

2021

Social Participation in College Students with Chronic Pain

Karen McCarthy

Dominican University of California, karen.mccarthy@dominican.edu

Megan Chamberlain

Dominican University of California, megan9715@gmail.com

Megan Chinn

Dominican University of California, meganchinn7@gmail.com

Jennifer Pineda

Dominican University of California, jenniferpinedav05@gmail.com

Camille Santiago

Dominican University of California, camilleasantiago@gmail.com

See next page for additional authors

<https://doi.org/10.15453/2168-6408.1711>

Survey: Let us know how this paper benefits you.

Recommended Citation

McCarthy, Karen; Chamberlain, Megan; Chinn, Megan; Pineda, Jennifer; Santiago, Camille; Spitzer, Jamie; and Tran, Patricia, "Social Participation in College Students with Chronic Pain" (2021). *Occupational Therapy | Faculty Scholarship*. 12.
<https://doi.org/10.15453/2168-6408.1711>

This Article is brought to you for free and open access by the Department of Occupational Therapy at Dominican Scholar. It has been accepted for inclusion in Occupational Therapy | Faculty Scholarship by an authorized administrator of Dominican Scholar. For more information, please contact michael.pujals@dominican.edu.

Authors

Karen McCarthy, Megan Chamberlain, Megan Chinn, Jennifer Pineda, Camille Santiago, Jamie Spitzer, and Patricia Tran



January 2021

Social Participation in College Students with Chronic Pain

Karen McCarthy

Dominican University of California – USA, karen.mccarthy@dominican.edu

Megan Chamberlain

Dominican University of California – USA, Megan.Chamberlain@students.dominican.edu

Megan Chinn

Dominican University of California – USA, Megan.Chinn@students.dominican.edu

Jennifer Pineda

Dominican University of California – USA, Jennifer.Pineda@students.dominican.edu

Camille Santiago

Dominican University of California – USA, Camille.Santiago@students.dominican.edu

See next page for additional authors

Follow this and additional works at: <https://scholarworks.wmich.edu/ojot>



Part of the Disability and Equity in Education Commons, Higher Education Administration Commons, and the Occupational Therapy Commons

Recommended Citation

McCarthy, K., Chamberlain, M., Chinn, M., Pineda, J., Santiago, C., Spitzer, J., & Tran, P. (2021). Social Participation in College Students with Chronic Pain. *The Open Journal of Occupational Therapy*, 9(1), 1-12. <https://doi.org/10.15453/2168-6408.1711>

This document has been accepted for inclusion in The Open Journal of Occupational Therapy by the editors. Free, open access is provided by ScholarWorks at WMU. For more information, please contact wmu-scholarworks@wmich.edu.

Social Participation in College Students with Chronic Pain

Abstract

Background: College students with invisible disabilities, including chronic pain, often experience difficulty engaging in social occupations, both on and off campus, because of stigma, misconceptions, or social exclusion. Previous research has examined the use of academic accommodations to address these concerns or focused on the physical barriers to participation, failing to address the psychosocial and holistic impact of pain. Chronic pain can affect a variety of occupations, including social participation, which is a significant occupation for college students. This research explores the lived experience of chronic pain for college students and the impact of pain on social participation from an occupational perspective.

Method: To fully understand the impact that chronic pain has on social engagement, the researchers employed a qualitative phenomenological approach using semi-structured interviews to explore the lived experiences of 15 college students with chronic pain.

Results: Four main themes were identified: personality and chronic pain, stigma, the “domino effect,” and self-awareness. College students with chronic pain were able to push through the pain using coping strategies, pain management, and adaptations to promote social engagement.

Conclusion: By understanding the lived experiences of college students with chronic pain, occupational therapists can engage in an open dialogue with clients about the holistic nature of their pain and collaborate with them to create strategies to curtail occupational injustice and promote engagement in meaningful social occupation.

Comments

The authors report no potential conflicts of interest.

Keywords

chronic pain, college students, social participation

Complete Author List

Karen McCarthy, Megan Chamberlain, Megan Chinn, Jennifer Pineda, Camille Santiago, Jamie Spitzer, and Patricia Tran

Credentials Display

Karen McCarthy, OTD, OTR/L; Megan Chamberlain, OTS; Megan Chinn, OTS; Jennifer Pineda, OTS; Camille Santiago, OTS; Jamie Spitzer, OTS; Patricia Tran, OTS

Copyright transfer agreements are not obtained by The Open Journal of Occupational Therapy (OJOT). Reprint permission for this Applied Research should be obtained from the corresponding author(s). Click here to view our open access statement regarding user rights and distribution of this Applied Research.

DOI: 10.15453/2168-6408.1711

Individuals with invisible disabilities, such as chronic pain, are less likely to engage in social participation, such as family, school, and community activities, and often have problems in academics because of stigma, social exclusion, and misperceptions (Culp & Rojas-Guyler, 2014). Culp and Rojas-Guyler (2014) defined invisible disability as “conditions or diseases that limit [individuals’] abilities to perform daily activities and participate in society, even though they look healthy and appear to have ‘normal’ physical characteristics” (p. 7–8). Because of the stigma that chronic pain only impacts older adults, college-aged individuals may be considered too young to experience chronic pain and, therefore, lack the necessary accommodations to address their occupational barriers. For college students with disabilities, colleges provide physical and academic accommodations to meet students’ needs in the classroom, such as providing extended time on exams and assignments, environmental modifications, or service animals (Koch et al., 2017). However, there is a lack of evidence-based practice focusing on pain management and lifestyle adaptation to address social engagement and satisfaction for these students outside of the academic environment. This lack of evidence may limit students to receiving only classroom and housing accommodations. Although helpful, these accommodations alone do not encompass the entire social experience of college students that chronic pain may impact. Social participation and occupations in college students can be examined through their lived experiences, which are often shaped by the individual’s personality traits, such as extroversion, neuroticism, and openness to experience (Zhang & Renshaw, 2019). This study will explore the lived experiences of college students with chronic pain to provide a better understanding of the unique impact of chronic pain on social participation from the participants’ perspectives. This study aims to further advance occupational therapy by using college students’ perspectives to create a more holistic environment where college students do not need to choose between pain management and social participation.

Background and Literature Review

For the purpose of this study, chronic pain was defined as pain lasting longer than 6 months that impacts at least one aspect of the individual’s daily occupational engagement. Sanders et al. (2005) further defined chronic pain as:

any set of behaviors that involves the complaint of enduring or recurring pain; has persisted longer than typical for an associated condition, or is associated with an intermittent or chronic disease process; has responded inadequately to appropriate medical and/or invasive care; and is associated with significant and reliable impairment of functional status. (p. 304)

Clarke and Iphofen (2008) stated that, in addition to pain, individuals with chronic pain may also experience symptoms such as mood disturbance, anger, or hostility. While some individuals with chronic pain may have these emotions, they are not essential symptoms to confirm a diagnosis of chronic pain (Clarke & Iphofen, 2008). Chronic pain can stem from an initial injury, such as a back sprain, or something ongoing, such as an illness. Illnesses that can cause chronic pain include, but are not limited to, fibromyalgia, rheumatoid arthritis, or lower back pain (National Institute of Health MedlinePlus, 2018).

Chronic pain can be managed by various pain management strategies. Tse et al. (2017) conducted a study looking at experienced pain, management strategies, and knowledge of self-medication to understand how college students manage their pain. The study found that although students preferred to use non-pharmacological methods, they most often use over-the-counter drugs as a common strategy to relieve pain quickly. Matthias et al. (2016) further described three benefits to pain

management based on a qualitative investigation with veterans living with chronic pain: “making interpersonal connections, providing/receiving encouragement and support, and facilitating the use of pain self-management strategies” (p. 2247). Participants in the study valued interacting with peers and getting to know them by discussing common interests that were unrelated to the participant’s pain because it helped to ease the stress and isolation. Social occupations, therefore, can be part of a person’s pain management strategies. More information is needed about the value of social connection for college students managing chronic pain.

An individual with chronic pain can experience difficulty carrying out a variety of occupations, such as activities of daily living, instrumental activities of daily living, leisure, and social participation (Duenas et al., 2016). Intensity, duration, or location of the individual’s chronic pain can limit movements and reduce flexibility or strength (Duenas et al., 2016; National Institute of Health MedlinePlus, 2018). Physical limitations are not the only restrictions these individuals experience. The presence of pain was also found to impact socialization and one’s ability to maintain an independent lifestyle (Duenas et al., 2019). With this difficulty or inability to complete occupations, individuals can become discouraged or unwilling to complete them, which can lead to a decline in physical capacity, mental health, or quality of life. Individuals with frequent or severe chronic pain often report poorer quality of life than those who have moderate or less frequent pain (Duenas et al., 2016). This self-reported poorer quality of life is thought to be due, in part, to the restriction of their leisure activities and social contacts because of the presence of chronic pain. Lack of attendance to social events could be caused by negative emotions, irritability, and feelings of anger that often affect those with chronic pain. These emotions often have a negative impact on interpersonal relationships, as well as stress levels in families (Duenas et al., 2016). Those with chronic pain experienced difficulties planning social activities in advance because of their unpredictable pain, which led to limited social participation (Closs et al., 2009). Since college student occupations greatly revolve around social participation, the purpose of this study was to explore the impact of chronic pain and the various barriers to social engagement for college students.

The aforementioned research on college students and chronic pain focuses primarily on physical impacts of chronic pain but is limited in terms of individualized experiences in social participation and college students’ distinctive occupational demands (Closs et al., 2009; Koch et al., 2017; Zhang & Renshaw, 2019). College students with chronic pain may be restricted from full participation in social occupations, which might also be beneficial in their management of pain. Little is known about the experience of chronic pain for college students and the subsequent impact on their engagement in college life from an occupational perspective. The aim of this study was to explore the lived experiences of college students with chronic pain to provide a better understanding of the unique impact of chronic pain on social participation from the participants’ perspectives.

Method

Research Design

A qualitative research design allows for a more personalized and detailed description of participants’ unique and individual daily lives and experiences. Considering the subjective experiences of social occupations, the researchers used a phenomenological approach to understand the impact of chronic pain on college students in their terms. Phenomenology brings forth “experiences and perceptions of individuals from their own perspectives” (Lester, 1999, p. 1), therefore adding depth and valuable insight to research. Specifically, the researchers used descriptive phenomenology to ensure the

intrinsic meaning of the participant narratives is accurately presented and to reveal the essence of the experience of chronic pain (Todres, 2005). Previous qualitative research studies focused more on other areas of life impacted by pain, such as activities of daily living, instrumental activities of daily living, education, independence, and quality of life. However, there is currently a gap in research concerning how chronic pain impacts socialization, which may play as a factor in co-occurring occupations. The researchers hoped to answer the question: How does the invisible disability of chronic pain impact social participation among college students?

Participants and Recruitment

The inclusion criteria for the sample were college students between 18–28 years of age who experienced chronic pain for at least 6 months. A college student was defined as an individual that is 18–28 years of age and currently enrolled in on-campus college classes. The term college included community college, university, state, public and private colleges, and any other postsecondary education. The majority of each individual’s classes must take place on campus and not online. The age range was chosen because most students begin college at 18 years of age. The age limit of 28 was chosen to include a 10-year range for students who may have taken gap years during college, students who entered college as a freshman (freshman-entry), college transfer students, and graduate students. Since adults might go back to college after taking time off, their engagement in social participation, as well as their preferred social occupations, may differ from that of younger college students. This age range would also decrease the chances of extreme variations of social participation. For the purpose of this study, students may be medically diagnosed or self-diagnosed with chronic pain, which is defined as pain lasting longer than 6 months that impacts at least one aspect of the individual’s daily occupational engagement. Chronic pain may be associated with invisible disabilities, which are defined as “conditions or diseases that limit [individuals’] abilities to perform daily activities and participate in society, even though they look healthy and appear to have ‘normal’ physical characteristics” (Culp & Rojas-Guyler, 2014, p. 7–8). Specifications for social participation include, but are not limited to, spending time with friends, going out to dinner, going to the movies, participating in events on and off campus, studying with others, and joining campus clubs.

Prospective participants were contacted through various means, including emails to disability resource centers at universities across the United States, messages to Facebook support groups for chronic pain, emails through the Occupational Therapy Association of California, and snowball sampling. In the messages, prospective participants were provided a link to complete in order to enroll in the study and were later contacted by the research team at the email they provided. All of the participants provided informed consent. The IRB approval for the research was granted through the Dominican University of California.

Data Collection and Analysis

Interviews were conducted either in-person or online through video conferencing using Google Meet to perform semi-structured interviews. All interviews were recorded and then transcribed verbatim. The theoretical framework used to shape the interview questions is the Person-Environment-Occupation model (Law et al., 1996). The Person-Environment-Occupation model guided the interview questions because it explored how the participants, their social and physical environments, and their social occupations interact with each other to affect occupational performance.

College students with various types of chronic pain were interviewed. Chronic pain could be the disability or an outcome of an illness or disability (e.g., stemming from a previous injury and/or

preexisting medical condition). The varying types of chronic pain can assist the research team to accurately understand how chronic pain impacts lives and social occupations differently depending on the students' individualized experiences, their ability to cope and manage their pain, and environmental factors. Each individual had a different life experience, which allowed the research team to understand how chronic pain impacts lives differently, and especially how it impacted social occupations. The research team also planned to eliminate personal bias by maintaining a neutral stance and showing non-judgmental actions.

The participants were first asked about their current living situation, education, history of chronic pain, and self-identification of personal attributes (e.g., introvert vs. extrovert). Later questions were more focused on the impact of chronic pain on the participant's daily life, friendships and relationships, extracurricular activities, energy levels, sleep, and ability to attend events. Guided by the research question, the researchers also asked the participants to discuss their level of satisfaction and feelings about their social participation, supports, and barriers to social occupations; their pain management techniques; and their coping strategies used during their experience with chronic pain. More specific follow-up questions were asked based on the participant's response and for clarification purposes, if needed. The length of the participant interviews ranged from 30 min to 1 hr.

Audio-recorded interviews were transcribed verbatim. The participants' identities were protected through the use of pseudonyms randomly assigned by the research team. The qualitative software package Dedoose Version 8.0.42 was used to organize the data. Codes and themes were developed using Braun and Clarke's (2006) thematic analysis. The authors immersed themselves into the data with repeated reading of the interviews. Initial codes were generated by the authors, both individually and in a group, by looking at the interview transcriptions for "the most basic segment, or element, of the raw data" that was "meaningful . . . regarding the phenomenon" (Boyatzis, 1998, p. 63). The authors sorted the codes into potential themes that summarized recurring or poignant messages being communicated. All of the authors discussed the initial themes and underlying codes for consensus, and relationships between the themes (main overarching themes and sub-themes in them) were established. The authors reviewed the themes at the level of coded data extracts in relation to the entire data set. The final themes were defined and established, determining the relevance of the themes to the research question: How does the invisible disability of chronic pain impact social participation among college students?

After all data was analyzed, the results were sent to the participants through email for member checking. The participants were given an opportunity to further explain, clarify, or discuss their responses, more accurately represent themselves, and establish a mutual understanding with the research team. In addition, to further enhance the trustworthiness, the research team provided direct quotes from the participants to support data analysis and themes discovered in the research.

Results

The sample included 15 college students, 18–28 years of age, who experienced chronic pain defined as experiencing pain for at least 6 months. Out of the 15 participants interviewed, 13 identified as female and two identified as male. The age of the participants in the sample ranged from 18 to 26 years, with a mean age of 21 years. The majority of the participants lived in California, with a few who lived in other states in the US, and one who lived in Canada. Out of the 15 participants, only two participants were not formally diagnosed with a chronic pain condition but did identify as living with chronic pain. The spread between the participants attending public and private universities was relatively evenly distributed (nine participants attending public universities and six attending private). There was

also a fairly even distribution of students in each year of college, allowing for an even representation of a variety of college experiences.

After a thorough analysis of the interview transcriptions, four prominent themes were identified: personality and chronic pain, stigma, “domino effect,” and self-awareness. These four themes examine the impact chronic pain has on social participation in college students because of individualized experiences dependent on each student’s lifestyle, environment, pain levels, and chosen occupations.

Personality and Chronic Pain

The participants’ personalities, in addition to chronic pain, impacted their decisions to engage in and their preference for social activities. Personality is defined as “individual differences in characteristic patterns of thinking, feeling and behaving” (American Psychological Association, 2019). Extroversion or introversion, as well as optimism or pessimism, played a large role in a participant’s decision to opt-out or push themselves to the limit to engage. For example, a participant who self-identified as an introvert may have chosen to stay at home with friends rather than go out, regardless of their current level of pain. However, many would assume that if the individual was feeling little to no pain, they would choose to go out with friends, meaning that their pain level may not have impacted their choice as heavily as it would have seemed. Amy stated, “It’s hard to parse out where chronic pain and other things like that [are] getting in the way versus things like just being an introvert.” Individuals similar to Amy may experience little to no pain, which they would be able to tolerate in order to participate in various social activities; however, because of the nature of their personality, these individuals may prefer to stay at home because it is more comfortable to them.

In contrast, the participants who self-identified as extroverted more often than not decided to go out with friends despite their current pain level. This led to many of their peers assuming that they were not feeling pain when they often reported they were feeling varying levels of pain. Optimistic and pessimistic traits also dictated the decision-making and perception of pain. Those who self-identified as being more optimistic tended to be more proactive when dealing with their pain, demonstrated by setting limitations and seeking to find the positive aspects of their situation. In addition, these participants reported being more accepting of their pain and embracing it, stating they were determined not to allow their pain to dictate their life.

I think that the pain is always going to be there. So, I just want to get out and have those breaks from my daily routine. So, I think that it doesn’t affect me as much now where even if I’m feeling pain, I try to kind of push through it. (James)

Because of the demand and intensity of chronic pain, the participants also discussed whether they viewed chronic pain as a central part of their identity. Some stated that while their pain is a large part of their life, they did not think that the pain defined or engulfed their entire identity. On the other hand, some of the participants stated that it defined them because of all the limitations they experienced. These different outlooks impacted how they viewed their pain and dealt with daily life.

Stigma

The stigma of disability hindered the participants from creating or maintaining relationships because of others’ skepticism of pain or inability to understand. Factors of stigma included the lack of understanding of chronic pain since it is an invisible disability. Because pain is invisible, it was difficult for peers to know when the participants were in pain or exactly how much pain they were experiencing.

Pain levels are also subjective, meaning that one person's perception of pain did not generalize or provide objective information that could be understood, experienced, or communicated to other individuals in society. Given this, peers expressed difficulty understanding why the participants could not engage in an activity, especially because they appeared to be normal. Some of the participants felt judged because their peers thought they were faking it, making up excuses, or just being lazy. "Pain and fatigue make it really hard to be able to clean my room or get up and do things, so a couple of times my roommate has been like 'hey is the lazy spell over?'" said Savannah. Other peers thought the participants were overreacting to the pain and being overly cautious. This lack of understanding negatively affected relationships between peers and led to many being selective or hesitant to share their experience of chronic pain. Amy stated, "In general, I don't bring it [chronic pain] up for fear of people either trying to walk on eggshells around me or treat me differently." Some of the participants stated that they had support systems of either family or friends but still faced a lack of understanding. While family members did not doubt that their pain existed, they did not fully understand the daily impact of the pain, creating confusing and uncomfortable situations. Many of the participants believed that others cannot fully understand chronic pain and how to alleviate pain unless they experience it firsthand. In addition, many of the participants stated that it was difficult to discuss chronic pain since there was no real vocabulary or norm of discussing pain, as if it was taboo to talk about a college student experiencing chronic pain: "It was sort of like, how can I help, how can I make it better rather than, this is part of the reality of dealing with it . . . and granted we didn't have the vocabulary," Lily said. Many outsiders believed that only the elderly or those with severe disabilities could feel that much pain, as opposed to someone in their twenties who appears to be normal. This contributed to the stigma surrounding invisible disabilities, such as chronic pain, since people cannot always comprehend why someone with a healthy appearance requires accommodations for a chronic pain condition.

I get ready, I do my makeup, I do my hair, I get dressed, I like look, you know, normal or I look like I feel good. You know, people don't really see it or know until they see . . . an episode or an attack or whatever. (Audrey)

In addition to stigma or misunderstandings from peers, those with chronic pain had expectations for others and oftentimes compared themselves to society's standards. This included comparing themselves to peers, or to themselves before their chronic pain, and their expectations. These actions created additional stress to the individual since negative judgment and misunderstandings led to self-doubt.

Domino Effect

The participants discussed how fatigue or pain tolerance caused a domino effect that influenced their decisions to opt out of occupations. Many of the participants discussed how self-managed factors, such as pain or lack of sleep, can lead to larger occupational challenges. These larger problems, including sleepless nights, increased pain, discomfort, and/or decreased attention, can hinder the overall quality of life. The participants stated that the domino effect impacted their energy levels and fatigue. With increased fatigue and low energy, they experienced difficulty engaging in desired occupations. Actions such as getting ready in the morning were difficult, which prompted some of the participants to stay home or be late for commitments. Though participants often did attend class, they described their attention and engagement in class as limited because of the described domino effect. In addition, class

assignments, studying, group projects, and classroom activities suffered because of the decreased sleep and attention caused by their pain. While they did require more rest, many stated that their sleep quality was diminished by pain or discomfort.

And even though I get about 8 hr of sleep every day, just because my sleep is so fractured, I'm still super tired during the day. Um, and just being really tired. It makes it difficult to just be fully engaged or go out and do activities with friends (Savannah).

The lack of sleep caused them to have less energy and, therefore, to be unable to complete occupations. While the participants wanted to engage in a variety of occupations, the spiraling nature of their condition prevented them from doing so. "If you have pain in one area, it will affect connecting areas of your body," said Sarah. The domino effect caused an increase in pain because of the participants' symptoms transforming from manageable to unmanageable. Increased pain and the inability to engage in desired occupations led to feelings of exclusion from campus clubs and events, Greek life, and gathering with friends. To some college students, these events were perceived as crucial parts of their college experience in which they were unable to participate.

Self-Awareness

The domino effect led the participants to take more breaks and rest throughout the day. Their self-awareness manifested as the distinction between their mind and body, which prompted them to set limits for themselves. Increased self-awareness also allowed the participants to gauge their activity tolerance and adjust activities as needed. Many of the participants stated that they felt as though they were at war with their own body because they wanted to engage, but their body's pain held them back. One participant, Lily, stated, "It is hard to grapple with the fact that I might not have the stamina or ability to just push through things that I used to be able to do." With this conflict, pain tolerance came into play. If the pain was unbearable, necessary changes were made to their day. The participants stated that they knew they could only go out with friends for a certain amount of time before their pain was exacerbated. With this knowledge, they had awareness of when to preemptively set a limit for themselves to not engage and go home. Regarding the decision to engage in activities, many were self-aware that they would need to take time for themselves to allow for recovery afterward. "I also have to be very cognizant of the fact that, um, I could be pushing myself too far to a point, so I have to have put a damper on some activities . . . I definitely cannot do too many," said Amy. If they planned on going out with friends, they needed to use the following day to rest. If the individual, for whatever reason, decided not to go out, many stated that they would bring their social lives home. This was done by inviting friends to their homes to watch movies, play games, or order in food, among other things. By having social events at home, the participants engaged with their friends on their terms. The participants described that even though they were experiencing pain, they were still able to engage in alternative ways, such as taking on a coaching role rather than being a player on the team. Others described engaging in occupations that were not as taxing or physically demanding on their bodies but still allowed for similar social experiences, outcomes, and satisfaction.

Discussion

The research findings provided insight into how chronic pain affects social participation among college students. While existing studies express accommodations as either physical or academic (Deckoff-Jones & Duell, 2018), this study highlights what it means to live with an invisible disability and its possibility to severely impact many areas of occupation and overall quality of life. College students are subjected to different kinds of stressors, such as academic pressures, social issues, social engagement, and even financial problems. This can affect all areas of the student's life, such as their academic achievements, social participation, and quality of life. Through the domino effect, pain can spiral to impact various occupations and make it difficult for individuals to participate and engage in their chosen activities. Health-related quality of life of a college student can be impacted immensely by the presence of chronic pain. Appropriate health-related measures should be modified or adapted to achieve an adequate quality of life (Klemenc-Ketis et al., 2011). This leads to prioritizing valued occupations, which can negatively impact one's occupational balance, or the ability to have the right amount of variation between occupations being completed (Wagman et al., 2012). College students reported finding themselves sacrificing social activities to go to class, complete projects, or go to work, which can lead to occupational imbalance, creating burnout or decreased quality of life.

Personality and Chronic Pain

The data gathered indicates that self-reported personality traits may possibly play a factor in the individual's decision to push themselves through the pain to engage in social events, bring their social activities home (e.g., watching a movie with friends), or relax at home alone. Both introverted and extroverted college students were still able to enjoy time spent with friends, though they used individualized approaches to alleviate pain. For more introverted college students, the quality of time spent with friends and family was more valuable than the location or activities completed. In contrast, the students who self-identified as an extrovert were most likely to push past their limits to engage since they considered social interaction as a coping strategy and distraction from the pain. This supported previous evidence that individuals with chronic pain actively seek approaches that work best for them, such as distraction techniques, avoiding situations that may exacerbate their symptoms, or activity pacing to provide greater occupational balance (Andrews et al., 2018; Firmin et al., 2011). In addition, adaptations to occupations may be influenced by one's enthusiasm and openness to "try new things or challenge convention" (Woods & Sofat, 2013, p. 2204). Self-identifiable attributes differentiated the college students who were more willing to adapt their social activities from those who would opt out of social activities because of their pain level. Since the college students were living independently in new social environments, many reported discovering and exploring their social preferences based on self-identified traits, such as introversion, extroversion, pessimism, and optimism.

Stigma

The participants reported frequently experiencing stigma and a lack of understanding from others regarding their pain. These social attitudes and misunderstandings made it difficult to engage in social relationships and occupations, putting the participants at risk for occupational marginalization, which includes social exclusion because of invisible norms (Stadnyk et al., 2010). A previous study explained that caregivers of those with chronic pain based their perception of the individual's pain on behavioral and visual cues (Gold et al., 2009). This relates to how the participants' peers could not accurately identify the participants' pain level based solely on social participation or physical appearance. Outward appearance, behavioral cues, visual cues, and engagement do not determine the amount of pain felt,

since the individual may have adapted to and accepted their chronic pain while the caregiver or peer has not (Gold et al., 2009). Peers, family members, and academic faculty had difficulty grasping the severity of chronic pain and the necessary accommodations needed to alleviate the pain and additional symptoms experienced from the domino effect. These factors support the existing research because of the disruption of successful development of social relationships with both friends and family members (Jordan et al., 2017). College students felt that negative responses and misconceptions were formed around their coping strategies and behavior, leading to increased marginalization and an extreme lack of empathy from others.

Domino Effect

The findings supported the fact that chronic pain impacts students, both in the classroom and beyond, when engaging in other college activities and peer interactions because of the domino effect of pain. Although an occupational justice framework was not used, the findings contribute to previous research. This further illuminates how individuals with chronic pain may have experienced social exclusion and forms of occupational injustice, including occupational deprivation, marginalization, and/or imbalance, which results in the disempowerment of the individual (Stadnyk et al., 2010). Some college students were deprived of their meaningful occupations because of social exclusion or the need to set boundaries for themselves. This deprivation led to occupational imbalance, causing them to prioritize school or work over social participation. If a student had to miss class because of their pain, they needed to complete missed work outside of class, which often led to decreased time spent with others. For individuals experiencing pain, quality time spent with peers was valuable because it helped keep their mind off of the pain and feel less isolated (Matthias et al., 2016). Chronic pain has the potential to affect social participation, sleep, academic engagement, and relationships, indicating that chronic pain impacts a person beyond academics. Andrews et al. (2016) found that college students who reported more activity or social engagement and low avoidance of pain were more likely to report poor sleep quality and higher pain levels than those who were more avoidant of activity engagement. Previous research stated that chronic pain can also affect movement, flexibility, and strength, leading to the hindrance of daily activities, such as mobility, chores, and social engagement (Duenas et al., 2016; National Institute of Health MedlinePlus, 2018). This study builds on the research by supporting that in addition to physical repercussions of chronic pain, college students' fractured energy levels and fatigue create a domino effect that impacts occupational performance.

Self-Awareness

Different types of fatigue (e.g., general fatigue, cognitive fatigue, and sleep or rest fatigue) may require more breaks and rest, impair attention and memory, and affect energy levels (Gold et al., 2009). With the ability to identify their pain tolerance, triggers, or factors that exacerbate their pain, the participants become more self-aware of the duration of social engagement or the number of breaks needed to prevent worsening their pain. The inability to complete occupations because of chronic pain can discourage individuals to engage in activities and affect physical and mental health (Duenas et al., 2016). College students with more frequent or severe pain are more likely to have a decline in health. The physical inability to participate in social activities, because of the severity of pain, caused a domino effect on the students' mental health because of feelings of social isolation, the fear of missing out, and the misconceptions from peers. The study also supports previous findings suggesting that adolescents with chronic pain had impaired social participation since they could not be as carefree as their peers

(Forgeron et al., 2013). However, the interviews revealed that pain is not the only factor that influences social participation.

While pain impacts social participation, some college students were able to push through the pain using self-awareness and adaptations that promoted meaningful engagement. This relates to occupational adaptation, which occurs when there has been some sort of disruption to participation and alteration to one's occupational identity and occupational competence (Klinger, 2005). Since previous occupations now required greater demands for energy or physical capabilities, college students who strongly identified with a specific role, such as a team player, could no longer fully engage in those occupations. Some college students, however, embraced their situation and learned to adapt their occupations, such as becoming a coach, to continue engagement. Although the context of the occupations may have been altered, the meaning remained the same.

Adaptation is vital for increasing the individual's ability to participate or engage in leisure activities (Grove, 2008). While adapting activities did not help all college students meet their needs, this study supported Schkade and Schultz's (1992) theory that occupational adaptation enables individuals to "perform occupations with greater efficiency, effectiveness, and satisfaction" (p. 830). Social adaptations mentioned by the participants included bringing their social life home rather than going out. This gave the students the satisfaction of spending time with friends while accommodating their own boundaries.

Limitations

Limitations to the study included having 15 participants, only two participants identifying as male, and the majority of the participants attending a California university. Therefore, the researchers could not assume the data represented all college students with chronic pain. While there may be gender differences in social participation and chronic pain experiences, the researchers could not draw conclusions, since only two of the participants identified as male. In addition, certain barriers to engagement, such as extreme weather conditions, were not covered in many of the interviews because the majority of the participants lived in California. Other limitations include varying campus cultures, which promoted different forms of social participation for the students. For example, some schools have an active party scene, while others promote a calmer, quieter environment. The college students interviewed were hesitant to go to campus-affiliated activities because of how those activities impacted their pain levels. Limitations of this study included the use of only one method of data collection, which was semi-structured interviews. Triangulation of data would add to the rigor of this study.

Implications for Occupational Therapy Practice and Future Research

Occupational therapists and the wider community must understand that chronic pain can affect all occupations. Since pain is subjective, no two college students will have the same experience. Overall, by understanding the lived experience of students with chronic pain, occupational therapists can collaborate with these students to prioritize, adapt, and plan ahead for all occupations based on their interests, preferences, and environment to promote engagement and prevent exacerbation of symptoms.

For occupational therapists to support students with chronic pain, they should be aware of how various domino effects prevent effective engagement in occupations. This will assist both the occupational therapist and the student to plan and adapt daily activities. Spreading awareness to health care professionals and academic faculty and advocating for accommodations can promote participation and empowerment. Resilience can stem from self-reflection, mindfulness, and evaluation of current occupations, satisfaction, and performance. Pain management techniques may include aromatherapy,

meditation, lighting, TENs units, stretching, and exercise. Although the slightest forms of engagement may seem small and insignificant, they can play a major part in the satisfaction levels of clients with chronic pain.

Future research can enhance the understanding of those with chronic pain and add to the trustworthiness of this study by using multiple data collection methods, such as surveys, virtual diaries, and/or visual methodologies (e.g., photovoice or photo elicitation). Future research can further explore how personal attributes and gender influence the daily lives and levels of social participation for college students with chronic pain. Gender differences may create differences in chosen occupations or relationships with others. It would be beneficial to explore how travel, such as long car rides or airplane trips, can influence their choice to partake in activities that require specific options of travel. Furthermore, future studies can explore how the physical attributes (e.g., weather and location), the campus culture, and campus size can impact social participation. This population rarely mentions the use of occupational therapy services, despite research showing that occupational therapy services can assist with improving and restoring function and improving body mechanics and activity tolerance for those with chronic pain (Lagueux et al., 2018). Since occupational therapists provide holistic care, the client's social participation and interests are recognized when examining various physical limitations. With this holistic approach, the occupational therapist can better serve the client and allow for them to engage to the best of their ability when they may not have been able to do so previously.

Conclusion

This study's findings display how an individual's ability to engage in social occupations is impacted by more than just their pain level. Personality, self-awareness, stigma, and the domino effect all impact the social participation of college students with chronic pain. These findings show the need to address the domino effect through various strategies in pain management, coping, energy conservation, and empowerment to support individuals with chronic pain. There is also a need to create an open dialogue with the wider community, including academic and medical professionals, to address the stigma surrounding chronic pain and to expand awareness of invisible disabilities. While these recommendations do not solve all of the problems stemming from a chronic pain disorder, they can better support those living with chronic pain. By providing strategies and starting a dialogue about the nature of chronic pain, individuals may be better positioned to engage in meaningful social occupation.

References

- American Psychological Association. (2019). *Personality*. <https://www.apa.org/topics/personality/>
- Andrews, N. E., Strong, J., Meredith, P. J., & Branjerdporn, G. S. (2018). Approach to activity engagement and differences in activity participation in chronic pain: A five-day observational study. *Australian Occupational Therapy Journal*, 65(6), 575. <https://doi.org/10.1111/1440-1630.12516>
- Andrews, N. E., Strong, J., & Meredith, P. J. (2016). The relationship between approach to activity engagement, specific aspects of physical function, and pain duration in chronic pain. *The Clinical Journal of Pain*, 32(1), 20–31. <https://doi.org/10.1097/ajp.0000000000000226>
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Clarke, K. A., & Iphofen, R. (2008). A phenomenological hermeneutic study into unseen chronic pain. *British Journal of Nursing*, 17(10), 658–663. <https://doi.org/10.12968/bjon.2008.17.10.29482>
- Closs, S. J., Staples, V., Reid, I., Bennett, M. I., & Briggs, M. (2009). The impact of neuropathic pain on relationships. *Journal of Advanced Nursing*, 65(2), 402–411. <https://doi.org/10.1111/j.1365-2648.2008.04892.x>
- Culp, A., & Rojas-Guyler, L. (2014). Invisible disabilities: An opportunity for health education. *Health Education Monograph Series*, 31(1), 7–11.
- Deckoff-Jones, A., & Duell, M. N. (2018). Perceptions of

- appropriateness of accommodations for university students: Does disability type matter? *Rehabilitation Psychology*, 63(1), 68.
<https://doi.org/10.1037/rep0000213>
- Dueñas, M., Ojeda, B., Salazar, A., Mico, J. A., & Failde, I. (2016). A review of chronic pain impact on patients, their social environment and the health care system. *Journal of Pain Research*, 9, 457–467.
<https://doi.org/10.2147/jpr.s105892>
- Dueñas, M., Salazar, A., Sola, H., & Failde, I. (2019). Limitations in activities of daily living in people with chronic pain: Identification of groups using clusters analysis. *Pain Practice*, 20(2), 179–187.
<https://doi.org/10.1111/papr.12842>
- Firmin, M. W., Burger, A. J., Grigsby, M. E., Sherman, A. L., & Croft, J. N. (2011). Coping constructs related to college students with chronic pain. *Journal of Ethnographic & Qualitative research*, 6(1), 32–44.
- Forgeron, P. A., Evans, J., McGrath, P. J., Stevens, B., & Finley, G. A. (2013). Living with difference: Exploring the social self of adolescents with chronic pain. *Pain Research and Management*, 18(6), E115–E123. <https://doi.org/10.1155/2013/120632>
- Gold, J. I., Mahrer, N. E., Yee, J., & Palermo, T. M. (2009). Pain, fatigue, and health-related quality of life in children and adolescents with chronic pain. *The Clinical Journal of Pain*, 25(5), 407–412.
<https://doi.org/10.1097/ajp.0b013e318192bfb1>
- Grove, E. (2008). The role of occupational therapy in the assessment of neurological disability. *Occupational Therapy Today - Tomorrow*, 129–129.
<https://doi.org/10.1159/000392325>
- Jordan, A., Family, H., & Forgeron, P. (2017). Interpersonal relationships in adolescent chronic pain: A qualitative synthesis. *Clinical Practice in Pediatric Psychology*, 5(4), 303–318. <https://doi.org/10.1037/cpp0000215>
- Klemenc-Ketis, Z., Kersnik, J., Eder, K., & Colaric, D. (2011). Factors associated with health-related quality of life among university students. *Srpski arhiv za celokupno lekarstvo*, 139(3–4), 197–202.
<https://doi.org/10.2298/sarh1104197k>
- Klinger, L. (2005). Occupational adaptation: Perspectives of people with traumatic brain injury. *Journal of Occupational Science*, 12(1), 9–16.
<https://doi.org/10.1080/14427591.2005.9686543>
- Koch, L. C., Mamiseishvili, K., & Wilkins, M. (2017). Integrated postsecondary services and supports for college students with psychiatric disabilities. *Journal of Applied Rehabilitation Counseling*, 48(1), 16–24.
<https://doi.org/10.1891/0047-2220.48.1.16>
- Lagueux, É., Dépelteau, A., & Masse, J. (2018). Occupational therapy's unique contribution to chronic pain management: A scoping review. *Pain Research and Management*. <https://doi.org/10.1155/2018/5378451>
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9–23.
<https://doi.org/10.1177/000841749606300103>
- Lester, Stan. (1999). *An introduction to phenomenological research*.
- Matthias, M. S., Kukla, M., McGuire, A. B., & Bair, M. J. (2016). How do patients with chronic pain benefit from a peer-supported pain self-management intervention: A qualitative investigation. *Pain Medicine*, 17(12), 2247–2255.
<https://doi.org/10.1093/pm/pnw138>
- National Institute of Health MedlinePlus. (2018). Chronic pain: Symptoms, diagnosis, & treatment. *NIH MedlinePlus the Magazine*.
- Sanders, S., Harden, R., & Vicente, P. (2005). Evidence-based clinical practice guidelines for interdisciplinary rehabilitation of chronic nonmalignant pain syndrome patients. *Pain Practice*, 5(4), 303–315.
<https://doi.org/10.1111/j.1533-2500.2005.00033.x>
- Schkade, J. K., & Schultz, S. (1992). Occupational adaptation: Toward a holistic approach for contemporary practice, part 1. *American Journal of Occupational Therapy*, 46(9), 829–837.
<https://doi.org/10.5014/ajot.46.9.829>
- Stadnyk, R., Townsend, E., & Wilcock, A. (2010). Occupational justice. In E. Townsend & C. H. Christiansen (Eds.), *Introduction to occupation: The art and science of living* (pp. 329–351). Pearson.
- Todres, L. (2005). Clarifying the life-world: Descriptive phenomenology. In I. Holloway (Ed.), *Qualitative Research in Health Care* (pp. 104–124). Blackwell.
- Tse, M. M. Y., Tang, A., Budnick, A., Ng, S. S. M., & Yeung, S. S. Y. (2017). Pain and pain management among university students: Online survey and web-based education. *CyberPsychology, Behavior & Social Networking*, 20(5), 305–313. <https://doi.org/10.1089/cyber.2016.0580>
- Wagman P., Håkansson, C., & Björklund, A. (2012). Occupational balance as used in occupational therapy: A concept analysis. *Scandinavian Journal of Occupational Therapy*, 19(4), 322–327.
<https://doi.org/10.3109/11038128.2011.596219>
- Woods, S. A., & Sofat, J. A. (2013). Personality and engagement at work: the mediating role of psychological meaningfulness. *Journal of Applied Social Psychology*, 43(11), 2203–2210.
<https://doi.org/10.1111/jasp.12171>
- Zhang, D. C., & Renshaw, T. L. (2019). Personality and college student subjective wellbeing: A domain-specific approach. *Journal of Happiness Studies*, 21(3), 997–1014. <https://doi.org/10.1007/s10902-019-00116-8>