EMERGING ADULTS AND CHRONIC PAIN: EXPLORING THE IMPACT OF CHRONIC PAIN ON EMERGING ADULTS AND THEIR ABILITY TO ADAPT

by

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December, 2022

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Emerging adulthood is a period of exploration and uncertainty where individuals between 18 and 29 years old investigate the abundance of opportunities available to them in regard to love, work, and worldviews. Although chronic pain is typically not life threatening, it does pose a myriad of psychosocial challenges to emerging adults as they work to achieve developmental milestones such as identity formation and relationship building. As physical and mental health often begin to decline, it is increasingly important for positive forms of adaptation remain imminent to reduce anxiety and restore equilibrium. Using a qualitative descriptive approach, this study explored the perceptions of 8 emerging adults through semi-structured interviews in order to better understand the impact chronic pain has on their ability to execute developmental milestones and adapt to the inevitable challenges associated. A thematic content analysis was utilized to identify five major themes: 1) restricted exploration, 2) relationship building barriers causing uncertainty, 3) lack of independence, 4) identity confusing restricting adaptation, and 5) adaptation. Emerging adults are a unique population to consider in regard to chronic pain as this is already a tumultuous life phase. Many transitions are present, such as pediatric to adult health care, educational and career opportunities, and support systems, so understanding how chronic

pain challenges these transitions is vital. More so, hearing personal testimonies is a powerful means in achieving this understanding so that individualized supports are fostered.

Keywords: chronic pain, emerging adulthood, young adults, coping, adaptation, developmental milestones, resources, identity, mental health

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A Thesis

Presented To the Faculty of the Department of Human Development and Family Science

East Carolina University

In Partial Fulfillment of the Requirements for the Degree

Master of Science in Human Development and Family Science

by

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ACKNOWLEDGEMENTS

This research would not have been possible without the encouragement I received from my thesis chair, Dr. Natalia Sira. Your dedication and inspiration has been indispensable in my personal and professional life. I would not be the person, student, or professional I am today without your positive example that has provided me with a home away from home for the last two years. Thank you for believing in me even when I did not believe in myself. I would also like to acknowledge my other committee members, Dr. Archana Hegde and Dr. Marissa Carraway, for their unconditional support. I will forever be thankful for your ability to push me outside of my comfort zone to believe that I can achieve more than I ever thought possible.

I would like to thank my parents for their selflessness and guidance. You were there to celebrate my successes and pick me up during my opportunities for growth and for that I will always be grateful. To my friends who live hundreds of miles away but stuck by me as if there were no distance between us: words will never express how lucky I feel to have such intentional people in my life. I would also to thank my cohort for whom I would not have survived the last few years without. Did you ever think we would actually get to this point? Thank you for being there for me without hesitation to provide moments of much needed distraction and laughter.

To my participants, thank you for having the courage to share your powerful stories because they matter immensely. You matter immensely. It will always be the greatest honor to have been trusted to share your experiences. This thesis is dedicated to everyone who perseveres despite the intricacies of living with chronic pain. Your experience is valid, and you are worthy of a life filled with infinite possibilities. As Maya Angelou once said, “stand up straight and realize who you are. That *you* tower over your circumstances.”

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CHAPTER 1: INTRODUCTION

Since the early 2000s, emerging adulthood (EA) has made monumental strides from its early conception as a theoretical proposal into a flourishing field distinguishing the phase between adolescence and adulthood (Arnett, 2015) where young people between the ages of 18 and 29 avoid responsibilities and engage in a period of exploration and identity construction (Padilla-Walker et al., 2017). The EA years are often thought to be "the most impactful and impressionable" in the lives of young people (Peer & McAuslan, 2016, *p* 176). Jeffrey Arnett presented EA not as a universal life stage, but as one that has come to light in industrialized societies due to the ever-changing social and economic climate resulting in delays of expected adult roles such as permanent partnership, parenthood, and career commitment (Arnett, 2015; Schwartz et al., 2013). More specifically, Schwartz (2016) characterizes this phase as "two-faced" due to the simultaneous optimism and perpetual uncertainty present during this phase. This age group is participating in activities surrounding love, work, and worldviews to better help these individuals develop his or her identity. An individual's development and developmental tasks, though, can be questioned when traumatic life events take place, such as the impact of chronic pain or conditions (Falvo & Holland, 2017).

Chronic pain has been found to impact at least 15% of emerging adults in the United States (Dezutter et al, 2015). Chronic pain conditions are typically not life threatening but they pose many challenges to the individual who is experiencing the pain, as well as their friends and family. From a medical perspective, chronic pain is defined as pain that lasts for at least three months (Meyer et al., 2020). Chronic pain goes far beyond the medical diagnoses, though, causing individuals to have difficulties in daily life activities such as studying, working, socializing, and household chores. For emerging adults in particular, chronic pain can cause

difficulties with psychosocial factors including autonomy and independence, planning for the future such as a professional career, and a shifting self-concept and identity (Falvo & Holland, 2017). Adaptation plays a key role in an individual's ability to successfully adapt to chronic pain in order to reduce anxiety and restore equilibrium in times of need, but adaptation can also take the form of maladaptive strategies or behaviors which inhibits growth, hinders physical and mental health, and impacts the developmental tasks of EA (Stinson et al., 2013; Twiddy et al., 2017). Limited research has been conducted, though, regarding the impact of chronic pain during EA and their ability to adapt to the impact on achieving their developmental tasks.

CHAPTER 2: THEORETICAL FRAMEWORK

While unique in essence, adolescents and emerging adults share many similar characteristics. The major distinction is in how individuals in each stage experiences noteworthy milestones. Adolescents between the ages of 13 and 17 are first confronted with Erik Erikson's identity versus role confusion stage of psychosocial development (Erikson, 1950), in which individuals are eager to identify who one is and flourish whole doing so; flourishing refers to an individual's life moving smoothly in hedonic (feeling good) and eudaimonic (functioning well) ways (de la Fuente et al., 2020). Individuals are often afflicted with disturbances and confusion surrounding new conflicts and demands within the larger social order, though (Erikson, 1950; Padilla-Walker et al., 2017). Adolescents are often overwhelmed with uncertainty surrounding the number of options available for their future (Arnett, 2015), which tends to end in psychosocial moratorium during which individuals are actively exploring potential futures by making minimal commitments to avoid foreclosure – or making commitments without exploring all options. For example, children are typically raised with the religious identity their caregivers hold. Once they reach adolescence, though, they are exposed to peers who believe in differing religions. They are able to explore these differing religions as psychosocial moratorium suggests, or they follow foreclosure and commit themselves to one particular religion without exploring other options (Schwartz et al., 2013). In addition to religious identity, adolescence must also consider occupation, political views, gender identity and sexual orientation. It is no surprise then that identity development is often an overwhelming experience and individuals must take the time to explore all opportunities before committing to adult roles to ensure they are not foreclosing on options.

Identity formation primarily begins in adolescence, but this inner development is a lifelong process that escalates between the ages of 18 and 29 during emerging adulthood (Arnett, 2015; Erikson, 1950). Emerging adults are customarily thought to be stuck in an "in-between" period where they have more autonomy than they did as adolescents, but they are still encouraged to explore romantic relationships, religious faith, occupational options, political beliefs, and gender roles – just to name a few – and are not quite ready to commit to these adult roles (Schwartz et al., 2013). Identity versus role confusion becomes the forefront of an individual's life during this time as they are typically pursuing higher education, exploring potential career paths, and experimenting in regard to relationships with friends, family, and romantic partners (Arnett, 2015; Padilla-Walker et al., 2017). Many changes are present during this age, with the college years being the most notable (Arnett, 2015). Pursuing higher education challenges individuals to leave their families and friends for the first time, gain autonomy, and take on additional responsibilities surrounding both mental and physical health such as seeking support from healthcare professionals, getting enough sleep, working out, and eating healthy (Arnett, 2015).

It is important to note that EA is an international phenomenon inciting demarcation between life stages even though it has emerged mostly in developed countries; the differences lie in the variations of how this phase is experienced across cultures, ethnicities, races, and genders (Arnett, 2015; de la Fuente et al., 2019; Padilla-Walker et al., 2017). One way in which these variations can be accounted for is the connection with Erikson's stages of psychosocial development. As Schwartz et al. (2013) states, Erikson's idea that identity is a fundamental task between adolescence and adulthood is a longstanding fact that has been cited in much literature since its inception. The acts in which young people partake in, including volunteerism, services,

religious and political exploration, and preparation for careers – which varies greatly depending on cultural norms – provides a lens through which positive development can be examined (Arnett, 2015; Padilla-Walker et al., 2017).

During this developmental phase that is known for its explorative nature, emerging adults often experience identity confusion, symptoms of anxiety and depression, and other forms of maladjustment (Falvo & Holland, 2017). Several characteristics take shape during this phase such as peer relationships, familial context, resilience, gender, race and ethnicity, and cognitive development and work in tandem to develop one's identity (Arnett, 2015). These characteristics influence relationships of all kinds, sexuality, mental health, one's ability to consider diverse information and reflect, focus on the self, and adapt to situational demands. One hopes to build a strong foundation of confidence, competence, and connection within their character, their community, and the people within it by the time they reach adulthood, so they are able to successfully contribute to the societies within which they belong, allowing them to thrive emotionally, socially, and psychologically (Arnett, 2015; Padilla-Walker et al., 2017). In other words, one hopes to flourish rather than merely adapt to the world around them.

Adjusting to a new environment like a college campus is often a stressful event to emerging adults. In a 2015 study by Peer et al., personal reports were collected from college students to determine the most stressful factors. The most prevalent stressors reported were unattainable pressure by family to do well in classes, adjustments to living conditions, making and executing career decisions, juggling a busy academic lifestyle, and coping with a lack of sleep (Arnett, 2015; Peer et al., 2015). Participants did, however, report that the ability to proactively identify potential stressors, rely on social support, and partake in healthy behaviors

such as eating appropriately, exercising, and utilizing mindfulness activities, helped manage their stress most effectively (Peer et al., 2015). A similar study conducted by Peer and McAuslan (2016) identified mindfulness encompassing awareness and attention on the environment and experiences as a key contributor to mediating the impact of self-doubt on emerging adults.

While EA is often considered a period of good health in most people's lives, research shows that health behaviors and coping habits that persist across adulthood often begin during this life stage (Calamidas & Crowell, 2018). Researchers view EA as a "vulnerable developmental period in need of specific focus and attention" (SAHM, 2017, *p* 758) especially when an individual is faced with conditions that manifest with pain episodes. The EA years and coinciding developmental challenges such as establishing independence, identity, including professional identity, and building friendships and intimate relationships, could be affected if an individual in this active part of life suffers from adverse experiences such as chronic pain. The current study will investigate the influence of chronic pain on the developmental challenges present during EA in a group of individuals from across the United States between 18 and 29 years old with chronic pain.

CHAPTER 3: LITERATURE REVIEW

Impact of Chronic Pain

Chronic pain is a pervasive condition found in 25% of the of the EA population in Europe (Hiort et al., 2017), at least 15% of emerging adults in the United States (Dezutter et al., 2015), and approximately 20% of people worldwide (Treede et al., 2015). Chronic pain has been defined as being an unpleasant emotional and sensory experience with pain behaviors resulting from the interaction of somatic (biological), psychological, and environmental factors (Hunfeld et al., 2001; Treede et al., 2015). This recurrent pain must last at least three to six months and is considered as a widespread condition associated with long-term negative consequences (Schenk et al., 2020). Medically, when individuals are managing their chronic pain, their pain is considered *stable*; the state of progression in pain and decline in health is considered *progressive*; and when flare-ups are experienced fairly often with periods of exacerbations and remissions, the pain is considered *episodic* (Falvo & Holland, 2017). Additionally, the International Classification of Diseases of the World Health Organization recognized chronic pain as falling into the following common groups: primary pain, cancer, posttraumatic and postsurgical, neuropathic, headache or orofacial, visceral, and musculoskeletal (Treede et al., 2015). In four out of five studies, limb pain, headache, and abdominal and back pain were cited as the most prevalent pain areas (Hunfeld et al., 2001; Meyer et al., 2020; Tran et al., 2015; Williams et al., 2016). While there is little research surrounding EA and chronic pain, common consequences have been cited. These consequences are often seen in areas such as role confusion and physical, emotional, social, and cognitive functioning, as suggested by Higginson et al. (2019) who studied young adults transitioning from a pediatric chronic pain clinic to an adult setting. Additionally, self-perception and feeling understood and accepted were cited in a study

of young adults between 20 and 31 years old (Hiort et al., 2017). In regard to self-perception, participants felt a discrepancy between how they viewed themselves versus how they thought others perceived them (Hiort et al., 2017).

Challenges for EAs with Chronic Pain

Additional obstacles may be present during EA due to the onset of chronic pain surrounding pain management strategies, service delivery, and barriers to care at the patient, health care system, and societal level (Stinson et al., 2013). Taking into consideration the milestones present during EA with the accompanied chronic pain, these individuals are left vulnerable and susceptible to financial instability (Falvo & Holland, 2017), thwarted opportunities, peer separation, and dependency on parents at a time when they are craving autonomy (Twiddy et al., 2017). Due to the subjectivity of pain challenging the efficacy of understanding, many emerging adults feel as though they are not receiving the care they so desperately need because others do not truly understand what they are experiencing. It was reported that neurodevelopment during EA is still sensitive to environmental conditions and experiences (D'Agostino et al., 2011; Tanner & Arnett, 2009), which contributes to the subjectively of pain and often mismanagement (Falvo & Holland, 2017).

Further, Falvo & Holland (2017) delineate the circular influence of socioeconomic status, culture, personal factors, environment, social and family relationships and support, daily activities, and goals with chronic pain. Individuals vary in regard to their tolerance of symptoms, functional capacity, aptness of coping, and general support they receive from those around them. While emerging adults are already facing threats to life and physical well-being, body integrity and comfort, privacy, control and autonomy, self-concept and fulfillment of expected roles,

future plans, relationships with friends and family, and economic well-being, the experience of chronic pain only exacerbates these threats. Disruption of these typical experiences has the potential to delay and impair social and emotional development while decreasing confidence, so it is critical to establish an understanding of chronic pain that goes beyond the medical diagnoses (Stinson et al., 2013). It must encapsulate the individual's ability to function in their daily life and how that may have physical and mental repercussions (Falvo & Holland, 2017).

Quality of Life, Pain, and Developmental Challenges for Emerging Adults

Quality of life (QoL) is commonly known as personal satisfaction drawn from cultural backgrounds, spiritual beliefs, moral systems, and attitudes in tandem with environmental influences (Williams et al., 2016). Therefore, individuals within the same developmental stage with similar diagnoses, pain symptoms, limitations, and treatments do not experience it in the same way; rather, it is a unique experience in which they are the only ones capable of defining its impact. For these reasons, it is often a difficult feat to assess the ambiguous nature of QoL (Falvo & Holland, 2017). In many cases, though, quality of life is defined as, "a multidimensional concept that encompasses broad domains of quality of life (e.g., physical, psychological, social functioning, and functional status) and the individual's overall satisfaction with life and health" (Hunfeld et al., 2001, *p* 146).

Pain can cause psychological difficulties, including but not limited to, difficulties concentrating and comprehending, dizziness, fatigue, and insomnia (Williams et al., 2016). Habitually, these symptoms cause reverberations in daily tasks such as daily household chores, lifestyle choices, social participation, and vocational endeavors (Falvo & Holland, 2017). Of the utmost importance to note is the impact of chronic pain and the coinciding effects on QoL

resulting in mental health distress. Padilla-Walker et al. (2017) defines mental health as a state of well-being in which one is capable of coping with life stressors and can work successfully to contribute to the larger society surrounding them. Anxiety and depression are often identified in those with chronic pain due to psychological and personal factors such as uncertainty, adaptability, self and outside views of one's body, stigma, level of support received by family, friends, and providers, as well as self-esteem, concept, and identity (Dezutter et al., 2014; Falvo & Holland, 2017; Lee et al., 2020; Tran et al., 2015). Many of these factors are already present during EA whether chronic pain is experienced or not (Arnett, 2015; Schwartz et al., 2013), so the addition of chronic pain only exacerbates these mental health issues. In fact, Peer et al. (2015) reports that 40% of their 20 emerging adult college student participants did not feel as though they were able to effectively manage the stress in their lives without chronic pain being present; while Padilla-Walker et al. (2017) found that at least 40% of emerging adults meet criteria for at least 1 psychiatric disorder with additional individuals meeting criteria for 2 or more. Unfortunately, professional mental health support is rarely sought out by emerging adults due to stigma and time constraints (Padilla-Walker et al., 2017), but the integration of psychosocial interventions is indispensable to ensure positive development in adulthood.

Coping and Adaptation

Possessing meaning in life, as well as reshaping it, when necessary, is a key characteristic in completing the task of identity development during the EA life stage (Dezutter et al., 2014; 2015). Individuals with chronic pain are better able to work through pain-induced psychological distress when a sense of purpose is present (Schwartz et al., 2013). In order to develop a sense of purpose amidst the developmental stage of EA as well as chronic pain, one must learn how to

appropriately cope with the stressors that have or may arise. Coping is a subconscious mechanism individuals use to reduce anxiety and restore equilibrium when they are confronted with stress (Falvo & Holland, 2017). Stress is one of the most impactful psychological phenomena in regard to its consequences for mental and physical health. In fact, researchers have found that daily micro-stressors, like those brought on by chronic pain, are likely to accumulate into detrimental effects over time having innumerous health implications (Howland et al., 2017). Although the following emotional reactions are often presented in a negative light, they can have quite positive results if channeled in appropriate ways: *grief* allows individuals to accept their loss emotionally in order to redefine their space within life. *Fear and anxiety* can be helpful when used to regain control of a situation and empower individuals to have a say in the everyday decision-making process. *Anger* at oneself or others can be expressed in therapeutic ways to relieve stress (Falvo & Holland, 2017). *Depressed mood* typically works in tandem with hopelessness, helplessness, and indifference leading to changes in appetite, difficulty focusing, and sleep disturbances (Falvo & Holland, 2017). If experienced for extensive periods of time, depression could result in substance abuse or suicide. Identifying these behavioral changes can allow family, peers, and professionals to address these behavior changes directly as well as find the root cause. Lastly, *guilt* can result in unhealthy perceptions of self-concepts, so steps should be taken to reframe this mindset (Falvo & Holland, 2017). These emotional reactions are innate reactions to stress that are habitually addressed through the use of the following coping strategies: denial, regression, compensation, and diversion of feelings; these are often seen as negative reactions, but issues only arise when they are sustained for prolonged periods of time with no resolve (Falvo & Holland, 2017).

Pain Management

Pain management facilities have made monumental strides in incorporating the biopsychosocial model into medical care, which integrates measuring the possibility of mental health conditions, such as stress and depression, and providing interventions when psychosocial conditions are present alongside care for the physical condition (Williams et al., 2016). More specifically, the biopsychosocial model considers the impact of biological, psychological, and social factors on health. It is imperative for professionals working with individuals experiencing chronic pain to continue this trend of understanding the functional ability and an individual's perception of the experience to ensure proper interventions are prescribed to safeguard general and health related QoL and well-being (Dezutter et al., 2014; 2015; Peer et al., 2015; Williams et al., 2016).

The need for a sound mind and body is of the utmost importance during EA as these individuals are experiencing much self-doubt as they navigate the opportunities and risks associated with finding the most advantageous activities and people to commit to (Peer et al., 2015). Chronic pain only exacerbates the experience of self-doubt due to the grappling reality that they must advocate for themselves and their daily experiences with pain due to the invisibility that often persists (Schenk et al., 2020; Stinson et al., 2013; Twiddy et al., 2017). Peer and McAuslan (2016) sought to better understand how mindfulness can play a crucial role in encouraging the normative experiences of EA and mediate for the effect of self-doubt. Born from Buddhist tradition, mindfulness encompasses the act of paying attention to one's present-moment experiences without judgment. In an additional study by Peer et al. (2015), they found that emerging adult college students also found this experience to improve their health and well-

being including anxiety and chronic pain. Researchers enthusiastically encourage college administrators and mental health professionals to provide mindfulness activities, to emerging adults whether they are experiencing chronic pain and mental health difficulties or not, as it has led to improvements in areas such as decision-making (Peer & McAuslan, 2016).

Education

Education tends to be another key component in one's ability to adapt and adjust to their chronic pain and its impending effects. Acceptance coinciding with the role of responsibility and self-determination is necessary for an individual to strive to reach day-to-day and lifelong goals (Peer et al., 2015). Education can take place individually or in a group setting both formally or informally and can cover topics such as the pain they are experiencing, its impact on their daily lives, and stress and its effects on mental and physical health (Falvo & Holland, 2017). With this, education can be used as an ongoing resource or can utilize self-directed learning. Patient education has been seen to increase awareness and motivation to use positive health behaviors to avert stress (Peer et al., 2015). Further, individuals with chronic pain often feel as though they are not understood, so family and peer education can make an indispensable impact on breaking down the barrier of invisibility (Falvo & Holland, 2017) and increasing social support (Peer et al., 2015). Regardless of strategy, effective practices are ones that incorporate the individual's specific circumstances as well as their goals moving forward.

Pain and Identity

In light of developmental challenges, interventions for emerging adult chronic pain patients tend to target common areas of misperception involving identity development such as

self-concept, self-esteem, and social identity, body image, and uncertainty (Arnett, 2015; Padilla-Walker et al., 2017). More distinctly, self-concept refers to an individuals' perception of their strengths and weaknesses along with other people's opinions of these qualities. In parallel, self-esteem can be defined as the evaluative component of one's self-concept, which sways their perception of other's opinions (Berk, 2021; Falvo & Holland, 2017). Uniquely, social identity involves individuals viewing themselves based on their perceived group membership and the way in which they exhibit group inclusion and exclusion behaviors (Falvo & Holland, 2017). Shifting the focus to body image, young people often have distorted views of their appearance, sexuality, and abilities in regard to physical tasks based on their perceived self-concept (Falvo & Holland, 2017; Peer et al., 2015; Sira & White, 2010).

EA consists of exploration in all areas of life while trying to understand who they are and where they fit in the larger society around them (Arnett, 2017; Erikson, 1950). With this in mind, uncertainty, distress, and insecurity make it difficult for emerging adults to plan for their future, which, more often than not, worsens physical and mental well-being (de la Fuenta et al., 2019). Chronic pain only heightens these negative mental images that are already prevalent during EA as they experience changes to their body and lack a sense of control and privacy (Schenk et al., 2020). For these aforementioned reasons, the overarching goal of these interventions should be to help young people adjust their self-views to healthier habits. Patients are encouraged to embrace the importance of living in the present moment rather than dwelling on what may or may not occur (Falvo & Holland, 2017). Life will move forward regardless, so individuals are encouraged to shift their mindset to reduce stress and anxiety while strengthening QoL (Howland et al., 2017; Twiddy et al., 2017).

Purpose of the Current Study

EA accounts for the tumultuous life phase known for exploration, transitions, and identity development where individuals between 18 and 29 years old are encountering abundant opportunities to develop a sense of self surrounding love, work, and worldviews (Arnett, 2015; Schwartz, 2016). Although chronic pain is not life threatening, it poses many challenges to daily activities, psychosocial functioning, and developmental tasks present during EA such as identity formation, relationship building, and educational or career decisions. These difficulties often negatively impact QoL, which further worsens physical and mental health (Higginson et al., 2019). Positive forms of adaptation are vital in ensuring individuals are adapting successfully to reduce anxiety and restore equilibrium (Falvo & Holland, 2017). While much work has been done to address the challenges apparent with this life phase, additional research is needed to truly understand the experiences of emerging adults facing chronic pain and its repercussions. For these reasons, the current study advances the limited research surrounding the impact of chronic pain on emerging adults and their ability to cope with a diverse range of participants. Using EA as a theoretical framework, the current study investigated the impact of chronic pain on the developmental milestones associated with EA and the forms of adaptation utilized.

The research questions for this study are as follows:

1. What is the impact of chronic pain on the developmental milestones associated with EA, such as identity formation in regard to work, love, and worldviews?
2. What forms of adaptation are utilized by emerging adults experiencing chronic pain?

Hypotheses

1. Emerging adults are challenged in many developmental milestones present during EA, such as exploration, independence, relationship formation, and educational/career goals, due to their chronic pain.
2. Identity development will be impacted by the experience of chronic pain.
3. Forms of adaptation utilized will reflect both positive and negative strategies.

CHAPTER 4: METHODOLOGY

The goal of this study was to investigate the impact of chronic pain on the lives and developmental tasks, such as independence and exploration, associated with emerging adults. Using Arnett's theoretical framework of emerging adulthood, this study explored experiences of EA and the forms of adaptation used when dealing with chronic pain.

Design

Approximately 20% of people within the world suffer from chronic pain (Treede et al., 2015), but each of them recounts a unique story surrounding pain, its impact, and their ability to adapt. In order to allow the researcher to examine a complex, ambiguous, and emotionally laden topic that is vastly understudied, a qualitative descriptive approach was utilized to collect insight into how each individual perceived their given experience (Rossman & Rallis, 1998). To this end, qualitative research relies on description and inductive processes in which the researcher conveys abstractions and conceptions from details portrayed by participants (Creswell, 1994). Additionally, bracketing is involved to allow the researcher to separate themselves from the narratives so the phenomena can speak for itself (Smith & Osborn, 2014). Research following this design is "interested in meaning – how people make sense of their lives, experiences, and their structures of the world" (Creswell, 1994, *p* 145). As such, a qualitative descriptive approach allowed us to shine light on an experience that is often plagued with invisibility by investigating an area of research that is limited. The impact of chronic pain in emerging adults was seen in an exploratory nature by observing participants and utilizing open-ended interviews in order to collect rich descriptions of each participant's unique experiences in terms of developmental tasks and adaptation (Creswell, 1994).

Validity and Trustworthiness

Qualitative approaches require strict examination of validity and trustworthiness to ensure the integrity of the research study at hand. Credibility was achieved through a theory-driven evaluation of relevant themes and a data-packed codebook. The systematic codebook held the researcher accountable to evaluate interpretations of significant findings. The analysis process aligns with DeCuir-Gunby & Schutz's (2017) guidelines to code interviews a minimum of two times. Along with the participant's recorded interview, the coding process analyzed gestures, body language, voice changes, and response delays (Creswell, 1994). To establish trustworthiness, an additional coder reviewed the transcripts in conjunction with the codebook. Additionally, rich descriptions were used to provide perceptions of experiences in the participant's "actual language and words" (DeCuir-Gunby & Schutz, 2017, *p* 192), to reinforce analysis interpretations. This research achieved validity and trustworthiness through its focus on empowering participants and ensuring rich descriptions in portraying the impact of chronic pain on emerging adults' developmental tasks, including adaptation.

Ethical Considerations

Data collection began upon approval from East Carolina University's Institutional Review Board. Additionally, participants were informed that their participation was voluntary, and their confidentiality was of the utmost importance. Informed consent was signed before proceeding with the interviews. All identifying information related to each participant was anonymized. The research team members are the only approved individuals to access the participant number coding list. Additionally, interviews were recorded in order to review all pertinent information shared by participants. Collected data was saved on the research investigator's password protected computer.

Sampling

In conjunction with the descriptive approach where the topic of interest dictates the method (Rossman & Rallis, 1998), emerging adults with chronic pain with diverse identities with regard to gender, race, ethnicity, and geographic location were recruited through social media to participate in individual, semi-structured interviews. Purposive sampling via social media took place as to find a closely defined group of emerging adults experiencing chronic pain. Participating individuals were required to meet the following inclusion requirements: participants must 1) be between 18 and 29 years old 2) have experienced chronic pain for 6 or more months, 3) experience chronic pain on a weekly basis and 4) be able to complete an interview, in English, over a video conferencing platform such as Zoom Videoconferencing.

Procedure

Eligible participants were recruited via inquiry through a flyer posted on social media. Flyers were posted on the researcher's Instagram and Facebook three times to improve the number of individuals viewing this information and invited to join this study. Those interested were encouraged to email the research investigator where they were provided screening questions to determine their appropriateness for the study. A double screening process through the flyer posted as well as clarification through email with the researcher ensured qualification requirements were met. Once participants were identified, interviews were completed through Zoom Videoconferencing.

Data Collection

The research objective was to learn more about the EA participants' experience with chronic pain and adaptation while reaching the developmental tasks of EA. Data collection took place from January 2022 to March 2022. Before beginning, participants were reminded about the

rights they hold, including but not limited to, confidentiality. Once informed consent was signed, a questionnaire via Qualtrics was sent to participants through email prior to their scheduled interview in order to collect demographic information and details surrounding their experience with chronic pain. The detailed questionnaire can be found in Appendix B.

Following demographic collection, a semi-structured interview consisting of 6 guiding questions that pertain to the participant's chronic pain, its impact in regard to developmental milestones, and their adaptation was conducted. Example questions include but are not limited to 1) how has living with chronic pain changed your relationship with those in your social circle, 2) how independent have you been able to be in regard to managing your pain, 3) how do you feel your chronic pain has impacted your ability to be spontaneous in regard to traveling, social gatherings, etc., and 4) how has chronic pain impacted the way you see yourself/your purpose in life? A full list of questions can be found in Appendix C. Semi-structured interviews allow the interviewer to depart from their interview guide when appropriate to fully investigate the participants' experiences. Open ended questions guided the conversation while probing questions assisted to guide communication in a conversational style. The interview questions were designed to elicit and encourage narrative descriptions revealing their impressions. Additionally, question development was informed by the literature as well as an experienced research team (Hunfeld et al., 2001; Riddle & Jensen, 2013; Stinson et al., 2013; Lee et al., 2020). To ensure credibility, the interview questions went through many revision stages by scholars, iterative questioning was included, and probes elicited detailed data collection (Shenton, 2004). Additionally, bracketing took place to ensure the researcher could separate her thoughts from those she interviewed (Finlay, 2008). As such, the interviewer conducted interviewers with the mindset to learn about participants' specific experiences. Interviews lasted no more than an hour

and were recorded to then be transcribed by the Group Transcribe application on the researcher's login-protected phone. Interviews were transcribed in real time then transferred to the researcher's password protected computer and assigned a corresponding number to ensure confidentiality.

Data Analysis

Arnett's theory of emerging adulthood was used to identify key themes expressed by our sample. In consideration of the descriptive approach, which provides flexible guidelines in order to achieve analysis of research objectives, the following data analysis process for qualitative research from Pietkiewicz & Smith (2014) was used. Additionally, a second rater completed the same analysis process following the primary researcher in order to ensure reliability of identified themes. This process is detailed below.

Note Taking

Each transcript was read several times in order to ensure a thorough discovery of interesting or significant responses in each interview. The right-hand margin was used to collect summaries, connections, and preliminary interpretations found.

Emergent Themes

Following the note taking stage, each transcript was examined in order to document the emerging themes. Concise descriptions were annotated from the initial notes to capture the essence of our participants' experiences. The number of themes were determined by the richness of each transcript and its applicability to the developmental milestones present during emerging adulthood and/or the forms utilized in adapting.

Cluster Themes

Once emergent themes were identified in each transcript, researchers then analyzed each theme in terms of the theoretical foundation of emerging adulthood, as described by Arnett (Arnett, 2015). Connections in themes were drawn in terms of clusters while considering over-arching themes that were expressed by participants. Additionally, transcripts were consulted to ensure connections were, in fact, related in context. Following the cluster of themes, each cluster was given a name to represent each sub-theme. A codebook was created to represent the sub-themes coinciding with each over-arching theme. An identifier was added to ensure each theme and sub-theme was connected to participant interviews. An additional analysis was done for each participant interview to analyze data in terms of the noted themes and sub-themes. Any theme that did not fit well with the structuring theory or provide rich evidence within the transcript was not considered in analysis. Themes were considered if they were expressed by more than half of the participants.

Final Conclusions

Lastly, the final themes were examined, described, and interpreted to identify the experiences of each participant in terms of emerging adulthood, the impact of chronic pain, and the forms of adaptation utilized. In doing so, a narrative account of experiences was distinguished resulting in five distinct themes: *restricted exploration, relationship building barriers causing uncertainty, lack of independence, identity confusion restricting adaptation, and adaptation.*

CHAPTER 5: RESULTS

In order to collect rich descriptions of each participant's unique experience, a qualitative descriptive approach was utilized to better understand the impact chronic pain has on the achievement of developmental tasks present in EA. This chapter includes a description of the demographic data as well as the thematic content analysis of the semi-structured interviews conducted, uncovering five distinct themes: *restricted exploration, relationship building barriers causing uncertainty, lack of independence, identity confusion restricting adaptation, and adaptation*. The display of data is informed by the two overarching research questions targeted within the study: 1) what is the impact of chronic pain on the developmental milestones associated with EA, and 2) what forms of adaptation are utilized by emerging adults experiencing chronic pain?

Demographic Information

The sample consisted of eight ($N = 8$) emerging adults, with six ($n = 6$) identifying as female, one ($n = 1$) identifying as male, and one ($n = 1$) identifying as non-binary. Ten individuals responded to the demographic survey, however, two were removed due to a lack of response in scheduling interviews. Thus, the final analysis consisted of 8 participants equaling an 80% response rate. All participants align with the emerging adult developmental period ranging from 24 to 28 years old, with a mean age of 25.3. This sample is diverse with regard to geographic location, educational attainment, employment, and marital status as described in Table 1.

Table 1

Participants' Demographic Information

Demographics	Descriptive Statistics
Gender	

Female	6 (75%)
Male	1 (12.5%)
Non-binary	1 (12.5%)
Age	
24	4 (50%)
25	1 (12.5%)
26	1 (12.5%)
27	1 (12.5%)
28	1 (12.5%)
Ethnicity	
White/Caucasian	7 (87.5%)
Other	1 (12.5%)
Geographic location	
KY	3 (37.5%)
NC	1 (12.5%)
TN	1 (12.5%)
OK	1 (12.5%)
PA	1 (12.5%)
WI	1 (12.5%)
Education	
High school degree	1 (12.5%)
Some college	2 (25%)
Bachelor's degree	4 (50%)
Professional degree	1 (12.5%)
Marital Status	
Single	5 (62.5%)
Married / domestic partnership	3 (37.5%)
Employment	
Full time	3 (37.5%)
Part time	1 (12.5%)
Disabled	2 (25%)
Student	2 (25%)
Unemployed	1 (12.5%)

* Participant self-reports as disabled and working part time

All study participants (n = 8) have unique diagnoses and pain experiences but meet the pain requirements necessary to be considered as experiencing chronic pain, as defined by pain lasting for at least six months. In fact, 88% of participants (n = 7) reported their chronic pain being present six or more years. Another 88% of participants (n =7) experience pain daily with 13% of participants (n = 1) suffering from chronic pain two to three times a week. Additionally, 88% (n = 7) reported pain in two or more locations including head (n = 3), neck (n = 3), back (n

= 3), upper/lower limbs (*n* = 2), and full body (*n* = 2). Interestingly, each participant shared the similar sentiment of seeing a distinct change in their life following the onset of their pain. Although varying levels of severity and periodicity were described, all participants shared the experience of chronic pain impacting at least one, if not several, developmental tasks present during EA. Additional demographics surrounding chronic pain are described in Table 2.

EA is often considered as a period of instability as individuals explore the multitude of opportunities available to them in regard to establishing peer relationships – both romantic and professional, discussing family composition, and constructing identity (Arnett, 2015). While this instability and uncertainty often results in identity confusion, symptoms of anxiety and depression, and other forms of maladjustment, chronic pain only exacerbates this uncertainty as exploration is often restricted (Falvo & Holland, 2017). Given this knowledge, it is not surprising that 38% of participants (*n* = 3) reported diagnoses such as the following: generalized anxiety disorder (GAD), major depressive disorder (MDD), post-traumatic stress disorder (PTSD).

Table 2

Participant's Chronic Pain Information

Participant	Pain for	Onset	How Often	Diagnosis*	Pain Location*	Pain Scale*	Mental Health Diagnosis*
1	6+ years	Middle school	Daily	Scheuermann's Kyphosis	Upper / mid back, neck	4	N/A
2	6+ years	High school	Daily	Rheumatoid arthritis, fibromyalgia, irritable bowel syndrome (IBS), tachycardia, narcolepsy	Elbows, knees, head, toes, hands, fingers	4	ASD without developmental delay, GAD, MDD
3	6+ years	Elementary school	Daily	Migraine	Head	7	N/A

4	6+ years	Middle school	2-3 times/week	N/A	Head, neck	7	N/A
5	6+ years	High school	Daily	Fibromyalgia, osteoarthritis, ankylosing spondylitis, bulging discs, mass on thyroid, Cavernous Venus malformation, IBS	Lower back, arms, full body	10	Anxiety, depression, ADD/hyperawareness, night terrors, PTSD
6	6+ years	High school	Daily	Pre-arthritis	Neck, upper back	5	N/A
7	3-5 years	Early 20s	Daily	Bilateral labral tears, autoimmune arthritis in bilateral knees, shoulders, and wrists, autoimmune arthritis in back and neck	Bilateral hips and knees	4	N/A
8	6+ years	Early childhood	Daily	Fibromyalgia	Full body	6	Borderline Personality Disorder (BPD), depression, PTSD, ADHD

* According to participant self-report

Qualitative Description of Pain

Chronic pain has been defined as an unpleasant emotional and sensory experience with pain behaviors that last for three to six months (Hunfeld et al., 2001; Treede et al., 2015). This experience, though, goes far beyond the medical diagnosis encompassing a myriad of psychosocial implications (Falvo & Holland, 2017). The perception of pain is unique to each individual dependent upon gender, temperament, age, and tolerance to pain so everyone has a unique story to tell, but when it comes to fears and limitations, chronic pain survivors share

much more in common than they may think. Pain is a subjective experience that often challenges the efficacy of understanding (D'Agostino et al., 2011). For the purpose of this study, the common pain graphic rating scale was utilized. This subjective measure is presented as a continuum consisting of a straight line with endpoints "defining extreme limits such as 'no pain at all' and 'pain as bad as it could be'" (Haefeli & Elfering, 2006, *p* S18). A numerical scale is added from 0 (no pain) to 10 (as bad as it could be) to represent the rise in pain severity from mild to moderate to severe (Haefeli & Elfering, 2006). For those with chronic pain, though, as reported by participants, their baseline is typically midrange on the common pain scale. P5 explains her individual perception of pain:

> "I know the common pain scale goes up to ten, but my pain level stays at a six or seven every single day… when I say I'm at a 10, but I'm not screaming or crying, they don't believe me, but I've dealt with this for so many years, the typical pain scale does not apply to the experience those with chronic pain have." – P5

Another participant, P2, expresses a similar concern in individual perception sharing, "I hate the common pain scale from one to ten. My normal day is a 4. I've literally made my own pain scale to use at this point so I can reference it in my appointments." Chronic pain has become a normal occurrence that these individuals (n = 8) have had to adapt to in their day-to-day lives.

Invisibility of Pain

With pain being a subjective interpretation defined by each individual's perception of their experience and its impact, all participants (n = 8) reported on the invisibility of pain that required them to make lifestyle changes in order to make it through their daily tasks. It is "difficult for others to fully understand" the experience of chronic pain especially when, at first glance, someone looks young and healthy. This invisibility tends to strain relationships with

family, friends, strangers, and healthcare professionals and requires participants to advocate for themselves on a daily basis (Schenk et al., 2020; Stinson et al., 2013). “People understand to a degree, but they don’t because they’re not in my body,” one “young, seemingly healthy” participant shares; “they don’t understand that when I say I can’t do something, the pain is high enough.”

Christine Miserandino, a woman living with lupus, is often referred to as “the spoon lady” for her revolutionary creation of the spoon theory (Miserandino, 2017). Christine used a pile of spoons to explain “that while most people have plenty of ‘spoons,’ those with chronic illness have limited energy, and each action costs them a spoon” (Miserandino, 2017, *p* 13). This theory has since been adopted by those with chronic pain as individuals are having to choose the most energy efficient activities to take part in. P2 utilizes this metaphor to explain that “grocery shopping for most people is like a quarter of a spoon. For me, it’s two or three.”

Taking into consideration the chronic pain experience, participant explanations of invisibility, and the depleted energy associated with chronic pain, as described by the spoon theory, the goal of this study was to investigate specific milestones of EA, such as relationship building, exploration of opportunities, independence and autonomy seeking, and identity development among emerging adults with chronic pain (Arnett, 2015). The following themes reflected by participants will be reported on: *restricted exploration, relationship building barriers causing uncertainty, lack of independence, identity confusion restricting adaptation, and adaptation*.

Restricted Exploration

EA often begins with the exploration of potential professional endeavors associated with higher education and career opportunities (Arnett, 2015). The college years present a unique set

of stressors including but not limited to adjusting to new living conditions, making and executing career decisions, juggling busy academic lives, coping with the ongoing changes in relationships and lifestyles, and accommodating the unattainable pressure families often push on individuals to do well in college (Peer et al., 2015). The addition of chronic pain, which comes with its own set of restrictions, only exacerbates these challenges (Twiddy et al., 2017). As such, participants shared the struggles surrounding educational attainment as it is difficult to "hold attention", "receive accommodations" from professors, and stabilize stress levels. Our sample ranged from individuals who were able to obtain degrees in higher education (n = 6) and others who were unable to receive the support necessary (n = 2). P7, a 24-year-old veteran working towards his bachelor's degree, shared his challenges in pursuing an education with the difficulty of simply sitting in class.

> "Sometimes I get uncomfortable and it's hard to pay attention because I'm trying to get in a comfortable spot or I'll go to readjust how I'm sitting, and I'll miss something and kind of have to get reoriented back into class." – P7

Another participant, P2, had a very similar incident when working towards her bachelor's degree. Following the first day of class, she met with her professor to disclose her chronic pain and the accommodations she had discussed with the accessibility resource center. The professor responded by saying that he "was not going to help her with anything she were to miss." P4 explained her comparable experience sharing, "I would find myself getting really, really bad migraines, which then made it more difficult to complete that work and come to class with my best foot forward or put my best effort into a test or an assignment or project." Even those who have received degrees, though, are still feeling the long-term impact these experiences had on them. P3, a 27-year-old woman who received her doctorate degree, shared the following:

> "I know that migraines have impacted my education and my success. I still feel like I've been very successful, but I can only imagine if I didn't have migraines and chronic pain what more I could do with my life or how much energy I'd have back from that." – P3

Another area of prioritization that must be considered for participants is professional and career accommodations. Career prospects must be open and willing to accommodate challenges that may arise. As many as 37.5% (n = 3) of participants were unable to find places of employment that could meet their needs, leaving them unemployed and/or disabled. Many participants fear the disclosure of pain to employers due to the previously described invisibility and "negative responses" they have received in the past. As such, P8 explained that he is "nervous and afraid to ask a job or talk about my struggles with an employer." He continues:

> "I don't want them to seem like 'oh, I'm not going to hire you. Why do you need so many things? Why can't you just do whatever everyone else is doing' especially because I don't have any type of visible disability." – P8

This experience feeds into the assumption that "young, visibly healthy individuals" must "not have any difficulties" regarding their ability to function in society. Participants continued by sharing the challenge for "employers to understand" that some days they may be able to achieve all tasks set out, but other days may be much more difficult and may require accommodations. As P2 shared:

> "I worked in a research lab in college. I loved the teacher I worked with, but the lab was her number one priority, not her students. I ended up quitting my senior year and I feel like I lost respect from that professor because I had to tap out for my own health." – P2

Despite this hardship, some were able to prioritize themselves and find careers (n = 4) that fit their evolving needs. P4 and P3 discuss the changes they have had to make in their careers to prioritize their health:

> "I've really had to even change within my career what I'm able to do and kind of put those boundaries set forward for my health and so that really limits me on like I'm lucky that I have a place that is totally understanding about that, but I've had to step back from certain roles because it didn't fit me anymore in my place in life." – P4
>
> "I was working at a job that had long days, long nights, evening meetings, sometimes weekends and I was driving an hour each way for my commute. I knew that was really hard for my body. So, I left that job and I've had less migraines now." – P3

Although both P4 and P3 were able to recognize their needs and advocate for themselves, they both acknowledged how this is a "privilege" not everyone can access.

Unfortunately, restricted exploration impacts much more than education and career endeavors. The majority of participants (n = 8) experienced a direct restriction on exploration throughout their EA years as spontaneity was greatly hindered. Although the majority of participants (n = 6) "still try to be spontaneous and try to not let [chronic pain] dictate life," as P3 explained, "there are special considerations" that must be embraced. P1, a 24-year-old woman, shared the importance of proactivity and its inclusion in her day-to-day life: "I think the biggest thing is having to be proactive in thinking about if I can do this, and if not, how can I make it work." Another participant, P3, explained a similar process that she utilizes within her life by "looking ahead at my calendar." She continued to share that, "yeah, activities might not fit perfectly with my migraines, but I'm still going to do it. I'm just going to try to manage as best I can." Participants (n = 6) shared the devastating impact this ongoing experience can have on

their mental health as they question their "self-worth" and "ability to contribute" to those in their life. Occurrences such as this "ruin the 'fun'" in life, further isolating individuals. P4, a married woman who goes on annual vacations to the beach with her family shared:

> "I'm not spontaneous at all because I have to make sure that I have my medications available and that I am going to be able to have my routine in place. Even when planning vacation, which you think is going to be so fun and relaxing, but I have to pre plan and figure out how far I'm going to be from the beach so if I get a migraine, am I going to have the ability to go back to the room?" – P4

Some participants (n = 4), though, do not have the ability to act as though their pain is not present.

> "With friends, they'll want to do activities outside like 'hey, let's go for a bike ride' or 'let's go for a walk' and I can't do that…and it's just hard to not be able to enjoy things like a simple walk." – P8

This limitation can cause damaging effects on relationships as others do not fully understand why something as "simple" as a walk is not possible. P6 described how friends repeatedly tell her to "just do it" when it comes to different social activities. Over time she has become "more aware" of the fact that sometimes "it's just not worth it" due to the grueling impact it is likely to have immediately following.

Relationship Building Barriers causing Uncertainty

The EA years are known for feeling "in-between" as individuals are encouraged to experiment in regard to relationships with friends, family, and romantic partners, which has the potential to result in complicated communication barriers (Padilla-Walker et al., 2017). Due to a lack in spontaneity and independence, as discussed further under the themes *Restricted*

Exploration and *Lack of Independence*, participants found romantic partners and friends to "blow [them] off" because "everyone thought [they] were exaggerating [their] pain." Participants reported having to rely heavily on their professional relationship in order to achieve daily tasks assigned during the workday. Additionally, health professionals were found to "belittle" participant experiences (n = 7) sharing that they were just being "stubborn." Family members only furthered this "self-doubt," as one participant shared, "my dad though it was all in my head…that I just wanted to get attention." "For people to not believe you, that can have a really big impact on a lot of things in life," P1 explained. As such, building relationships and having open communication with friends or intimate partners was cited by the majority of participants (n = 7) as a key "resource" in lessening the effects misunderstandings can have in regard to intimacy and disclosure of pain. Intimacy is characterized by closeness, honesty, and love for relationships of all kinds (Liang & Feiring, 2020). As such, participants (n = 6) expressed a need for trust and open communication in order to form intimacy within their romantic relationships. P4, a married woman who has experienced chronic pain for over 6 years, described this need for communication amidst the experience of chronic pain:

> "I think that communication is the core of all of that…I have that very strong communication from the start regarding my pain because I am forced to be honest about how I feel because I will not put myself in a situation where I am in so much pain. And then them being honest back is just as important." – P4

However, as mentioned by participant 2, open communication is often difficult to develop when one person within the relationship has chronic pain. Thus, she shared the following:

> "You're not supposed to be in pain. Dating while on disability with chronic pain feels impossible. I have to tell people up front, 'hey, this is an issue. If it is too much, I need to

know.' An example is with my ex – I told him about my health in the beginning and when he broke up with me, that was the only thing he could identify as a reason. Dating with chronic health conditions creates this belief in you that you are a burden." – P2

Although communication and intimacy are often difficult to obtain, it is needed for participants to feel comfortable enough to disclose their pain. As one participant shared, "I typically don't disclose to people that I have migraines right off the bat. When we get deeper into the friendship or relationship then I'll reveal it." Similarly, P1 shared that, "if it comes up, it comes up, but I would say the majority of people in my life probably have no idea I have chronic back pain." The challenge of intimacy development alongside the invisibility of pain that often ensues, can be a difficult experience to work through. The majority of participants (n = 8) shared the desire and need to disclose their pain, but all expressed fear in being "misunderstood" and "further isolated." "This is our real life," P2 shared, "and we need to be believed."

EA is characterized as a time in which individuals explore the opportunities available to them before committing to adult roles such as marriage and starting a family (Arnett, 2015). The majority of participants (n = 5) reported being single at the time of this study while 37.5% of participants (n = 3) reported being married or in a domestic partnership. The experience of chronic pain, though, mystifies this exploration and commitment as participants often harbor fears regarding the personal impact of pregnancy and the possibility of passing on chronic pain conditions to a child. In regard to the impact pregnancy can have on a woman's body, especially when chronic pain is present, participants shared a need in better understanding their options. P1, a married woman who has experienced back pain for over 6 years, shared,

"Pregnancy is hard on your body in general. I mean, that's always a fear of mine – is my body going to be able to handle it, because I already have back pain as it is, pregnancy is

> probably going to make it worse. It hasn't deterred us from having children, but I think we have had to consider it a lot because I will have limitations and my husband will have to work with me on those limitations." – P1

Not only is pregnancy "hard on the body" but raising a young child can take a toll on the body, as well. Thus, P5 explained the fear she holds regarding the impact her pain could have on her ability to raise a child and the possibility of her children watching her deal with her daily pain:

> "I want at least one that is my own blood, but I am terrified to have a child and not be able to take care of it because of my pain. Or them growing up and then me having to watch them suffer and not being able to help them." – P5

P7, a male participant, also shared this concern in explaining his, "only concern would be when the kids are running around and playing like I wouldn't always be able to join in, which I would have to have that discussion with them as they grow up." The majority of participants (n = 7) expressed this guilt they feel surrounding the idea that their significant other may have to carry more of the weight when it comes to the physical side of parenting due to their pain.

Limited Independence

Feelings of "helplessness" and reliance on others is present for many experiencing chronic pain (n = 6) as they are unable to obtain the experience of autonomy and independence that often comes during the emerging adult period of time (Berk, 2021). It is important to note that independence varied by person, but it also varies day-to-day for any given participant, as described by the majority of participants (n = 5). Typical daily tasks, such as house chores and personal hygiene, as well as health behaviors, such as getting to doctor's appointments, are often difficult tasks for those who experience chronic pain. Pain can cause all-encompassing psychological symptoms such as fatigue and difficulties concentrating, which leads to

repercussions in daily household chores, social participation, and lifestyle choices (Williams et al., 2016). As such, participants often found themselves relying on friends and family for support. P8, a 24-year-old living with full body chronic pain, relies heavily on his boyfriend and roommates in order to achieve daily tasks.

> "I don't think I am capable of doing all the things that I need to do on a daily basis. Having roommates and a boyfriend, it's nice because we can switch off doing dishes like I'll do as much as I can, but my roommates will do some dishes too and so when it's split between a couple different people, we can get it done." - P8

There are times when the pain gets so bad for participants that they are physically unable to take part in personal hygiene tasks, let alone household chores or socialization. For example, P4 shared how her family, friends, and husband have been vital in ensuring her safety and care.

> "I would say my husband especially is someone that I lean on even to the point where he's washed my hair because I've just almost been unable to move. I've been in so much pain that I feel like if I even open my eyes, I don't know what is going to happen, so I've had to literally depend on this person to wash my hair and help me get dressed." – P4

Although participants express gratitude for this support, having such a reliance on others can cause damaging internal effects. As one participant shared, "you don't grow up dreaming of being dependent on someone." P5 – a 24-year-old female on disability due to the extensive impact of chronic pain – shared the internal battle she must confront as she relies on her husband and mother:

> "I hate when people say a relationship is 50/50 because it's not. You know, if he's sick, I would pick up the slack. It would be 80/20. But the thing is, it has been him 80 and me 20 and I feel so guilty about that because I want to be a better wife. I want to be a better

daughter. I want to be a better everything. My mother does the grocery shopping and takes me to my appointments. My husband has to carry me to the bathroom sometimes. It makes me feel humiliated that I'm 24 years old and I'm not able to do all this stuff by myself on a daily basis." – P5

Another contributing factor limiting independence for emerging adults facing chronic pain is the financial burden associated. Chronic pain often requires financial obligations in the form of pain management that causes great financial strain. As P4 so perfectly summed up, "if I could put all my chronic pain things in a box and get all my money back, I could probably put a down payment on a house." This financial strain adds a sense of dependence. As such, half of participants (n = 4) report how they regularly find themselves having to depend upon their family members to support them financially. P2 shared that, "you don't grow up with dreams to be financially dependent on someone." This can be a demoralizing experience as emerging adults are craving autonomy during this time in their lives (Padilla-Walker et al., 2017).

Identity Confusion Restricting Adaptation

Identity formation is a lifelong process exacerbated during EA due to the exploration of personal and professional roles available, such as religious participation, political affiliation, gender and sexual orientation, and family roles (Padilla-Walker et al., 2017). Chronic pain further challenges this formation as exploration could be altered due to its impact, as explained by participants (n = 6). As P5 explained, "I know my pain does not define me, but it is a huge part of my life." Goals that were once a realistic ambition with feasible steppingstones leading to success for participants (n = 4), were now questionable and unresolving. P7, a veteran who intended to live through this dream for years to come, found himself at a crossroads unsure of what was next: "…that whole dream I had as a child is gone." Another example of this

renegotiation of personal identity was introduced by P2, a 25-year-old female who is still coming to terms with the fact that her goals of becoming a therapist were halted due to her pain. She shared that her experience with chronic pain has "changed me into an advocate for myself and others which is good, but it's not always great when advocacy is forced upon you." For others who were still able to achieve their childhood dreams (n = 4), they are still working to renegotiate the long-lasting impact their chronic pain is likely to have. A good example of this renegotiation is provided by P3, a woman who has obtained her PhD and is working full time, sharing that she "personally never identified as disabled" despite her recognition that migraines and chronic pain do, in fact, signify a disability. Over time she has come to realize that sometimes, "this is a disability for me." This acknowledgement and acceptance is likely to remain unpredictable lending to the need for renegotiation based on her chronic pain progression. Confusion surrounding social and professional roles as well as future plans often presents itself for those experiencing chronic pain due to the restriction of independence and lifestyle changes (Higginson et al., 2019).

Adaptation

Having a repertoire of coping skills is vital in fostering an individual's ability to adapt or adjust to chronic pain in order to reduce anxiety and restore equilibrium in times of need (Falvo & Holland, 2017). Chronic pain complicates the ability to call upon these skills, though, as managing pain typically remains at the forefront of one's mind (Robinson-Lane, 2020). In these cases, maladaptive coping can take place in which inadequate or inappropriate skills are utilized such as increased alcohol consumption or self-harm (Twiddy et al., 2017). Positive forms of adaptation vary depending on an individual's specific needs at any given time, but tend to

include managing one's physical needs, negotiating a self-concept, identifying roles, and maintaining relationships (Robinson-Lane, 2020).

Chronic pain was seen to have an impact on participant's mental health (n = 8) as expressed through anxiety, depression, body image issues, lowered self-esteem, suicidal ideations, and PTSD. The need for internal and external resources to foster adaptation is at an all-time high as the majority of participants (n = 7) feel as though they are "worth less" because of their chronic pain. When participants were able to "know their worth past their physical limitations," as P7 explained, they were able to foster three critical components of resilience and adaptation: resources, pain management and relationships. Although negative effects of chronic pain were reported by all participants (n = 8), ongoing adaptation was also reported prevalently.

P5, a 25-year-old female working part-time, shared how "it's hard because when you get belittled that long, you start to believe it." P4, a married 28-year-old who is employed full-time, shared a similar sentiment in feeling the negative effects of chronic pain on one's ability to adapt: "logically, I can say that my pain…and doing things to take care of myself are not any reason that I lose value, but emotionally and mentally, I still feel those things." This "shame" often led to a "lowered self-esteem" and -image impacting the experience of depression (Tran et al., 2015). Additionally, participants explain that they relish periods of relief making it difficult to accomplish tasks for the fear of exacerbating their pain. As such, motivation is greatly influenced by the experience chronic pain.

> "I think the most impact I see is with my motivation. A lot of times I just don't want to get out of a comfortable place because I've been uncomfortable all day so it's hard to get up and want to do a lot of things." – P7

Resources

Participants (n = 7) adapted to the challenges associated with chronic pain by taking part in practices that support a "positive mindset" and the prioritization of the self. Participants shared a variety of internal and external resources including therapy, giving self-grace, advocacy, mindfulness, support groups, healthy communication, and not allowing pain to limit self-views. As supported by past literature, education is vital in fostering adaptation and adjustment to chronic pain and its impending impact on various aspects of life (Peer et al., 2015). In conjunction with this idea, P3 shared the following:

> "When I first started researching migraines, I found one thing that said migraines can also be caused with a dip in serotonin. I was like you know what that makes so much sense. It gave me so much clarity." – P3

Education has been seen to increase awareness as well as motivate individuals to use positive health behaviors to avert stress (Peer et al., 2015). Participants (n = 5) share that therapy, mindfulness, and support groups were helpful in identifying and addressing misperceptions in areas such as self-concept, self-esteem, social identity, body image, and uncertainty. Living in the present moment rather than dwelling on the impact of chronic pain is encouraged (Falvo & Holland, 2017). As P5 shares, "there is always something worth living for."

Pain Management

Society often assumes that once a diagnosis is made, effective treatment is then provided. Unfortunately, more times than none, that is not the case. This often leads to "self-doubt" as participants work to navigate opportunities and risks in life. As P4 explained, "the more stress I was in…I would find myself getting really, really bad migraines." Stress is often carried in different parts of the body, as P6 described in her experience, "I think it's very common to carry your stress in your neck and so I have to be very aware when I'm tensing up. I hold my shoulders

up and that'll cause a lot more pain." Common stressors expressed by participants and past literature were associated with the common developmental tasks present during EA as well as the impact chronic pain often has on these tasks, such as obtaining education, pursuing certain careers, building relationships, and exploring one's identity (Twiddy et al., 2017). As such, having "rest periods" is vital in stabilizing pain, along with taking part in yoga, seeking out care from chiropractors, maintaining a routine, utilizing a heating pad, and speaking with healthcare professionals about appropriate medications to sustain pain and/or stress that is associated with mental health conditions such as anxiety.

Relationships

Building friendships and intimate relationships while reconstructing relationships with family members is a prevalent developmental task present in EA (Arnett, 2015). Finding people that "understand the experience of chronic pain" is a key resource alongside having people in your life that provide "normalization." P8, a participant who values his relationships with those going through similar situations, shared, "I definitely think it's way easier to have roommates and a boyfriend that have chronic pain. He understood the struggle of going to the doctor and trying to explain your symptoms…and it was very comforting to know that they understand what I am going through…and say it is valid to feel the way I do." On the other hand, when those in your life do not understand the experience of living with chronic pain, relationships can take time to adapt. Participants urged those in their lives to be "open" to learning how to best support them. This is described best by P2, who has lived with chronic pain for over 6 years:

> "One thing I've learned to do when talking to others is that it is okay to say 'I don't know how to help you right now. Do you want space? Do you want a distraction? Do you want

to talk about it?' Those are the options that I give my friends always and when they can do the same thing for me. Giving options like that really helps." – P2

P7 furthered this need for adaptation and openness following the onset of chronic pain. As Arnett (2015) and Padilla-Walker et al. (2017) explain, interventions targeting common areas of misperception involving identity development such as independence is vital. P7, a veteran injured in combat, shared, "when I got injured, everyone was always overly helpful, and that kind of made me feel worse than before, but as they got used to me being injured and me having that discussion with them, they've let me be more independent, and it's helped me regain that part of myself." In order to help the support system surrounding those with chronic pain, "open conversations" must be had to "challenge stigmas" and foster understanding (Lee et al., 2020).

CHAPTER 6: DISCUSSION

The current study highlights the unique experience of emerging adults with chronic pain and their ability to achieve developmental milestones, such as the exploration of educational and vocational endeavors, building romantic and peer relationships, gaining independence, and forming one's identity (Padilla-Walker et al., 2017). Although chronic pain is typically not life threatening, it does pose a myriad of physical and psychosocial challenges in achieving these milestones (Falvo & Holland, 2017). This study confirms these challenges through powerful personal testimonies.

As Falvo & Holland (2017) explain, there is a circular influence of socioeconomic status, culture, personal factors, environment, social and family relationships, daily activities, and pain. In fact, participants describe a palpable divergence between their lives before and after the onset of their pain, as described through these factors, despite the variance of diagnoses. Given the subjectivity of pain and the influence it has on physical, emotional, social, and cognitive functioning, study participants reported specific alterations in reaching developmental milestones associated with EA, which requires a specific focus from educators, medical providers, and social services as their experience is much different than the general public (Higginson et al., 2019; Meyer et al., 2020). Overall, the results supported Arnett's (2015) theory of EA revealing the substantial impact chronic pain has on the developmental milestones present during EA in regard to relationship building, identity exploration, autonomy seeking, and future planning. Participants' personal experiences, as obtained through semi-structured interviews, added to the limited literature by exemplifying the damaging effects and resiliency factors present.

Impact of Chronic Pain on Developmental Milestones

Perception of Pain

Previous studies indicated that emerging adults are often facing a period of instability in which they experience thwarted opportunities, peer separation, and dependency on others (Twiddy et al., 2017). The reality of chronic pain only intensifies these challenges by complicating communication, spontaneity, and intimacy. Participants in the current study commonly cited the origin for these difficulties to be invisibility, which often plagues chronic pain survivors as they are the only person capable of defining its impact (Williams et al., 2016). Life with pain is usually associated with older populations, yet chronic pain occurs in the lives of many emerging adults, lending to the idea that it is often seen as an invisible and unrecognized experience. This subjectivity of pain complicates healthcare professionals' ability to adequately assess pain and offer resources as they are unaware of the full impact chronic pain presents (D'Agostino et al., 2011). This leaves emerging adults "vulnerable," "isolated," and in need of specific attention and support.

Achieving Developmental Milestones

Autonomy and Relationships. Emerging adults require adequate time to explore all opportunities available to them before committing to adult roles, but chronic pain threatens this exploration influencing one's ability to focus on the self and adapt to situational demands related to intimacy and seeking independence (Arnett, 2015). Although EA is a time in which its inhabitants are craving autonomy, our participants share the restrictive nature of this endeavor in that they are having to rely heavily on others to assist them in daily household chores, personal hygiene tasks, and health behaviors (Falvo & Holland, 2017). Open communication and active

listening are cited as fundamental needs between those with chronic pain and their social network. This ensures intimacy is built to sustain relationships through the inevitable challenges associated with disclosure, spontaneity, and relying on others (Liang & Feiring, 2020). As reported by participants, closeness and intimacy allow for the creation of safety between relationships and environments. When levels of openness and intimacy are significantly diminished, relationships of all kinds are complicated, adding additional levels of isolation, restricted exploration, and identity confusion, which is central to development during this time (Padilla-Walker et al., 2017).

Exploration. An area of great focus during EA is the exploration of possibilities surrounding professional endeavors such as higher education and career opportunities (Arnett, 2015). Stress factors surrounding college include but are not limited to adjusting to new living conditions, withstanding the unattainable pressure placed on emerging adults by family members to succeed in classes, making life decisions with little experience, and juggling a busy lifestyle (Peer et al., 2015). When considering the impact chronic pain can have on these factors, research suggests that the coinciding limitations complicate one's ability to address the pressures placed on emerging adults by adding restrictions to class achievement, contradicting decision making, and halting busy lifestyles. To make matters worse, participants reported that accommodations are hard to come by, and even when they are obtained, they are often not followed in an effective manner indicating that the college environment is not created for young people with chronic pain. This is showcased in both educational and career opportunities as participants share how difficult it is to put their best foot forward or are having to ask for support and accommodations in achieving goals. Keeping these challenges in mind, hypothesis one was confirmed in that

emerging adults with chronic pain experience difficulties in developmental milestones, such as exploration, independence, relationship formation, and educational/career goals.

Identity Development. Additionally, this research lends to the confirmation of hypothesis two given that identity development was found to be impacted by the experience of chronic pain for emerging adults. Self-doubt, in particular, was found to be a difficulty faced by participants as they grapple with the reality that they must advocate for themselves and their daily experiences with pain due to the invisibility present (Shenk et al., 2020). Although we often consider advocacy as a positive attribute, it can be damaging when it is "forced upon you" as it lends to identity confusion in the realm of social roles, future plans, independence, and lifestyle changes (Higginson et al., 2019). Identity formation is a lifelong process with a specific focus in EA as exploration is at the forefront of developmental milestones (Arnett, 2015). This means that many individuals are investigating lifelong dreams and creating new possibilities. This also indicates that these individuals go through a period requiring the renegotiation of identity goals, especially when chronic pain is present. Emerging adults are working to understand who they are and where they fit into the larger society in which they live while also taking into consideration how chronic pain impacts this role in the future (Schenk et al., 2020). This experience, reported by participants within this study, often lends to uncertainty, distress, and insecurity with chronic pain only causing further confusion (de la Fuenta et al., 2019). As such, participants have a direct need for education to increase awareness and motivation of positive health behaviors as well as foster adaptation and adjustment (Peer et al., 2015).

Forms of Adaptation Utilized

In regard to the third hypothesis stated within this research, forms of adaptation did, in fact, reflect both positive and negative strategies. Due to the instability present in EA as a result

of the transitional factors associated with the exploration of love, work, and worldviews, mental health concerns are noteworthy for the general population (Peer et al., 2015). In consideration with previous literature and participant responses, mental health difficulties are prominent in the chronic pain community, as well. It is clear that chronic pain has the potential to exacerbate these concerns leading to uncertainty; stigma; fluctuating self-esteem, concept, and identity; and the inability to positively adapt (Lee et al., 2020; Tran et al., 2015). This often lends to the experience of anxiety, depression, PTSD, body image concerns, and even suicidal ideations (Dezutter et al., 2014). Common emotional reactions experienced by participants include but are not limited to grief, fear, anger, depressed mood, and guilt as they confront and adapt to the alterations in life presented by chronic pain (Falvo & Holland, 2017). This indicates the limitations in coping and adaptation of this population, which requires specific attention.

It is important to note that individuals vary in regard to their tolerance of symptoms, functional capacity, aptness of coping, and general support they receive from those around them, therefore requiring unique resources (Falvo & Holland, 2017). Participants share essential ingredients involved in fostering resilience in order to not let their chronic pain limit their experiences in life: pain management, resources, and relationships. Participants indicated that pain management strategies have been found beneficial with the inclusion of the biopsychosocial model which values psychosocial support alongside care for the physical condition (Williams et al., 2016). Pain free is not a goal of our participants. Instead, finding a way to maintain stress levels and daily activities while dealing with pain is key. As such, interventions targeting common areas of misperception such as body image and self-esteem are strongly encouraged as they have been seen to help young people adjust their self-views to healthier habits (Falvo & Holland, 2017; Howland et al., 2017). Unfortunately, though, there is a clear lack of accessibility

when it comes to these supports. Oftentimes, finances are having to focus on physical aspects of care due to the lack of contribution by insurance companies. Without financial compensation, the necessary resources to continue as a contributing member of society are unable to be obtained leaving this population isolated. Fortunately, participants describe a resource that costs nothing: relationships. Relationship building is not only a core developmental task of EA, but it is also a crux in providing normalization, validation, and tangible support (Arnett, 2015). The circular nature of social factors and adapting to chronic pain is evident in both research and participant experiences (Falvo & Holland, 2017). Although continual adjustment is required throughout the relationship as the impact of chronic pain varies and the young adult grows throughout life, social support has the potential to lessen the invisibility associated with this experience and fosters the aforementioned positive coping strategies.

Limitations and Future Research

Despite the much-needed insight this research is bringing to light on the experience of chronic pain in EA, it is not without its limitations. With the majority of participant's being White/Caucasian females, the current study's sample did not fully represent the racial, ethnic, and gender diversity of those experiencing chronic pain. Additionally, although there were a variety of chronic pain diagnoses, locations, severities, and periodicities, this study did not represent an exhaustive list of chronic pain experiences. With a deficit of variability and a small sample size, there is a clear lack of generalizability present within this study. At the same time, though, the experience of emerging adults with chronic pain should not be ignored as it represents a much larger population. The inclusion of gender diverse and multicultural perspectives would be useful for future research to ensure a well-informed picture of chronic pain in EA (Arnett, 2015). Additional research on chronic pain in EA including interviews with

family members and peers could provide a more complete picture on life with chronic pain as a young age.

In continuation with the lack of focus on how the experience of applying for and not receiving disability accommodations, the current study did not take into account the impact extraneous variables may have on the experience of chronic pain. For example, half of our participants express the influence childhood and adolescent experiences and traumas had on their chronic pain experience. For some participants, this took the form of family members not believing the extent of their experience with pain, which led to questioning in regard to self-worth. For others, the impact of feeling like a burden to others left a lifelong impact on their ability to form and maintain relationships. These experiences extend to the interactions those with chronic pain have with healthcare professionals. The invisibility of chronic pain can be frustrating when individuals are not believed by healthcare professionals, or they are passed along from doctor to doctor for a prolonged period of time holding out hope that one will have a fix for their pain. In addition, stigmas surrounding chronic pain were mentioned by participants within this study but were not rendered relevant to the purpose of this research. Stigmas can have damaging effects to emerging adults as they are trying to find their place in society, so future research should target the impact of this experience in order to inform better practices and assist in dispelling misunderstandings. With chronic pain being a subjective experience with each individual having a unique journey in regard to its impact, the generalizability of this research is called into question. Future research should consider the full experience those with chronic pain have to better determine appropriate resources and ways to offer support. One way in which future researchers should consider achieving this goal is through a mixed methods approach as it could be helpful to quantify the impact chronic pain has on developmental milestones.

Practical Recommendations

Taking into account the specifics of the pain experience in young adults, healthcare professionals often have a difficult time offering adequate resources to those who experience chronic pain due to the subjectivity of pain. An indispensable means in which this challenge could be targeted is through the creation of a pain scale that encompasses the unique experience of those living with chronic pain on a daily basis. Research shows that health behaviors and coping habits often take shape during this life stage, so when professionals are able to better understand the experience of those with chronic pain, they are able to improve pain management strategies, service delivery, and barriers to care at the patient health care system level as well as at a societal level (Calamidas & Crowell, 2018; Stinson et al., 2013). Further, those who interact with individuals who have chronic pain should be cognizant of their unique needs in order to provide appropriate physical and mental support while also ensuring normalization when possible. Normalization allows participants to experience a semblance of the independence they desperately need during this time but cannot obtain as fully as the average emerging adult can. A way in which to achieve this is through family and peer education. This resource has the potential to breakdown the barrier of invisibility and increase social support through understanding and adjustments (Falvo & Holland, 2017; Peer et al., 2015). In addition to the ways in which others can support emerging adults facing chronic pain, the individual should also utilize resources such as therapy or support groups which foster self-grace, advocacy, mindfulness, and healthy communication. This allows individuals to create tangible goals and action steps needed to cultivate positive mindsets and prioritization of the self.

Almost half of our participants express concerns surrounding the lack of accessibility in receiving accommodations, such as disability, for the impact chronic pain has on their lives. Accommodations are available to assist individuals in gaining access to or completing any daily life tasks that are not easily accessible given a certain circumstance (HDSA, 2015). This research demonstrates the negative impact chronic pain can have on emerging adults' ability to gain access to and complete developmental milestones such as exploration in education and career opportunities and spontaneity in social activities. As such, these individuals should be eligible for accommodations to assist in these tasks. More times than not, though, our participants were declined disability, which is set in place to provide accommodations when necessary. This additional stress can be damaging for chronic pain victims as stress has been found to worsen pain experiences. As such, it is vital for educational institutions and employers to foster a relationship of open communication and respect in understanding that being "young, visibility healthy individuals" does not mean that there will never need to be support in place for the execution of day-to-day functioning. These individuals are intelligent, strong, and compassionate making them valuable assets to any environment, despite their experience with chronic pain. Further research is needed to better understand how those with chronic pain may or may not qualify for disability and decipher which accommodations are needed for developmental milestones to be achieved. This research should inform healthcare professionals' – doctors, physical therapists, social workers, insurance companies, etc. – decisions in supporting these individuals through accommodations and resource topics (i.e., family planning, assistive organizations, advocacy, support groups, etc.).

Conclusion

This research suggests that chronic pain impacts developmental milestones including but not limited to relationship building, exploration of educational and vocational endeavors, autonomy, and identity development. The reduction of anxiety and maintaining of equilibrium by fostering adaptation is key in ensuring hedonic and eudaimonic flourishing in life. The limited research on the impact of chronic pain during EA, though, makes it difficult to understand how one can foster adaptation. As such, it is vital for those within an individual's life – healthcare professionals, educational and career professionals, family members, and peers – to understand this impact in order to adopt appropriate practices that support emerging adults in their unique areas for growth.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board
4N-64 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** ·
rede.ecu.edu/umcirb/

Notification of Exempt Certification

From: Social/Behavioral IRB
To: Kayla Geistman
CC: Natalia Sira
Date: 12/14/2021
Re: UMCIRB 21-002588
The Impact of Chronic Pain on Emerging Adults

I am pleased to inform you that your research submission has been certified as exempt on 12/14/2021. This study is eligible for Exempt Certification under category # 2ab.

It is your responsibility to ensure that this research is conducted in the manner reported in your application and/or protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMCIRB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMCIRB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

Document	Description
categories of data(0.01)	Data Collection Sheet
Consent form (0.01)	Consent Forms
questionnaire(0.01)	Surveys and Questionnaires
Questionnaire and interview questions(0.01)	Interview/Focus Group Scripts/Questions
thesis flyer(0.01)	Recruitment Documents/Scripts
Thesis proposal(0.01)	Study Protocol or Grant Application

For research studies where a waiver or alteration of HIPAA Authorization has been approved, the IRB states that each of the waiver criteria in 45 CFR 164.512(i)(1)(i)(A) and (2)(i) through (v) have been met. Additionally, the elements of PHI to be collected as described in items 1 and 2 of the Application for Waiver of Authorization have been determined to be the minimal necessary for the specified research.

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

APPENDIX B: SURVEY

Informed Consent

You are being invited to participate in a research study titled The Impact of Chronic Pain on Emerging Adults: Exploring Developmental Challenges and Coping being conducted by Kayla Geistman, a graduate student at East Carolina University in the Human Development and Family Science department, alongside an experienced research team. The interview will take approximately 40 minutes to complete, will be video recorded, and will be transcribed. The information gathered will assist us in better understanding the influence of chronic pain on the developmental challenges present during emerging adulthood and the coping mechanisms utilized. Your responses will be kept confidential, and your participation is voluntary. Please call Kayla Geistman at (615) 477-7371 for any research related questions or the University & Medical Center Institutional Review Board (UNCIRB) at (252) 744-2914 for questions about your rights as a research participant.

Do you consent to taking part in this research study?

i. Yes
ii. No

Demographic

Personal Characteristics

1) First name _____
2) Email address _____
3) What is your age? _____
4) What is your gender
    a. Male
    b. Female
    c. Non-binary
    d. Other _____
    e. Prefer not to say
5) How would you describe yourself? Please select all that apply
    a. White
    b. Black or African American
    c. American Indian or Alaska Native
    d. Asian
    e. Native Hawaiian or Pacific Islander
    f. Other
6) Are you of Hispanic, Latino, or Spanish Origin?
    a. Yes
    b. No

7) State in which you live _____

8) What is the highest degree of school you have completed?
    a. Less than a high school diploma
    b. High school degree or equivalent (e.g., GED)
    c. Some college, no degree
    d. Associate's degree (e.g., AA, AS)
    e. Bachelor's degree (e.g., BA, BS)
    f. Master's degree (e.g., MA, MS, MEd)
    g. Doctorate or professional degree (e.g., MD, DDS, PhD)

9) What is your marital status?
    a. Married or in a domestic partnership
    b. Widowed
    c. Divorced
    d. Separated
    e. Single

10) What is your current employment status?
    a. Employed full time (40+ hours per week)
    b. Employed part time (up to 39 hours per week)
    c. Unemployed looking for work
    d. Unemployed not looking for work
    e. Student
    f. Disabled

11) If you are currently employed, what field of work are you in? _____

Chronic Pain

1) How long have you experienced chronic pain?
    a. 6 months
    b. 1-2 years
    c. 3-5 years
    d. 6 or more years
    e. Unknown

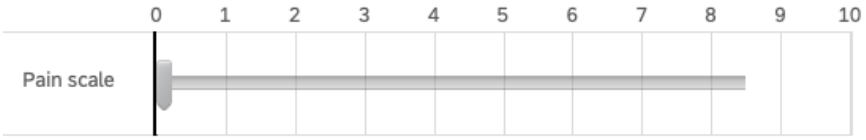
2) How often do you experience pain (i.e., daily, weekly, monthly, seasonally, etc.)? Please explain _____

3) Have you received a diagnosis for your chronic pain?

    a. Please write your diagnosis below _____
    b. Prefer not to answer
    c. Not applicable

4) What are you most prevalent pain locations? _____

5) What is your average pain intensity of a scale of 0 (no pain) to 10 (worst pain)



6) Have you received a mental health diagnosis in connection to your pain?
   a. Please write your diagnosis below _____
   b. Prefer not to answer
   c. Not applicable

We thank you for your time spent taking this survey. Your responses have been recorded and we will be in touch shortly to schedule your virtual interview via Zoom Videoconferencing. In the meantime, if you have any questions please reach out to Kayla Geistman at (615) 477-7371 or geistmank20@students.ecu.edu

APPENDIX C: INTERVIEW QUESTIONS

1) Tell me about yourself and your goals/aspirations in life.
    a. How has your chronic pain impacted your ability to achieve your goals regarding education? How has chronic pain impacted your ability to go to school?
    b. Has your chronic pain impacted your ability to pursue certain careers? How has your chronic pain impacted the career you are working towards? How has chronic pain impacted your ability to go to work?
    c. How has living with chronic pain impacted your ability to be financially independent?
2) How has your chronic pain impacted your ability to function in your day-to-day life?
    a. Tell me about your pain. Does it affect your daily life/routine? How? Or how much?
    b. How has your chronic pain impacted your ability to do household chores?
    c. In regard to managing your chronic pain, how independent have you been able to be (i.e., doctors' appointments, caring for yourself, taking medications, going to physical therapy, grocery shopping, food preparation, etc.)?
    d. Are you having to rely on your family members/friends to help you in your day-to-day life?
3) Tell me about your relationships, friendships and romantic relationships?
    a. How has living with chronic pain changed your relationship with your social circle? Caregivers? Friends? Romantic relationships?
    b. What is it like talking about your chronic pain to your friends and family?
    c. Intimacy is characterized by closeness, honesty, and love. How has living with chronic pain impacted your ability to form intimacy within your relationships?
    d. Do you plan to start a family? Do you think having chronic pain would influence your decision to become a parent? How?
        i. Does your chronic pain impact your ability to parent your child(ren)? How?
    e. In relation to your friends, how do you feel your chronic pain has impacted your ability to be spontaneous (i.e., travel, places to live, social gatherings, etc.)?
    f. What special considerations do you have to keep in mind about your chronic pain when making decisions to move, travel, explore new job opportunities?
4) How has chronic pain impacted the way you see yourself?
    a. How has living with chronic pain impacted who you are/your identity? Your purpose in life? Future plans? Aspiration?
5) What has been the most helpful in managing or coping with your chronic pain?
    a. Does your chronic pain impact your mental health? If so, tell me how.
    b. Do you receive support from family and friends? If so, tell me how.
    c. What are the best strategies that have helped you manage or cope with your pain?
    d. If you have to tell someone else about how to manage or cope with their chronic pain what would you tell them?
6) Is there anything else you would like to share regarding your experience with chronic pain and its impact on your life?

APPENDIX D: QUALITATIVE RESULTS THEMES

Themes	Examples
Relationship Building Barriers causing Uncertainty	"I think that communication is the core of all of that…I have that very strong communication from the start regarding my pain because I am forced to be honest about how I feel because I will not put myself in a situation where I am in so much pain." – P4
	"Dating while on disability with chronic pain feels impossible…Dating with chronic health conditions creates this belief in you that you are a burden." – P2
	"Pregnancy is hard on your body in general. I mean, that's always a fear of mine – is my body going to be able to handle it because I already have back pain as it is and pregnancy is probably going to make it worse." – P1
Restricted Exploration	"I can only imagine if I didn't have migraines and chronic pain what more I could do with my life or how much energy I'd have back from that." – P3
	"I don't want them to seem like 'oh, I'm not going to hire you. Why do you need so many things? Why can't you just do whatever everyone else is doing' especially because it's not visible like I don't have any type of visible disability." – P8
Lack of Independence	"My mother does the grocery shopping and takes me to my appointments. My husband has to carry me to the bathroom sometimes. It makes me feel humiliated that I'm 24 years old and I'm not able to do all this stuff by myself on a daily basis." – P5
	"You don't grow up with dreams to be financially dependent on someone." – P2

Identity Confusion Restricting Adaptation	"I know my pain does not define me, but it is a huge part of my life." – P5 "…that whole dream I had as a child is gone." – P7
Adaptation	"Logically, I can say that my pain…and doing things to take care of myself are not any reason that I lose value, but emotionally and mentally, I still feel those things." – P4 "I think it's very common to carry your stress in your neck and so I have to be very aware when I'm tensing up like I hold my shoulders up and that'll cause a lot more pain." – P6 "When I got injured, everyone was always overly helpful, and that kind of made me feel worse than before, but as they got used to me being injured and kind of like me having that discussion with them, they've let me be more independent, and it's helped me regain that part of myself." – P7