open her world, not only through what she was learning, but also by giving her confidence to do and try things that she would never have chosen to do and to interact with people she wouldn’t have had the opportunity to meet. She became involved with the community theater which connected her to an old friend, new friends, and professors at her college. The more
worlds people belong to the more resources they have access to through social capital (Gladwell, 1999; Glover & Hemingway, 2005).

While the leisure world offered a break from the burden of caregiving through social capital, the academic world offered resources that enhanced human and cultural capital. The majority of participants in this study indicated that school offered them some resources to help ease the burden of caregiving. The ways in which school helped them cope were with concrete resources such as health care insurance, student health services, supportive faculty, flexibility in class schedules, and access to technology and social connections. Academic work often provided an escape from caregiving duties. The credential at the end of the program also gave student caregivers a means for social mobility.

Coping is a process that uses primary and secondary appraisal to gauge whether an event is a threat or a challenge (Folkman, Schaefer, & Lazarus, 1979). People who have access to coping resources are more likely to appraise a stressful situation as a challenge rather than as a threat. The appraisal of an event may change over time, something that causes stress at one time may be considered a challenge when new skills are learned and additional resources are attained. Student caregivers in this study, expressed that they did learn how to cope more effectively as time went on. One participant stated that the way he coped was staying in survival mode while he was a caregiver, but developed healthier coping strategies once his father passed away and he lost his caregiver identity. He wishes he would have reached out for help and support while he was a caregiver, he is using that awareness as an end of life care physician for
both his and his patients’ caregivers well-being. This demonstrates that coping is a process that has implications for future personal and professional situations.

Learning transforms the journey. Academic content combined with caregiving experiences and personal reflection lead to transformative learning for student caregivers. “Learning should be seen as a qualitative change in a person’s way of seeing, experiencing, understanding, conceptualizing something in the real world—rather than as a quantitative change in the amount of knowledge someone possesses” (Ramsden, 1988, p. 271). The personal reflection component was essential in finding meaning and purpose in their struggles. The most vivid example of this in this study was Waldo’s final paper in his death and dying class. He indicated that paper was the catalyst to bring all his experiences together so he could make sense of them, then he could compartmentalize them so he did not have to carry his trauma as an open wound.

Waldo was able to write about his trauma because he had built a trusting relationship with his professor by engaging in discussions with him during office hours, safe conversations outside of class time. Trolian, Jach, Hanson, & Pascarella (2016) state that academic motivation is “...associated with resilience and helping students cope with stress” (p. 4) and suggest that informal student-faculty interactions are correlated with increased levels of academic success and personal development. This has significant benefits for Waldo’s own long-term health because it helped him build resiliency.

“Resiliency, defined as the ability to bounce back from stressful and adverse situations, has been associated with positive health outcomes...Resiliency also depends on the breadth and accessibility of one’s coping arsenal...” (Shaffer, et al., 2016, p. 2). Writing
to compartmentalize his pain in a healthy way was the first of many coping strategies that Waldo developed throughout his journey as a student caregiver. Writing has been identified as a strategy to help caregivers make meaning of their experiences and promote health (Butcher & Buckwalter, 2002).

The tools student caregivers developed in their disciplines helped them problem-solve throughout their student caregiver journey. Alex provided multiple examples of how his education gave him the tools to help him solve problems and prioritize tasks as a student caregiver. During the acute phase after his mom’s stroke he used his research skills to find information about her particular type of stroke. This allowed him to feel more competent when he interacted with her physician. He then used his teaching skills to relay information to the rest of his family in a manner that they could understand. Alex employed his expertise in event planning to prioritize tasks so that he could organize and manage his responsibilities in his student and caregiving roles. He drew on his knowledge as a leisure studies professional to incorporate time for himself so that he had the energy and perspective to continue to provide care and complete his academic goals in a healthy manner. Alex’s experience is consistent with a recent study by Milligan & Morbey (2016) that looked at coping and identity for older male caregivers and found that caregivers used problem-solving skills that stemmed from their previous education. This suggests that the problem-solving skills student caregivers develop may have benefits throughout their lives in multiple contexts.

Every student caregiver indicated that providing care for a person with a chronic illness or disability while pursuing a college degree transformed who they were as a
person. “Transformative education...places the student’s reflective processes at the core of the learning experience and asks the student to evaluate both new information and the frames of reference through which the information acquires meaning” (Keeling, 2004, p. 9). The dual roles made them mature faster than peers of the same age; positively affected their career path and how they practiced in their chosen field; it fundamentally altered their personal identity. This is consistent with prior research that suggests nontraditional students experience a more significant change in identity than traditional students and they perceive more value in their education (Taylor, 2010).

Every participant in this study reflected on how their experience as both a student and a caregiver informed each role, how the content and skills they learned in the academy cultivated resources, and how the intellectual and social connections they made will foster lifelong human capital, cultural capital, and social capital.

**Implications for Theory**

The results from this study support previous research that suggests using theories of student-centered teaching, transformative learning theory, and self-authorship theory in higher education practice promotes identity development, academic success, and personal and professional growth (Chism, 2002; Hodge, et al., 2009; Keeling, 2004; Weimer, 2002). These theories, as they are discussed in previous literature, are interconnected but not necessarily hierarchical. However, in the context of this study, I will discuss them as progressive to align with the hierarchical structure of the themes. Student-centered teaching provides a foundation for student caregivers to experience a safe and flexible learning environment no matter what time in their academic or life phase they become student caregivers. Transformative learning
emerges in a safe and flexible student-centered atmosphere, both in and out of the classroom, and promotes the ability for student caregivers to transfer information to negotiate identities and coping strategies across contexts. Self-authorship builds and strengthens a student caregiver’s capacity to use personal and intellectual growth to develop a secure identity that is conducive to lifelong learning and advocacy. This study provides new ways of understanding how the theories of student-centered teaching, transformative learning theory, and self-authorship theory can foster academic success, identity development, and health for student caregivers who are a growing and understudied student population with diverse needs.

Student-centered teaching highlights shared authority in learning environments, actively connecting prior knowledge to new knowledge, and incorporating time to reflect on about how personal history, values, and health inform how students make meaning of newly acquired knowledge (Weimer, 2002). Active learning is prioritized over passive learning in these contexts and instructors see themselves as facilitators in the learning process rather than as experts. Thus, students are able to view themselves as partners in the learning process and learn to value their experiences as integral components of development. Participants in this study who had professors that practiced student-centered teaching were granted flexibility to meet the responsibilities for both their student and caregiver roles; whereas, instructors who used teacher-centered practices created a structure of class requirements that were inflexible and exacerbated role strain. Student caregivers who did not experience a flexible student-centered learning environment were met with resistance when they tried to explain
their particular circumstances. Professors indicated that making any modifications for them would be unfair to other students. Chism (2002) asserts that fair treatment does not mean the same treatment. When students in this study were forced to decide between caring for a loved one and completing academic tasks, all students chose their caregiver role over their student role. For some students who made this choice, it had a negative impact on their learning outcomes and academic success. Student caregivers that experienced support from professors that practiced student-centered teaching were better able to negotiate their dual identities, which mediated the negative effects of role strain and promoted positive learning outcomes and academic success. Student-centered teaching facilitated perceived control and increased help-seeking behaviors for student caregivers; prior research shows that both perceived control and help-seeking promote greater academic achievement (Pintrich & Zusho 2007). This study expands the benefits of student-centered teaching to student caregivers by illustrating that the flexibility inherent in the theory-informed practices of student-centered teaching create an atmosphere that increases the opportunity for success and development among student caregivers.

Transformative learning incorporates the reflexive process of applying new concepts and skills from one context to another context (Keeling, 2004). It is important to remember that transformative learning requires the cognitive ability to apply knowledge from one context to another. When the student caregivers in this study were in the acute stages of coping with trauma, they did not have the cognitive ability to engage in transformative learning—or the capacity to effectively communicate that they
were experiencing trauma. Student-centered teachers were able to notice changes in a student’s communication and cognitive abilities that affected academic success; while teacher-centered instructors adhered to rigid standards without taking personal circumstances into consideration. This is an example of the progressive nature of these theories in the context of this study; student-centered teaching is the foundation for respecting and accommodating diverse learning needs. Chism (2002) discusses student-centered teaching as a means of respecting student diversity, and this study supports including the diverse needs of student caregivers. The findings in this study elaborate on existing transformative learning theory by demonstrating how trauma may affect the capability for transformative learning and how student-centered teaching supports transformative learning.

Transformative learning promotes self-authorship. Self-authorship is the ability to acquire knowledge and process that information so that it facilitates the development of a secure identity and cultivates the ability to make internally informed decisions (Hodge, et al., 2009). These decisions allow one to make healthy choices based on current personal needs rather than blindly obeying an authority figure or replicating unhealthy behavior patterns. Student caregivers in this study exhibited growth in self-authorship when they learned how to cope with their student and caregiving responsibilities and tend to their own health needs. Participants in Baxter Magolda’s (2001b & 2007) longitudinal studies (traditional students at the time of the original study) indicated that they did not experience these types of choices until their post-college adult lives; thus, self-authoring began later. Students who did not have
provocative experiences in college that disrupted their equilibrium were not pushed to a crossroad where they had to make self-authored decisions in order to accomplish their aspirations. On the other hand, students who are considered “high risk” because of marginalized identities are often “…thrust into self-authorship if they wanted to achieve their goals” (Pizzolato, 2003, p.807). Since student caregivers are at risk for stress-related illnesses they can be considered “high risk” students. The lived experience of student caregivers deepens our understanding of self-authorship theory by demonstrating that the choices they are required to make in order to care for a vulnerable human being, complete academic tasks, and attend to their own health facilitate self-authorship while still in the academy.

Student caregivers are “high risk” students because they are at greater risk for stress-related illnesses, thus, they have diverse needs. Health has a significant impact on learning outcomes (Allensworth, 2011; Burke Harris, 2012; Stern, 2002; Sumowski, Wylie, DeLuca, & Chiaravalloti, 2010; Woolf, Johnson, Phillips Jr, & Philipsen, 2007), thus, health considerations should be a component of student-centered teaching. Many educators and student affairs professionals have not been sufficiently trained in anatomy and physiology to understand how emotional and physiological responses during the learning process affect learning outcomes. Negative and positive emotions have different effects on the cardiovascular and nervous systems, as well, as cognition (Fredrickson, 2000; Sternberg, 2000). Negative emotions activate the sympathetic nervous system, which floods the body with stress hormones that directs blood flow to the organs of the body needed for physical action, narrows cognition to focus on
survival, and inhibits the immune system. The findings in this study indicate that student caregivers experienced negative emotions when their student and caregiver identities collided. On the other hand, positive emotions: activate the parasympathetic nervous system, which releases hormones that widen blood vessels to promote circulation of oxygenated blood to the brain; broaden cognition to incorporate multiple courses of action, not just survival; and strengthen the immune system. Keeling (2004) states that “relaxed alertness” (p. 12) is necessary for transformative learning. Thus, positive emotions are essential for building a healthy and transformative learning environment. In this study, student caregivers expressed that using information they learned through their academic disciplines helped them make meaning of their dual roles, and produced more positive feelings toward the experience of student caregiving.

The Broaden and Build Theory of Positive Emotions illustrates how positive emotions enhance intellectual, physical, social, and emotional resources (Fredrickson, 2000). “Emotions are short-lived experiences that produce coordinated changes in people’s thoughts, actions, and physiological responses” (Fredrickson & Branigan, 2005). In other words, emotions, both positive and negative, alter a person’s cognition, choices, and physical responses. Negative emotions evoke specific action tendencies, which narrow response choices physically and cognitively; as increased blood flows away from the heart and brain and to the muscles. The lack of rich oxygenated blood in the brain reduces a person’s choices of how to respond to a situation. Positive emotions evoke thought-action repertoire, which broadens a person’s choices of how to respond to a situation, as the body increases blood flow to the brain and heart.
Positive emotions promote coping; coping fosters resilience; and resilience helps access positive emotions (Fredrickson, Tugade, Waugh & Larkin 2003). This creates an upward spiral towards greater health and more resilience. Understanding biological connections to stress and disease provides a student caregiver more perceived control (Sternberg, 2001) and it provides context and a rationale for self-care. Self-care leads to improved coping, healthy coping leads to resilience, and resilience leads to confidence in the ability to cope in the future. An essential theme of the lived experience of student caregivers in this study was coping, including a thematic element of self-care. This process was particularly evident in Ed’s interview. He stated that when he went to student health and received counseling he learned that he did not have resiliency skills, but he developed them through counseling, finding social support networks in his department, and he continued to learn more about them in his psychiatry rotation in medical school. The resilience he started building as a student caregiver is helping him cope with losing a friend and colleague to suicide. And he is reaching out to other colleagues to help them cope. In these ways, the findings of this study offer a new source of validation of some key features of the Broaden and Build Theory of Positive Emotions. Resilient people are able to generate positive emotions for themselves while also stimulating positive emotions in others (Fredrickson, et al., 2003).

**Implications for practice**

Spring 2012-Fall 2016

I earned the Certificate in College Teaching, which emphasized student-centered teaching. The classes attracted students from disciplines across the campus, many of whom were not necessarily familiar with this theory or practice because it was not utilized in their disciplines. When I read the following quote in the scholarship of teaching and learning literature, it was transformative; “Equal treatment involves not necessarily same treatment, then, but treatment that respects the
individual circumstances of particular learners” (Chism, 2002, p. 145). I connected student-centered teaching with the way I practiced patient-centered care as a recreational therapist.

In any activity I led, I could have patients who were undergoing chemo, recovering from a stroke and experiencing dominant side limitations and/or speech difficulties, enduring neurological disorders, and waiting for a heart transplant. My responsibility was to make sure each participant was able to participate at their ability level. That means I had to figure out how to adapt every activity for every single patient in the room. I had to decide how to modify the activity for each person as I was leading the activity. This skill translates well into student-centered teaching in significant ways. As students in my certificate classes were wondering or suggesting that adapting instruction styles and modifying due dates to meet students’ particular needs was coddling or reducing standards—I was thinking that it’s just what you do if your goal is to have all students participate at their fullest potential. My interdisciplinary perspective was invaluable to me because I could see how a skill I had already established would be useful in a new context. My advisor, who also taught a class in the certificate program, told me, “You have multiple hats inside your teaching hat.”

I used that insight in every class I taught. One semester, I had a student who looked visibly distressed during the first test. She was beet red, literally had sweat dripping from her brow, and fidgeted the whole time. She failed the test despite her insightful contributions in class and satisfactory work on class assignments. From a research perspective, I knew that her test grade was not an accurate measure of her ability. I spoke to her after the first test and asked if there was anything I could do to help her. I also asked if she had any accommodations that I should know about. She went into a well-practiced diatribe about how she has never been good at tests and most teachers give her extra assignments to do to make up for her test grades. I explained that I would rather she experience some control and success taking a test rather than just writing herself off as a terrible test taker. We worked on a plan together so she was able to make decisions and construct the experience in a way that allowed her to feel perceived control. She was a recreational therapy student and I stressed that modifying the activity and environment to produce successful outcomes is the biggest part of the job and the best way to practice is to do it for yourself (I emphasize this to all my students). She explained that she got very distracted by sounds and movements from classmates while she took tests. When I asked her what she did to help her focus in other contexts, she indicated pacing helped her relax and think more clearly and she was able to concentrate better when she listened to music. I asked her what was one little thing that she could bring with her to the test that would make her happy and she said a snack. For her, pacing, eating, and listening to music were leisure activities. The classroom I taught in that semester had a nook right outside our room that was sheltered from the main hallway. For the second test, we set
up her desk in the nook and our agreement was that she could pace as she needed to, eat a snack, and listen to music with headphones (she used a device that did not have access to the internet). When she handed in her exam, she said, “I don’t know how I did, but it was the first test ever that I did not feel sick.” Her grade for that exam was 31% higher than the previous exam, despite more difficult content. She employed the same strategies for the final exam and made an incremental grade improvement, but her posture, breathing rate, and self-talk going into the final gave me cues that her experience with success was transformative. When she realized that changes in the conditions of the testing situation had an effect on her success, she was finally willing to seek the accommodations with Student Disability Services she needed to promote a healthier test taking experience that demonstrated what she actually learned. The positive emotions she nurtured through developing healthy coping strategies transformed her performance and re-authored how she viewed herself as a test-taker.

In the current study, Pooja provided an example of how student-centered teaching helped her succeed and promoted positive emotions. She had a very difficult time learning math concepts through her online course. Pooja started back to college at fifty years old, she had not taken a math class in three decades, and the self-instruction required for online learning did not fit with her learning style—particularly for math. The math department provided an alternative structure for learning and offered her a tutor, which provided her with flexibility in how the content was presented. I remember how her demeanor changed in the interview when she recalled that “everything clicked for me” when she had personal instruction; she sat up straighter and smiled. The memory of success elicited the positive emotion joy, for her. While Pooja was in school, the joy she felt with each accomplishment she achieved facilitated interest in learning more and allowed her to be more content with herself. The student-centered teaching that promoted positive emotions transformed Pooja’s perception of herself and she said that when she reflects on that time, she realizes that she is a
completely different person than when she began school because of the positive emotions associated with her experience.

Orla offered another perspective about how interest in a particular assignment elicited positive emotions and helped her cope with her caregiver role by establishing boundaries with the care receivers. She wrote a paper that aligned with her interests in human rights and she had fun doing the “mental gymnastics” that she had to do to conceptualize and write the paper. Taking time to block off two weeks to completely focus on a paper produced feelings of contentment, and she said that she was “in sync with the world.” Orla felt that she was able to set boundaries without feeling guilty. Reframing an academic project as leisure helped her cope with her caregiving role.

Leisure is an avenue for building positive emotions and for coping (Schumacher, et al., 2012). Iwasaki, et al. (2005) suggest the benefits of using leisure to cope are: it generates hope, it grants opportunities for personal development and self-transformation, and allows for new life meaning to emerge. Leisure is subjective; it is different for everyone. Whether I am teaching technology classes for pre-service teachers or recreational therapy classes, I always suggest to my students that they make sure they are taking time to have fun and to figure out ways to make learning fun. I tell them the story of how I survived my statistics class. I bought myself a mini trampoline and I’d read a problem and then jump until I could figure out how to approach it. I told them that I know that the research indicates that moving while you are learning helps build neuropathways for retaining and retrieving knowledge (Jensen, 2005). And the silliness of “jumping my way through stats” just made me laugh. Many students, years
after they have taken my class, have told me that they often think of this story when they have to tackle something difficult.

Eliciting positive emotions can be incorporated into student-centered teaching and it is beneficial for both the students and the teachers. I know that when I am joyful, interested, or content when I am standing in front of my classroom, I am a better teacher. I have more energy, perspective, and empathy for students’ individual needs.

Based on this study’s findings, student caregivers would benefit in multiple ways if their instructors were to take a student-centered approach to teaching. The practices associated with a student-centered approach would provide flexibility for student caregivers in regard to assignment deadlines and content choice. These practices will also allow alternative learning structures and opportunities for personal instruction, such as tutoring or peer mentoring. Effective student-centered instruction incorporates the understanding that fair treatment does not mean exactly the same treatment, which acknowledges that making accommodations for when emergencies arise demonstrates empathy, not compromised standards. This allows student caregivers to maintain their dignity. Finally, creating an inclusive classroom climate that generates and elicits positive emotions will best serve the diverse needs of all students in the class. Student-centered teaching practices offer resources for student caregivers to build personal coping strategies. Healthy coping strategies buffer the stress of balancing the dual identities of student and caregiver. These types of teaching practices are especially important for the unpredictable timing of caregiving expectations that student caregivers encounter.
Centers for teaching on college campuses should provide workshops to facilitate innovative teaching strategies for faculty, teaching assistants, and adjunct instructors. I suggest that centers for teaching include workshops that teach student-centered skills like those mentioned above which were identified to be effective for student caregivers in this study.

One of the many roles in which student affairs professionals serve is as advisors. Advisors are obligated to make sure academic requirements are met. Student caregivers in this study had both positive and negative experiences with advisors. Meeting their academic requirements, while also meeting all the demanding needs of their respective care receivers, is a consistent source of significant stress. Participants who had advisors that demonstrated warmth and tried to make a personal connection had a much more positive experience, had better learning outcomes, and coped in a healthier way than participants who did not. Based on the findings of this study, I recommend that student affairs associations and conferences offer professional development workshops that focus on advising sessions and the development of advising skills that facilitate a more comprehensive understanding how positive emotions can build trusting relationships and enhance personal resources. This study indicates that student caregivers have special needs for, and benefit from personal connection, empathy, and skills and resources for coping with the conflict between two identities—student and caregiver. Therefore, student affairs professionals in the role of advisors should also ask students to provide information about their interests and personal challenges—if they choose to reveal personal information—so that advisors
can help students develop a system that connects them with peers who can offer social support.

Implications for Policy

When I teach introductory recreational therapy classes I often have students who like the idea of helping people who have a disability or a serious illness but who have never actually encountered or helped a person with a disability or serious illness. I always require volunteer hours to allow students to practice relating with people with a variety of illnesses and disabilities. It is important to remember that trauma, illness, and disability alter communication styles; a recreational therapist has to adapt to communicating through means other than spoken language. I also like to prepare students that when people are adjusting to a new illness or disability, they are afraid, and nobody is their best self when they are afraid. I tell them the following stories to illustrate my point.

One patient I saw had throat cancer and the radiation to treat the cancer damaged his vocal cords and he was unable to speak. He was illiterate so he was also unable to write so that he could communicate his wants and needs. He did not have private insurance and the state papers did not give him access to technological devices that could have helped him communicate. When I visited him he was scared and lonely. The university hospital was the only one in the state that accepted state papers so he was hours away from his support system. His countenance, posture, and body language clearly communicated his fear and feelings of helplessness. My initial goal was to help him feel comfortable with me, so I did my usual goofy stuff to get people to laugh. As we got more comfortable with each other, I suggested that we play charades. After several games when we both started to learn how to understand what the other person was trying to say by using gestures and body language, I used it as the opportunity to remind him that he had a lot of skills that allowed him to communicate. One day when I walked into the office, my boss told me I needed to get to his room right away. He refused to have a necessary procedure done unless I went with him. I went with him to the procedure to provide the support he needed to feel safe, which allowed his body to get the support it needed to heal. Later I asked a nurse how he communicated his desire for me to accompany him. She told me that when the orderly came to pick him up he held on to the bed rail and refused to let go. When the nurse was called to “reason with him” he shook his head. He used his hands to make the outline of a person, then smiled and pointed to his smile, and used his hands to indicate a small person (I am 4’9"). It was through the game that he learned how to access his personal resources to get his needs met.

The other patient story I tell my students is about a man who all doctors, nurses, and therapists labeled as non-compliant. He yelled and screamed at anyone who came into his room—including me, initially. He was literally stuck in the hospital,
no nursing facility would take him so the hospital could not release him. Most professionals refused to work with him beyond what was critical to keep his condition stable. After weeks of me coming and being goofy despite his yelling and swearing at me, he asked why I kept coming. I told him that I love a good challenge and he was a bit challenging. He actually laughed. Thus, began our relationship. And on my birthday, he was the one that bought me a birthday cake so we could celebrate at the hospital when I worked. An occupational therapist asked me how I got him to be “nice.” I said that I listened to him, made him feel safe, and had empathy for his particular circumstances. After years of being dismissed by occupational therapists and physical therapists they approached me and asked if I would visit him right before his therapy appointments. I agreed, which started better care for the patient and a more respectful professional relationship with the occupational and physical therapists for me.

Each time I reflect on those experiences, new meanings emerge. When I reflect on them in the context of this study, I see how helpful it was for me to have my health care background as I cared for my son and how helpful it is for me to have my healthcare background as a teacher and student affairs professional. The combination of my experiences affect the way I teach and approach student affairs practice and made this study possible.

My interdisciplinary perspective on trauma, disability, and illness has been invaluable to me as a teacher and student affairs professional because it helps me understand how trauma affects communication and cognition. I have the benefit of knowing how the body physically and emotionally responds to stress and trauma because of the curriculum I was required to take in my training as a recreational therapist. That curriculum also provided me with specific knowledge about a spectrum of illnesses and disabilities. However, there was no comparable content in the certificate in college teaching or in my student affairs training.

Student caregivers in this study experienced trauma, stress-related health issues, and anxiety, which shaped their identity development, coping strategies, and had an impact on learning outcomes. Understanding a few relevant aspects of human physiology would help faculty and student affairs professionals to better recognize
when the stress response will impede learning outcomes for student caregivers. Similarly, understanding the effects of trauma would also help faculty and student affairs professionals identify when changes in communication, learning, and health may interfere with academic and developmental growth. Finally, having a basic understanding of the physical and emotional effects of a variety of illnesses and disabilities would also help faculty and student affairs professionals give the identities of student caregivers an equal place in the conversation about diversity. Because improving learning outcomes is a core goal for faculty and respecting students as holistic beings is a core goal for student affairs professionals, then the curricula to prepare professionals for these roles might be enriched if programs were to consider offering at least some content representing a basic knowledge of some relevant elements of human physiology and the effects of trauma.

In this study, Jessica, Waldo, Jenna, and Amy expressed that they shut down and stopped communicating with professors because they didn’t have the energy or communication skills (as a result of their trauma) to fully explain their situations in a way that was either heard or respected by their professors. It is possible that these students’ professors did not recognize the signs of trauma, or how the rigid structure they imposed to meet the standards of “fair for all students” was having a negative impact on the student caregivers’ academic success. With this in mind, I suggest a possible policy change for curricular content in Certificate in College Teaching programs; I suggest that such programs consider including at least some course content that
delineates how human anatomy and physiology affect cognition and communication, which have a significant impact on learning outcomes.

Student caregivers in this study used student affairs services as methods for coping with trauma and negotiating their dual identities. I suggest that one possible policy change for curricular content in student affairs programs might be to consider at least some relevant content on human anatomy and physiology to promote a better understanding of how bodily functions can impede or facilitate transformative learning and self-authorship.

Some student affairs professionals are employed in disability services, student health and wellness, and recreational services. Each of these services are intended to help students cope with the stresses of college life based on their particular needs. In my study, Cassandra sought accommodations with disability services to cope with her own disability. Ed went to student health to cope with his grief and depression after he lost his father. Waldo used the recreational facilities to cope with the multiple traumas he endured. Based on the overall findings of my study, I suggest that student affairs programs consider offering a curriculum that includes at least some content related to physiology, health, and disability.

Implications for Future Research

Alex and Jenna are currently teaching in higher education institutions and they have indicated that their student caregiving experience has changed who they are as teachers. Natalia expressed that her student caregiving experience challenges her to think about how she will create flexible and inclusive environments for students when she begins to teach. Future research should investigate the ways in which faculty, who
once were student caregivers, facilitate student-centered learning and construct flexible learning environments.

This study found that the majority of student caregivers experienced anxiety and/or depression, and the participants that did not state that they had anxiety and/or depression described feelings or behaviors that are often experienced with anxiety and depression. This finding is consistent with other studies that suggest caregivers are at risk for anxiety and depression (Pickett, et al., 2007; Sansoni, et al., 2004; Shaffer, et al., 2016). Student caregivers in this study who had access to student health insurance utilized counseling services to get help for their anxiety and depression. Health has an impact on learning and development, therefore, counseling to improve mental health should have a positive impact on academic success. A suggestion for further research is to examine factors that allow or encourage student caregivers to seek professional help and investigate if these do reduce the symptoms of anxiety and depression and improve academic outcomes.

Student caregivers indicated that social support on campus was beneficial because it helped decrease their feelings of isolation. However, they had significant time constraints due to their dual roles that they often were unable to engage in socializing on campus. It would be beneficial for future research to explore the factors that promote socialization on campus or through social media for student caregivers.

The participants in this study indicated that invisible illnesses had a negative impact on their ability to persist and succeed. Sometimes it was because the illness created unpredictability and sometimes it was because it was hard to explain the stress
and strain of caring for a person when others could not see the care that needed to be given. A suggestion for future research is to explore how different types of illnesses or disabilities impact student caregivers’ academic success.

A significant limitation in this study is that there was not racial and ethnic diversity. Future studies should focus on how race and ethnicity impact student caregiver experiences. This study does advance the diversity of student caregivers by demonstrating that men are providing care while in the academy. Three males participated in this study, however, I know of five other men who qualified for the study but chose not to participate. Two participants also lived in significant poverty, which increased the caregiving burden. Further research should examine the intersectionality between race, class, and gender and how the multiple identities shape the student caregiving experience.

**Summary of Findings and Implications**

The purpose of this phenomenological study was to describe the lived experience of students who provide care for a person with a chronic illness or a disability. The results indicated that coping with the demands of both roles affected identity development, academic success, and health. I have summarized each theme using the thematic elements of that theme to describe it; the themes and thematic elements are italicized. Table 9 provides a visual reminder of the Essential Themes and Thematic Elements. I have also included theory, practice, policy, or research implications that align with the theme presented.
The theme *timing affects everything* encompasses how academic phase, personal development, and care receiver health changes influence a student caregiver’s journey. *Academic phase is crucial* for access to faculty support and institutional resources: participants who were in the dissertation phase when they became caregivers generally had the most faculty support and were adept at finding institutional resources to cope with personal and academic struggles. *Previous life experience* with successfully navigating through trauma helped participants find ways to cope with the trauma they experienced as a student caregiver. *Health affects progress* for participants, both the health of the care receiver and the health of the student.
caregiver. I recommend adding content to the Certificate in College Teaching and student affairs curriculum that addresses how physical health and development impacts transformative learning and self-authorship.

The theme *identities collide across contexts* emphasizes the utter exhaustion of role strain. Student caregivers must constantly switch between their student and caregiver identities, which require different responsibilities and different ways of physically being in their bodies. Negotiating *roles between places* is a continuous struggle and is often exacerbated when student expectations conflict with caregiving expectations. Student caregivers acknowledged their caregiver identities more readily than their student identities—they did not hesitate to declare "Caregiver, it’s who I am.” Thus, when they were at school where their student identities were supposed to take precedence, *students learned the master narrative* of academia in order to achieve their goals. Student affairs addresses identity development and the needs of underrepresented students in their mission. Therefore, I suggest that more student affairs research and practice specifically focus on the process of identity development for student caregivers.

The theme *structure and flexibility enhance capacity* highlights how competing forces need to be balanced in a student caregiver’s life in order to succeed. *Uncertainty causes problems* for student caregivers when the person they care for has unpredictable needs and they are unable to organize their time to manage academic tasks; the struggle is compounded when school requirements are rigid and do not account for personal circumstances. However, participants benefitted from student-centered
learning environments where *flexibility took the pressure off*. Technology offers *freedom* by incorporating individualized ways of coping with time, resource, and energy constraints. A healthy balance between structure and flexibility fosters more opportunities for *caring, learning, and teaching with dignity*. Student-centered teaching theories focus on the individual learning needs of students. I recommend that research in the scholarship of teaching and learning concentrates on how an academic climate that promotes flexibility affects student caregivers who are at risk for stress-related illnesses.

The theme *coping facilitates health and growth* demonstrates the importance of finding coping strategies that match student caregivers’ interests, values, and time constraints. *Coping with trauma* takes time and patience. *Self-care is necessary* for effective coping, and self-care is different for everyone. When student caregivers are able to prioritize their own health needs and personal goals, they can proclaim “*Boundaries give me control.*” *School is an ally* for student caregivers when they use the social and academic aspects of higher education to help them cope with their dual roles.

The ability to identify and utilize healthy coping strategies, in my experience as a teacher and recreational therapist, is the most important skill a person has in navigating through trauma. The positive emotions that emanate from healthy coping cultivate resilience, which, in turn promotes positive emotional responses in future situations of adversity. Positive emotions and resilience build on each other. I recommend that faculty, advisors, and student affairs professionals incorporate the development of coping
strategies, both in and out of the classroom, so students can apply them when they are needed throughout their lives.

The theme *learning transforms the journey* affirms that transformative learning and self-authorship is occurring for student caregivers in this study. Student caregivers use *academic language and content as tools for reflection* to make meaning of their experiences. They recognize that *education helps everything* by setting the foundation for lifelong resources that builds human, cultural, and social capital. When student caregivers can say “*I have options,*” they declare to themselves that they have the capacity to make choices that allow them to achieve their personal and professional goals, while staying true to their values. Student caregivers, as high risk students, experience challenging situations that propel them into self-authoring. I suggest that future student-centered teaching and student affairs scholarship explore the ways in which former student caregivers are translating their experiences into practice.

My contribution to higher education and student affairs scholarship is that I am introducing the voices of student caregivers into the body of literature. Faculty and administration across the academy should be aware of the unique challenges of student caregivers who want to succeed in the classroom and fulfill their own aspirations. My perspective on the meaning of this study is that building resilience through healthy coping strategies is essential for student caregivers to experience transformative learning and self-authorship.
References


doi:10.1111/1468-0009.00177


Taylor, J. (2010). An Exploration of Identity, Motivations and Concerns of Non-Traditional Students at Different Stages of Higher Education. Psychology teaching review, 16(1), 46.


**Appendix A**

**IRB Approval**

<table>
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<tr>
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<td>To:</td>
<td>Lisa Schumacher</td>
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<tr>
<td>From:</td>
<td>IRB-02 DHHS Registration # IRB00000100, Univ of Iowa, DHHS Federalwide Assurance # FWA00003007</td>
</tr>
<tr>
<td>Re:</td>
<td>The Lived Experience of Student Caregivers: A Phenomenological Study</td>
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| Approval Date:       | 09/14/16 |
| Next IRB Approval    | N/A |
| Due Before:          | N/A |
| Type of Application: | New Project |
|                      | Continuing Review |
|                      | Modification Neonates |
| Type of Application Review: | Full Board: |
|                      | Meeting Date: |
|                      | Expedited |
| Approved for Populations: | Children |
|                      | Prisoners |
|                      | Pregnant Women, Fetuses, Neonates |
|                      | Exempt |

Source of Support: College of Education Research Fund

This approval has been electronically signed by IRB Chair:

Brian Bishop, CIP, MA

09/14/16 1535
Appendix B
Informed Consent

Project Title: The Lived Experience of Student Caregivers: A Phenomenological Study

Principal Investigator: Lisa Schumacher, MA, CTRS

We are inviting you to participate in a research study. The purpose of this research study is to gain a better understanding of how health is experienced by nontraditional students who care for a person with a disability or chronic illness.

We are inviting you to be in this study because you are or were a student who has cared for a person with a disability or chronic illness while enrolled in a college degree program. Approximately 15 people will take part in this study.

If you agree to be in this study, we would like you to complete a single interview that will last approximately one to two hours. This will be scheduled at a time and place that is mutually convenient for you and the researcher. The interview may be conducted at your home, or in a public establishment in person, by phone or via Skype if you have it installed on your computer. The questions will ask you to describe your experience as you care or cared for a person with a disability or chronic illness while juggling the demands of a post-secondary degree program. The conversation will be audiotaped in order to ensure that your responses are captured accurately and will be used so that the researcher can later transcribe the data. The audio recording will be identified by a pseudonym and will not contain any identifying information about you. You may be in the study without agreeing to the audio recording. If you choose not to be audio recorded, the interviewer will take written notes during the interview. If you use Skype to do the interview, we encourage you to select a private place for participating. For example, a home computer or a public computer that is in a private room rather than one in a public space.

At the end of the interview you will be asked if you would like to participate in a focus group. Participation in the focus group is optional. The focus group will include 3 to 5 people who are/were also student caregivers. Once I have focus group participants we will set up a mutually agreeable time and place. The questions asked will be similar to the questions asked in the individual interview about your experience as a student caregiver. The conversation will be videotaped and audiotaped in order to ensure that your responses are captured accurately and will be used so that the researcher can later transcribe the data. The video tapes will be kept until the study is concluded then they will be deleted.

Once the conversation has been completed, and the data has been transcribed, it is possible that you may be contacted by phone or email to ensure that your information
was recorded accurately or to get more information based on your response. The follow-up phone call will take approximately 5-20 minutes.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. To help protect your confidentiality all paper data forms will be kept in a locked file cabinet. The video and audio-tapes and the transcriptions will be locked in the same filing system. All study computer data will be kept in password protected computer files. We will use a pseudonym to identify your study information. There will be one document that links your name with the pseudonym that will also be kept in the locked file cabinet. If we write a report about this study we will do so in such a way that you cannot be identified.

You may be uncomfortable talking about your experiences as a student and caregiver with the researcher. We are not responsible for the risks you incur by using Skype. Skype does not encrypt your data and so when you use Skype they may be able to see or store your information. You may skip any questions you do not wish to answer and you may end the interview at any time. You will not benefit personally from being in this study. However, we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any costs for being in this research study. You will not be paid for being in this research study.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won’t be penalized or lose any benefits for which you otherwise qualify.

We encourage you to ask questions. If you have any questions about the research study itself or to report a research related problem, please contact: Lisa Schumacher at (502)445-3504 or email lisa-schumacher@uiowa.edu or Renita Schmidt at (319)335-5589 or email renita-schmidt@uiowa.edu.

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-6564, or email irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

If you agree to continue with the interview procedures, please provide your verbal consent to begin. Please also indicate if you give permission for the interview to be audio recorded.
Appendix C
Recruitment Email

[Research] Caregivers who are Current/Former Students

Caregivers who are/were also students are invited to participate in a study with a graduate student in the College of Education.

The study focuses on people who:

- Care or cared for a person with a disability or chronic illness
- While enrolled in a college program

The study will include an interview and a potential focus group that:

- focuses on the daily experiences of juggling caregiver and student responsibilities
- will last approximately 1-2 hours
- will be at a convenient location of the participant’s choice

The goal of this study is to learn more about the unique experiences of student caregivers so more can be done to help you.

Please feel free to forward this email to anyone you know who may qualify.

If interested, please contact Lisa Schumacher at lisa-schumacher@uiowa.edu or (502)445-3504.
Appendix D
Member Checks

Alex

Sent: Saturday, September 17, 2016 8:37 AM  
To: Schumacher, Lisa A  
Subject: Re: member checking

Lisa,

Overall, this is very good. I can be lighthearted and laugh would be my only correction. It was only during those times that I found it very hard to laugh. Slowly being able to laugh returned.

From: Schumacher, Lisa A  
Sent: Friday, September 30, 2016 12:59 PM  
To: 
Subject: Re: member checking

Does this seem more accurate now?

Alex is currently an Assistant Professor and remains a primary caregiver for his mom and is a secondary caregiver for others member of his family. Alex said that caregiving has changed him both as a person and as a teacher. The joyful lighthearted side of himself got buried under the weight of caregiving, though it is slowly returning. His approach to teaching has shifted as well. Prior to his mom's stroke he was stern about requiring documentation for student absences. But now he does not ask for verification because he worries that asking a student caregiver to do one more thing may be the catalyst to push him/her over the edge. He is sure he will get burned at some point but chooses to err on the side of compassion.

Sent: Friday, September 30, 2016 1:02 PM  
To: Schumacher, Lisa A  
Subject: Re: member checking

Yes, ma'am.
Amy
Sent: Sunday, October 9, 2016 2:17:06 PM
To: Schumacher, Lisa A
Subject: Re: caregiver study question

Hi Lisa,

Thanks for running this by me. There are a couple of things that I would like you to change.

1) I did and do not attribute _____ challenges to inadequate parenting. (That line doesn’t settle well with me.) Wondering if you could tweak that a bit? I was stumped as to why the things that had worked to motivate and instruct Z and A were not helpful in my interactions with ______. ______ on the other hand thought that perhaps it was because I was weary of being at home with young children.

2) My other request is that in addition to changing my and _____ names (which you have done) please also change my program of study and my internship placement. It’s a small world and a small program leaving these two components in feel exposing.

I would like to see it again when these changes have been made.

Thanks!

Sent: Monday, October 10, 2016 10:51 AM
To: Schumacher, Lisa A
Subject: Re: caregiver study question

I give Lisa my permission to use this version of my experience/story.

Anne
Sent: Tuesday, October 11, 2016 6:41 AM
To: Schumacher, Lisa A
Subject: RE: caregiver study question

This looks fine, except that my advisor is female. : )

I actually just got the position as the ______, so that’s exciting and helpful financially I hope.

Anyway, thanks for letting me preview this. Hope all is going well with you.
Cassandra

Sent: Tuesday, September 27, 2016 5:51 PM
To: Schumacher, Lisa A;
Subject: Re: member checking

Hi, Lisa, thanks for doing this member check. I added in some clarification. One of them I thought about mentioning at the focus group, but then I felt I'd already monopolized enough of the conversation, so I didn't. It was that even though I'd been told not to mention my struggles, I do. And I said that was not strategic of me.... it's not, if we're talking about strategizing for how to play the game as it stands, but I am strategic about sharing my struggles, and I probably do it more than I would otherwise if it didn't feel like there was a political stance to take.

Anyhow, I'm wordy. Thanks, though! It has been eye-opening to me to have to think about all of this for myself.

Sent: Thursday, September 29, 2016 4:02 PM
To: Schumacher, Lisa A
Subject: Re: member checking

Hi, Lisa, yes those seem more accurate to me. Thanks for being so conscientious! I did add one thing: ____ has generalized anxiety disorder AND ADHD. I wasn't clear. Sorry!

Ed

Sent: Friday, September 30, 2016 5:50 PM
To: Schumacher, Lisa A
Subject: Re: member checking

Hey Lisa,

Thank you for the reminder email! I read the transcription – that look like a ton of work, thank you. I agree with your transcript and fully approve use of it. I also appreciate the last paragraph or so, I feel like you had good insight into my mental state that week.

Hope all is well, best,

Elizabeth

Sent: Monday, September 26, 2016 3:21 PM
To: Schumacher, Lisa A
Subject: Re: member checking

Hi Lisa,

This is great! I was here in the US - the specialist called me on my US cell-phone number which I had left with his secretary.

Good work!
Jenna

Sent: Saturday, October 15, 2016 3:10 PM  
To: Schumacher, Lisa A  
Subject: Re: member checking caregiver study

Lisa,

Yes, your interpretation of our interview accurately describes my experiences.

Jessica

Sent: Friday, September 16, 2016 3:15 PM  
To: Schumacher, Lisa A  
Subject: RE: member checking

Very accurate synopsis. Thanks again Lisa!!

Natalia

Sent: Thursday, October 6, 2016 6:47 AM  
To: Schumacher, Lisa A  
Subject: Re: Fw: member checking!

Lisa,

I had a chance to review this last night and I definitely feel comfortable with it. It is very validating to see that someone heard my story and took the time to reflect on it and make sense of it! Thanks so much for sharing it with me.

As an update for you, my mom was finishing up chemo so I decided to speed up my work and finish my degree so I defended last month! There are still some loose ends to tie up but I have started a new job as a research fellow and am feeling a lot of pressure relieved. She is going for her first follow-up next week and she’s already very anxious about the test results she will get at that meeting— it feels good to have my defense behind me and know that I can step up if any bad news comes our way. Once again, my advisors were supportive in letting me set a timeline that made sense for my whole life, not just their own academic schedule. What a blessing!

Thanks again for sharing the synopsis—you have the go-ahead from me!  
Best wishes to you with your program, and good luck! Happy to chat about research any time of course :)


I hope all is well...and it has sunk in that you are DONE! (I hear that takes a while :))

I am creating a document as an appendix to demonstrate member checking. May I have permission to use your full response? I think your response is amazing because it shows how the caregiving impacts so many of your decisions AND how your advisor support enables you to make those decisions. I think it is an amazing piece of data (tho it pains me to boil it down to that in this moment).

Thank you for checking, Lisa—and yes, you have my permission. I am glad it will be helpful to you!

Done! You are a master at getting to the essence of our conversation and what I said during the focus group.

I have 2 corrections: my mother did not die of cancer. Her body just gave out. She had COPD and rheumatoid arthritis, and her body just said enough is enough. Her death certificate says the cause was COPD, but that's malarkey.

Also, ______ does not know of the burden I carry as a caregiver. At least, I have never spoken to him at any length about it. ______ knows more, but he is not my advisor.

Your account reads very sympathetically. I like this [Orla] lady!!

Best,

Changes are just fine. You are welcome to use these email conversations.

Best,
Pooja

Sent: Tuesday, October 11, 2016 9:35:03 AM
To: Schumacher, Lisa A
Subject: RE: member checking

Just a couple of things:
I received an Associate of Applied Science degree rather than a certificate in both Medical Assisting and Medical Office Technology.
My zip lining was with the Student Senate rather than Work Study. Being in the Student Senate was important to me, since I was able to give something back to my school.

Other than that it all looks really good!

Hope things are going well with you!

Waldo

Sent: Sunday, October 9, 2016 1:33 PM
To: Schumacher, Lisa A
Subject: RE: caregiver study question

Beautiful!!
Thanks for letting me take part in your study.
It was the first time in a very long time that I was able to talk about myself and my experiences!
Good luck!

Lisa,

Looks great!

Thanks!
Appendix E
Audit Trail Sample Documents

Initial Reflection Documents

<table>
<thead>
<tr>
<th>Page 1</th>
<th>Page 2</th>
<th>Page 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Running head: THE LIVED EXPERIENCE OF STUDENT CAREGIVERS</td>
<td>Initial Reflection Documents</td>
<td>Initial Reflection Documents</td>
</tr>
<tr>
<td>Appendix E</td>
<td>Audit Trail Sample Documents</td>
<td>Initial Reflection Documents</td>
</tr>
<tr>
<td>Initial Reflection Documents</td>
<td>Initial Reflection Documents</td>
<td>Initial Reflection Documents</td>
</tr>
</tbody>
</table>

[Handwritten text]

Dear Dr. Smith,

I love my job, but after the initial excitement, I realized that I knew I'd need to balance my responsibilities. It's challenging to juggle the demands of work and personal life.

Best,
Dr. Johnson
## Preliminary Code Chart

<table>
<thead>
<tr>
<th>NVivo Codes</th>
<th>Descriptive Codes</th>
<th>Emotional Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>52:39</td>
<td>Put it on hold until I was in a better mental place</td>
<td>Boundaries</td>
</tr>
<tr>
<td>53:28</td>
<td>Timing is clutch</td>
<td>Timing is everything</td>
</tr>
<tr>
<td>58</td>
<td>Warring paradigms</td>
<td>Interdependency</td>
</tr>
<tr>
<td>58:29</td>
<td>Put the twinkie down</td>
<td>Sacrifice</td>
</tr>
<tr>
<td>1.06:45</td>
<td>Never calm down—when the phone rings</td>
<td>Choices</td>
</tr>
<tr>
<td>1.08:22</td>
<td>Doing the most and receiving the least</td>
<td>Financial security</td>
</tr>
<tr>
<td>1.10:55</td>
<td>Self care-keep expectations low</td>
<td>change</td>
</tr>
<tr>
<td>1.16</td>
<td>Flexibility took pressure off</td>
<td>Closer to people with shared caregiving experience</td>
</tr>
<tr>
<td>1.17:46</td>
<td>Did not have emotional reserve</td>
<td>Self care-time to do nothing</td>
</tr>
<tr>
<td>1.17:57</td>
<td>Made Sense and had rhythm</td>
<td>Supportive committee</td>
</tr>
<tr>
<td>1.19</td>
<td>Pick battles</td>
<td>flexibility</td>
</tr>
<tr>
<td>NVivo Codes</td>
<td>Descriptive Codes</td>
<td>Emotional Codes</td>
</tr>
<tr>
<td>-------------</td>
<td>-------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>1.20</td>
<td>routine</td>
<td>1.17</td>
</tr>
<tr>
<td>1.26</td>
<td>I don’t think you can separate education from anything</td>
<td>1.42, 2.20</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.32</td>
<td>Support from faculty was both an institutional resource and a coping strategy</td>
<td>1.36</td>
</tr>
<tr>
<td>1.41</td>
<td>Growing up as the peacekeeper</td>
<td>1.42</td>
</tr>
<tr>
<td>1.45</td>
<td>Lifetime of commitment</td>
<td>1.44</td>
</tr>
<tr>
<td>2.05</td>
<td>Education helped me most</td>
<td>1.45</td>
</tr>
<tr>
<td>2.05.10</td>
<td>I get why people make poor decisions, they don’t the resources</td>
<td>2.04</td>
</tr>
<tr>
<td>2.08.55</td>
<td>My education made me comfortable seeking more education</td>
<td>2.08</td>
</tr>
<tr>
<td>2.14.11</td>
<td>Dissertation topic made me sensitive to creating a built environment that was accessible for my mom</td>
<td>2.10</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.16</td>
<td>Uncertainty causes problems</td>
<td>2.19</td>
</tr>
<tr>
<td>2.17</td>
<td>A person can only take so much</td>
<td>2.24</td>
</tr>
<tr>
<td>NVivo Codes</td>
<td>Descriptive Codes</td>
<td>Emotional Codes</td>
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<tr>
<td>-------------</td>
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<td>-----------------</td>
</tr>
<tr>
<td></td>
<td>life issues that may affect academics</td>
<td></td>
</tr>
<tr>
<td>2.19</td>
<td>Stress of phd, caregiver, and starting a new job</td>
<td>2.26 Watch for mental and physical changes in students</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I.e. drinking heavily, drugs</td>
</tr>
<tr>
<td>2.19</td>
<td>Not something I would ever wish on another person</td>
<td>2.27 Someone in dept trained to know about health/behavior changes as a result of personal stress/trauma</td>
</tr>
<tr>
<td>2.19</td>
<td>You just get through it</td>
<td></td>
</tr>
<tr>
<td>2.20, 2.22</td>
<td>You grow. Things don’t get better, you just grow to deal with them better</td>
<td></td>
</tr>
<tr>
<td>2.20.35</td>
<td>Fundamentally changed</td>
<td></td>
</tr>
<tr>
<td>2.22</td>
<td>Phd changes you too Lost my sense of humor thru phd process and caregiving</td>
<td></td>
</tr>
<tr>
<td>2.22</td>
<td>See depth of life in a very different way [going thru both at same time]</td>
<td></td>
</tr>
<tr>
<td>2.24</td>
<td>Actively engage with students KNOW your students Advisor can buffer/information point</td>
<td></td>
</tr>
<tr>
<td>2.27</td>
<td>Healthy gatekeeper</td>
<td></td>
</tr>
<tr>
<td>2.28</td>
<td>Changed the way he interacts with students...does not ask for documentation if they</td>
<td></td>
</tr>
<tr>
<td>NVivo Codes</td>
<td>Descriptive Codes</td>
<td>Emotional Codes</td>
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<tr>
<td>-------------</td>
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<td>-----------------</td>
</tr>
<tr>
<td>say they have something going on with family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.29.40</td>
<td>I am willing to get burnt rather than ask for documentation and have that be the thing that pushes them over the edge when they have enough on their plate...directly related to my experience</td>
<td></td>
</tr>
<tr>
<td>2.30</td>
<td>My courses are universal design</td>
<td></td>
</tr>
<tr>
<td>2.30</td>
<td>Also more rigid</td>
<td></td>
</tr>
<tr>
<td>2.30.31</td>
<td>In one way it softened me and in one way it hardened me</td>
<td></td>
</tr>
<tr>
<td>2.31</td>
<td>I’ve seen that when you don’t have plans and when those bad things happen, you got nothin’</td>
<td></td>
</tr>
<tr>
<td>2.34</td>
<td>I have options</td>
<td></td>
</tr>
</tbody>
</table>
| 2.34.35     | PhD teaches you how to dance  
Great deal of hazing  
Goes out of his way NOT TO HAZE | | |
| 2.36        | You can’t undo your breeding | | |
| 2.37        | Got texts from mom during interview | | |