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## Social Participation in College Students with Chronic Pain

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# **Social Participation in College Students with Chronic Pain**

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A culminating capstone project submitted to the faculty of Dominican University of California in  
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## Abstract

College students with chronic pain often experience difficulty engaging in social activities both on and off campus due to stigma, misconceptions, or social exclusions (Culp & Rojas-Guyler, 2014). To fully understand the barriers to social engagement, the researchers used a qualitative phenomenological approach and semi-structured interviews to explore the lived experiences of 15 college students with chronic pain (pain lasting more than six months). Four main themes were identified: the additional influence of personality on social participation; stigma and lack of understanding of chronic pain; the “domino effect” of pain impacting energy, sleep quality, and ability to function throughout the day; and lastly, self-awareness of the participant’s own body, pain tolerance, and self-boundaries. The reviewed literature examined disabilities as physical, visible impairments, and focused on limited access as the primary barrier to engagement. Although previous research notes the physical environment and occupational injustice as the barriers to social engagement, this study broadened the focus to also include personal and occupational barriers. Participants were able to push through the pain using coping strategies, pain management, and adaptations to promote social engagement. By understanding the lived experiences of individuals with chronic pain, occupational therapists can work with individuals to restore meaning to their occupations.

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## **Introduction**

Culp and Rojas-Guyler (2014) defined invisible disability as “have[ing] conditions or diseases that limit their abilities to perform daily activities and participate in society, even though they look healthy and appear to have ‘normal’ physical characteristics” (pp.7-8). Those with invisible disabilities, such as chronic pain, are less likely to engage social participation such as family, school, and community activities, and have problems in academic due to stigma, social exclusion, and misperceptions (Culp & Rojas-Guyler, 2014). To assist students with various disabilities such as chronic pain, colleges provide academic accommodations to allow students to have the same opportunities as their peers. There are many different accommodations available, and are offered to fit to a student’s needs. Different accommodations include, but are not limited to extra time on exams and homework assignments, a quiet environment to take exams in, allowing individuals to bring service animals, single-room housing, and the ability to stand up and move around in class (Koch, Mamiseishvili & Wilkins, 2017).

## **Literature Review**

For the purpose of the study, chronic pain was defined as pain lasting longer than six months that impacts at least one aspect of the individual's daily occupational engagement. Sanders, Harden, and Vicente (2005) further defined chronic pain as a pattern of behaviors that involves enduring recurring pain; has persisted longer than typical or is associated with a chronic disease process; has responded inadequately to appropriate medical and/or invasive care; and is associated with impairment of functional status” (p. 304). In addition to the pain, Clarke and Iphofen (2008) state that individuals with chronic pain may also experience symptoms such as mood disturbance, anger or hostility. While some 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). Using an online survey, Tse, Tang, Budnick, NG & Yeung (2017) developed 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, most often use over-the-counter drugs as a common strategy to quickly relieve pain. Matthias, Kukla, McGuire, & Bair (2016) further described three benefits to pain management based on qualitative investigation with patients living with chronic pain: “making interpersonal connections, providing/receiving encouragement and support, and facilitating the use of 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 their pain because it helped to ease the stress and isolation caused by their pain.

With chronic pain, an individual can experience difficulty carrying out occupations such as activities of daily living (ADLs), instrumental activities of daily living (IADLs), leisure, and social participation (Duenas, Ojeda, Salazar, Mico & Failde, 2016). Intensity, duration, or location of the individual’s chronic pain can limit movements, reduce flexibility or strength (National Institute of Health MedlinePlus, 2018; Duenas, et al., 2016). Occupations that include intense physical exercise, walking, performing chores, participation in social activities, or maintaining an independent lifestyle are especially difficult (Duenas et al., 2016). 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 partially due to the restriction of their leisure activities and social contacts because of the presence of chronic pain. Duena et al., (2016) reported half of the participants stated that chronic pain had prevented them from attending social or family events. Lack of attendance 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 the levels of stress in families (Duenas et al. 2016). Those with chronic pain experienced difficulties planning social activities in advance due to their unpredictable pain which led to them having limited social participation (Closs, Staples, Reid, Bennett & Briggs, 2009).

## **Purpose**

Since college occupations greatly revolve around social participation, the purpose of this study was to explore the impact of chronic pain on this specific population and the various barriers to social engagement. The purpose of our study is to explore the impact chronic pain has on social participation in college students. Because the previous research is mainly quantitative, it lacked the lived experiences of college students with chronic pain and their level of social participation. The researchers hoped to answer the question: how does the invisible disability of chronic pain impact social participation among college students? The hypothesis was that chronic pain creates a barrier for college students, in which impacts their ability to socially participate both on and off campus.

## **Participants**

**To participate in the study, a college student was defined as an individual that is 18 - 28 years old and currently enrolled in on-campus college classes. The term college included community college, university, state, public/private colleges and any other post-secondary 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 ten year range for students who may have taken gap years during college and include students who entered college as a Freshman (Freshman-entry), college transfer, and graduate students. Since adults might go back to college after taking year(s) off, their social participation may differ from that of the 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 "have[ing] conditions or diseases that limit their 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, pp.7-8). Specifications for social participation include but is not limited to spending time with friends, going out to dinner, going to the movies, participating in on-campus and off-campus events, studying with others, and on-campus clubs.**

## **Method**

The sample included 15 college students, between the ages of 18-28, who experienced chronic pain for at least six months. Participants were contacted through various means including: disability resource centers from universities across the United States, Facebook support groups for chronic pain, Occupational Therapy Association of California (OTAC), and snowball sampling. The IRB approval for the research was granted through Dominican University of California. Interviews were conducted either in-person, or online video conferencing using Google Meet to perform semi-structured interviews. All interviews were recorded and then transcribed verbatim.

## **Methodology**

A qualitative research design was utilized to better understand the lived experiences and perspectives concerning chronic pain. The theoretical framework used to shape our research and interview questions is the PEO (Person Environment Occupation Model). The PEO model defined the person (P) as their values, interests, life experiences, abilities, skills or what that individual finds meaningful. The environment (E) is defined as contexts where occupations take place such as physical, cultural, and social environment. The occupation (O) is defined as self-directed tasks that someone engages in over the course of their life which includes but is not limited to self-care, productivity and leisure (Law et al., 1996). PEO guided the study because it explored how the participants, their social and physical environments, and social occupations interact with each other to affect occupational performance. Therefore, college students with a wide range of disabilities all of which result in chronic pain were interviewed. Each individual had a different life experience, which allowed the research team to understand how chronic pain

impacts lives differently, and especially how social occupations were impacted. This was relevant to the occupation of social participation since everyone with chronic pain will have subjective experiences. The research team also planned to eliminate personal bias by maintaining a neutral stance and showing non-judgmental actions.

### **Data Collection and Analysis**

The primary data collection was gathered through semi-structured interviews that were audio recorded on the research team members with consent from the participant. These recordings were then organized transcribed using Temi. The data was analyzed using a coding software called Dedoose (Version 7.0.23). Data was analyzed using thematic analysis (Braun & Clarke, 2006). The phases of thematic analysis included familiarizing the researchers with data transcribed from the interviews. The next step included finding common patterns among the data collected using the Dedoose Software. The common patterns and ideas from the transcriptions were reviewed, and themes were defined and named. The final phase was producing the report.

After all research was analyzed, completed, and sent out, participants were free to email researchers with questions or to request results. The research team answered questions, being sure not to reveal identities of any of the other participants.

### **Demographics of Participants**

Demographics of the 15 participants are reported in Table 1. This includes each person's name (changed for confidentiality), age, gender, country they currently reside in, standing year in college (undergraduate/graduate), living status (on/off-campus), type of university (private/public), school status (freshman-entry/transfer student), major, and whether or not they were formally diagnosed with chronic pain. Out of the 15 participants interviewed, 13

participants identified as female and two identified as male. Age of the participants in the sample ranged from 18 to 26, with a mean age of 21 years old. The majority of the participants lived in California, a few participants lived in other states within the U.S., and one participant 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 for more than six months. The spread between participants attending public and private universities were relatively evenly distributed (nine participants attending public universities and six in 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.

*Table 1 Demographics of Participants*

Name	Age	Gender	Country	Year in College	Living Status	Type of Higher Education	School Status	Major	Formally Diagnosed
Hannah	22	F	USA	Senior	Off campus	Private University	Freshman Entry	Health Science	Yes
Lily	21	F	USA	Junior	Off campus	Private University	Freshman Entry	Popular Music Performance	Yes
Natalie	20	F	Canada	Sophomore	Off	Public	Transfer	Child	Yes



					campus	University		Studies and Youth Care Counsel- ing	
James	19	M	USA	Sophomore	On campus	Private University	Transfer	Biology	Yes
Savannah	19	F	USA	Freshman	On campus	Private University	Freshman Entry	Pre- Occu- pational Therapy	Yes
Brooklyn	21	F	USA	Senior	Off campus	Private University	Freshman Entry	Health Science	No
Leah	19	F	USA	Sophomore	On campus	Public University	Freshman Entry	Liberal Studies	No
Audrey	19	F	USA	Freshman	On campus	Public University	Freshman Entry	Soci- ology	Yes
Claire	20	F	USA	Junior	Off campus	Public University	Freshman Entry	Aero- space	Yes

								Engineer -ing	
Amy	24	F	USA	Graduate	Off campus	Public University	Freshman Entry	Bio- logical Studies	Yes
Sarah	24	F	USA	Graduate	Off campus	Public University	Transfer	Occu- pational Therapy	Yes
Gabriella	26	F	USA	Sophomore	Off campus	Private University	Transfer	Pre- Occu- pational Therapy	Yes
Hailey	20	F	USA	Junior	Off campus	Public University	Freshman Entry	Mechan- ical Engineer -ing	Yes
Nicholas	22	M	USA	Senior	On campus	Public University	Freshman Entry	Business Manage- ment, Eco- nomics	Yes

								and Account- ing	
Julianna	18	F	USA	Freshman	On campus	Public University	Freshman Entry	Psych- ology	Yes

**Among all participants, analysis of the transcribed interviews revealed four overarching themes: personality and chronic pain, stigma, “domino effect,” and self-awareness. While it may be assumed that individuals in pain are more likely to stay home and opt out of social occupations, there are more factors that impacted the decision-making process than solely pain levels.**

## **Findings**

The four main themes from the interviews are, personality type, stigma, domino effect, and self awareness. The two different personality types are introverts (individuals that prefer to stay home), and extroverts (individuals who prefer to spend time outside of their home). Introverts reported that they were more likely to stay home and watch a movie with friends as opposed to going out dancing, however, this choice had nothing to do with their pain. Similarly, extroverts reported that they are more likely to go out with friends as a distraction to their pain. Stigma refers to others' perception of chronic pain as an invisible disability. Family, friends, and even significant others would push somebody to go out when they were in pain, and not understand why somebody was not able to leave the house. The domino effect refers to how one event can lead to another. For example, if a person is unable to sleep due to pain, they could have trouble waking up in the morning and be unable to attend class. Finally, self-awareness refers to how a person with chronic pain learns to understand their body, what causes their pain, how to best manage it. For example, one needs to set limits in order to be able to engage in occupations without the pain overwhelming them.

### **Personality and Chronic Pain**

The participants' personalities, in addition to chronic pain, impacted their decisions to engage and 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 role in participant's decision to opt out, or push themselves to the limit in order to engage. For example, a participant who identified as an introvert may have chosen to stay at home with friends rather

than go out, meaning that their pain level may not have impacted their choice as heavily as it would have seemed.

“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” said Amy.

Participants who identified as extroverted most likely decided to go out with friends in spite of their pain, which led to peers assuming that they were not feeling pain. Optimistic and pessimistic traits also dictated the decision-making and perception of pain. Those who identified as being more optimistic tended to be more proactive when dealing with their pain, demonstrated by setting limitations for themselves and seeking to find the positive aspects of their situation. As well as being more accepting of their pain and embracing it, these participants were determined to not 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" said James.

Due to the demand and intensity of chronic pain, 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 them, or engulfed their entire identity. On the other hand, some participants stated that it defined them due to all of the limitations they experienced. These different outlooks impacted how people viewed their pain and how they dealt with day to day life.

## Stigma

The stigma of disability hindered participants from creating or maintaining relationships due to others' skepticism of pain, or the inability to understand. The main factor of stigma included the lack of understanding of the chronic pain condition since it is an invisible disability and cannot be seen by others. Since pain is invisible, it was difficult for peers they encountered to know when the participants were in pain, or exactly how much pain they were in. In addition, pain levels are 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, encountered peers had difficulty understanding why the participants could not engage in an activity, especially because they appeared to be normal. Some 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 the fact they have chronic pain, or the fact they experiencing pain. One participant 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" said Amy. Some participants stated that they had support systems of either family or friends, but still faced limitations related to 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 participants believed that others cannot fully understand chronic pain unless they experience it first-hand, and that outsiders did not always understand that

chronic pain is not easily alleviated. In addition, many 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 disconnect helped to promote the stigma surrounding invisible disabilities such as chronic pain, since there is nothing visibly seen or recognized to show that the individual has a medical condition. This contributed to the stigma, since people cannot always comprehend why someone who appears "healthy" or "normal" 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," said 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 comparing themselves to their prior self before chronic pain, and to what they think they should be able to do. For example, participants chose to go out with friends, or that they should engage in physical activities since their limitations were not visible. This added additional stress to the individual since negative judgement and misunderstandings led to self-doubt and judgement in many cases.

## **Domino Effect**

Participants discussed how fatigue or pain tolerance caused a domino effect that influenced their decision to opt out of occupations. Many participants discussed how occupations that can usually be self-managed, such as pain or lack of sleep, can lead to larger occupational challenges. These larger problems included sleepless nights, increased pain or discomfort, difficulty going about daily life, decreased attention, and more. These problems grew to the point where it greatly hindered engagement in occupations as well as overall quality of life. Participants stated that this domino effect greatly impacted their energy levels and fatigue. With increased fatigue and low energy, they experienced difficulty engaging in occupations that they either needed to or wanted to participate in. Actions such as getting ready in the morning were difficult, which prompted some participants to either stay home, or be late for other activities. Because of their pain, they were unable to engage in desired occupations. As a result, they had to prioritize what needed to be done in their day, so that necessities such as having to get up and go to class were priorities, while involvement in social participation suffered. Along with low energy and fatigue, many stated that while they did require more rest, that their sleep quality was diminished. Although they were sleeping more than their peers, the quality of their sleep did not allow for them to be fully rested. Due to pain, discomfort, or other factors, they were unable to sleep enough to be fully recovered and rested.

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

This then spiraled to make them more tired, have low energy and 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 some participants to be in more pain, due to the collection of their symptoms transforming from being manageable, to unmanageable.

## Self-Awareness

The after effects caused by the domino effect led participants to report they take more breaks and rest throughout the day, promoting self-awareness. Their awareness, manifested as the distinction between their mind and body which prompted them to set limits for themselves. Many 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, their pain tolerance came into play. If the pain was too much, they identified and made necessary changes to their day. Participants stated that they at times knew that they could only go out with friends for a certain amount of time before their pain was exacerbated. With this knowledge, they had awareness when to either take it easy, or go home. On the other hand, it could mean that they know they should not engage in a certain occupation for a variety of reasons from increased pain when completing to inability to engage, so they preemptively set a limit for themselves not to engage. Regarding deciding whether or not to engage, many stated that they knew that they would need to take time for themselves to allow for them to recover afterwards. "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, or to not be active. If the individual, for whatever reason decided to not 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, participants engaged with their friends on their own terms. Participants described that

**even though they were experiencing pain, that they still were able to engage, just in a different way.**

## Discussion

The research findings provided insight into how chronic pain affects social participation among college students. The findings supported the fact that chronic pain impacts students, both in the classroom and beyond, when engaging in other college activities and peer interaction. This study contributes to previous research further illuminating how individuals with chronic pain may have experienced social exclusion and forms of occupational injustice, including occupational deprivation, alienation, and/or imbalance which results in the disempowerment of the individual, as described by Stadnyk, Townsend & Wilcock (2010). Some participants felt socially excluded from college events such as orientation, campus clubs, or Greek life events because they knew these events would either exacerbate their pain, or that they would be unable to tolerate the pain. To some participants, these events were perceived as being crucial parts of their college experience despite their inability to participate. Participants who were more inclined to set boundaries for themselves were deprived of their meaningful occupations, whether it was from direct symptoms of chronic pain, or an indirect impact from the domino effect. This led to occupational imbalance, which caused them to prioritize school or work over social participation. If a student had to miss class due to their pain, they needed to complete missed work outside of class, which often led to decreased time spent with friends or peers. Quality time spent with peers for individuals experiencing pain was valuable because it helped keep their mind off the pain and feel less isolated (Matthias et al., 2016).

Occupational alienation was another commonality among participants experiencing chronic pain, partially because of stigma and lack of understanding from peers. Peers, family members, and even 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. The domino effect, which was often associated with the participant's energy levels and mentality, supported the findings of existing research that these factors can disrupt the successful development of social relationships with both friends and family members (Jordan, Family, & Forgeron, 2017). Given this, participants felt that negative responses and misconceptions were formed around their coping strategies and behavior of the participants, leading to increased alienation and an extreme lack of empathy from others. This hindered the relationships that participants were able to form with those around them, which in turn limited their social participation.

To expand on the current state of research, this study examines the invisible disability of chronic pain and its accompanying elements, separate from physical access and academic achievement. Existing studies express accommodations as either accessibility for those with a physical disability, or academic accommodations to help a person with a disability participate in class (Deckoff-Jones & Duell, 2018). Chronic pain has the potential to affect social participation, sleep, academic engagement, and relationships, indicating that chronic pain impacts a person beyond academics. 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 (National Institute of Health MedlinePlus, 2018; Duenas et al., 2016). This study builds on those statements by demonstrating that in addition to these physical repercussions of chronic pain, participants' fractured energy levels and fatigue started a domino effect that later impacted occupational performance. With the ability to identify their pain tolerance, pain triggers, or factors that exacerbate their pain, participants become more self-aware of the duration of social engagement or the number of breaks needed to be taken to prevent worsening their pain. Due to the nature of chronic pain, helpful accommodations include

special seating and desks, extra time to complete assignments, and additional absences for high pain days.

This current study builds on the existing research which primarily indicates the inability to complete occupations due to chronic pain can discourage individuals to engage in activities, and affect physical and mental health (Duenas et al., 2016). Individuals with more frequent or severe pain are more likely to have a decline in health. The study built upon the findings of another study where it was suggested that adolescents with chronic pain had impaired social participation since they could not be carefree as their peers were (Forgeron, Evans, McGrath, Stevens & Finley, 2013). However, the interviews revealed that pain is not the only factor that influences social participation.

Participant data indicates that personality plays a factor in the individuals' decisions to either push themselves through the pain and engage in social events, or bring their social activities home (i.e. watching a movie with friends) or relaxing at home alone. Participants who identified as an extrovert were most likely to push past their limits and engage since social interaction was considered by them to be a coping strategy and distraction from the pain. Therefore, decisions about activities were partially determined by whether or not the individual identified as an extrovert or introvert. As mentioned earlier, optimistic and pessimistic traits also influenced decision-making regarding activities and the participants' perception of pain.

While pain impacts social participation as originally hypothesized, the researchers discovered that some participants were able to push through the pain using self-awareness, coping strategies, pain management techniques, and adaptations that promoted meaningful engagement. This relates to the existing theory of 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). For participants, previous occupations now required greater demands for energy or physical capabilities, resulting in many of them feeling unable to identify with roles and routines that were once very familiar to them. Some participants embraced their situation, and learned to adapt their occupations so they could continue to engage. While the contexts behind the occupations may have been altered, the meaning of the occupations remained the same. For instance, leisure adaptations still involved the individual in his or her leisure occupations to maintain the same purpose and meaning, even if they were playing a different role in those occupations. This also ensured that the activity was adapted to fit the person and not the other way around. In addition to adapting an occupation as a way to maintain the meaning, adaptation is also vital for increasing the individual's ability to participate or engage in their leisure activities (Grove, 2008). For those who strongly identified with a specific role, such as a team player, parts of their identity were compromised since they could no longer fully engage in those occupations. Therefore, they adapted their engagement and became a coach instead, which still allowed them to participate in the meaningful sport of their choice. Others felt as though these adapted roles did not offer the engagement they wished for. Although adapting activities did not help all the participants meet their needs, this study supported Schkade & Schultz's (1992) theory that occupational adaptation enables individuals to "perform occupations with greater efficiency, effectiveness, and satisfaction" (p. 830).

Adaptations mentioned by participants were found to go beyond the typical physical or environmental adaptations such as ramps or elevators. Social adaptations included bringing their social life home, meaning that participants were able to meet with friends at home, rather than going out to places (e.g. movie theater.) This gave individuals the satisfaction of spending time with friends, accommodating their own boundaries. Occupations completed at home were also



found to be correlated to the person's personality. Despite both introverted and extroverted participants engaging in social occupations in different ways, they were still able to enjoy their time spent with friends through the individualized approach they each took to alleviate pain. To the participants, what was more valuable was the quality of time spent with friends and family, rather than the location, or activities completed. Ultimately, this backed up previous evidence that individuals with chronic pain actively seek approaches that work best for them, such as distraction techniques or avoiding situations that may exacerbate their symptoms (Firmin et al., 2011). In this case, many participants chose adaptation as their approach to managing their pain while still engaging in social participation.

This study highlighted 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, for example, academic pressures, social issues, social engagement and even financial problems. This can affect their academic achievements, social participation and quality of life. Chronic pain can impact all areas of life and occupation either directly, or indirectly. Through the domino effect, pain can spiral to impact various occupations making it difficult for individuals to be able to participate and engage in what they want to. 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, Kersnik, Eder, & Colaric, 2011). This leads to having to prioritize what occupations are going to be completed, if any. Due to the prioritization of occupations, occupational balance, or the individual's ability to have the right amount of variation between occupations being completed may be negatively impacted (Wagman et al., 2012). Areas that can impact one's occupational balance are the particular occupations being

completed and how much time is spent for each occupation (Wagman et al., 2012). Participants stated that prioritizing led to activities that included social participation to not be completed in order to go to class, complete projects, or go to work. Issues with occupational balance can lead to burnout or decreased quality of life. As occupational therapists, it is important to remember that while a person may need to go to school, or go to work, they also need time to complete leisure activities or be with friends.

### **Limitations**

Limitations to the study included 15 participants, with only two identifying as male, and a majority attending a California university. Therefore, the research team could not assume the data represented all college students with chronic pain. These researchers considered differences in the way that genders experience chronic pain, however, due to there only being two participants who identified as male, it was difficult to draw conclusions. In addition, certain barriers to engagement, such as extreme weather conditions, were not covered in many of the interviews due to the majority of the participants living in California. Other limitations include varying campus cultures, which promoted different forms of social participation or engagement for students. For example, some schools have an active party scene, while others promote a calmer, quieter environment. The research found that many students are hesitant to go to campus affiliated activities (i.e. clubs, parties, Greek societies, etc.) because of how it impacts pain levels. Limitations to this study included the use of only one method of data collection, which was semi-structured interviews.

## **Implications for OT Practice and Future Research**

It is crucial for occupational therapists and the wider community to understand that pain can affect all occupations. Chronic pain does not just impact activities when an individual is being active, so it is not just limited to a few occupations they can avoid. A wide variety of occupations can trigger, or exacerbate pain since all pain is different. For example, many would consider occupations completed while sitting would not increase an individual's pain, however being in one position for an extended period of time can lead to increased pain. Similarly, pain can decrease the motivation to engage in social activities and individual occupations. By understanding the lived experience of chronic pain, occupational therapists can work with an individual to prioritize, adapt, and plan ahead for occupations to promote engagement and prevent exacerbation of symptoms. A way to do this is to utilize the PEO model, in order to holistically look at the person and their engagement in occupations (Law et al., 1996). As occupational therapists create a profile for their clients, they must take note of whether or not they identify as outgoing or reserved, and what they like to do during their leisure. This information will help OTs collaborate with the clients to decide what type of social activity will be motivating to engage in. With this, OTs can figure how to modify or adapt that activity to support their interests, strengths, and decreased environmental limitations. Since the individual may be experiencing limitations due to their chronic pain, a practitioner can look at the person and what their needs or capabilities are. Then, after examining the individual's needs, they will look at the occupation they want to engage in and the environments that it can occur in. With this, adaptations or modifications to either the environment or occupation can be examined with the individual to see what can be done to promote engagement. In addition, it is essential to keep in mind the person and what they want to be able to do. A practitioner cannot pick occupations

for the individual to complete without considering their likes and dislikes. If clients are not interested or do not want to engage in the occupation, engagement satisfaction will not be met.

Occupational therapists should also keep in mind the domino effect, which emphasizes the importance of rest and sleep, since energy levels and stamina greatly influence one's ability to engage in occupations. Especially since many participants noted that they either require rest to help cope with the domino effect, which commonly leads to decreases in sleep quality. To prevent disempowerment of individuals with chronic pain, OTs, healthcare professionals, and academic faculty can explore accommodations beyond physical access, and promote resilience and self-empowerment. Resilience can stem from self-reflection, mindfulness, and evaluation of current occupations, satisfaction, and performance. Occupational therapists can also suggest pain management techniques to alleviate pain such as aromatherapy, meditation, color changing light bulbs that can adapt to the individual's mood, TENs units, and stretching/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. Considering the potential occupational deprivation, imbalance, and/or alienation that can occur when living with chronic pain, it is not the place of the professional to determine which occupations and engagements have the greatest or smallest impact on the client.

**Future researchers can build off of the limitations of this study. While themes were identified, there are areas that can be examined further to better understand the impacts of chronic pain. Future studies could examine how gender influences social participation in those with chronic pain. These gender differences may create differences in chosen occupations, or relationships with others. Some college students claimed that sitting for a long period of time can trigger pain, but the study did not explore how it might affect social participation. Therefore, learning more about how pain affects travel such as long car rides or airplane trips, can identify whether or not it affects a student's choice to partake in school activities that require travel such as club competitions and study abroad, or simply affect their decision to go on vacation with their friends. In addition, other studies can explore the differences between campus culture (i.e. Greek life, academic-focused, etc.), active campus clubs/organizations, campus size, and how it impacts perceived level of social participation. Also, when looking at campuses, it is important to further examine how weather and location can impact social participation. It would also be useful to know whether or not the participants were seeing an occupational or physical therapist. Knowing this might illuminate the reason for their pain, their pain management plan, and help understand their coping skills. In addition, other research methodologies such as questionnaires, surveys, and virtual diaries can be sought to collect additional specific data that could enhance the understanding of the lives of those with chronic pain.**

## **Conclusion**

**In conclusion, the findings display how more than just an individual's pain level impacts their ability to engage in social occupations. 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 pain management techniques, coping strategies, energy conservation strategies and empowerment to support individuals with chronic pain. There is also a need to create an open dialogue with the wider community, such as 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 able to engage in meaningful social occupation**

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## **Appendix A: Interview Questions**

## Interview Questions

- What college or university did you go to?
- What year are you in currently?
- Have you ever transferred schools and if so was your transferring related to chronic pain
- If you transferred because of your pain have you seen a difference in your pain from transferring?
- What is your major and/or minor in college?
- What made you choose your area of study?
- What influenced you to choose your college?
- Did your chronic pain have anything to do with your college choice?
- Do you live with roommates or do you live alone?
- Do you live on or off campus?
- If you live with roommates, how long have you known/lived with them?
- Have you ever been diagnosed with a chronic pain condition, and if so, which one(s)?
- Do you have any other conditions that you are comfortable disclosing?
- If yes, does this condition also cause chronic pain, or affect your chronic pain in any way?
- Do you see chronic pain as a central part of your identity, and if so why or why not?
- How does your chronic pain condition affect your daily life?
- How does your chronic pain affect your ability to go to class?
- Does your chronic pain impact your ability to participate in group activities such as, but not limited to, group projects or events on campus?

- Does being in class for an extended period of time cause you to be less likely to go out and do something with friends, for example; if you have a full day of class will you feel as though you are able to go out to dinner or have a night in with your friends??
- How do you feel about your current level of social participation?
- What are some things you are happy and not happy about with your current level of social participation?
- Does your current level of social participation have anything to do with your pain, or is it due something not being available on campus, or being too busy?
- How has your chronic impacted your friendships and/or relationships in college?
- How has your chronic pain impacted your relationships with peers and friends?
- How has your chronic pain impacted your relationships with your roommates and housemates?
- How has your chronic pain impacted your romantic relationships and dating if you are comfortable sharing?
- If you feel comfortable disclosing, do you feel as if your chronic pain hinders or negatively impacts your relationships with others?
- How has your chronic pain impacted your social participation in extracurricular sports?
- If you are no longer playing a sport you used to play, would you want to continue playing if you did not have chronic pain?
- How if at all has your chronic pain impacted your participation in school clubs, and if you could start a club at your school what would it be?
- Who are some supports who have helped you through your college experience?
- Is there anything you would want your supporters to do differently?

- If you are comfortable sharing what or who are barriers that have hindered you throughout college?
- What or who has supported you and allowed you to engage in social activities, and how have they supported you?
- What or who are barriers that have hindered your ability to engage in social activities; and if you are comfortable sharing how have they hindered you?
- What do you wish the people that have hindered you would have done differently?
- How has your chronic influenced your energy level, if at all?
- Does low energy impact your ability to spend time with your friends at home?
- Does low energy impact your ability to go out with your friends?
- Does low energy impact your ability to engage in on-campus activities?
- How do you control your pain on a daily basis?
- Is there anything you would like to change about how you are currently managing your pain?
- How, if at all, does your pain management technique impact your social relationships with friends?
- How does your pain impact your sleep?
- How does your pain impact your ability to go places?
- Has your pain ever stopped you from going somewhere?
- Do your friends understand if you have to cancel plans due to pain?
- Do you have trouble going to certain places either alone or with friends due to your pain?
- Is there anything else you want to tell us?

## **Appendix B: IRB Approval**



December 19, 2018

Patricia Tran

50 Acacia Avenue

San Rafael, CA 94901

Dear Patricia,

On behalf of the Dominican University of California Institutional Review Board for the Protection of Human Participants, I am pleased to inform you that your proposal entitled *Chronic Pain and Social Participation for Students in Higher Education* (IRBPHP application #10739) has been approved.

In your final report or paper please indicate that your project was approved by the IRBPHP and indicate the identification number.

I wish you well in your very interesting research effort.

Sincerely,



Randall Hall, PhD

Chair, IRBPHP

**[Institutional Review Board for the Protection of Human Participants](#)**

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