


5-2020

Stigma and Disclosure of Chronic Pain in Higher Education: A Qualitative Study

Jennifer K. Davenport
University of Arkansas, Fayetteville

Follow this and additional works at: <https://scholarworks.uark.edu/etd>

 Part of the [Accessibility Commons](#), [Disability Studies Commons](#), [Higher Education Commons](#), [Personality and Social Contexts Commons](#), and the [Social Psychology Commons](#)

Citation

Davenport, J. K. (2020). Stigma and Disclosure of Chronic Pain in Higher Education: A Qualitative Study. *Theses and Dissertations* Retrieved from <https://scholarworks.uark.edu/etd/3695>

This Dissertation is brought to you for free and open access by ScholarWorks@UARK. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of ScholarWorks@UARK. For more information, please contact ccmiddle@uark.edu.

Stigma and Disclosure of Chronic Pain in Higher Education: A Qualitative Study

A dissertation submitted in partial fulfillment
of the requirement for the degree of
Doctor of Philosophy in Rehabilitation

by

Jennifer K. Davenport
University of Arkansas
Bachelor of Arts in English, 2013
University of Arkansas
Master of Education in Higher Education, 2015

May 2020
University of Arkansas

This dissertation is approved for recommendation to the Graduate Council.

Brent Williams, Ph.D
Dissertation Director

Keith Vire, Ph.D
Committee Member

Stephanie Lusk, Ph.D
Committee Member

Abstract

Students with chronic pain represent an overlooked population in higher education institutions, due to the barriers their conditions present and the stigma associated with chronic pain. There is existing research examines treatment of elderly populations and best practices for university students with disabilities, facing discrimination. This study sheds light on a gap in the existing research, where a niche population of students in chronic pain navigated disclosure issues and stigma in the academic environment. The purpose of the qualitative research study was to examine how anticipated or experienced stigma associated with chronic pain conditions influenced disclosure of chronic pain for students in higher education. The researcher used Charmaz's constructivist grounded theory as the model, and the instrument was a semi-constructed interview. Participants for the interview were selected based on answers to a preliminary survey. The researcher created a conceptual framework from the emergent themes.

Acknowledgments

To my participants, thank you for having the courage to speak up about your experiences. I value the trust you placed in me. Your voices are not lost, and your stories matter immensely. Hold on to the hope that it will get better – the pain, life, this moment – whatever “it” is!

To my committee members – Dr. Stephanie Lusk and Dr. Keith Vire, thank you for your persistence and patience with me on this journey over the last four years. Your understanding reinforced my passion for rehabilitation counseling. You are both my mentors, inside the classroom and out.

To Dr. Brent Williams, I appreciate you for standing by me as my chair when it seemed like finishing my doctorate was impossible. I fondly remember many of our office chats about my future and am certain I would not have made it to the finish line without your support. From our first conversation four years ago to your advocacy for me over fellowships, you encouraged me to trust you to have my back. You were right, thank you!

To the strong women who bolstered my success and held my hand as I overcame the comical number of obstacles from my doctorate, my gratitude for your support is hard to condense into words on a page. Dr. Julie Hill, the Isles to my Rizzoli, my pixie sister – I would not have survived a step of this doctorate without your friendship. You encouraged me on days when I stopped believing in myself, let me vent to you, and celebrated every small victory with me along the way (with inspirational quotes). I love you dearly, my pixie sister. Tarryn, you majestic sunflower - with your positive affirmations and daily hugs, you balance out my negativity with your infectious spirit. You are the bright, warm light that shines and glows on the people around you; I am so grateful to have you in my life. Tiff and Sadaf, my pillars of sanity and silliness at just the right moments. When I find myself mid-meltdown, your voices are my

guiding moral compass back to steady ground and sometimes to the donut shop. I love you both!
Mom, I cannot write this without tearing up because I am overwhelmed with gratitude toward you; you made every fast food stop, caffeine-fueled all-nighter, hospital trip, and escape home possible. The woman I want to be the most when I grow up is you. You are my Lorelai.

There are many friends and family that guided me along the way and made this path possible for me. You validated my pain, which is more than I could ask or expect of anyone, and you made a sanctuary for me at a time where nothing felt sacred. You know who you are, my loved ones, I humbly thank and cherish you.

Table of Contents

CHAPTER

1. INTRODUCTION.....	1
Background of the Study.....	1
Theoretical Perspective.....	1
Statement of the Problem	4
Significance of the Study.....	6
Research Questions.....	7
Definition of Terms.....	7
2. LITERATURE REVIEW.....	10
Introduction.....	10
Severity of Life with Chronic Pain.....	10
1. Physicality.....	10
a. Coping Mechanisms.....	11
b. Self-Efficacy.....	13
2. Burden.....	14
3. Societal.....	15
The Decision to Disclose.....	17
1. Work-Related Stigma.....	17
2. Risks of Disclosure.....	18
3. Disability Type.....	18
4. Perception of Ability.....	19
a. Transitional Impact.....	20
Stigma.....	21
1. Anticipated.....	21
a. Concealability.....	22
2. Experienced.....	22
a. Controllability.....	23
Conceptual Framework.....	25
Limitations of Existing Research.....	26
Contributions of Proposed Study.....	27
Summary.....	28
3. METHODS.....	29
Introduction.....	29
Constructivist Grounded Theory Design.....	30
Sample and Participants.....	31
Data Collection.....	34
Data Analysis.....	36

Validity and Trustworthiness.....	38
Role of the Researcher.....	39
Conclusion.....	39
4. RESULTS.....	41
Introduction.....	41
Research Design.....	41
Data Collection.....	41
Data Analysis.....	42
1. Coding.....	43
2. Themes.....	60
Conclusion.....	65
5. DISCUSSION.....	66
Introduction.....	66
Research Questions	66
Researcher Reflexivity.....	67
Implications.....	67
Limitations of the Study.....	71
Conclusion.....	72
REFERENCES.....	74
APPENDICES.....	78
Appendix A: IRB Approval Letter.....	78
Appendix B: Survey Informed Consent.....	79
Appendix C: Study Recruitment Letter.....	81
Appendix D: Interview Informed Consent.....	82
Appendix E: Demographics Questionnaire.....	84
Appendix F: The Chronic Pain Grade Questionnaire.....	86
Appendix G: Adapted Stigma Scale.....	87
Appendix H: Stigma & Disclosure Interview.....	89

CHAPTER 1: INTRODUCTION

Background of the Study

Per revisions through the Americans with Disabilities Act Amendments Act of 2008 (ADAAA), the Office of Civil Rights and United States Department of Education amended the former Americans with Disabilities Act of 1990, which broadened the meaning and interpretation of disability (U.S. Department of Education, 2018). Following the ADAAA in 2008, the Department of Education actively enforced Section 504 of the Rehabilitation Act of 1973 that legally protects students with disabilities from discrimination and preserves their rights to education (U.S. Department of Education, 2018). By federal law, the Section 504 regulations require provisions and services to students with disability-specific barriers in need of accommodations. Of the many populations served by disability resource offices in school and universities, individuals in chronic pain can be overlooked, due to the stigma attached to the invisible nature of their conditions, or the habitual minimizing of pain from the community and health care professionals (Lacasse, Connelly & Choiniere, 2016).

Theoretical Perspective

The theoretical perspective is a culmination of theories about anticipated and experienced stigma that build the underlying foundation for the proposed study. King, Dinos, Shaw, Watson, Stevens, Passetti, Weich, & Serfaty's (2007) theory of how the lived experiences of stigma exist in negative correlation with those of self-esteem served as a foundational perspective for the survey portion of the research study. Stigmatization can occur when people with disabilities sustain negative reactions or discriminatory behavior from the general population, so individuals with chronic conditions face the decision between disclosure of their diagnoses and attempting to keep them concealed (Joachim & Acorn, 2000). The qualitative study examines the experience

of stigma, interventions, unmet needs, coping mechanisms, and detrimental effect stigma has on caregivers (Tilahun, Hanlon, Fekadu, Tekola, Baheretibeb, & Hoekstra, 2016).

Inquiry Worldview. The conceptual framework is situated through dual worldviews related to the study context and type of qualitative design (Creswell & Plano Clark, 2018). There are some occasions in research that require flexibility with multiple worldviews occurring in a design; for instance, if a study begins with a survey, the researcher's worldview may initially be postpositivist but becomes constructivist if I opt to facilitate a focus group for the qualitative section, in order to stimulate meaningful responses from participants. Should that researcher decide to merge the two data sets together for interpretation in order to create a dialogue between the multiple worldviews, this would be called a "dialectical perspective" (Creswell & Plano Clark, 2018, p.41).

Following the example provided by Creswell and Plano Clark (2018), I employed two inquiry worldviews in the design that are transformative and constructivist. The transformative lens that shapes the framework of this study lends itself to encourage participants to actively engage in the study's narrative (DeCuir-Gunby & Schutz, 2017). This worldview recognizes disparate power dynamics and the need for active collaboration between researchers and participants. Regarding this researcher's qualitative study, the transformative application occurred while participants contributed to interviews about their experiences with stigma, disclosure, and chronic pain. Other elements of transformative practices in the study include: the researcher's language advocated for change in the stigma towards people with disabilities, and self-advocacy for individuals with chronic pain. Participants were selected based on preliminary questions introduced in a survey – demonstrating how the study is participant-focused, which is a hallmark of transformative practices. The less formal semi-constructed interview allowed for an

illustration of participants' different perspectives and views, which exemplified the constructivist worldview at work (Creswell & Plano Clark, 2018). Furthermore, the researcher transcribed and analyzed the qualitative data through the use of Charmaz's Constructivist Grounded Theory, separating the interviews into organized groups that are coded by overlapping themes (Charmaz, 2015).

Substantive Content Theories. Following guidance by the inquiry worldview, I was guided by associated experiences elicited from preliminary surveys and an interview about pain, stigma, and disclosure. The Chronic Pain Grade Questionnaire (1992) encouraged participants to assess every facet of their pain – the way it oscillates, its location, what aggravates or soothes it, and a Likert ranking from mild to excruciating – a higher overall score indicates more significant pain. The Chronic Pain Grade Questionnaire (1992) applied to this study in the way the participants rated the acuteness of their pain, so the participants' pain severity was measured objectively before thoroughly examining their experiences with stigma. The Stigma Scale (2007) amended to replace test items “mental health” with “chronic pain” reflected the lived experiences of stigma in a negative correlation with self-esteem (p.252). In this scale, participants self-reported levels of stigma, as measured by the constructs of disclosure and discrimination that are conducive to the goals of this study (King et al., 2007). Throughout completion of this scale, participants questioned the assumptions of society towards treatment of them regarding discrimination and disclosure, as demonstrated in test item 5: “I have been discriminated against in my education because of my [chronic pain] problems” (King et al., 2007, p. 252). The 28-item Stigma Scale (2007) measures the constructs of discrimination, disclosure and self-esteem, but I amended the scale by adding test items in order to measure self-advocacy, a construct more germane to the goals of this study than self-esteem.

Statement of the Problem

The student population living with chronic pain carries more than the burden of meeting academic demands; many of those individuals can feel constricted by the fear that their chronic pain will stigmatize them in their higher education environment, and therefore they may choose not to disclose their diagnoses to peers and professors. The attitudes of faculty members, preconceived stereotypes about disabilities, and a lack of knowledge about academic accommodations can create barriers to students' success (Baker, Boland, & Nowik, 2012). A quantitative study examining issues of chronic pain management for college students observed that participants' pain "interfered with their school work," (Thomas, Roy, Cook, & Marykuca, 1992, p. 2597). Furthermore, the students "expressed dissatisfaction with treatment" thereby resorting to self-medicating with analgesics and alcohol (Thomas et al., 1992, p. 2597). The Americans with Disabilities Act Amendments Act (ADAAA) of 2008 along with Section 504 of the Rehabilitation Act of 1973 provide accommodations for students with disabilities in higher education institutions, should those students choose to disclose to a Disability Resource office on campus (U.S. Department of Education, 2018); however, many individuals in chronic pain express fear that the stigma of disclosure will follow them throughout college.

Purpose Statement. The purpose of the study is to examine how anticipated or experienced stigma associated with chronic pain conditions influences disclosure of chronic pain for students in higher education. The issue of how the stigma of chronic pain influences disclosure in higher education is important because it does not receive recognition, due in part to the invisible nature of its symptoms. Working as an accommodation counselor for the Center for Educational Access, this researcher provided accommodations to students with disabilities, and some of those students report fear that their disabilities will be disclosed to their professors and

peers. Another factor surrounding disclosure is the anxiety that professors perceive the students as weak or less capable than their peers for accruing absences, due to their pain severity (Baker, Boland, & Nowik, 2012). As someone who also experiences chronic pain and disclosure-related barriers, the academic-work environment became more isolated and reinforced my fears about the anticipated and perceived stigma surrounding disclosure of a disability. From there, I wondered how to collaborate with others so their voices may be a beacon of change and self-advocacy for higher education students in chronic pain.

Goal of the Research. While it is effective to create practices that reinforce openness and acceptance towards disabilities at the employment level, it would be beneficial to manifest an open dialogue at the higher education level that pre-empts workforce barriers (Monsivais, 2013). This researcher's aim was to bridge the gap between faculty and students, students in chronic pain and their uninformed peers. In conversations with students in the past year, it has been my experience that many students in chronic pain are afraid that faculty members will not understand them and will judge them for having accommodations for their condition (Baker, Boland, & Nowik, 2012). There is evidence to support outreach for individuals in chronic pain over the age of 50 through advocacy programs with networks like the YMCA, since research shows that pain conditions are considered more socially acceptable for older populations (Monsivais, 2013). Traditional-aged students in chronic pain can receive encouragement through online advocacy groups and "cyberhugs," but filling that role on campus for students and faculty would grant both parties a form of closer support and sense of belonging (Becker, 2013). Evidence of these interactions suggests that the stigma surrounding disclosure of chronic pain in a higher education setting may not ever be eradicated, but it can be mediated.

The goals of the current study are multilevel: first to increase self-advocacy for individuals who have it through the survey and discussion during the interview, and awareness about chronic pain for those who do not (through publication of this study). Increase of self-agency leads to more disclosure, which reduces myths & stigma about disabilities, thereby creating opportunity for educational conversations between professors and students about barriers to accommodations. On the psychosocial level, one goal is to reduce the feeling of isolation among peers through establishing a sense of commonality, by allowing those with shared experiences the chance to safely recount their stories without fear of retribution. Finally, individuals with chronic pain often feel as though their actions are incapable of enacting change, or if they do, it is to their own detriment; for instance, overactivity can result in exacerbated pain (Lacasse et al., 2016). Through the use of qualitative research, the intent is for participants to actively engage in the study, self-advocate and potentially make a difference for other students through reflection of lived experiences with chronic pain.

Significance of the Study

The research study is significant because it contributes to the fields of rehabilitation education and higher education on a specialized topic within disability studies (the stigma surrounding disclosure of chronic pain) that is relatable to a broad population (higher education communities and disability communities). Additionally, it utilizes a constructivist grounded research design, marking its methodological contribution to research as noteworthy. There is a gap in existing literature on research studies that focus on students in pain; current trends in the field of disability research require cross-references from nursing and medical journals, since that is where cases of stigmatization towards individuals with persistent pain are most documented (Lacasse, Connelly, & Choiniere, 2015). In contrast to acute pain, the American Chronic Pain

Association (ACPA) defines chronic pain as “ongoing or recurrent pain, lasting beyond the usual course of acute illness or injury healing ...which adversely affects the individual’s well-being” (2015, p.10). Although chronic pain can occur on emotional levels and within chronic illness, for this study, participants were chosen for specifically physical pain that lasts or “recurs for more than 3 to 6 months” (Merskey & Bogduk, 1994, p. 1).

Research Questions

The study included semi-constructed interview data to answer the following research questions:

1. How does the social perception of chronic pain influence student disclosure behaviors in the academic environment?
2. How do participants define anticipated and experienced stigma as it relates to chronic pain, and have they experienced this type of stigma?
 - a. If yes, what was the experience?
3. What conditions in higher education encourage students to disclose their chronic pain to their professors? To their peers?
4. What conditions in higher education discourage students from disclosing their chronic pain to their professors? To their peers?

Definition of Terms

Chronic Pain – “Ongoing or recurrent pain, lasting beyond the usual course of acute illness or injury healing,” which adversely affects the individual’s well-being (ACPA, 2015, p.10).

Disability – A physical or mental condition that limits a person’s movements, senses or activities.

Stigma – The negative evaluation of a person as tainted or discredited on the basis of attributes such as mental disorder, ethnicity, drug misuse or physical disability (Goffman, 1963).

Invisible Disability – Hidden disabilities that are not immediately apparent, and can include neurological conditions, cognitive disorders, auditory disorders, visual disorders, traumatic brain injury, chronic back pain, fibromyalgia, diabetes, mental illness, etc. (Disabled World, 2018).

Disclosure – By law a personal decision that individuals with disabilities must make for themselves to receive accommodations.

Discrimination – The unjust and prejudicial treatment of different categories of people or things especially on the grounds of race, age, sex or disability.

Self-efficacy – The belief in one’s ability to succeed in specific situations or accomplish a task (Bandura, 1994).

Conclusion

In this chapter, the researcher identified the existence of a problem and used the constructivist grounded theory to explore it further. For this study, I used a dual framework approach – transformative and constructive - to understand the occurrences of experienced or anticipated stigma for individuals with chronic pain. Furthermore, the substantive content theories pertaining to stigma and chronic pain used survey questionnaires gauge the presence of each construct (e.g. discrimination, severity of pain, self-efficacy, etc.) in participants’ daily lives. In the literature review, I identified the dearth of fundamental research that exists on the subject. One of the pitfalls of current research on the topic is that the literature dithers over the subject without committing to it. While most research studies have an extensive prior engagement, gaps exist because this research area is larger than other areas of the field. In the following chapter, the literature review will outline how previous researchers touched on important aspects in their studies, relevant to the proposed topic, while also illuminating limitations to their findings. I chose the topic of the stigma surrounding disclosure of chronic

pain, not because the current literature is voluminous, but because of the topic's personal relevance to my life, the interesting subject matter, and because there is a need to contribute research on the connections between pain, stigma and disclosure.

CHAPTER 2: LITERATURE REVIEW

Introduction

The overarching frame of the research design is a qualitative design with a conceptual framework of Charmaz's (2015) constructivist grounded theory. My review of the literature revealed that individuals with chronic pain are willing and able to contribute to research studies in which their identities are not consumed primarily by their diagnoses and graded by their pain ratings (Lacasse, Connelly, & Choiniere, 2015). Outside of the hospital and research facility, individuals with chronic pain face categorization and grading by others, often without disclosing their condition. Due to extensive, pervasive societal stigma—specifically perceived and/or experiential stigma—people with pain diagnoses weigh the decision between disclosing their disability to family and friends or choosing to keep it confidential. Those with invisible pain conditions often hear that they do not appear sick or pained, which is usually a well-intended comment, received with mixed feelings of guilt, relief and invalidation (Thomas, 2000). In a higher education setting, students confront the decision to disclose to peers and professors, while developing coping skills, balancing pain management with classes, and building meaningful relationships with other people their age.

Severity of Life with Chronic Pain

Physicality. Those who undergo the experience of life with chronic pain undergo a redefinition of a “new normal” recalcitrant body; healthy individuals only notice a difference from their routine bodies when their foot is asleep, or a muscle is pulled. In contrast, a person in chronic pain is “exquisitely and perpetually aware of the body” (Thomas, 2000, p. 690). In order to distance themselves from physically or psychologically feeling pain, college students reported

using distractions, avoiding harmful physical activities or minimizing pain's presence in their lives (Firmin, Burger, Grigsby, Sherman, & Croft, 2011).

Within the body is housed the pain, which has become the most salient aspect of daily existence. For most of these study participants, every movement of the body produces twinges, aches, spasms, or other unpleasant consequences. They do not have the healthy person's luxury of moving the body spontaneously and thoughtlessly, and the body cannot be ordered to perform desired movements. (Thomas, 2000, p. 690)

Due to the mobility limitations and often disorienting side effects of medications, participants in Thomas' (2000) study described their relationships with their pain as more exclusive than those with people. The study further described the experience as a running dialogue between themselves and their pain that became increasingly familiar and intimate (Thomas, 2000). Participants are able to describe their pain with specific familiarity – vivid metaphorical language. For example, one participant detailed his experience by stating, “I can feel my leg cramping, just like a steel rod was embedded, anchored in my toe and around up my leg, up to my groin, and somebody's drawing on the steel wire” (Thomas, 2000, p. 691). There is a noteworthy tension between the medical community and pain community that, even when Thomas's (2000) study attempted to bridge the gap between the two, could not be closed; Patients are defined by overly clinical, medical representations of their condition, rather than health care professionals seeing them as people in pain, who need relief.

Coping mechanisms. The coping constructs pertaining to college students while in chronic pain arose from high demands to function socially, academically and physically in rigorous environments (Firmin, Burger, Grigsby, Sherman, & Croft, 2011). The coping strategies that college students used to manage the pain emerged into four major categories in the study of Firmin et al. (2011): *Distraction; Minimizing pain's effects; Advantageous comparison; Search for meaning.* Within the context of a university setting, students coped with chronic pain through

distraction or disengagement from their pain – such activities included “soldiering through... in order to accomplish tasks and objectives necessary in their respective daily activities” (Firmin et al., 2011, p. 37). Distractions also included full immersion into activities that occupied the mind, like hiking, shopping and athletics (Firmin et al., 2011). The second coping strategy employed by college students in chronic pain in the study (2011) is *minimizing pain’s effects*, which can be shifting from uncomfortable positions in a chair to actively reframing the perception of pain’s effect on their daily lives (Firmin et al.). Students voiced self-dismissive statements of, “Oh, it’s nothing,” when the pain impacts their ability to function because of the burden – or perceived burden – it may have on their relationships (Firmin et al, 2011). Although participants expressed a desire for friends to be aware of their pain, the students preferred their friendships and relationships not focus on pain as the epicenter. College students also coped with chronic pain through *advantageous comparisons*, meaning they used cognitive reframe to shift their perspective by comparing their perception of suffering to those who they perceive “have it worse than they do;” thus the contrasts allow the students to take comfort in their abilities and sympathize with those who experience more severe chronic pain (Firmin et al., 2011, p.38). The reframing practice of *advantageous comparisons* is positive for students to recognize empathy and attitudes toward pain. More importantly, because of the shared experiences with pain, college students can be both advocates for themselves and allies for each other; Rather than seeing their pain purely as a destructive force in their lives, the coping mechanisms allowed the college students to see their pain through silver lining, “as a means to better empathize and understand the pain of someone else,” some participants entertained and accepted the possibility it served a purpose “as a potential benefit” to comfort others who suffer (Firmin et al., 2011, 39). Finally, *search for meaning* is the fourth coping construct observed within the sample of college

students in chronic pain (Firmin et al., 2011). When struggling to assign significance to the physical challenges, students sought comfort in relinquishing control to spiritual beings, or higher purposes; one participant alluded to trusting in a spiritual purpose – “God gave me this pain for a reason and He’ll take care of it when He wants to...” (Firmin et al., 2011, p.39). The relentless pain also served as a reminder of their personal purpose to which participants ascribed meaning, in order to soldier through their daily challenges - a sentiment articulated by one participant and echoed by several others (Firmin et al., 2011)

It definitely helps me to remember that I am alive. I know that sounds weird, but we can get so numb, getting in schedules and everything and when I stop and realize, Oh, I’m hurting, I’m like, this is life, I’m still here, I need to wake up and keep going. (p. 39)

Learning adaptive skills through coping with pain forces college students in the study to confront the purpose and meaning in their lives at a different rate than college students who do not have chronic pain (Firmin et al., 2011). Due to their lived experiences with chronic pain and empathy from *advantageous comparisons*, the students in the study expressed an interest in professions focused on helping others in pain. The participants expressed “possessing a maturity level, with regard to being others-focused, that likely deepened their overall life maturity” (Firmin et al., 2011, p. 39).

Self-efficacy. In a study that compared chronic pain and recurrent pain in college students, researchers Hadjistavropoulos, Dash, Hadjistavropoulos, and Sullivan observed how perfectionism influenced self-efficacy in relation to pain severity (2006). “According to self-efficacy theory, perceived self-efficacy influences adjustment to major life stressors, including chronic pain” (Anderson, Dowds, Pelletz, Edwards, & Peeters-Asdourian, 1995; Hadjistavropoulos, Dash, Hadjistavropoulos, & Sullivan, 2006, p.1082. With self-efficacy’s significant contribution to disability noted in the research, among chronic pain patients, it

“mediates the relationship between pain intensity and disability” (Hadjistavropoulos et al., 2006, p. 1082). Regarding pain management, the self-efficacy theory suggests that students with strong self-efficacy beliefs “are more persistent in their attempts to manage prolonged, painful stimuli” and consequently, “display fewer pain behaviors and experience lower levels of distress and disability” (Hadjistavropoulos et al., 2006, p. 1082). The study (2006) performed by Hadjistavropoulos et al. focused on goals of perfectionism self-inflicted by the individual and socially-prescribed by others for the individual to attain in order to be accepted; “Socially prescribed perfectionism involves the belief that one needs to attain standards set by significant others and that others are imposing unrealistic standards, pressuring the individual to be perfect” (Hadjistavropoulos et al., 2006, p.1083). Consistent with other pain models, the researchers infer that perfectionism may make university students more susceptible to pain development (Hadjistavropoulos et al., 2006). “One common element to low self-efficacy and socially prescribed perfectionism is that they both involve a lack of control” (Hadjistavropoulos et al., 2006, p.1089). Because individuals in chronic pain often feel a loss of control due to the nature of their symptoms, the pressures of unmet perfectionism can exacerbate pain conditions and lower the belief in one’s ability to accomplish tasks. Among those in chronic pain who identified themselves perpetually unable to attain their goals – in terms of perfectionism, a pattern of low self-efficacy and negative affect emerged in the research (Hadjistavropoulos et al., 2006). “The biopsychosocial perspective of chronic pain emphasizes that the experience of pain is not solely a function of physical factors but is influenced by a wide range of psychological (e.g., cognition, affect and personality) and social-cultural factors” (Hadjistavropoulos et al., 2006, p. 1089).

Burden. The burden of life with chronic pain is a complex mixture of the internal physicality of pain and external societal influences and perceptions. The experience of women

with chronic pain is embedded in social roles and responsibilities. The burden of expectation is for women to be “nurturing, cheerful, family-oriented, selfless and sensitive to the needs of others” which leads women to minimize their personal suffering compared to that of their family and friends (Hurd Clarke & Bennett’s, 2012, p. 345). This results in women constructing a narrative of their pain and illness “as less biographically disruptive and physically harrowing” from habitually downplaying its severity (Hurd Clarke & Bennett, 2012, p.345). They emphasized the importance of “not dwelling on their physical problems as well as of keeping busy and maintaining a positive outlook irrespective of their bodily suffering” (Hurd Clarke & Bennett, 2012, p.345). Social isolation reinforces the loneliness that envelops the individual’s fear of disclosure; one research participant recounted the difficulty of maintaining authentic relationships with people who do not experience chronic pain, because “pain separates you. My life is pulled in to where I have very little contact with anybody. I am absolutely alone” (Thomas, 2000, p. 692). Families can be divided over the emotional, physical and budgetary turmoil when one member has a chronic pain condition and the others feel helpless - “the financial strain on the family related to numerous appointments can be perceived by the [one] with chronic pain as a burden and could lead to self-blame or internalized stigma” (Wakefield, Zempskyp, Puhl, & Litt, 2018, p.3).

Societal. The societal view of pain severity is the most external for individuals with chronic pain. Individuals with chronic pain bear no outward appearances of their barriers; they grow “accustomed to hostile glances when they disembark from vehicles parked in spaces for the handicapped” (Thomas, 2000, p.691). Demonstrating some tension between individuals with visible and invisible disabilities where they might come to a crux in situations such as handicapped parking, Thomas (2000) pointed out that one individual with rheumatoid arthritis

confessed how difficult it is for people to understand her pain, since they cannot see it - because she does not use a wheelchair or cane. A woman whose arm was in a sling saw her injury less as a badge of legitimacy, and more as an inconvenience; she resented the attention and wished for a sign that said, "Please don't ask" (Thomas, 2000, p. 691). Applying a similar response to the college level, the Firmin et al. study (2011) showed that college students sought to adamantly avoid drawing unnecessary attention to their pain, stating that keeping social interactions upbeat made maintaining pain more manageable. Consistently, college students in chronic pain stated throughout the study (2011) that minimizing pain's effects on their lives helped them to cope in various social capacities, even if the relief was temporary (Firmin et al.).

Hurd Clarke and Bennett's (2012) study of gender and experiences of chronic conditions found that masculinity and femininity are social constructs that influence how men and women internalize their pain. For instance, the fatigue, pain and muscle deterioration from chronic conditions can undermine men's hegemonic masculinity, which is "ambition, autonomy...control, [and] invulnerability" (Hurd Clarke & Bennett, 2012, p.344). While experiences vary based on each individual, traditionally males maintain ideals of stoicism and self-reliance by concealing their pain or physical symptoms of distress (Hurd Clarke & Bennett, 2012). On the other hand, the same study showed women are taught from an early age to focus less on body functionality and more on physical appearance, so a chronic condition or treatment can damage a woman's self-concept (Hurd Clarke & Bennett, 2012). Female participants referred to examples of medication that cause weight gain, visibility of their illness, bodily tremors, and an inability to engage in physical activity due to multiple chronic conditions (Hurd Clarke & Bennett, 2012). After medical practitioners were unable to diagnose female patients

reporting back pain, it “has been minimized to ‘only psychological’ when there is an absence of medical findings” (Wakefield, Zempsky, Puhl, & Litt, 2018, p.3).

The Decision to Disclose

Work-related stigma. Sassin (2011) addressed the lack of congruence between rehabilitation counselors, employers and people with disabilities trying to navigate disclosure in the workplace; while a rehabilitation counselor or employer may advise a person with a disability toward disclosure, doing so could cross legal boundaries, violate ethical practices and create a hostile work environment (Sassin, 2011). There is further tension when the person has a disability that is aggravated by stress, like pain, so failure to report discrimination or harassment in the workplace would contribute to a flair of health problems and diminished job productivity. Research shows that employer discrimination is staggering against people who disclose their disabilities on job applications, regardless of whether or not that disability may limit productivity of the potential job (Ameri, Schur, Adya, Bentley, McKay, & Kruse, 2015). The Americans with Disabilities Act (ADA) (1990) protects employees who choose not to disclose, and employers are not allowed to ask about disabilities. However, the ADA (1990) specifies protected resources called accommodations that are tools to help individuals who disclose their disability overcome workplace barriers. From the perspective of the employer, a business may not hire an individual with a disability out of reluctance to pay for associated costs for accommodations, additional supervision, or loss of productivity (Sasson, 2011). It is an essential rite of passage into adulthood for students to transition into the career world, where they trade in their classroom responsibilities and learn to navigate the daily demands of an 8-to-5 job. For students with chronic pain conditions, understanding the similarities and differences between the everyday

requirements of college and the workplace is imperative to their transition into employment (Firmin, Burger, Sherman, Grigsby, & Croft, 2011).

Risks of disclosure. Whether individuals have a visible or invisible disability, how they manage their information and the decision to disclose can dictate the environment in which they work. Individuals must also consider the risks of the decision to hide the condition, which could lead to the persistent threat of discovery, thus intensifying their anxiety and worsening the associative disability symptoms. On the contrary, those who have visible disabilities with no choice but to disclose may be subjected to a hostile work environment in which they are treated like pariahs or feel pressured with excessive accommodations (Joachim & Acorn, 2000). The difficulty in deciding to disclose derives from the fear of how others will perceive the individual with the disability. The stigma perpetuates the misconception that people with disabilities are incapable of performing their required tasks in academic and professional settings.

Disability type. The type of disability impacts an individual's decision to disclose based on the visibility of the condition and how it impacts his/her ability to perform job tasks. Invisible disabilities are hidden disabilities that are not immediately apparent, and can include neurological conditions, cognitive disorders, auditory disorders, visual disorders, traumatic brain injury, chronic back pain, fibromyalgia, diabetes, mental illness, etc. (Disabled World, 2018). The gradual onset of a disability, compared to sudden onset, may allow for more time to adjust if a student or employee becomes diagnosed with cancer. Observing the younger population, "adolescents with more severe pain conditions reported poorer attendance, increased academic pressure, and more experiences of bullying relative to nonaffected classmates" (Wakefield, Zempsky, Puhl, & Litt, 2018, p. 3). Individuals with a highly visible disability may be forced to disclose their condition, since they are unable to hide it in the workplace or school. De Cesarei

(2014) performed a study that revealed students are more comfortable disclosing their disabilities in social sciences than hard sciences. Furthermore, the most impacting factor for disclosure is self-efficacy – the belief in one’s ability to use motivation and cognitive resources to meet situational demands (De Cesarei, 2014).

Perception of ability. The transition from adolescence to adulthood for understanding chronic pain impacts an individual’s perception of identity and can be tainted by preconceived attitudes towards disabilities. “Just as parents’ perceptions of causes of their children’s pain appear to influence decisions they make about their child’s treatment, teachers’ perceptions about causes of students’ pain are potentially important in determining whether their responses to pain encourage or discourage adaptive functioning in school” (Logan, Catanese, Coakley, & Scharff, 2007, p.249). As teachers, students and health practitioners in school follow individualized education plans for students with complex disabilities, students with chronic pain could engage a biopsychosocial model adaptable for higher education or employment. “One research study revealed that 47.1% of school nurses believed that students with chronic pain were faking or seeking attention for their pain symptoms” (Wakefield et al., 2018, p.3). The perception that students would use their chronic conditions to manipulate or deceive reflects an institutional need to educate faculty and staff about removing the stigma toward disabilities at all grade levels. Apart from the institutional barriers presented by lack of education for accommodations and treatment towards chronic pain conditions, another issue includes teachers’ “implicit and/or explicit biases about people with chronic pain, which may extend to negative attitudes toward their students” (Wakefield et al., 2018, p.3). In order to subjugate workplace barriers, Joachim and Acorn (2000) propose individuals with invisible disabilities use *spontaneous disclosing* in which the individual emotionally divulges his/ her diagnosis as a

direct result from a doctor's diagnosis, for example. The alternative is *protective disclosing*, which gives the power and control back to the individual in the decision to disclose "how, what, when and who to tell about their condition" (Charmaz, 1991, p.119); this shields the individual and increases support from sympathetic people. Granting an individual the decision to inform, as opposed to disclose, removes the threat of stigma by preventing negative perceptions of them that might occur if co-workers and peers were to find out against the individual's will (Charmaz, 1991). Through informing, the individual does not feel at risk and takes the objective position to claim their condition, usually motivated by other positive interactions with disclosure in previous situations; this serves as an opportunity for growth so the individual in chronic pain can be a mentor for others and allow people in the work or academic environment to learn appropriate etiquette for continued dialogue.

Transitional impact. The perception of ability can come from the students' reflection of their own experiences or as a projection of beliefs and biases from others. In the context of an educational environment, attitudinal barriers from their teachers may lead them to experience stigma at a young age. Currently there is not a model for this transitional impact, so "further research should focus on developing a model for understanding the transition between adolescence and young adulthood for those who struggle with pediatric chronic pain" (Firmin et al., 2011, p. 41). During the period from youth to adulthood "is potentially manageable and, in order to help youth more effectively navigate this transition, future research should focus on identifying strategies and methods to assist youth facing chronic pain issues in this transition stage" (Firmin et al., 2011, p. 41). In their recent study, Wakefield, Zempsky, Puhl, and Litt examined the stigma directed toward adolescent chronic pain conditions, specifically HIV, epilepsy, obesity and sickle cell disease (2018). Although chronic pain recovery is elusive, it

requires functioning on an escalating pain scale that houses blame and fuels stigma, under the scrutiny of judgmental peers and authority figures, while self-sustaining coping mechanisms (Wakefield et al., 2018).

Stigma

Anticipated stigma. Anticipated stigma is the culmination of constituent elements of the decision to disclose and severity of life with chronic pain. People of color with disabilities may struggle to affiliate with groups based on either racial/ethnic or disability identification and can face discrimination due to association with either group (McDonalds, Keys, Balcazar, 2007). Though intersectionality between disability, gender, and race aims to have a mediating effect, oppression of multiple identities or “spirit murder” can result in the brutalization or “deadly consequences for disabled people of color caught in the violent interstices of multiple differences” (Erevelles & Minear, 2010, p.128). Ethnic minorities with disabilities who struggle on two fronts may find it more difficult to overcome negative stereotypes for either of their minority statuses. For instance, a Latino male with cerebral palsy may fear his employment outcomes in a work environment where he is a minority (McDonalds et al., 2007). Disclosure of a disability may continue to isolate them from their ethnic/racial group. Another preconceived notion is women with disabilities are perceived as weak and dependent; the stigma they anticipate is the inability to fulfill traditional roles of homemaker, wife, employee or mother (McDonalds et al., 2007). Choosing to conceal an invisible disability in order to align with a racial/ethnic group may result in disability shame in terms of self-construct. Not accessing disability resources may lead the individual to be disconnected from sources of support for his/her disability when the tension between the two social identities increases (McDonald et al., 2007). Minority populations with disabilities encounter the fear of alienating one support group,

which fractures their identity, to rely on unstable social ties in hopes of finding acceptance.

Tilahun et al. (2016) expanded the definition of stigma to *felt stigma* and *enacted stigma*; *felt stigma* induces shame in anticipation of prejudice, silences those who experience stigma, and “impedes them looking for help” (Tilahun et al., 2016, p.2).

Concealability. Within the context of anticipated stigma, concealability “refers to how well the stigmatized attribute of an individual can be hidden from others, either in certain situations or all the time.” (Wakefield, Zempsky, Puhl, & Litt, 2018, p.3). This affords a level of protection to those who can and want to hide their identities, “such as those with mental illness or substance abuse, [who] may be buffered from exposure to societal stigma while their identity is hidden.” (Wakefield, et al., 2018, p.3). Concealability is applicable to chronic pain conditions because it allows individuals to manage anticipated stigma from peers or employers through masking of pain symptoms (if mobility is unaffected) and prolonging the decision to disclose.

Experienced stigma. There are many reasons that a person who lives with chronic pain may choose not to disclose. “Pain-related stigma has been linked to increased stress and anxiety, disruptions in social and romantic relationships, social isolation, employment difficulties, and reduced educational opportunities in adults” (Wakefield et al., 2018, p. 3). In higher education, students living with chronic pain may choose not to disclose their chronic pain to friends, classmates, or professors out of fear of rejection, stigma or discrimination. An example of experienced stigma, or *enacted stigma*, is an external stigma inflicted by the population onto an individual with a disability, such as discrimination or evasion (Tilahun et al., 2016, p. 2). Students who register with accessibility offices on campus receive protected confidentiality of their diagnoses under Section 504 of the 1973 Rehabilitation Act, and the Americans with Disabilities Act (1990). Because these students may have a small support system, they need a

safe place to discuss their shared experiences in a way that facilitates validation and encouragement (Becker, 2013).

Chronic pain sufferers often fall into a pattern of communication that is more harmful than helpful. Keeping pain private may protect against unwanted inquiries into subjective experiences, but it can lead to feelings of isolation and marginalization of voice. Additionally, not only is it linguistically unfeasible to articulate pain as well as socially stigmatized, physical limitations and emotional complications work to further alienate the population. (Becker, 2013, p. 123)

Individuals with chronic pain are well acquainted with the tedious tasks of scheduling doctors' appointments months in advance and bringing their prescription bottles, followed by a urine sample, to minimize suspicion of substance abuse of prescribed narcotics. From the patient's perspective, he or she is usually in search of relief: relief from pain, from the burden of living a life of chronic pain, from the burden of perpetually feeling like a burden – none of these that a doctor can necessarily accommodate in a quick visit, according to the literature (Thomas, 2000). Another reported source of experienced stigma discussed in the literature includes unmet needs, such as educational provisions, financial support, or health care (Tilahun et al., 2016).

“Stigmatizing attitudes from multiple sources may drive social isolation and suffering,” which is evident in comorbidities among students with chronic pain conditions, “including depression, anxiety, poor school functioning, and social impairment” (Wakefield et al., 2018, p.2). The luxury of communicating with several people over the internet, who can share experiences and symptoms, from the comfort of one's home allows individuals in chronic pain to access unmarketable resources, such as a sense of camaraderie and spread positivity towards disclosure, or coping mechanisms against stigma that they might otherwise lack (Becker, 2013).

Controllability. Controllability “relates to the perception of how much an individual is perceived to be at fault or is blamed for acquiring the stigmatizing attribute” (Wakefield et al., 2018, p.4). An example of controllability is if society blames an individual who is overweight for

the excess pounds, because those are seen as something within the realm of his/her control. Within the context of experienced stigma and chronic pain, controllability is applicable “depending on the extent to which psychological factors are attributed to the onset or maintenance of their condition” (Wakefield et al., 2018, p.4). The dichotomy of ‘medical’ vs ‘psychological,’ as perceived by medical providers and school personnel may play an important role in perceptions of controllability of chronic pain. When an adolescent receives the message that his/her pain is “all in your head” and thus perceived by others to be psychological in nature, it may lead to self-blame and internalized stigma.” (Wakefield et al., 2018, p.4). The nature and impact of anticipated or experienced stigma associated with chronic pain on an individual can have a detrimental impact on health outcomes due to the adverse impact on social relationships and self-regard (Wakefield et al., 2018).

Internalized stigma is when stigmatized individuals adopt negative societal beliefs and stereotypes, and engage in self-blame, applying societal stigma to oneself. Thus, stigma consists of intersecting social processes: (1) an individual enacting the stigma belief onto the stigmatized person, and (2) the stigmatized person experiencing distress in response to the stigmatizing event. These distinctions may also be relevant to the impact on well-being that stigmatization may have on an individual, particularly if that stigmatization becomes internalized. (Wakefield et al., 2018, p. 2)

Internalized stigma risks detrimental effects on self-concept and “psychological well-being, whereas anticipated or experienced stigma could adversely impact social relationships and school avoidance.” (Wakefield et al., p. 4).

The establishment of a chronic pain community – online or on campus - opens up a safe space for dialogue and education about the best practices for combating the experienced and anticipated stigma around disclosure of chronic pain. For individuals in chronic pain who do not have the resources or physical strength to pursue accommodations outside of their homes, the Internet provides a low-cost easily accessible medium through which empathizers can provide

support at all hours. Social support buffers adolescents with chronic pain from negative health outcomes. Furthermore, social functioning mediates the relationship between adolescents' chronic pain experience and school impairment. This practice also builds resilience, increases self-advocacy and fosters a sense of community – all of which are useful skills when individuals with chronic pain conditions transition into higher education or employment (Wakefield et al., 2018). Blogs such as *Cyberhugs* (Becker, 2013) allow people with chronic illness and pain to share experiences, send advice from all over the country, dialog about medication side effects, and network about treatments & specialists all from the luxury of their homes via computer support groups.

Conceptual Framework

According to Ravitch and Mittenfelner Carl (2016), a conceptual framework offers a rationale for the focal point of a study and guides the researcher on the design approach, core constructs, and clarifies the researcher's social identity and “positionality and its relationship to the study goals and its setting” (p.85). Within the conceptual framework is the theoretical framework, which gives context to a phenomenon and deepens the understanding of its construction and meaning (Ravitch & Mittenfelner Carl, 2016). I used Charmaz's constructivist grounded theory, which utilizes “flexible guidelines, a focus on theory developed that enriches the researcher's view, learning about the experience within embedded, hidden networks, situations, and relationships,” (Creswell, 2007, p.65). I chose the constructivist grounded theory approach based on the emphasis of “views, values, beliefs, feelings, assumptions and ideologies,” gathered by the individuals in the study (Creswell, 2007, p.65). The intention of the study was to give a voice to an underrepresented population. The researcher intended to gather information about university students' perceptions of stigma and experiences disclosing chronic

pain, if any. Students in chronic pain must face the choice regarding disclosure to their peers and professors, and/or to seek accommodating services on campus. The aim of the interview was to provide an opportunity for people with disabilities to speak openly about their experiences, which will ultimately help people without disabilities understand how their thoughts and behaviors may contribute to stigma in the workplace for people with disabilities (Johnson & Russinova, 2008).

Limitations of Existing Research

The limitations of previous research are voluminous. The existing literature has briefly addressed disclosure, physicality, adolescents in chronic pain, internalized stigma, perfectionism & self-efficacy, associations between “functional disability, future pain, and depressive symptoms with participants’ coping strategies” (Ramirez-Maestre, Esteve, & Lopez, 2008; Firmin et al., 2018, p. 40); yet the road ahead is left unpaved. There is a lack of sufficient exploration on higher education students in chronic pain. The research on students with disabilities favors an interest in ADHD or autism spectrum disorder as opposed to pain, while studies of chronic pain apply to primarily older populations (Taylor, Sleton, & Butcher, 1984). Researchers Firmin, Burger, Sherman, Grigsby, and Croft found themes in their study on a burgeoning topic called post-traumatic growth involving resilience-building and coping adaptation (2011). Post-traumatic growth applies to students in chronic pain through finding “a transcendent meaning for life’s circumstances,” which allows individuals to “appreciate life more fully, consider priorities, and feel more spiritually connected after a trauma” (Firmin et al., 2011, p. 41). Typically, post-traumatic growth literature concentrates on traumatic events such as “terrorist attacks, natural disasters, abuse or cancer,” thus suggesting the onset of chronic pain is new to the literature, but still traumatic enough to be included because of the adaptations it

necessitates (Firmin et al., 2011, p. 41). “Specifically, in student populations, optimization of coping strategies and efforts to educate and inform these students of effective coping mechanisms could enhance daily functioning and academic performance,” which would help dispel some of the stigma surrounding perception of ability (Firmin et al., 2011, p. 41).

Contribution of Proposed Study

Disability is uniquely transcendent because it crosses social divides like nothing else; anyone from any socioeconomic class, gender, age, religion, sex, and ethnicity can have a disability or disabilities. For many individuals with chronic illness, the literature is voluminous in its understanding of patient perspectives from the medical standpoint, focusing on patients with substance abuse, poor coping strategies, fatigue, and helplessness (Thomas, 2000). One study documented patients’ behaviors as “manipulative” and “addictive” or “demanding,” while noting that in a study of 268 registered nurses, the “chronic pain sufferer was negatively stereotyped and judged to have less intense suffering than an individual with acute pain” (Taylor, Sleton, & Butcher, 1984). The journals that document these interactions between patients of chronic pain and medical professionals are often nursing journals, rather than vocational rehabilitation or counselor education journals. From this finding, one can deduce a significant gap in understanding of these issues in the vocational rehabilitation field. This study achieved contribution to existing research by filling a void in the literature with insights that former qualitative studies have yet to cover. This stigma and disclosure of chronic pain research study aimed to inspire actions that will impact the present and future for students in chronic pain. As a person with chronic pain, the I can empathize with the struggle to enact change while at war with the body such that other students in chronic pain describe (Baker, Boland, Nowik, 2012).

Conclusion

In chapter two, the literature examined three constructs: severity of pain, the decision to disclose, and stigma. These three components are best suited for constructivist grounded theory in order to provide rich details of the participants' lived experiences within their constructed reality of life with pain. The analysis for stigma is subjective, where some of the value can be lost in statements made qualitatively. Chapter three examines the research methodology of using Charmaz's constructivist grounded theory design first in order to gauge pain severity and prevalence of stigma associated with chronic pain disclosure. Next, I gathered data through interviews to assess the complexities of anticipated and experienced stigma with chronic pain.

CHAPTER 3: METHODS

Introduction

The purpose of the research study was to enact change through self-efficacy, whether it is on a small scale by allowing voices of an underrepresented population to feel heard, or on a large scale by contributing to a void in literature among academics. It is this researcher's hope that increased discussion of better practices for treatment of chronic pain will prompt more conversations between professors and students, thereby reducing some of the stigma surrounding disclosure of chronic pain. I also aspired to spark self-advocacy for participants through reflection of experiences with disclosure, sparked by in-depth interviews about interactions with professors and/or peers that shaped their views on stigma.

In order for there to be growth, there must be a way to bridge the gap between those who feel stigmatized and those who discriminate against people in chronic pain. The notion of pain is both highly subjective and highly stigmatized, however the experience of pain for the individual is more complex. The stigma of pain is greatly contingent on age, gender, type of disability, and visibility of condition, and perception of discrimination. Because the types of stigma and pain are both highly variable, there needs to be an objectifying framework in the research in order discuss pain more coherently. Because pain and stigma are both nebulous constructs, there is a need in the literature for more objective measures to rate them, which is what inspired the qualitative design for this study. With more objective measure to rate pain and stigma, this opens the door for improved communication and understanding between people *with* disabilities and people *without* disabilities. The hope is that this study will be a launching pad for reduced stigma and, ideally, less discrimination towards people with disabilities.

Research Questions

The qualitative study included data from semi-constructed interviews to answer the following research questions:

1. How does the social perception of chronic pain influence student disclosure behaviors in the academic environment?
2. How do participants define anticipated and experienced stigma as it relates to chronic pain, and have they experienced this type of stigma?
 - a. If yes, what was the experience?
3. What conditions in higher education encourage students to disclose their chronic pain to their professors? To their peers?
4. What conditions in higher education discourage students from disclosing their chronic pain to their professors? To their peers?

The following section outlines the participants, procedure, instruments and data analysis for the study.

Qualitative Design

For this study, the researcher used a qualitative approach to access a better understanding of a subject through semi-structured interviews that integrate depth and variety of participants' experiences in the analysis. In conjunction with theoretical framework and inquiry worldview, which aims to evoke a change through sharing of the participants' experiences and encourages active engagement with participants in the study, the research design for the study reflected the same intent.

The researcher used constructivist grounded theory as an objectifying framework to sample perspectives from the pool of consenting, voluntary participants in order to determine the

population most nascent to the study, instead of screening them. The participants briefly completed a preliminary informational survey before the semi-constructed interviews, so the researcher could recruit appropriate and willing participants based on their responses. During interviews, the participants provided rich, anecdotal quotations about their lived experiences that the researcher incorporated into the results through categories and emergent themes.

Sample and Participants

Context. This study took place in the context of a public higher education institution with approximately 22,548 undergraduate students and 4,105 graduate students (Arkansas Enrollment Report, 2017). Among those students, there is an estimated population of 2,722 students registered with the Center for Educational Access (CEA), the disability services office on campus. The Associate Director of Assistive and Instruction Technology at the CEA elaborated in a phone interview that 355 of those students self-identify with painful conditions including, but not limited to, cystic fibrosis, migraine, celiac disease, chronic fatigue syndrome, Crohn's disease, neuropathy, arthritis, cancer, cerebral palsy, fibromyalgia, lupus, multiple sclerosis, and irritable bowel syndrome (H. Scher, personal communication, August 28, 2018). The addition of the non-descript "other" category, which allows students to specify unlisted conditions, the shifted the total number of students in the "Chronic/Medical" category to 558 students. There are also 95 students who classify in the "Mobility/ Orthopedic Injury" category; their conditions vary from muscular dystrophy, spinal cord injury, degenerative disc disease, lower back injury, and carpal tunnel syndrome. Both undergraduate and graduate students from this university were recruited to participate in the study.

Sampling. For the informational preliminary survey, random sampling was employed. Individuals completed surveys on the *British Journal of Psychiatry's* (2007) Stigma Scale and

the Chronic Pain Grade Questionnaire (1992). The researcher employed purposeful sampling to guide the qualitative data; participants consented and volunteered for the study, and the researcher mutually selected them based on their responses.

From the 21 participants, nested in the survey data set, the researcher selected six representative samples for the qualitative interviews. The six individuals are a representation of those who measured with high pain scores, high stigma scores, and fit the disclosure categories answered– disclosed to no one, disclosed to peers, disclosed to peers & faculty. The researcher compared the survey data scores' descriptive statistics, then selected the six participants with the highest scores from the Stigma Scale and Chronic Pain Grade Scale calculations.

Procedures

The procedure of this qualitative research design occurred in two stages. First, potential participants were recruited for the preliminary informational survey in a recruitment letter, distributed via email over the University of Arkansas listserv, that invited them to participate in an Internet survey through Qualtrics software. The recruitment email detailed an incentive for participants with chronic pain to complete a survey, and those who consented to the survey were considered for a potential follow-up interview. The incentive was a \$30 Walmart gift card, applicable only for those who chose to take the survey and participate in the interviews. The intention of the study was to give a voice to an underrepresented population and to gather information about the perceptions and experiences of students in higher education regarding the stigma associated with disclosure of a disability, specifically chronic pain. Students in chronic pain must face the choice regarding disclosure to their peers and professors, and/or to seek accommodating services on campus.

Preliminary Survey: Data Collection

Before data collection began, the researcher obtained approval from the University of Arkansas Institutional Review Board (IRB). Following approval (attached in appendix), participants received two informed consent forms to participate in the demographic survey, Stigma Scale and Chronic Pain Grade questionnaire portion of the study and the semi-structured interview portion of the study. Participants were instructed they could withdraw consent at any point during the study. The first instrument of data collection in the initial stage was the survey to collect groundwork about participants' interest and experiences. The three surveys were framed with closed-ended questions ranked by different Likert scales. 6 participants for the interview portion were selected from the population of 21 survey participants.

Instrumentation. The instrumentation includes the types of data to be collected and instruments the researcher used to collect initial data and set a foundation for participants' engagement.

The Demographics Questionnaire. The demographic questionnaire is a self-reporting instrument that measures ethnicity, gender, sex, current degree program, onset of pain, time elapsed since pain onset, and to whom participants have disclosed their condition. All items on this scale are close ended with multiple choice options provided from which participants selected an answer before proceeding to the next question. The disclosure aspect was vital to the study because the multiple-choice answer informed the next stage of the design; participants were selected for the semi-constructed interviews based on their responses to these questions.

The Chronic Pain Grade Scale (1992). The Chronic Pain Grade Scale (CPGS) provides a standard for health practitioners to assess patients' pain and disability. There are seven close-ended test items on the questionnaire. Respondents answered the questionnaire using an 11-point

Likert scoring system (Smith, Penny, Purves, Munro, Wilson, Grimshaw, Chambers, & Smith, 1996).

The Stigma Scale (2007). The Stigma Scale is a self-reported instrument intended to measure the stigma associated with mental illness but adapted for this study to measure chronic pain. The original scale contains 28 test items for participants to indicate how true each item was for them, using a 5-point Likert scale from 1 to 5 in the direction of greater stigma.

Preliminary Survey: Data Analysis

Following the interview, the researcher analyzed both datasets before making conclusory findings with a significant focus on findings from the interview data. Analysis of the qualitative data followed the same organizational structure as the data collection. After the participants completed the demographics questionnaire and the surveys, the researcher reviewed the data set for inconsistencies, incomplete data and data cleaning (DeCuir-Gunby & Schutz, 2017). Next, the researcher conducted descriptive statistical analyses of the data. After conducting the interviews, the data was transcribed and coded.

Interviews: Data Collection

The second instrument of data collection was an interview, because it provided insight into individuals' lives through a social interaction in a story-sharing manner that allows meaningful experiences to organically unfold. An interview "becomes a forum and process by which [one] can explore people's perspectives to achieve fuller development of information within and across experiences in ways that help decipher meaning, experience, similarity, and difference" (Ravitch & Mittenfelner Carl, 2016, p. 147). Interviews allowed the researcher to understand each participant in the context of his/her view of his/her lived experiences. From that interpretation, the researcher can extrapolate applied insights and shared responses with other

participants in the same phenomenon. The interviews were conducted in person in the participants' homes – for those who are local and felt comfortable with the interviewer in their domain, or over Skype/ Facetime video call, so the conversation could be safely recorded. It was preferable that I saw and heard the participants' expressions, inflections and gestures for the qualitative data collection.

Conducting semi-structured interview. After each participant received an invitation to join the next part of the study, participants were asked to sign another informed consent form. The consent forms will be preserved for a minimum of seven years. Next, the semi-structured interview began in the format most accessible for the participant's condition (i.e. telephone, Skype video conference, or in person on campus). The interviews were audio-recorded for privacy, so if the meeting is over Skype then only the audio content will be recorded. As stated in the recruitment email, there were \$30 Walmart gift cards as incentives for participants in the interview. The researcher distributed the gift card immediately to in-person participants at the start of the study and mailed them to those who participated electronically.

The researcher asked the following questions during the interview portion of the study:

1. If any, what experiences have you had with stigma toward chronic pain?
2. What effect has stigma and the fear of disclosure had on your life as a student, if at all?
3. Have you had any positive experiences with disclosing about your chronic pain before? If so, please describe what transpired.
4. Have you had any negative experiences with disclosing about your chronic pain before? If so, please describe what transpired.

5. Do you consider yourself an advocate? If so, please explain (i.e. for yourself and/or others).
6. If you could educate your professors and peers about the stigma associated with disclosure of chronic pain, what would you say?
7. Is there anything else you would like to share with me?

Following the interview portion, the researcher turned off the audio recorder and informed the participant of the option to receive a copy of the data transcription, thereby concluding the qualitative section. I assigned each participant a pseudonym (ex: Participant 14) to keep their identities anonymous. Notes collected during the interviews, interview transcriptions, list of participant pseudonyms, audio and visual recordings, notes from the data findings are locked desk drawer in the researcher's home office, as well as a password-protected computer. The researcher is the only person with the key to unlock the desk and the password to the computer. The data from the study will be retained until the completion of the researcher's dissertation.

Interviews: Data Analysis

Responses for the qualitative portion of the interview were transcribed and coded in a codebook in order to illuminate any overlapping themes among participants' experiences of stigma, pain and disclosure. The semi-structured interview consisted of seven open-response questions. For example, "If any, what experiences have you had with stigma toward chronic pain?". Additional questions may be asked depending on the respondents' answers. The goal of the semi-structured interview was to explore a topic on which there is little literature or understanding, known as "exploratory," in order to contribute to the existing field of research. For this particular design, it is important for the researcher to categorize and code the qualitative

data, using grounded theory, in order to observe interactions, stories, and how individual experiences shape cultural themes. Gleaning the richest themes from the data, the researcher incorporated pre-coding and analytic memos; this will allow organization and maintain a wider scope over recurring ideas, as demonstrated by Ravitch & Mittenfelner Carl (2016).

Procedure. After pre-coding for this design, the researcher performed open coding by reviewing the transcriptions of the interviews and highlighting repeated words or phrases. Charmaz (2006) identifies the first stage as *open coding*, or *initial coding* during which the researcher read the interview transcript line-by-line and "mine(s) early data for analytic ideas to pursue in further data collection and analysis...the goal is to remain open to all possible theoretical directions indicated by your readings of the data" (p.114). The researcher may perform initial open coding by reviewing the transcripts and highlighting significant words or phrases from the interviews and creating codes that define meaning; this allows the researcher to maintain a continuous active engagement with the data, even when the interviewees are no longer present (Charmaz, 2006). Because this design focuses on the stigma associated with disclosure of chronic pain, an example of open coding can be gleaned from the participant's language in the interview, such as "embarrassment," "lack of control," "misunderstood" and "isolated." Next, the researcher used focused coding by hand to subcategorize the highlighted data into systematic themes based on relationships between the codes (Charmaz, 2006). For instance, in a sample interview, repetition of the word "embarrassed" and a description of a sample participant's body as a "problem" or "defective" could indicate a negative self-concept and her vulnerability to societal implications regarding people with disabilities; from this connection, one might infer a reason behind her reluctance to disclose about her chronic pain and place it in the context of greater meaning.

Validity and Trustworthiness

Validity and trustworthiness are equally important to the integrity of the study as establishing reliability and validity to the qualitative. To assess credibility of the qualitative data, this researcher demonstrated believability of the results through a complex theory-driven, data-packed codebook. The hand-organized, systematic codebook holds the researcher accountable to check interpretations of significant research findings, where the interviews were coded a minimum of two times, as recommended by DeCuir-Gunby & Schutz (2017). To establish trustworthiness, or accuracy of research findings and reasonableness to the people who were studied, the researcher applied member checking and thick, rich descriptions (DeCuir-Gunby & Schutz, 2017). Thick, rich descriptions allow readers to experience the participants' "actual language and words," which reinforces the research interpretations made during the analysis (DeCuir-Gunby & Schutz, 2017, p.192). *Participant validation/ member checking*: this approach a) establishes credibility for the investigator, and b) gives the participants an opportunity to interact with the study by responding to the investigator's representations of their experiences (Ravitch & Mittenfelner, 2016). Maxwell clarifies trustworthiness through specific procedures including "member checks, prolonged engagement in the setting studied, peer review, rich description, and an 'audit trail' of research, such as fairness in representing different realities, and helping to empower members of the group studied" among a few others (Maxwell, 2012, p. 129). This research design is trustworthy because it illuminated a reliance on authenticity, empowerment of students with chronic pain, and also rich descriptions of various experiences with stigma or disclosure of chronic pain in higher education. When performing a constructivist grounded theory study, it is important to explore the study's impact at a micro and macro level -

on the participants, since the topic of stigma and disclosure of pain can be emotionally triggering, and to readers of journal publications.

Role of the Researcher

When constructing codes, I confronted my personal assumptions projected through the language used in coding, as well as what I deemed significant in the data (Charmaz, 2006). The process of coding and analyzing data granted an opportunity for mindfulness about my involvement in the analytical practices as to what the codes defined and revealed (Charmaz, 2006). In consideration of possible limitations, this researcher runs the risk that disclosure of personal chronic pain could alter the outcome of the data, based on how the participant responds; he or she could either confide more and appreciate the mutual intimacy exchange, or consider it inappropriate and unprofessional. I elected not to discuss it. Another potential limitation was that participants in chronic pain can be unreliable with attendance; one of them could have an extreme pain day, and opt to cancel at the last second, or be stingy with their answers in order to hasten the interview. This potentially impacted the number of volunteer participants in the study, severely limiting the sample size. Also due to participants' concern with violation of confidentiality, which often stems from shame of their condition or the fear of nonconsensual disclosure, their participation may be less cooperative.

Conclusion

In conclusion, the researcher aimed to provide students with chronic pain in higher education with better coping mechanisms than "passing strategies," which merely serve to get them through the day, in hopes of progressively restoring future plans (Lonardi, 2007). There also needs to be education for potential employers or faculty members in higher education institutions about how chronic pain impacts the individual, in order to dispel myths. While there

are many steps ahead to improve the attitudes towards stigma and chronic pain for students in higher education, I conclude that the need for the study derives from the stigma-induced disruption to an individual's identity, which can correlate with his/ her performance or perceived capabilities in higher education, and the motivating factors behind the decision to disclose their chronic pain. The underlying factors (burden, perception of ability, pain severity, risks of disclosure, disability type, etc.) that impact such a decision are more complex than the degree of pain that manifests in the individual – whether they are visible or invisible. The researcher chose to use a constructivist grounded research design because it offered an enhanced viewpoint over traditional grounded theory, while preserving the participants' recollections of their experiences in their constructed realities.

CHAPTER 4: RESULTS

Introduction

Semi-structured interviews were conducted over a three-month time span. Interview participants were selected based in responses to a preliminary survey. Six individuals were interviewed; three participants were male, and three participants were female. The interviews were transcribed verbatim through a transcription service. The interviews were analyzed using the framework of constructivist grounded theory and categories and themes were determined as part of this process. This chapter will discuss the interview process, the questions asked, and the categories and themes that emerged. The results will be discussed with quotes from the participants to contextualize the categories and themes that were determined.

Data Collection: Interviews

The researcher emailed several participants to partake in the interview; one said yes but did not respond to follow up emails. The timing of the study proved difficult, since the data collection and analysis both occurred over the summer – when students frequently travel and/or are less likely to check their email, which is the primary source of communication for the study. Also, a participant needed to reschedule her interview twice due to pain from weather fluctuations and resulting inflammation. Seven people sat for interviews, but poor audio quality of one account made the interview unintelligible for transcription, so only six are retained: Participants 19, 16, 18, 3, 17, and 14. All participants received a \$30 Walmart gift card at the time of their semi-constructed interview.

Constructivist Grounded Theory

Charmaz's constructivist grounded theory assumes social reality is multiple and constructed, taking the researcher's privileges, interactions and perspectives into account as part

of the research reality (2014, p.13). Because the research reality is constructed, rather than discovered, by participant-researcher engagement, the neutral observer does not exist. “The constructivist approach treats research as a construction but acknowledges that it occurs under specific conditions of which we may not be aware and which may not be of our choosing” (Charmaz, 2014, p. 18). Charmaz posits that neither data nor theory are discovered either as given in the data or the analysis we produce. Rather we are part of the world we study, the data we collect, and the analyses we produce. A grounded theory interview allowed the researcher to ask a few questions and for participants to tell their whole story without the researcher preconceiving the content; challenge to common power dynamic between researcher and participant; ‘silent dialogue’ may arise for sensitive topics during the interview (Charmaz, 2014, p. 93).

Field Notes

Upon concluding the interviews, I took field notes to remind me of each participant’s demeanor and nonverbal cues. Because constructivist grounded theory relies heavily on staying present in the participant’s constructed reality, it is important to preserve his/her voice and tone from their interview without casting judgment. The researcher walked a delicate balance of observing participants and preserving their memory as they are in the interview environment, without inflicting bias or eclipsing their perspectives.

Data Management and Analysis

In order to facilitate constant data interaction, I transcribed three of the six interviews. For the sake of time management, I utilized a transcription service Rev.com for the remaining three interviews, then copy-edited them for errors. Next, I applied member checking by sending the completed transcriptions to each of the interview participants and requested feedback or

asked if they wished to change anything. One participant wished to expand upon an original answer; everyone else was otherwise content. Before I began initial coding, I listened to the audio recordings of each participant's interview as I read through the transcription, which allowed me to immerse myself in the nuances of their answers. Of particular importance, I could ascribe meaning to words that otherwise seemed ordinary but were spoken with a marked inflection on the recording. Possibly, the word had meaning to just the one participant but was meaningless to anyone else. For instance, Participant 3 spoke about the pressure to meet familial expectations and when disclosing her condition to someone new, she just wants them to "behave correctly" with that information. This choice of wording stood out to me because of its association with a petulant child or teething puppy – something that cannot be trusted with the fragility of disability disclosure.

Initial Coding

Line-by-Line. After cleaning the data, the researcher practiced initial coding on the semi-open interview transcripts in order to perform initial coding. In constructivist grounded theory initial coding, the researcher read each transcript line-by-line with an open mind and recognition of personal biases. Line-by-line coding allows the reader to look for patterns in the data without reproducing the participants' assumptions in the research (Charmaz, 2014). The researcher coded with words close to the data that are reflective of action, while simple and precise (Charmaz, 2014, p. 116). Initial codes should answer questions such as, "What is the data a study of?" or "What theoretical category does this specific datum indicate?" (Charmaz, 2014, p.116). My initial codes among the participants include *Positive Experience*, *Advocate*, and *Minimizing Self*.

Focused Coding

Focused codes are the second phase of Constructivist Grounded Theory; researchers can use focus codes to “sift, sort, synthesize, and analyze large amounts of data” (Charmaz, 2014, p.138). Focus codes highlight important initial codes and synthesize them into condensed categories. During this process, I compiled a list of all initial codes from each participant’s interview into a universal list. Then, I took note of codes that reappeared more than once in the code list or stood out in importance. A few examples include *Stigma from Medical Professionals*, *Fear of Disclosure*, *Feeling Misunderstood*, *Epiphany Moment*, *Alternative Treatments*, *Self-Inflicted Stigma*, *Feeling Empowered*, and *Warrior Identity*.

Categories

Classical Grounded Theorists Glaser and Strauss (1967, p. 37) consider a category a “conceptual element in a theory,” so when codes become categories, it opens the door for a code to serve as an analytic tool for specifying relationships. As I selected focused codes, categories emerged as a way of reducing the data. Categories are significant because they organize codes into groups with common factors. In order to narrow 100 codes to 7-8, I observed word repetition among participant interviews in the handwritten codebook. More specifically, I put a star next to the terms or phrases that appeared most frequently, such as *fear of disclosure* or *fear of being stigmatized*, which became the Fears category. Organizing interview quotes in this manner allowed me to confirm my definition of the construct aligned with the construct measured. Each category means something different for each participant and is defined by their individual experiences with stigma and chronic pain, as illustrated by the quotations used in place of definitions. Per Charmaz’s (2014, p. 189) recommendation, I considered, “What

category does this code indicate?” upon review of each focused code and arrived at the following categories for this study:

Fears

The first category that was developed from the coding experience was fears. Participants described several different types of fear in relation to their chronic pain and disclosing that they have chronic pain. The six different types of fear included: fear of being misunderstood, fear of being stigmatized, fear of disclosure to friends and colleagues, fear of missing out on life, fear of judgment, and fear of getting treatment after discrimination from the medical community. These different aspects of fear will be discussed next and quotes from the participants will be used to illustrate these categories in the context of the lives of the participants.

Fear of being misunderstood.

The first fear that participants described was the fear of being misunderstood by others. Others in this sense refer to friends, family, work colleagues; essentially anyone that someone with chronic pain may interact with in their day to day lives. Participant 16 said:

“I think the most frustrating response I ever get is to exercise more when I’m saying, ‘No, I’m physically hurting when I do this thing,’ and they’re like, ‘No just keep doing it more.’ That’s not how that works. It still hurts. I understand muscles and how they work, and they help get things back where they’re supposed to go, but sometimes it just hurts and I’m often so very frustrated by that response.”

Participant 17 talked about his fear of being misunderstood:

“I always wonder what does the ‘normal’ person’s back feel like? It’s hard to compare because you can’t be two people. I don’t really know if when you tell somebody that you have chronic back pain if they really understand what that means. Does everybody hurt? Truly, right?”

Fear of being stigmatized.

The second type of fear that participants discussed was the fear of being stigmatized by others. Again, others can be friends, family, romantic partners, strangers, medical professionals, etc. Participant 16 discussed her experience when she said:

“It was always just comments about my sleep and being called lazy and stuff like that, which was awful. [The comments came from] usually my peers. Sometimes boyfriends, which was always really pleasant, because it was always someone where it wasn’t in grad school or wasn’t doing all the same type of things that I was trained to do and working full time and doing all this great stuff.”

Fear of disclosure (to work/ friends)

The third type of fear was the fear of disclosure to people at work, school, and with friends. Participant 3 talked about the connection between fear of disclosure and stigma when she said:

“Fear of disclosure. Stigma... I mean, the two are very intertwined, probably. Not wanting to lead with excuses, particularly in a classroom where you’re getting graded and you want to be viewed by the professor as at least at the same level, if not higher than your peers. And to come in with an excuse felt, to me, was putting me at a disadvantage.”

Participant 14 talked about her experience with disclosure in higher education when she said,

“When I was in graduate school in my master’s program, which wasn’t at Arkansas, I remember being really afraid to tell anyone because I was newly diagnosed with Ehlers-Danlos Syndrome (EDS).” Participant 16 referred to her experience with disclosure to her professors when she said,

“I never had a problem with teachers saying anything because I didn’t really disclose it to them.”

Participant 17 talked about his experience with disclosure and professors when he said:

“Yeah, I don’t know, but now when you put it like that, I didn’t want to tell [my peers or professors]. I didn’t feel the need to tell them because, I mean I don’t think they would have judged me, but I don’t think that was something I thought about. I just dealt with it for so long that I didn’t feel like it was going to impede anything I was doing with my friends or professors.”

Fear of missing out on life

The fourth type of fear that was discussed was the fear of missing out on life due to chronic pain. Participant 17 discussed this fear when he said:

“A lot of people don’t realize that they have a stigma sometimes, because they don’t realize that maybe not disclosing something just so you didn’t feel like a deterrent was actually, it wasn’t processing as a stigma, and so therefore people are quite unaware. Maybe it’s important to pay more attention to your friends rather than just letting what they say go in and out of your ear, because something they say might encourage you to want to know more about certain situations that you might put them in.”

Fear of judgment

The fifth type of fear that was discussed was the fear of judgement from others. Disclosure can be a challenging activity for people with chronic pain because of the fear that others will have preconceived notions about what it means to have chronic pain or simply will not understand what the experience of living with chronic pain is like on a daily basis. Participant 18 discussed this particular fear when he said, “[Negative experiences with disclosure are] people not believing you. Thinking you’re exaggerating it, and then fighting discomfort when you shouldn’t have to fight discomfort. Nothing drastically negative.”

Fear of getting treatment after discrimination from the medical community

The final type of fear that affects individuals with chronic pain is the fear of getting treatment after discrimination from the medical community. Stigma around chronic pain exists even in the medical community and at times, may be worse than in other settings because the expectation is that medical professionals have a better understanding of chronic pain than lay people. Participant 14 talked about a terrible experience with a pain clinic:

“I get so sick of people being like, ‘Just take some Tylenol.’ It’s not going to help.” The last pain clinic I went to was horrible; they gave me 180 pills for 30 days which is way too many pain pills. They also made me see their psychiatrist, that was a condition of being seen. I was like, ‘I’m a counseling major, and already have a therapist, I don’t need this.’

Identity

The second category that was determined from the coding experience was identity. Chronic pain impacts identity in a variety of ways. Three different ways that identity was discussed was crisis of identity, pain tied to their identity, and claiming of their self and new identity. These concepts are discussed with comments from the participants to demonstrate how these concepts of identity are seen in their lives.

Crisis of identity

People with chronic pain face different crises of their identity. This can include feeling the need to conceal the part of their identity related to chronic pain from others, as well as feeling the need to constantly explain their lives with chronic pain when they forget what that part of their lives means. Participant 3 spoke about issues around her identity when she said,

“People forget. My parents even. People who are very, very close to me absolutely forget that I am sick and constantly feel unwell...just to different degrees, but it’s always there. Things that are asked of me that are impossible, or that I think shouldn’t be asked of me, or putting me, I feel like, in a position of saying no when I don’t even want...Like don’t even bring this thing to me. You know better, but they don’t because I’m concealing it, which is in a way, lying. It’s a constant frustration because there’s this disconnect between me and my world, and it starts and ends with my body.”

Pain tied to identity

When one lives with chronic pain on a daily basis, it can become impossible separate who they are from the fact that they have chronic pain. Therefore, their pain becomes tied to their identity and cannot be separated. Participant 14 discussed the manner in which her pain is linked to her identity and how that impacts her life when she said:

“I could have taken that particular person’s advice [to not disclose], and I would have always felt like I was hiding a piece of who I am. Because I can’t remove that part of who I am. I would like to. I would love it if I could turn it off, but it impacts every – it impacts my whole life. It impacts my career choices. It impacted where I chose to move, because I had to think about how the weather would affect my condition. So as for me it’s the equivalent of denying my gender or my sexuality or whatever, like I can’t take away this

piece of who I am – which is why I’m in the field that I’m in. So why should I make it a secret?”

Claiming of self/ new identity

The journey to forming a new identity that includes chronic pain can be a complicated one. People with chronic pain may need to discard who they used to be and form a new identity and self-concept that includes chronic pain as a part of who they are. Participant 14 commented, “If you had said to me, I’m coming up on eight years since I’ve been diagnosed – it’s been an evolution, I’ve had to get comfortable with that piece of my identity.

Advocacy

Another category that was determined through the coding process was the concept of advocacy. Advocacy becomes an important component of life with chronic pain because the person with chronic pain must now become their own advocate in a variety of ways. They may need to advocate for treatments and medications with medical professionals. They may need to advocate for accommodations at work or at school. They may also eventually become advocates for others like them with shared experiences.

For self

Usually the first form of advocacy to develop for people with chronic pain is self-advocacy. This can give them an important sense of meaning and purpose in their lives.

Participant 3 explained the concept of re-enforcing a sense of purpose through advocacy when she said:

“I think probably the biggest way I’m an advocate would be if I am, in fact, that would be just how I like to go about the world leading with who I am rather than what I have, and then, when I get to know people a little better, and I disclose what’s actually going on in a very small way, and even then, that shock, I feel like is kind of fun and eye-opening, hopefully for them.”

Participant 14 contributed to this category as well:

“I do my best to get through all of this and find some positive aspects. I don’t want to dwell on the negative. It would be really easy to, but that’s also not really a life worth living to me. And I’m 34 almost, I still have a lot of years left – hopefully – I want to do something meaningful with that.”

Part of advocacy can include advocating for self-care and making sure that is a priority.

Participant 17 talked about the need for self-care when he said:

“I consider myself an advocate for self-care. The one way I’ve learned that I can control the pain is by working out and training the muscles that do hurt, so I’m an advocate in that sense for self-care, for taking care of your body because our body deteriorates so fast. When you’re young, you just don’t realize how fast it’s going to go.”

At some point in the advocacy journey, people with chronic pain may find themselves as an ally for others who also live with chronic pain. Participant 14 explained her views on becoming an ally when she said:

“I started a support group on campus. That’s what really got me thinking: okay somebody needs to do something about this, there’s not a lot of literature out there, so I decided to go for a doctoral program. I can include a small number of people and I’ve learned the power of storytelling. Maybe I could do that on a greater level and still feel like I was using – because I was kind of raised that you don’t give up. You just turn everything into some sort of opportunity.”

People with chronic pain also need allies in the form of people who do not have chronic pain.

They need these allies to be understanding and non-judgmental, especially when it comes to disclosing that they have chronic pain. Participant 14 explained this when she said, “Just because someone says they have chronic pain, don’t make assumptions about them. You should try to be an ally for those people. Make it so they can come talk to you when they’re frustrated, or they just need someone that’s compassionate. They’re not expecting you to solve their problems. We know you can’t cure chronic pain, but we need people who can understand and not judge us.”

Participant 18 talked about his views on being an ally, when he said, “I try to be an ally more so than maybe an advocate and that’s with if I see one of my friends parking in a handicap parking

place or something. I'll put them in their place on the appropriateness of that. Trying to be as conscious of those things as possible without raising attention so that you can be an ally."

For others

In addition to self-advocacy, for some people with chronic pain, it may become important to become an advocate for others and help them along their journey with chronic pain. One way this can happen is to provide hope for those newly diagnosed with chronic pain. Participant 14 explained the importance of giving hope to others when she said:

"We don't really give people tools to address stigma. We could do a better job of preparing people at the onset or diagnosis of chronic pain, since this is something you might encounter. I am proud of the warrior and the person I have become because of the experience of having chronic pain. I am not ashamed of the fact that I live with chronic pain. All of my experiences are living with chronic pain and chronic illness have made me into who I am today and being on the path that I am on today."

Participant 16 offered this advice around coping with chronic pain:

"I would encourage people to explore every other avenue before just committing to medicating yourself. There is so much more you can do than just medicate yourself, and it requires a lot more work and a lot more consistency, and that's the part that's difficult, but you're not alone in the process. Chiropractic is still not mainstream in the sense of insurance coverage. And then massage, often not covered, but also evidence-based, it helps with pain. Exercises, therapy as medication, and then there's evidence to show that cannabinoids can help with pain, so there are other routes; you don't have to worry that you're going to get addicted to opioids. Advocate for yourself when doctors try to give you that as a first route."

When living with chronic pain, it is important to find others who understand your life and understand what it means to live with chronic pain. Sharing stories can be a simple way to let others know they are not alone. Participant 3 discussed the power of sharing stories when she said:

"You know, my work with chronic pain, I think about more as helping the individual rather than helping the system. I'm thankful there are people willing to scream and shout and pound their fists to make change. I have never felt that calling, but I do love having smaller, intimate conversations with someone about their experience, or talking with someone about mine, just in a very informal way, and if there's any change I'm making, it would be one individual at a time at a very slow crawl."

Participant 14 recounted her experience with sharing stories when she said:

“Working with other people that were in chronic pain and seeing that my ability to tell my story empowered them to tell theirs and realize they weren’t alone. Chronic pain can be so isolating, and finding other people who get it, and they don’t need anything from you, they just need a safe place to act normal or ‘Let’s go have ice cream.’ I started an online community and then an in-person community.

Openly discussing chronic pain can start a dialogue for those with and without chronic pain.

Participant 14 relayed the power of opening a dialogue when he said:

“I really do try to be somebody they can go to if they need help or support, because I needed that. I still need that at points in my journey. I feel like I need somebody to listen and be like, ‘That sucks, I’m sorry.’ I don’t need anyone to fix it, because I can’t. I can’t fix other people’s situations; I can try to provide them with resources. I can try to provide them with empathy, but ultimately, I can’t take away their pain. I think it really helps to know that you’re not alone. Having somebody that you can *commiserate* with to be like, ‘Okay, I’m not the only one who experiences this.’”

Participant 19 talked about opening a dialogue at work when he said:

“In my professional career I’ve been able to [advocate] for people who experience chronic pain. I do feel like sometimes it’s like okay, they’ve missed X number of days of work because of this; you’ve got to be a little more understanding and give them the benefit of the doubt and at the end of the day, the truth does come out and it reveals itself. I think being understanding is important to advocate for people who can’t be there to advocate for themselves. I do feel like I’m sometimes that voice that’s like, hey, this might be a chronic issue that we know nothing about at this time.”

Positive Experience with Stigma

Another category discovered through the coding process was positive experiences with stigma. This can include encouraging interactions with others, as well as advice for those without chronic pain for what they can do to aid those living with chronic pain. Participant 14 gave this statement about ways to help people with chronic pain:

“If you truly want to do something to help someone with chronic pain, be an advocate. Write to legislators to help with laws and policies around pain management options, especially around medical marijuana. Donate to research to help us get better options for pain management or advocate for insurance companies to cover complementary and alternative treatments like acupuncture, massage, IV treatments, etc.”

Educating others about life with chronic pain is important to ending the stigma associated with chronic pain conditions. Participant 14 said,

“I wish people wouldn’t automatically jump to worst case scenario with chronic pain. Just because someone told me that they have chronic pain, don’t assume that they’re addicted to opioids. Don’t make assumptions based on what you’ve seen in the news or what you hear from stupid people in medicine.”

Participant 18 also spoke on the importance of education when he said, “Communication is the first step in the right direction. That’s the opportunity to educate people on it or to learn more about it yourself. But, if we stop talking about it, we will lose that battle.”

Educating others often leads to more awareness about the reality and truth about chronic pain. Participant 14 talked about her experience with awareness when she said:

“Eventually I was teaching subjects that relate to people with chronic pain and connecting, and I feel like students will learn from my experiences just as much as I did. And that’s something that showed up on my evaluation and they were like, ‘We appreciated that (Participant 14) was honest about her experience, and it meant so much more than just reading it out of a textbook.’”

Participant 14 went on to say:

“It came up again as I was applying for jobs, one particular professor was anti-disclosure, and was like, ‘Don’t tell anyone.’ I did, I put [my condition] in my cover letter because I didn’t want to go into serious detail, all I said was, ‘As a person living with invisible disabilities, I’ll bring a different perspective to the classroom,’ and I have no idea if that led to me getting my job or not, but it didn’t impede anything. They knew when they brought me in for the interview that I had some sort of invisible disability or condition, and I kind of disclosed a little bit here and there. Not too much, yet, but I said something, and I think if it helps other people be willing to tell their story.”

Keeping the experience of chronic pain hidden and feeling unable to comfortably talk to people about it can be isolating and difficult. Often there is a sense of relief and release when one is finally able to talk openly and honestly about the reality of life with chronic pain. Participant 17 talked about the relief and importance of disclosure when he said:

“It’s good to talk about it. Through life I’ve learned to realize that a lot of people just don’t care about you, and so why waste your breath? I’ve always been the type to just

bury things anyway. When I disclose it to my chiropractor, he fixes my issues, and I've talked to like personal trainers about it, and that's been beneficial because we've come up with workout routines that focused on strengthening my rear core and my back core."

In addition to the feeling of relief, disclosing chronic pain can also be an empowering experience. Participant 14 spoke about feeling empowered through disclosure when she said:

"I didn't even fully understand the condition myself or how I was going to be able to explain to other people. But I found...like when I found one person that I could trust to tell, it got a lot easier after that. It turned out my advisor also had pain issues too, she had Rheumatoid Arthritis and so I think that automatically takes the stress level down when you know you're disclosing to someone who also had – even if it's not chronic pain – health issues. Then I think that empowered me in a way that when I got to Arkansas for my doc program, I told everybody."

Helping others can lead to a validation of the individual's experience of chronic pain and can lead to a sense of meaning and purpose for the experiences the person has been through when they are able to use their experiences to help others. Participant 14 went on to say:

"It would have been a heck of a lot easier to lay on my couch and give up, but that wasn't really an option. I'm glad I did because I think helping other people work through their things has made me stronger and has made me – it's a coping mechanism for me. It's like if I can focus on someone else and helping someone else, it takes the focus off me and how much this sucks or this hurts."

Participant 19 talked about his experience when he said, "I think that everybody's been pretty understanding, when I've had to miss class or work due to [my chronic pain condition]."

Negative Experience with Stigma

Although there are positive experiences that come from life with chronic pain and disclosure, there are also negative experiences with stigma. This was another category that emerged from the coding experience. These negative experiences range from feeling pressure to conceal the chronic pain condition to discrimination in work or school settings to being accused of faking and much more. Quotes from the participants describe the range of the negative experiences that come from living with chronic pain.

Pressure to conceal condition

Some people with chronic pain experience pressure to conceal their condition(s) from others or pretend that their lives are unimpacted by pain, when in reality this is not the case.

Participant 3 said, “I think a big, big piece of that puzzle, almost all of it, is because I know that I’m disadvantaged as a chronically ill person, so I’m going to pretend not to be.”

Discrimination in work or academic environments

Discrimination at work and at school is an unfortunate reality of life with chronic pain. Participant 3 disclosed, “I had a teacher, who in front of the entire class at the end of the semester, commented on how informal I was (because I sit like this, with my knees up against the table).”

Participant 19 talked about the pressure to perform when he said:

“I don’t think anybody that’s experienced chronic pain wants to be made to feel like they’re crying wolf or that they’re, because of their condition, that they are not able to participate as equally. That pressure to always be on is there even with the chronic pain.”

Participant 19 added his experience in the workplace:

“I think we do a really good job, at least my employers do, to make sure that we’re not jumping to assumptions [about employees’ absences]. I guess that comes from understanding that you do want to give people the benefit of the doubt but there’s other positions that and there’s other employers that that’s not the case. We don’t have a point system [at my job] but there are places that do, so if you are not disclosing that because of the stigma around it, you could definitely see yourself unemployed.”

Accused of faking

One of the fears associated with chronic pain disclosure is the fear that others will not believe you or assume that you are faking for attention or sympathy. Participant 16 discussed her experience with the topic when she said, “I haven’t had too many people just blatantly tell me they don’t believe me, which is nice, but I think a lot of people roll their eyes when I tell them it hurts.”

Participant 18 talked about the frustration with managing invisible pain when he said:

“When I was an athlete growing up, having shoulder pains, shoulders that would constantly dislocate, it’s not a pain that is demonstrable. So, a lot of people would think that I was faking it and would chastise me and tease me as a result.”

Need to prove condition

If one is concerned with people assuming that the chronic pain is fake, then it leads to feeling the need to prove that one actually does have chronic pain. Participant 3 disclosed the pitfalls of disclosure and dating with chronic pain:

“I smile because all you can do is laugh at them. Typically, I don’t disclose on the first date. He was a med student. He thought he knew everything, and he knew nothing about me and had no ground on which to stand. I tried to explain to him this is my decision, and that was between me and my doctor, not me and my date.”

Stigma from medical community

Stigma from the medical community is an overwhelming problem for people with chronic pain, especially in the current climate of the opioid epidemic going on in the United States. This can lead to negative experiences when trying to seek treatment and medication to manage chronic pain. Participant 14 talked about experiences with family and medical personnel:

“A lot of my experiences have been from medical professionals – stigma from them, not being taken seriously, thinking that I was drug seeking when I needed pain relief especially in the emergency room. I just remember my mom coming into my apartment looking at my meds and flipping out. She was like, ‘I’m afraid you’re going to overdose or afraid you’re going to take too many.’ She didn’t understand that I needed them. I’ve been really lucky with employers, but most of my issues around stigma and being judged come from medical professionals and my family.”

Feeling unheard and minimized. Participant 14 added her negative experiences with feeling unheard and feeling discouraged from seeking treatment by medical professionals in the emergency room, when she said:

“The nurse gave me the shot and came in with discharge papers with a referral to a psychiatrist on there. I ended up bawling. This is why people don’t get treatment. This is why people commit suicide, because they just want it to go away. I never got to that point luckily. When I moved to Arkansas, trying to find a pain management doctor, they were

so inclined to blame it on everything else. I had a doctor who was like, ‘Oh you just need to get married and have a family,’ like that was going to fix my problems.”

Burden of Responsibility

Another category that emerged from the coding process was the idea of burden of responsibility. Whose responsibility is the disclosure experience? What can others do to make this experience easier or better?

Self

Participant 18 explained how he was responsible for maintaining his health needs and accommodations when it comes to pain concerns:

“Me, in school, I probably didn’t ever process that thought directly of, wow, this would benefit me with my shoulder issues, with my collarbone getting through it, I went without where I could’ve had support. If I was more aware of what was out there and there was a private way to disclose, then I think more people would do so. It’s such a serious issue and it often is invisible. Some people can be blind to it. There’s an educational curve there, a steep hill to climb. But I do think most people would relate and do their best to accommodate.”

Professors

Participant 18 added that the responsibility could be shared with professors, if done so appropriately:

“Give anyone an opportunity to [disclose] privately. Not in front of the class and not setting them aside but giving them an opportunity to make you aware of whatever their needs may be and to accommodate those to the best of your ability, but to do so privately so that it’s not stigmatized and blown out of proportion.

Friends

Participant 17 talked the about burden of disclosing conditions to friends, when he said:

“I think that there are a lot of people who are unaware that they might be stigmatizing themselves subconsciously and might be unaware that their peers might be more sympathetic if they did tell them. I think it could be [a burden or responsibility on others]. Not in my case, but with someone like that friend with IBS, if they want to go eat, they have to think about like what that person can eat, and so it can be a burden. I mean, even with knee pain, I guess if someone had really bad knee pain and they couldn’t go hiking

and all your friends are hikers, that would put the burden on them to find things that they enjoyed less. I mean, I guess, yeah it could be a burden.”

Journey

Learning to live with chronic pain is a journey and this is the final category that was determined based on the coding experience. This journey encompasses many experiences and includes ideas such as coping methods and finding the treatment(s) that work best. The process of learning to live the best life possible is an ever-evolving journey. For some of the participants, participating in the interviews gave them clarity about their experiences and led to epiphany moments about their journey.

Coping methods

It is crucial to life with chronic pain to discover the best ways to cope for the individual. Participant 16 talked about the importance of finding the right coping methods when she said, “It really sneaks up on me if I’m not very diligent about exercising, getting adjustments, and getting massages and all of these things all of the time. If I get off track even a little bit, it just snowballs.”

Alternative treatment

For some, traditional treatments may not be the best solution for them. Participant 16 spoke about her preference in alternative treatment over traditional pharmaceuticals:

“When I’ve ever said anything to people about it, they’ve asked me about chiropractic, so it’s been a good opportunity to share research and things about the benefits of chiropractic, which is helpful. I’ve had people say things like, ‘Oh I’ve got something similar.’ That’s been helpful from time to time.”

Epiphany moment

As stated previously, the process of participating in the interview led to an epiphany moment for some participants about their experiences with chronic pain, disclosure, and stigma.

Participant 3 reflected on her experiences with stigma when she said:

“It’s real interesting because I’m sitting here listening to you, and I’m like, well I haven’t experienced a huge backlash from being sick. And then, I think about how much time and energy I spend pretending to be well, and then that’s when I have to be like, well then, why am I doing that?”

Participant 16 contributed her experiences as well:

“And then as I learned more about pain and why I was tired all of the time, I really had more stigma about me being tired all the time, which is a result of me being in pain, more than anything. It was always just comments about my sleep and being called lazy and stuff like that, which was awful.”

Participant 17 added his experiences with stigma, unaware until the interview that the stigma fully existed:

“If I was doing something with my friends...see now I’m second-guessing myself because I wouldn’t want to tell them because I didn’t want to be like, ‘Oh, we can’t go climbing because my back hurts,’ so I guess I subconsciously felt some stigma.”

Participant 16 talked about her awareness process when she said:

“For me this has been a really interesting experience, because like I said, I never really thought about myself having chronic pain until I read the definition of chronic pain and I was like, ‘Oh yeah, that’s me for sure.’ So, I’m sure there’s more people out there like me that question their day-to-day life and are uncomfortable a lot of the time and don’t think about it, so that’s been really nice [to have the epiphany].”

Participant 18 talked about his experience with stigma and school when he said, “What I think of chronic pain and stigma associated with school, I do think of just how broad that is and how many students need that kind of assistance that aren’t even aware that they might need it.”

Participant 3 alluded to her expectations and the process involved for her following the epiphany about chronic pain:

“It has taken so much research and time and commitment for me to understand. I could never ask anyone to put in that same effort into what is, at the end of the day, still one piece of who I am and not all of me.”

Participant 16 talked about her epiphany moment when she said:

“I didn’t really realize I had chronic pain. I did not realize that other people didn’t have to go to the chiropractor multiple times a week, or every other week, and things like that, so I just thought it was completely normal.”

Participant 14 talked about her journey when she shared:

“I have a perspective. What if I tried to help other people like me? That’s what led me to my master’s thesis and then doing that made me realize the power of telling your story provides so many people who are like, ‘No one’s ever asked me this before’ or ‘No one’s ever let me that wasn’t a doctor or medical professional...’ And so I realized that if I wanted to truly be able to help other people which is truly my goal, then I had to be okay with telling my story and living all of who I was, and not shutting it off into little pieces.”

The idea of an epiphany moment is a testament to the power of telling one’s story and was an unexpected finding of this study. It was also hopefully an unintended benefit to the participants as a result of their openness and honesty during the interviews.

This section described the categories that emerged as a result of the coding process that was completed using the framework of constructivist grounded theory. The next section will explain and describe the themes that were discovered through this process.

Themes

In the context of this study, themes are conceptual relationships between categories and codes, linked together by ideas or words from the participant interview. In order to find emergent themes, I reviewed the transcripts several times while listening to the audio-recordings and took hand-written notes of inflected words or heavily repeated words, such as “advocacy.” I also made note of abstract concepts that appeared to be background noise on first examination. For instance, three participants separately stated that they did not realize they officially had chronic pain until reading the definition provided in the consent form and meeting for the interview.

What began as an interesting side note became heavily featured as a theme for half the sample: the epiphany moment.

The ten themes that were discovered were: commiserate over pain; advocacy through storytelling and voice; burden of responsibility; attitudes toward disclosure; epiphany about realizing chronic pain in adulthood; in-group vs. out-group comparisons; lying vs. concealing or minimizing; reclaiming identity after diagnosis; preoccupation with social approval; and accounts of discrimination from the medical community. These themes are discussed in the following paragraphs, with direct quotes from the participants included to enhance the description of these themes.

Commiserate over Pain

Participant 18 commented on commiseration when he said:

“The reflection of that being that the majority of the people that I have shared that with have something worse. It’s something that’s more obvious and you can relate to a certain extent, but it’s always good to find some common ground and learn what everyone else is going through.”

Advocacy through Storytelling and Voice

Participant 16 said, “I spend a lot of time advocating for students just in general and talking more about how to stand up for themselves in other contexts.” Participant 19 said, “I think it’s important to have each other’s back and to be supportive and understanding, and I guess ultimately learn and grow from the pain – and from others too.”

Burden of Responsibility- Self vs. Others

Participant 3 said, “For me, it’s like why can’t you understand? It’s an unfair expectation that I hold, but I hold it nevertheless. I can’t ask anyone to understand any experience of mine in the world.”

Participant 16 gave this perspective:

“If people [with chronic pain conditions] are high-performing, they have figured out how to... I guess not hide it, but work through it, and you get to a point where you can't do that. I think it's important that faculty, instructors, staff would pay attention to how their students react to things and what their normal looks like, just from typical interaction, but knowing how pain works, because we don't talk about it.”

Attitudes Toward Disclosure

Participant 3 expressed a positive attitude toward disclosure pro disclosure; she said:

“I would really encourage just a dialogue and asking questions because you can't control their reactions, and I think part of that stigma is rooted in this discomfort of discussing another person's medical history. So, we can't end stigmas without information, and we can't get information unless we ask for it.”

Epiphany About Realizing Chronic Pain in Adulthood

Participant 16 spoke about not realizing she had chronic pain until adulthood when she said:

“I think what's weird and sad is I didn't really realize I was someone that was in chronic pain, but I'm always someone that's very supportive of other people's experiences, and I am not dismissive of other people's pain or suffering of any kind, physical or emotional etc.”

In-Group Vs. Out-Group Comparisons

Participant 3 said,

“You know, you get the ‘Oh you wouldn't know it.’ Like someone's impressed. I think that's the biggest thing, is impressing people. It's like you have this superpower that you have all this going on underneath you, and no one knows it, and it's like a game. A very damaging game.”

Participant 3 p. also talked about expecting certain reactions from people when she said:

“I like to think once I disclose, okay, now we both have the same information. And, I want the person to *behave correctly* with that information. They often don't, because, how could they? It's such a specific experience, and my boyfriend, who I spend almost every single day and night with, still has questions about it.”

Participant 3 added more on her expectations of others when she said:

“If I'm at a wedding and I'm not dancing, it's easy to get down or to have a face looking like you're miserable perhaps. Someone will come up to you, and they're like, ‘Why aren't you dancing?’ I just want to be like, ‘You know, you have this information. Don't

be an idiot.’ But they don’t because they saw me dancing last night or earlier in the night even so.”

Participant 16 spoke about misconceptions of others when she said:

“We were talking about running. It doesn’t feel good, and even if I am enjoying the run, if I do it too often, it hurts. My friend, who’s an exercise scientist and a personal trainer, she’s like, ‘Just keep running. Just keep doing it.’ I’m like, ‘No man, it hurts. I’m going to swim or do the elliptical or something that’s more low-impact,’ and she just said, ‘No, you’ve got to keep trying.’ No, it doesn’t work that way.”

Participant 16 then talked about the importance of checking our assumptions:

“I think it’s important to realize how many people are in pain, and what pain looks like. I think just colloquially we only talk about pain and it’s supposed to be excruciating and you-can’t-get-off-the-floor and you-need-to-go-to-the-ER sort of situation, when really most people are not there very often. It’s more ongoing discomfort or like, for me, it’s exhaustion. Everyone manifests things in a different way.”

Lying Vs. Concealing or Minimizing

Participant 3 talked about the judgments she faces when disclosing her condition to dates:

“This comes back to you get in a position where you have to lie something when you’re trying to conceal. And, I chose not to lie and to be honest, and he was like, ‘You have an autoimmune disease, and you’re not treating it with TNF inhibitors or biologics. That is irresponsible.’”

Participant 16 weighed the choice to tell the truth about her condition to professors when she said:

“I lie to my professors a lot about why I’m not coming to class. I’ll lie and tell them I have a migraine when it’s just that I’m physically so tired that I can’t stay awake anymore. And sometimes I do have a migraine, but most of the time it’s just I’m physically so weak and exhausted that I can’t imagine sitting still for three hours at a time. So yeah, I’ve lied to people a lot about [my condition]. And then, jobs and things, I’ve had to try and fake it until you make it, sort of, and not say anything.”

Preoccupation with Social Approval

Participant 16 talked about her concern with the approval of others when she said:

“I guess I don’t want to come off as whiny or lazy, and a lot of times I think people just will pay lip service to say that they’re supportive and student-centered when that’s really

not the case. They're tenure-funding, and they're career-driven and they just happen to like teaching maybe. Sometimes it's easier just to tell somebody you have a migraine."

Reclaiming Identity after Diagnosis

Participant 16 spoke about identity issues:

"I did have a moment where I was like 'Oh man! That sucks!' But then, it's been helpful being like, 'Oh yeah, but this has been life for a long time, so it doesn't really matter if I have a label or not. This is just a thing.' I think that's been helpful just being able to, for me, identify, 'Yes, this is a characteristic of my life that other people don't experience. And that's okay.'"

Data Display

Using Participant Language to Identify Focused Codes and Themes

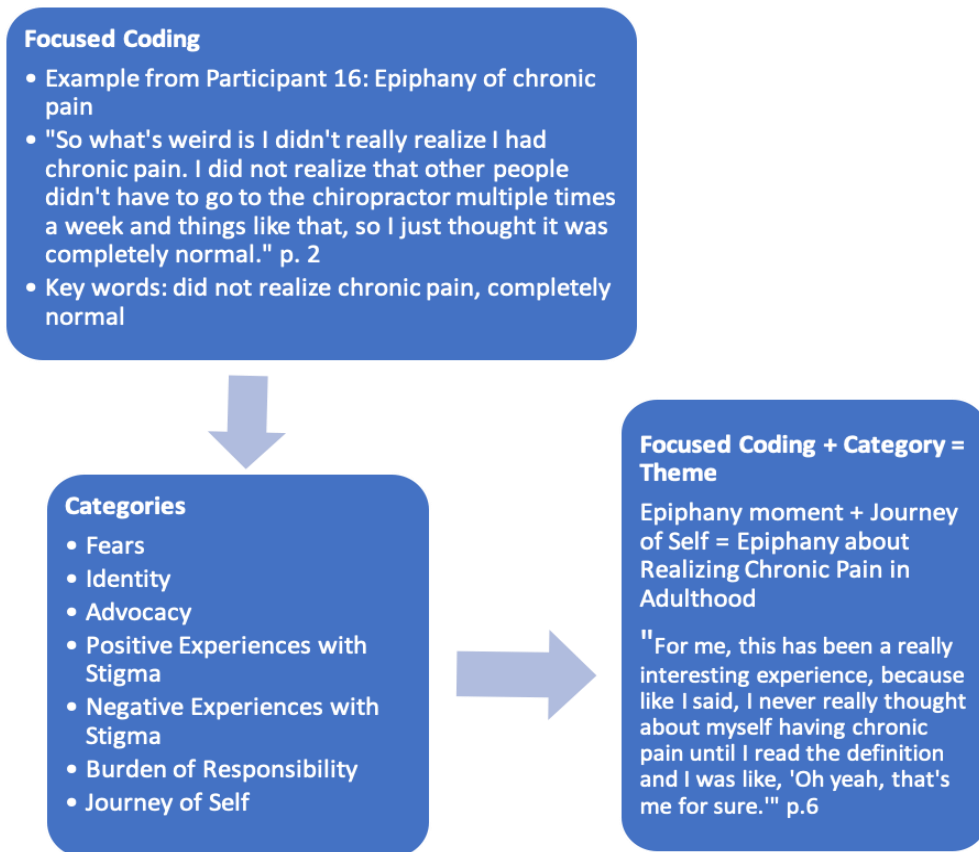


Figure 1: Stages in the process from focused coding to theme detection

Accounts of Discrimination from the Medical Community

Participant 14 addressed the source of negative experiences, when she specified, “Most of the negative experiences have come from doctors.”

Conclusion

During the data analysis process, close analysis of the data led to 109 focused codes, seven categories, and ten themes. This chapter discussed and described those categories and themes, with quotes from the participants used to explain the categories and themes within the context of their experiences in their lives. In the next chapter, chapter five, implications for practice and recommendations for future research will be discussed. This discussion will be based on the findings from the current study described in the current chapter.

CHAPTER 5: DISCUSSION

Introduction

Students in higher education living with chronic pain may experience social isolation from their peers, discrimination from the medical community, and/ or judgments from professors about their academic performance (Firmin et al., 2011). The specialized topic of students in chronic pain contributes to the literature for higher education and disability research. My goal in pursuing this study was to bridge the gap between professors and students, students in chronic pain, and their oblivious peers. The purpose of this study was to examine how anticipated or experienced stigma associated with chronic pain conditions influences disclosure of chronic pain for students in higher education. Because living with pain can be devastating, topped with academic pressures and social stigma, it is important that students have resources where they can safely disclose to an ally or learn to advocate for themselves (Venkatesh, Brown, & Sullivan, 2016).

The researcher conducted a qualitative constructivist grounded theory study and looked at the following research questions.

1. How does the social perception of chronic pain influence student disclosure behaviors in the academic environment?
2. How do participants define anticipated and experienced stigma as it relates to chronic pain, and have they experienced this type of stigma?
 - a. If yes, what was the experience?
3. What conditions in higher education encourage students to disclose their chronic pain to their professors? To their peers?

4. What conditions in higher education discourage students from disclosing their chronic pain to their professors? To their peers?

This chapter will discuss the relevant findings from this study and explain how those findings impact implications for practitioners, professors, higher education and disability service professionals, and policy makers. Recommendations for future research will also be discussed. Finally, limitations to the current study will be reported.

Researcher Reflexivity

As someone who is part of the chronic pain community, performing this study opened my eyes to how many participants' actions are dictated by fear, not pain. I also learned that for this population, coping is less about grief and more about managing expectations. This research study will impact my job as a disability services specialist by allowing me to accomplish my purpose of helping others find their voice through self-advocacy. My hope is to continue the disclosure of chronic pain research through perpetuating the advocacy cycle in this document, and advancing it further, since so much work remains.

Implications

One of the goals of the study was to evoke change through advocacy and stopping the spread of stigma. In order to accomplish that, the results from this study must inform future behaviors toward the stigma of chronic pain in higher education. When asked who is accountable for the bearing the burden of responsibility – that is, noticing and validating chronic pain - the participants cited family members, peers and themselves. In this section, I discuss how the burden of responsibility is best shared to alleviate the burden for those in chronic pain through providing resources, as well as allies/advocates, in trained practitioners.

Education

To improve the quality of care and education for students with chronic pain, training should be done at the masters and doctorate level for mental health, rehabilitation counseling, and counselor education. More specifically, train professionals in counseling and school counseling settings, not just rehabilitation about how to recognize individuals with chronic pain and understand what their role is in helping those students. With rehabilitation students, training should focus on employment and disclosure of chronic pain conditions, including advocacy efforts. Mental health studies should direct applicable theoretical orientations and techniques toward chronic pain patients during training. With regard to school counselors, consider how chronic pain affects behavior at school; for instance, attention-seeking or signs of acting out might be indicative of pain. It is also important to teach children the value of reporting persistent pain to adults, should it become chronic, and to advocate for their needs. This is essential, so if they pursue higher education or employment, it is not the first time for them to report chronic pain to a disability services office, or self-advocate.

For counselor educators, it is vital that they receive training about pain (including current laws and policies), so they can competently teach their doctoral students. Counselor educators can advocate for students in committees and be aware of policies around accommodations. An obvious, yet simple, gesture of support is including the paragraph in syllabus about the campus accessibility office or read the paragraph out loud about available accommodations. More importantly, be available to direct students to appropriate resources, which helps anyone with disability – not exclusively chronic pain. Another way counselor educators can be allies or advocates is by awareness of resources on campus and participation on campus (medical center,

counseling center,) if the need arises to provide appropriate referrals for someone with chronic illness and/or chronic pain.

Practice

The practice of training counselors can change by the attitude used towards people with chronic pain. In the interviews, a few participants elaborated on positive experiences with stigma, which may speak more to the integrity of their character than to the existence of the anomaly. Through nurturing hope, counselors can reinforce the practice of self-advocacy for those who are newly diagnosed, as they shed their former selves and rise from the ashes.

Policy

For employment policy, a rehabilitation counseling agency could provide a 1-2-hour training with resources in the community with Job Accommodation Network (JAN) resources for various conditions by job function. This training would educate employers and human resource representatives about how hiring and retaining people with chronic pain is more cost efficient, so employees with chronic pain will feel comfortable disclosing pain conditions in their work environments where accommodations are likely to be met. This in turn helps the rehabilitation counselor develop relationships with employers, so the counselor knows the employer is hiring-friendly towards candidates with chronic pain and the employer does not have to post a job search. The training results in a symbiotic relationship between an employer satisfied with a qualified employee pool and the rehabilitation counselor can refer qualified people to that employer.

Regarding higher education policy, universities can implement a disability awareness ally zone, a.k.a “Spoonie Zone.” In the Spoonie Zone, all attendees learn chronic illness and disability etiquette, person-first language, and the Spoonie origin story. Implement a safe space

to ask questions and provide basic information on what it is like to have a disability. At the end of the training, all attendees receive a Spoonie Zone sticker. Discussion items can include but are not limited to the prevalence of chronic pain, how to be an ally, overcoming stigma, resources on campus (CAPS, student orgs, medical resources, online support groups). Reinforce people with chronic pain do not want a cure, they want a safe place to talk and be heard without judgment.

Treatment options towards individuals with chronic pain should shift away from prescription narcotics towards insurance-covered alternative medicine, in the viewpoint of some participants. Chiropractor, massage-therapy and cannabinoids are a few examples Participant 16 suggested as alternatives to prevent opioid addiction. Likewise, Participant 14 echoed her sentiment but with more gusto:

If you truly want to do something to help someone in chronic pain, be an advocate. Write to legislators to help with laws and policies around pain management options, especially around medical marijuana. Donate to research to help us get better treatment options for pain management or advocate for insurance companies to cover complementary and alternative treatments like acupuncture, massage, IV treatments, etc.

Research

For future research studies, researchers could issue a disclaimer on surveys that they may unintentionally cause harm or stress due to the nature of the questions, so if someone is triggered and needs to process the experience, the researcher can make a mental health counselor's contact information available. Another option is the participants can elect not to proceed, like the almost-participant in my study who was triggered by the survey questions. Future researchers could extend the research I began but explore the perspective of educators in higher education with a survey to assess what resources they want to better equip them to help this population of students.

In consideration for future studies, I asked my participants during the close of the interview if they had suggestions for resolutions to barriers pertaining to stigma and disclosure of chronic pain. I found their answers to be remarkably transcendent across topics. Participant 3 implored teachers to undergo sensitivity training on invisible disabilities. She also encouraged a dialogue with respectful boundaries between people with disabilities and professors/peers, because as succinctly stated by Participant 3 during the interview, “stigma is rooted in discomfort of discussing medical history. We can’t end stigma without information, and we can’t get information unless we ask for it.”.

Limitations of the Study

Although I am pleased with the findings of this research study, it is important to acknowledge limitations within the study. As previously mentioned in the methods section, the participant sample size of 21 created some challenges in the informational survey data collection, which affected the interview data collection since that sample was nested. If the sample size was 100, that would yield greater power than 21 and providing a greater effect size, the ability to perform more statistical analyses and more certainty to make generalizations about the population. Another limitation was the choice of participant population. Despite that decision being highly intentional, selecting a niche population of undergraduate and graduate students at the University of Arkansas, who match a specific criterion for chronic pain and volunteered to participate in sequential studies, was limiting. One way the study could improve to expand the population is through incorporating the global campus, or University of Arkansas at Little Rock. A different approach would be to maintain the location but introduce professors’ perspectives into the population to provide another context. The third limitation of this research study is alteration of an existing survey in the qualitative phase. In order to maintain coherence and

minimize confusion for participants as they completed the Qualtrics questionnaire, I adapted the wording from King's et al., (2007) stigma scale. I replaced all occurrences of "mental illness" with "chronic pain," and in King's et al., (2007) item 18 replaced "police" with "medical personnel." This is a limitation because it blurred the previously established constructs defined by King et al., (2007).

Conclusion

This chapter highlighted implications of the study's findings on future research, practitioners, higher education environments, and the field of rehabilitation counseling and vocational rehabilitation. Both the researcher and the participant's research suggested changes to public policy as a method for reducing stigma toward people with chronic pain in the academic and employment fields. The dissertation study used an informational questionnaire to establish a foundation with student participants at the University of Arkansas who self-identified as having chronic pain, before engaging in the exploratory design of the underrepresented population. I used constructivist grounded theory to interview six participants – three who identified as male, three who identified as female – in pursuit of answers to my research questions about their perceived and lived experiences with stigma and chronic pain. Through the process of interview analysis, member-checking and triangulation for validity and trustworthiness, seven categories of focused codes emerged and led to ten themes, listed below:

1. Commiserate over pain
2. Advocacy through storytelling and voice
3. Burden of responsibility – Self vs. Others
4. Attitudes toward disclosure
5. Epiphany about realizing chronic pain in adulthood

6. In-group vs. Out-group comparisons
7. Lying vs. Concealing or minimizing
8. Preoccupation with social approval
9. Reclaiming identity after diagnosis
10. Accounts of discrimination from medical community

From this dissertation study, I discovered that in order to boost advocacy and reduce stigma for populations with chronic pain, change needs to start with communication and education. Three of my participants came to the epiphany that they had chronic pain after volunteering for the study. Through this realization, they were able to share in a sense of community and attach an identity to their pain condition(s) without allowing it to define them. While the participants did not specify outright acts of discrimination from their professors, they alluded to feeling misunderstood and judged, due to anxiety that social perception might be tainted by disclosure of their conditions – not only by professors, but also by their peers. In order to bridge the gap between those with chronic pain and those without it, there needs to be a breakdown of the stigma surrounding chronic pain by implementing disability awareness training programs, such as the “Spoonie Zone,” and providing education about alternative treatment (thereby reducing the association of chronic pain with opioid addiction).

REFERENCES

- Ameri, M., Schur, L., Adya, M., Bentley, S., McKay, P., Kruse, D. (2015). The Disability employment puzzle: A field experiment on employer hiring behavior. *National Bureau of Economic Research*. 71(2), 329-364.
- American Chronic Pain Association. (2015). *ACPA resource guide to chronic pain medication & treatment*. Rocklin, CA: American Chronic Pain Association, Inc.
- Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990).
- Bandura, A. (1994). Self-efficacy. In V.S. Ramachaudran (Ed.), *Encyclopedia of human behavior* (Vol. 4, pp. 71-81). New York: Academic Press. (Reprinted in H. Friedman [Ed.], *Encyclopedia of mental health*. San Diego: Academic Press, 1998).
- Baker, K.Q., Boland, K., & Nowik, C. M. (2012). A Campus survey of faculty and student perceptions of persons with disabilities. *Journal of Postsecondary Education and Disability*, 25(4), 309-329. <https://files.eric.ed.gov/fulltext/EJ1002143.pdf>
- Becker, K. L. (2013). Cyberhugs: Creating a voice for chronic pain sufferers through technology. *Cyberpsychology, Behavior, and Social Networking*, 16(2), 123-126. doi:10.1089/cyber.2012.0361
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (2006). *Constructing grounded theory*. London: SAGE Publications, Inc.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. Los Angeles, CA: SAGE Publications, Inc.
- Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 209–240). Thousand Oaks, CA: Sage.
- De Cesarei, A. (2014). Disclosure of disability by university students: Development of a study protocol. *Open Journal of Social Sciences*, 2(8), 71-76. doi: 10.4236/jss.2014.28012.
- DeCuir-Gunby, J, T. & Schutz, P.A. (2017). *Developing a mixed methods proposal: a practical guide for beginning researcher*. Los Angeles, CA: SAGE Publications, Inc.
- Disabled World. (2018-10-03). Invisible Disabilities: List and General Information. Retrieved 2018-10-12, from <https://www.disabled-world.com/disability/types/invisible/>

- Erevelles, N., & Minear, A. (2010). Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary & Cultural Disability Studies* 4(2) 127-146.
<http://drminearspage.pbworks.com/w/file/fetch/72153155/ErevellesMinearJLCDS.pdf>
- Firmin, M.W., Burger, A. J., Sherman, A. L., Grigsby, M. E., & Croft, J. N. (2011). Coping constructs related to college students with chronic pain. *Journal of Ethnographic and Qualitative Research*, 6, 32-44.
- Graham, J. E., & Streitl, K. L. (2010). Sleep quality and acute pain severity among young adults with and without chronic pain: the role of biobehavioral factors. *Journal of Behavioral Medicine*, 33, 335-345. DOI: 10.1007/s10865-010-9263-y
- Hadjistavropoulos, H., Dash, H., Hadjistavropoulos, T., & Sullivan, T-L. (2006). Recurrent pain among university students: Contributions of self-efficacy and perfectionism to the pain experience. *Personality and Individual Differences*, 42, 1081-1091. doi: 10.1016/j.paid.2006.09.013
- Hurd Clarke, L., & Bennett, E. (2013). ‘You learn to live with all the things that are wrong with you’: gender and the experience of multiple chronic conditions in later life. *Ageing & Society*, 33, 342-360. DOI: 10.1017/so144686x11001243
- Ivankova, N., & Stick, S. (2007, Feb). Students’ persistence in a Distributed Doctoral Program in Educational Leadership in Higher Education: A mixed methods study. *Research in Higher Education*, 48(1), 93-135. DOI: 10.1007/s11162-006-9025-4
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Midwifery and Women’s Health*, 32(1), 243-248. <https://doi.org/10.1046/j.1365-2648.2000.01466.x>
- Johnson, D., & Russinova, Z. (2008). Using Photovoice to fight the stigma of mental illness. *Recovery & Rehabilitation*, 4(4). Retrieved from <https://cpr.bu.edu/wp-content/uploads/downloads/2011/11/Using-Photovoice-to-Fight-the-Stigma-of-Mental-Illness.pdf>
- King, M., Dinos, S., Shaw, J., Watson, R., Stevens, S., Passetti, F...Serfaty, M. (2007). The Stigma Scale: Development of a standardized measure of the stigma of mental illness. *British Journal of Psychiatry*, 190(3), 248-254. Doi:10.1192/bjp.bp.106.024638
- Lacasse, A., Connelly, J.A., & Choiniere, M. (2016). The chronic pain myth scale: Development and validation of a French-Canadian instrument measuring knowledge, beliefs, and attitudes of people in the community towards chronic pain. *Pain Research and Management*, 2016, 1-12. doi:10.1155/2016/5940206

- Logan, D.E., Catanese, S.P., Coakley, R.M., & Scharff, L. (2007). Chronic pain in the classroom: Teachers' attributions about the causes of chronic pain. *The Journal of School Health* 77(5), 248-282.
- Lonardi, C. (2007). The passing dilemma in socially invisible diseases: Narratives on chronic headache. *Social Science & Medicine*, 65(8), 1619-1629.
doi: 10.1016/j.socscimed.2007.07.007
- Maxwell, J.A. (2012). *A realist approach for qualitative research*. Thousand Oaks, CA: Sage Publications, Inc.
- McDonald, K.E., Keys, C.B., Balcazar, F.E. (2007). Disability, race/ethnicity and gender: themes of cultural oppression, acts of individual resistance. *AmJ Community Psychol*, 39.
Retrieved from
https://www.pdx.edu/sites/www.pdx.edu.psy/files/media_assets/5_McDonald_AJCP_McDonaldKeys_Balcazar_March_2007.pdf
- Merskey, H., & Bogduk, N. (1994). *Classification of chronic pain*. 2nd ed. Seattle, WA: IASP Press.
- Monsivais, D. B. (2013). Decreasing the stigma burden of chronic pain. *Journal of the American Association of Nurse Practitioners*, 25(10), 551-556. doi:10.1111/1745-7599.12010
- Ravitch, S.M., & Mittenfelner Carl, N.C. (2016). *Qualitative research: Bridging the conceptual, theoretical, and methodological*. Thousand Oaks, CA: SAGE Publications, Inc.
- Sassin, J.E. (2011). Disclosing an invisible disability during the interview process: a qualitative study (Doctoral dissertation). *Theses and Dissertations*, 132. Retrieved from <http://scholarworks.uark.edu/etd/132>
- Smith, B. H., Penny, K. I., Purves, A. M., Munro, C., Wilson, B., Grimshaw, J., Chambers, W. A., & Cairns Smith, W. (1996). The Chronic Pain Grade questionnaire: validation and reliability in postal research. *Pain*, 71, 141-147.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: SAGE Publications, Inc.
- Taylor, A. G., Skelton, J. A., & Butcher, J. (1984). Duration of pain condition and physical pathology as determinants of nurses' assessments of patients in pain. *Nursing Research*, 33, 4-8.
- Thomas, M., Roy, R., Cook, A., & Marykuca, A. (1992). Chronic pain in college students: Issues of management. *Canadian Family Physician* 38, 2597-2601.

- Thomas, S. P. (2000). A phenomenological study of chronic pain. *Western Journal of Nursing Research*, 22(6), 683.
- Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R.A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. *PubMed.gov*. doi: 10.1186/s12913-016-1383-9.
- U. S. Department of Education, Office for Civil Rights. “Protecting Students with Disabilities” (2018-09-25). Retrieved from <https://www2.ed.gov/about/offices/list/ocr/504faq.html>
- Venkatesh, V., Brown, S.A., & Sullivan, Y.W. (2016). Guidelines for conducting mixed-methods research: an extension and illustration. *Journal for the Association of Information Systems*, 17 (7), 435-494.
- Wakefield, E. O., Zempsky, W. T. Puhl, R. M., & Litt, M. D. (2018). Conceptualizing pain-related stigma in adolescent chronic pain: a literature review and preliminary focus group findings. *PAIN Reports*, 3, e679.

APPENDICES

Appendix A: IRB Approval Letter



To: Jennifer Kay Davenport
BELL 4188

From: Douglas James Adams, Chair
IRB Committee

Date: 03/14/2019

Action: **Expedited Approval**

Action Date: 03/14/2019

Protocol #: 1901173224

Study Title: Stigma and Disclosure of Chronic Pain in Higher Education: A Mixed Methods Study

Expiration Date: 02/17/2020

Last Approval Date:

The above-referenced protocol has been approved following expedited review by the IRB Committee that oversees research with human subjects.

If the research involves collaboration with another institution then the research cannot commence until the Committee receives written notification of approval from the collaborating institution's IRB.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date.

Protocols are approved for a maximum period of one year. You may not continue any research activity beyond the expiration date without Committee approval. Please submit continuation requests early enough to allow sufficient time for review. Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol. Information collected following suspension is unapproved research and cannot be reported or published as research data. If you do not wish continued approval, please notify the Committee of the study closure.

Adverse Events: Any serious or unexpected adverse event must be reported to the IRB Committee within 48 hours. All other adverse events should be reported within 10 working days.

Amendments: If you wish to change any aspect of this study, such as the procedures, the consent forms, study personnel, or number of participants, please submit an amendment to the IRB. All changes must be approved by the IRB Committee before they can be initiated.

You must maintain a research file for at least 3 years after completion of the study. This file should include all correspondence with the IRB Committee, original signed consent forms, and study data.

cc: Brent Thomas Williams, Key Personnel

Appendix B: Survey Informed Consent

Qualitative Study of Chronic Pain and Stigma Consent to Participate in a Research Study

Principal Researcher: Jennifer Davenport

Faculty Advisor: Dr. Brent Williams

INVITATION TO PARTICIPATE

You are invited to participate in a research study of stigma and disclosure of chronic pain. You are being asked to participate in this study because you have a chronic pain condition.

WHAT YOU SHOULD KNOW ABOUT THE RESEARCH STUDY

Who is the Principal Researcher?

Jennifer Davenport, email: (redacted)

Who is the Faculty Advisor?

Dr. Brent Williams, email: (redacted)

What is the purpose of this research study?

The purpose of this study is to examine how real or perceived stigma, associated with chronic pain conditions, can influence disclosure of chronic pain for students in higher education.

Who will participate in this study?

Participants will be open to undergraduate and graduate students from the University of Arkansas, who self-identify with chronic pain conditions. Participation is voluntary.

What am I being asked to do?

Your participation will require the following:

Participants will answer a demographic questionnaire, a 7-item Chronic Pain Grade Scale, and a 33-item Stigma Scale. Expected time of completion is 30-60 minutes.

Once the data is analyzed, participants may be asked to complete a follow-up interview in-person, over-the-phone or via-Skype.

What are the possible risks or discomforts?

Possible discomforts could include emotional trauma from discussing experiences of stigma or physical discomfort due to pain. Please inform the Principal Researcher if you need assistance in accommodations.

What are the possible benefits of this study?

Participants have the opportunity to be heard in a safe space if they experienced discrimination for their chronic pain at this university. Their voices can create change in a meaningful way.

How long will the study last?

It is expected that participants will complete the survey and questionnaire in 30-60 minutes. The participants who are selected for the interview should expect it to last about an hour.

Will I receive compensation for my time and inconvenience if I choose to participate in this study?

Not for the questionnaire and survey portion of the study. Interview participants will receive compensation of a \$25 gift card.

Will I have to pay for anything?

No, there will be no cost associated with your participation.

What are the options if I do not want to be in the study?

If you do not want to be in this study, you may refuse to participate. Also, you may refuse to participate at any time during the study. Your job, your grade, your relationship with the University, etc. will not be affected in any way if you refuse to participate.

How will my confidentiality be protected?

All information will be kept confidential to the extent allowed by applicable State and Federal law. To further ensure confidentiality of each participant's identity, the participant has the option to choose a pseudonym or have one assigned, upon completion of the interview – due to the personal nature of the questions. All information collected during the study (notes, participant details, audio recordings, etc.) will be kept in a secure area.

Will I know the results of the study?

At the conclusion of the study you will have the right to request feedback about the results. You may contact the faculty advisor, Dr. Brent Williams, btwilli@uark.edu or Jennifer Davenport, jkdavep@uark.edu. You will receive a copy of this form for your files.

What do I do if I have questions about the research study?

You have the right to contact the Principal Researcher or Faculty Advisor as listed below for any concerns that you may have.

Jennifer Davenport, (redacted)

Dr. Brent Williams, (redacted)

You may also contact the University of Arkansas Research Compliance office listed below if you have questions about your rights as a participant, or to discuss any concerns about, or problems with the research.

Ro Windwalker, CIP
Institutional Review Board Coordinator
Research Compliance
University of Arkansas
109 MLKG Building
Fayetteville, AR 72701-1201
(redacted)

I have read the above statement and have been able to ask questions and express concerns, which have been satisfactorily responded to by the investigator. I understand the purpose of the study as well as the potential benefits and risks that are involved. I understand that participation is voluntary. I understand that significant new findings developed during this research will be shared with the participant. I understand that no rights have been waived by signing the consent form. I have been given a copy of the consent form.

Appendix C: Study Recruitment Letter

Hello! My name is Jennifer Davenport, and I am a Doctoral Candidate in the Rehabilitation Education and Research program at the University of Arkansas. I am conducting my dissertation research on the disclosure of chronic pain experiences for undergraduate students and graduate students in higher education.

I invite you to participate in this study if you:

- 1) Are currently enrolled in undergraduate studies or a graduate program at the University of Arkansas
- 2) Have been diagnosed with chronic physical pain recurring for more than 3 to 6 months, defined as “lasting beyond the usual course of... injury healing... which adversely affects the individual’s well-being” (American Chronic Pain Association, 2015, p.10).
- 3) Have experienced stigma or anticipated stigma (Stigma is defined as disapproval of a person or group of people based on stereotypes of exclusion).

Participation:

Participation in the study involves an online survey and a semi-structured interview.

During the online survey, participants will respond to a series of questions through web-based Qualtrics (link provided in email).

A select number of participants from the survey group will be asked to participate in the interview portion of the study, which will be conducted in person (or via video-conferencing). The researcher will use an audio recording device and take written notes in order to transcribe the interviews accurately. While the length of the interviews may differ, the intended amount of time planned per interview is one hour.

Participants in the interview will be compensated for their contribution with a \$25 Visa gift card.

If you are interested in participating in this study, or would like to refer someone to this study, please email me at (redacted)

Warmest regards,
Jennifer Davenport

This research is being overseen by an Institutional Review Board ("IRB"). If you have questions about your rights as a research subject, please contact the University of Arkansas IRB Coordinator at 479-575-2208.

Appendix D: Interview Informed Consent

Qualitative Study of Chronic Pain and Stigma Consent to Participate in a Research Study

Principal Researcher: Jennifer Davenport

Faculty Advisor: Dr. Brent Williams

INVITATION TO PARTICIPATE

You are invited to participate in a research study about stigma and disclosure of chronic pain. You are being asked to participate in this study because you have a chronic pain condition.

WHAT YOU SHOULD KNOW ABOUT THE RESEARCH STUDY

Who is the Principal Researcher?

Jennifer Davenport, (redacted)

Who is the Faculty Advisor?

Dr. Brent Williams, (redacted)

What is the purpose of this research study?

The purpose of this study is to examine how real or perceived stigma, associated with chronic pain conditions, can influence disclosure of chronic pain for students in higher education.

Who will participate in this study?

Participants will be open to undergraduate and graduate students from the University of Arkansas, who self-identify with chronic pain conditions. Participants will be selected from the population that completed the research survey on Chronic Pain Grade Scale and Stigma Scale. Six to eight participants will be chosen for the interview portion of the study.

What am I being asked to do?

Your participation will require the following:

Answer open-ended questions in person, over the phone or via-Skype, which will be audio recorded.

What are the possible risks or discomforts?

Possible discomforts could include emotional trauma from discussing experiences of stigma or physical discomfort due to pain. Please inform the Principal Researcher if you need assistance in accommodations.

What are the possible benefits of this study?

Participants have the opportunity to be heard in a safe space if they experienced discrimination for their chronic pain at this university. Their voices can create change in a meaningful way.

How long will the study last?

The interview could last 60 to 90 minutes, depending on each participant's responses.

Will I receive compensation for my time and inconvenience if I choose to participate in this study?

Yes, participants in the interview will receive a \$25 Visa gift card for their time and inconvenience.

Will I have to pay for anything?

No, there will be no cost associated with your participation.

What are the options if I do not want to be in the study?

If you do not want to be in this study, you may refuse to participate. Also, you may refuse to participate at any time during the study. Your job, your grade, your relationship with the University, etc. will not be affected in any way if you refuse to participate.

How will my confidentiality be protected?

All information will be kept confidential to the extent allowed by applicable State and Federal law. To further ensure confidentiality of each participant's identity, the participant has the option to choose a pseudonym or have one assigned, upon completion of the interview – due to the personal nature of the questions. All information collected during the study (notes, participant details, audio/visual recordings, etc.) will be kept in a secure area.

Will I know the results of the study?

At the conclusion of the study you will have the right to request feedback about the results. You may contact the faculty advisor, Dr. Brent Williams or Jennifer Davenport. You will receive a copy of this form for your files.

What do I do if I have questions about the research study?

You have the right to contact the Principal Researcher or Faculty Advisor as listed below for any concerns that you may have.

Jennifer Davenport, (redacted)

Dr. Brent Williams, (redacted)

You may also contact the University of Arkansas Research Compliance office listed below if you have questions about your rights as a participant, or to discuss any concerns about, or problems with the research.

Ro Windwalker, CIP
Institutional Review Board Coordinator
Research Compliance
University of Arkansas
109 MLKG Building
Fayetteville, AR 72701-1201
(redacted)

I have read the above statement and have been able to ask questions and express concerns, which have been satisfactorily responded to by the investigator. I understand the purpose of the study as well as the potential benefits and risks that are involved. I understand that participation is voluntary. I understand that significant new findings developed during this research will be shared with the participant. I understand that no rights have been waived by signing the consent form. I have been given a copy of the consent form.

Appendix E: Demographics Questionnaire

Thank you for your interest in this study! Please take a moment to fill out the following questions before continuing the survey:

1. Please select yes or no: Are you of Hispanic, Latino, or Spanish origin? (ethnicity)
2. If no, how would you describe yourself? (Choose any and all that apply.)
 - a. American Indian or Alaskan Native
 - b. Native Hawaiian or Other Pacific Islander
 - c. Black or African American
 - d. Asian
 - e. White
3. Which gender do you most identify with?
 - a. Male
 - b. Female
 - c. Transgender
4. Do you consider yourself to be:
 - a. Heterosexual or straight
 - b. Homosexual
 - c. Bisexual
 - d. Prefer not to answer
5. What is your current degree program?
 - a. Non-degree seeking
 - b. Bachelor's degree (BA, BS)
 - c. Master's degree (MEd, MS, MA)
 - d. Professional degree (MD, DDS)
 - e. Doctoral degree (PhD, EdD)
6. How would you describe the onset of your pain?
 - a. Congenital (since birth)
 - b. Pathological (built up over time)
 - c. Traumatic (triggered by a distressing event)
 - d. Idiopathic (The pain started suddenly without origin)
7. How much time has lapsed since the initial onset of your pain?
 - a. Less than 6 months
 - b. 6 months to 2 years
 - c. 2-5 years
 - d. Over 5 years
8. Do you consider your chronic pain condition(s) visible or invisible?
 - a. Visible
 - b. Invisible
 - c. It varies depending on the presentation of my symptoms.

9. What chronic pain conditions do you have? Select any and all that apply
- a. -Fibromyalgia -Migraine -Rheumatoid Arthritis -Diabetes/HIV
 - b. -Osteoarthritis -Neuropathy -Lupus/ Autoimmune Disorder
 - c. -CRPS/RSD -Trigeminal Neuralgia -Multiple Sclerosis
 - d. Cancer -Sports/Exercise Injury -Low-back Pain/ Spinal Cord Injury
 - e. My pain has not been diagnosed -None of the conditions listed

10. To whom have you disclosed about your chronic pain condition?

- a. Your peer(s)
- b. Your professor(s)
- c. Your professor(s) and peer(s)
- d. None of the above

Appendix F: The Chronic Pain Grade Questionnaire

For the following questions with a scale of 1-10 please circle one number only

1. How would you rate your pain on a 1-10 scale at the present time, that is right now, where 0 is "no pain" and 10 is "pain as bad as could be"?

No pain												Pain as bad as could be
0	1	2	3	4	5	6	7	8	9	10		

2. In the past six months, how intense was your worst pain rated on a 0-10 scale where 0 is "no pain" and 10 is "pain as bad as could be"?

No pain												Pain as bad as could be
0	1	2	3	4	5	6	7	8	9	10		

3. In the past six months, on average, how intense was your pain rated on a 1-10 scale, where 0 is "no pain" and 10 is "pain as bad as could be"? (That is, your usual pain at times you were experiencing pain.)

No pain												Pain as bad as could be
0	1	2	3	4	5	6	7	8	9	10		

4. About how many days in the last six months have you been kept from your usual activities (work, school or housework) because of this pain?

0-6 days	
7-14 days	
15-30 days	
31 or more days	

5. In the past six months, how much has this pain interfered with your daily activities rated on a 1-10 scale where 0 is "no interference" and 10 is "unable to carry on activities"?

No interference												Unable to carry on activities
0	1	2	3	4	5	6	7	8	9	10		

6. In the past six months, how much has this pain changed your ability to take part in recreational, social and family activities where 0 is "no change" and 10 is "extreme change"?

No change												Extreme change
0	1	2	3	4	5	6	7	8	9	10		

7. In the past six months, how much has this pain changed your ability to work (including housework) where 0 is "no change" and 10 is "extreme change"?

No change												Extreme change
0	1	2	3	4	5	6	7	8	9	10		

Appendix G: Adapted Stigma Scale

The researcher will replace all occurrences of “mental illness” with “chronic pain,” and in item 18 replace “police” with “medical personnel.”

Table 4 Descriptive statistics of final 28 item stigma scale

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Responses n	Mean (s.d.) Median
5 I have been discriminated against in education because of my mental health problems (Dc)	4	3	2	1	0	188	1.59 (1.03) 1.5
6 Sometimes I feel that I am being talked down to because of my mental health problems (Dc)	4	3	2	1	0	189	2.40 (1.24) 3.0
7 Having had mental health problems has made me a more understanding person (P)	0	1	2	3	4	190	1.08 (0.89) 1.0
10 I do not feel bad about having had mental health problems (D)	0	1	2	3	4	188	2.32 (1.26) 3.0
14 I worry about telling people I receive psychological treatment (D)	4	3	2	1	0	189	2.71 (1.18) 3.0
15 Some people with mental health problems are dangerous (P)	4	3	2	1	0	190	2.82 (0.95) 3.0
17 People have been understanding of my mental health problems (P)	0	1	2	3	4	185	1.84 (1.06) 2.0
18 I have been discriminated against by police because of my mental health problems (Dc)	4	3	2	1	0	188	1.72 (1.21) 2.0
19 I have been discriminated against by employers because of my mental health problems (Dc)	4	3	2	1	0	187	2.08 (1.16) 2.0
21 My mental health problems have made me more accepting of other people (P)	0	1	2	3	4	191	1.19 (1.01) 1.0
22 Very often I feel alone because of my mental health problems (Dc)	4	3	2	1	0	190	2.85 (1.14) 3.0
23 I am scared of how other people will react if they find out about my mental health problems (D)	4	3	2	1	0	192	2.65 (1.13) 3.0
24 I would have had better chances in life if I had not had mental health problems (D)	4	3	2	1	0	191	2.89 (1.15) 3.0
26 I do not mind people in my neighbourhood knowing I have had mental health problems (D)	0	1	2	3	4	192	2.58 (1.34) 3.0
27 I would say I have had mental health problems if I was applying for a job (D)	0	1	2	3	4	189	2.16 (1.31) 2.0
28 I worry about telling people that I take medicines/tablets for mental health problems (D)	4	3	2	1	0	191	2.58 (1.18) 3.0
29 People's reactions to my mental health problems make me keep myself to myself (Dc)	4	3	2	1	0	188	2.40 (1.19) 3.0
30 I am angry with the way people have reacted to my mental health problems (Dc)	4	3	2	1	0	190	2.23 (1.18) 2.0
31 I have not had any trouble from people because of my mental health problems (Dc)	0	1	2	3	4	192	2.24 (1.14) 2.0
32 I have been discriminated against by health professionals because of my mental health problems (Dc)	4	3	2	1	0	189	1.95 (1.28) 2.0
33 People have avoided me because of my mental health problems (Dc)	4	3	2	1	0	189	2.30 (1.18) 3.0
34 People have insulted me because of my mental health problems (Dc)	4	3	2	1	0	192	2.01 (1.20) 2.0
35 Having had mental health problems has made me a stronger person (P)	0	1	2	3	4	188	1.78 (1.23) 2.0
36 I do not feel embarrassed because of my mental health problems (D)	0	1	2	3	4	190	2.16 (1.22) 2.0
37 I avoid telling people about my mental health problems (D)	4	3	2	1	0	191	2.68 (1.10) 3.0
38 Having had mental health problems makes me feel that life is unfair (Dc)	4	3	2	1	0	191	2.53 (1.16) 3.0
40 I feel the need to hide my mental health problems from my friends (D)	4	3	2	1	0	190	2.12 (1.22) 2.0
41 I find it hard telling people I have mental health problems (D)	4	3	2	1	0	191	2.70 (1.16) 3.0

D, disclosure; Dc, discrimination; P, positive aspects.

Adapted Stigma Scale continued

Additional test items created to measure the self-advocacy (SA) construct

1. I feel comfortable sharing my experiences with other members of the chronic pain community.
2. I utilize academic accommodations provided by the Center for Educational Access (CEA).
(Accommodations could include a note-taker, extended time on tests, attendance flexibility, etc.)
3. My chronic pain condition makes me feel self-conscious about using on-campus resources like the CEA.
4. Because of my condition, I consider myself an advocate for my own needs.
5. Because of my condition, I feel I can advocate for the needs of others.

Appendix H: Stigma & Disclosure Interview

Stigma: The negative evaluation of a person as tainted or discredited on the basis of attributes such as mental disorder, ethnicity, drug misuse or physical disability (Goffman, 1963).

1. If any, what experiences have you had with stigma toward chronic pain?
2. What effect has stigma and the fear of disclosure had on your life as a student, if at all?
3. Have you had any positive experiences with disclosing about your chronic pain before? If so, please describe what transpired.
4. Have you had any negative experiences with disclosing about your chronic pain before? If so, please describe what transpired.
5. Do you consider yourself an advocate? If so, please explain (i.e. for yourself and/or others).
6. If you could educate your professors and peers about the stigma associated with disclosure of chronic pain, what would you say?
7. Is there anything else you would like to share with me?