6-2022

All in the Same Boat: A Qualitative Investigation into the Relationship Between Peer-Led Chronic Pain Support Groups and Chronic Pain Management

Avery Cook

Recommended Citation

Cook, Avery, "All in the Same Boat: A Qualitative Investigation into the Relationship Between Peer-Led Chronic Pain Support Groups and Chronic Pain Management" (2022). *Culminating Projects in Community Psychology, Counseling and Family Therapy*. 95.
https://repository.stcloudstate.edu/cpcf_etds/95

All in the Same Boat: A Qualitative Investigation into the Relationship Between Peer-Led Chronic Pain Support Groups and Chronic Pain Management

by

Avery B Cook

A Thesis

Submitted to the Graduate Faculty of

St. Cloud State University in Partial

Fulfillment of the Requirements

for the Degree of

Master of Science in

Rehabilitation Counseling

June, 2022

Thesis Committee:
Amy Hebert Knopf, Chairperson
Susan Dowds
Bradley Kuhlman

Abstract

Chronic pain is a current public health problem that significantly impacts the United States, including the disproportionate impact on specific communities, quality of life, and the impact on the U.S. economy (Institute of Medicine et al., 2011). Many chronic pain management techniques are used in modern pain management therapies; however, cost, ability, and opportunity can impact the effectiveness of these techniques. Social support documented as an efficacious pain management technique. However, peer-led chronic pain support groups are under-researched. Through a qualitative grounded theory approach, this research used semi-structured interviews to investigate the relationship between peer-led chronic pain support group membership and chronic pain management. In addition, this study investigated the relationship between membership of peer-led chronic pain support groups and if there is a connection to higher success in managing chronic pain while lessening the impact on quality of life and the fiscal impact.

The participants in the study identified the significant value that membership in a peer-led chronic pain support group had on the management of their chronic pain. The participants identified six themes while discussing the relationship between their membership in a peer-led support group and their chronic pain management: peer group support, the dichotomy of quality-of-life, self-concept, impacts of healthcare, family and communal relationships, and economic impact. The generated theory states that peer-led chronic pain support groups are an effective method of managing chronic pain due to their positive impact on quality of life and self-concept while relieving some of the financial burdens of chronic pain.

Key Words: chronic pain; social support; peer-led; support groups; pain management; grounded theory; peer-led support groups; chronic pain support groups; peer-led chronic pain support group; quality of life; financial impacts of chronic pain

Acknowledgments

First, I would like to acknowledge and thank the 5 participants in my study who volunteered their time, energy, and passion for this research. Without them, this research would not be possible. I would also like to thank my committee members, Dr. Susan Dowds and Dr. Brad Kuhlman, for their valuable feedback and support during this research. A huge thank you to Dr. Amy Hebert Knopf, the chairperson on my committee and my advisor, for her time, dedication, and unwavering belief in me and my vision for this research. She has taught me so much about becoming a better counselor and researcher, and I am so grateful for her encouraging me to achieve excellence.

Additionally, I would like to thank: my husband, Andrew, for his staunch support in my "big project" and for always being there for the highs and lows, to my mom for making sure that I always had food in my refrigerator and cheerleader I could always call, and to my dad for his steadfast support in all aspects of the last two years. Finally, a special thanks to my Grandma Bea for a supportive shoulder every Thursday night, Sarah Gorski for her unwavering positivity and late-night phone calls, and Jonathan Tigner for commiserating about each of our thesis work and his knowledge of Microsoft Excel. Thank you all for the time, dedication, and support in fostering my growth mentally, professionally, and academically.

“My chronic pain management is my group, and my group is my chronic pain management…”

– Geoff

Table of Contents

Page

Chapter Page

Chapter Page

List of Tables

Table Page

List of Figures

Chapter I: Introduction

"Unequivocally, across the board, everything from my relationship with my daughter, to my performance in my job, to my relationship with my husband, to my friends, my family, social support, yeah, I do not think there is one aspect of my world that has not been positively impacted by this group" – Kennedy

Scope of Chronic Pain in the United States

From chronic migraines to chronic lower back pain, chronic pain comes in many forms. The medical community defines chronic pain as pain that persists past the average time of healing (Harold & Bogduk, 1994). Chronic pain affects one in five people globally, approximately 1.5 billion people (Galea, 2017) , and at least 116 million Americans (Institute of Medicine et al., 2011). To put that number in context, the Institute of Medicine et al. (2011) states that the number of Americans living with chronic pain is greater than the combined total of individuals living with heart disease, diabetes, and cancer. Furthermore, chronic pain has been deemed a "significant public health problem" by the Institute of Medicine et al. (2011) as it actively decreases one's quality of life (p.20). Additionally, it disproportionately affects specific populations of people in the U.S. (Institute of Medicine et al., 2011) and costs society a significant amount of money, both in healthcare costs and productivity losses. Therefore, this research seeks to study the relationship between peer-led chronic pain support group membership, chronic pain management, and the impact on their finances and quality of life.

Disproportionate Impact

Chronic pain can affect everyone, from children and young adults to the elderly (Higginson et al., 2019). Recent studies predict that chronic pain will become more prevalent in society as modern medicine develops more life-saving techniques (Institute of Medicine et al., 2011). While chronic pain can happen to anyone, studies show that many populations in the U.S. are disproportionately affected by chronic pain (Dahlhamer et al., 2018; Institute of Medicine et al., 2011; Smith et al., 2001). Specific examples of populations that have increased vulnerability to chronic pain include women, older adults, individuals who learned English as a second language, racial and ethnic minorities, individuals with trauma symptoms, and veterans (Dahlhamer et al., 2018; Driscoll et al., 2015; Institute of Medicine et al., 2011; Rzeszutek et al., 2015; Smith et al., 2001). In addition, many of these populations also encounter systemic disparities in the U.S. regarding gender, race, and military services (Institute of Medicine et al., 2011). Another indicator of a population with a disproportionate rate of chronic pain is socioeconomic status (Dahlhamer et al., 2018). Individuals without a high school diploma or GED, a job or home, and currently experiencing poverty are at higher risk for chronic pain (Dahlhamer et al., 2018; Smith et al., 2001).

Impact on Quality of Life

Chronic pain is one of the most frequently reported medical complaints (McCarberg et al., 2008). Individuals with chronic pain often report low quality of life, specifically those with high-impact, more severe chronic pain (von Korff et al., 2016). It is well documented that chronic pain limits one’s ability to do daily activities, including restricted mobility (Gureje et al., 1998; Smith et al., 2001; von Korff et al., 2016). Research also shows that chronic pain interferes with the enjoyment of life activities (von Korff et al., 2016). Similarly, studies have shown that dependence on opioids and psychological disorders (such as depression and anxiety) are correlated to chronic pain (Cho et al., 2011; Gureje et al., 1998; Institute of Medicine et al., 2011; Smith et al., 2001). Lack of quality sleep, unstable employment status, unmet pain management needs, and negative impact on interpersonal relationships are commonly reported by individuals with chronic pain as what impact their quality of life (McCarberg et al., 2008).

Economic Impact

When discussing the holistic impact of chronic pain on an individual, one must look at the scope and physical impact, and the economic impact. Considering both healthcare expenses and productivity loss, the annual cost of chronic pain in the United States is $560-630 billion (Institute of Medicine et al., 2011). Research conducted by the Institute of Medicine et al. (2011) discusses the financial impact of chronic pain on the employers of individuals with chronic pain; these employers lose an estimated 260 billion dollars a year on productivity-related work costs due to chronic pain. An article by Smith et al. (2001) cites another study conducted in the United Kingdom that purports 45 million days of work were missed due to back pain alone every year (Smith et al., 2001). Von Korff et al. (2016) estimates that the mean cost of healthcare services for back pain in the U.S. is $11,932 annually. Smith et al. (2001) report that the unemployment rate of individuals with chronic pain is 81.2% in Scotland, while the rate for individuals without chronic pain is 23.9%. Finding a more cost-effective alternative for chronic pain management would benefit individuals with chronic pain, their families, and their community.

Research suggests that finding accessible (in both cost, ability, and opportunity) chronic pain support methods is urgently needed to address the public health problem of chronic pain. This research seeks to study the relationship between peer-led chronic pain support group membership and chronic pain management. This study hypothesizes that membership in peer-led chronic pain support groups will predict higher success in managing chronic pain while lessening the disproportionate impact on individuals in specific communities, the impact on quality of life, and the financial impact. The final research aims to expand the literature on peer-led chronic pain support and offer peer-led chronic pain support groups as a viable alternative to other chronic pain support methods.

Chapter II: Literature Review

The review of literature is organized into three categories. Firstly, it will briefly overview chronic pain management and standard management practices employed. Secondly, it will discuss social support and what is available for those with chronic pain. This section will focus on the subtleties between Health Care Provider (HCP)-led, HCP-facilitated, and peer-led groups. Lastly, it will review current research evidence on peer-led chronic pain support groups. Due to the dearth of information on chronic pain support groups (CPSG), research will be supplemented on peer-led chronic pain social support in various formats outside of the peer-led support group setting. The additional examination will provide a more holistic review. However, the final research goal is to expand the literature on peer-led chronic pain support groups.

Chronic Pain Management

McCracken et al., (2004) discuss what makes the distinction between proper pain management and pain control. They define pain control as a futile pain management strategy. The goal of pain control is to fully eliminate one’s pain. This is problematic because in chronic pain situations, this idea is unrealistic. The researchers discussed these efforts would be futile because patients would be unsuccessful trying to command their life around their pain. They possibly would have additional symptoms or side effects that could exacerbate the pain. Additionally, centering one’s life around pain control could further isolate them from the things they value or bring them joy (i.e., family, friends, health, work, etc.). The study emphasizes that many methods of pain control stem from fear and follow avoidance patterns while methods of proper pain management revolve around acceptance of the condition, leaving behind ineffective methods, and focusing on increasing the patient’s life satisfaction.

Prescription Opioids

Opioids are a common treatment given by primary care providers to alleviate chronic pain (Blau et al., 1999). Boudreau et al. (2009) states that 3 - 4% of older adults in the US are using long term opioid therapy, which is approximately 9.87 million - 13.2 million people. Between 21-29 percent of individuals who are prescribed opioids for chronic pain abuse them (National Institute on Drug Abuse, 2021), an abuse that has led to an opioid crisis in the US. In 2013, it was estimated that the opioid crisis has cost US society around $78.5 billion (Hagemeier, 2020).

Additionally, there is a controversy regarding the efficacy of long-term opioid usage for chronic pain (Hagemeier, 2020). Opioid therapy has been shown to be a very risky method of chronic pain management because long term use can lead to patients who develop a tolerance and physical dependency (Frieden & Houry, 2016). Tolerance is when the potency of the opioid decreases after long term use. To maintain the previous effects, the dosage has to be continually increased leading to an increased risk of an overdose. Approximately 50,000 people in the United States died of an opioid overdose in 2019 (National Institute on Drug Abuse, 2021). A leading cause of overdose is when an individual feels the effects of their current dose are no longer working like they used to and adjust their intake to maintain the previous effects (Volkow & McLellan, 2016). While there is a clear risk factor to using opioids for long term chronic pain management, the benefits are not as obvious, outside of temporary relief (Frieden & Houry, 2016; Hagemeier, 2020). Opioids are used in pain management because they give rapid relief to the individual (Volkow & McLellan, 2016).

The effects of long-term opioid use as a chronic pain management tool can be as small as fatigue and as serious as addiction (Benyamin, 2008). A study done in 2016 compromised of 69,000 postmenopausal women living with chronic recurrent pain found that those using opioids to treat their pain were more likely to have their level of functioning to decrease and less likely to have improvement to their condition (Frieden & Houry, 2016). The risk of addiction to opioids is an important note. Addiction to opioids comes through consistent, long-term use (Volkow & McLellan, 2016). Frieden and Houry (2016) state that prescription opioids that are often taken in correlation with chronic pain are “no less addictive than heroin” (p. 1502). Physical dependency is the materialization of withdrawal symptoms when long term opioid use is discontinued. Both physical dependency and tolerance are nearly guaranteed results of repeated use of opioids (Volkow & McLellan, 2016).

For many individuals with chronic pain, medication is not a lasting or viable long-term solution. In a study done by Subramaniam et al. (1999), a sample of 13 New Zealanders with chronic pain were examined and only 10 of those 13 (77%) were on pain management medication. Only 70% of the participants on pain medication thought their medicine was effective, which means only 7 out of 13 or 53% of participants found success with medication as a pain management technique. These findings are congruent with Frieden and Houry’s (2016) claim that nonpharmacologic treatments and therapies are shown to help alleviate chronic pain in a way that poses much less of a threat to patient’s health. Although people can be successful in managing their chronic pain with prescription opioids, this review will focus on nonpharmacological methods of pain management.

Physical and Psychological Therapies

Cognitive strategies for chronic pain self-management are very popular, especially with individuals who are unable to have or refuse pain management medication (Finlay et al., 2018). The goal of cognitive strategies is to use one’s mind to assist in regulating situations such as chronic pain. The negative effects of cognitive chronic pain self-management are minimal due to their therapeutic nature (Kashikar-Zuck et al., 2013). Some common psychological therapies for managing chronic pain are hypnosis, cognitive behavioral therapy (CBT), motivational interviewing, biofeedback, and relaxation therapies (American Chronic Pain Association & Stanford University Division of Pain Medicine, 2021; Institute of Medicine et al., 2011).

A common cognitive strategy for relieving chronic pain is distraction (Eccleston, 1995). Distraction has been shown to be both an effective overall pain management method and a method of relieving psychosomatic pain (Eccleston, 1995; Ersek et al., 2006). This strategy involves focusing one’s mind on something other than pain. Distraction is also one of the most accessible pain management techniques since it is a mental exercise and does not require a financial component or physical access (Finlay et al., 2018). Utilization of the distraction method varies from simple distractions such as watching television or reading a book to more complex distractions such as starting a new hobby or visiting with friends. Studies have shown that these types of pain self-management methods are successful in making pain more manageable by redirecting the mind away from pain thoughts (Ersek et al., 2006; Kashikar-Zuck et al., 2013).

Many pain self-management techniques involve more physical approaches. These techniques are seen as physical ways to lessen and often also include mentally manage pain. According to Ersek et al. (2006), the most common physical therapy strategies among older people with chronic (non-cancer) pain, according to the Chronic Pain Coping Inventory (CPCI), are task persistence, coping self-statements, and pacing. Each of these strategies have shown success in managing chronic pain (Ersek et al., 2006). These strategies are categorized as perseverance strategies which allow the individual a physical and mental outlet to manage their pain. In another study, many individuals found success in things such as water aerobics or swimming due to the water taking strain off their body (Subramaniam et al., 1999). In the same article, it is shown that many individuals who have chronic pain seek out relaxation techniques such as yoga, breathing strategies, or even light no-impact exercise. The effects of coping are usually better physical well-being and improved sense of self with a decline in negative effects such as depression (Ersek et al., 2006).

Social Support

The last pain management technique that this review will discuss is social support. Social support is an umbrella term that covers support systems that revolve around other people. This type of pain management is shown to be a successful method of protection against declining health by promoting connections with other individuals who can relate to chronic pain issues (Finlay et al., 2016). According to Finlay et al., (2016), there are two accepted forms of social support, the first a "primary, enduring, informal support structures (e.g., family and close friends)" and the second being "secondary, larger, more formalized groups (e.g., hobby groups or work colleagues)" (Finlay et al., 2016, p. 662).

Social support options have been shown to be an effective treatment for chronic pain for over three decades (Gil et. al., 1987). In a study done by van Dyke et al. (2018) emotional support and companionship were shown to improve quality of life. However, even though social support has been shown in many ways to positivity impact individuals with chronic pain, individuals with chronic pain are shown to be less likely to disclose their diagnosis to friends (Feldman et al., 2020). Studies regarding primary informal support (i.e., partners or close friends of individuals with chronic pain) have been shown to positivity impact individuals with chronic pain (Kindt et al., 2018). Providing individuals with chronic pain with the space to indulge in social support is very important. Research by Warwick et al. (2004) has shown that the ideal social support for women with chronic pelvic pain consisted of emotional and practical support while still maintaining autonomy. In the same study, the results suggested that the lack of engagement and empathy were the recurring themes regarding the weaknesses of social support.

Social support in modern days is not always restricted to in-person meetings. Research of online social support options has suggested that social support communities online can be an effective method of pain management (Young et al., 2018). A comparative research study done by Huber et al. (2017) suggested that both modalities of social support reported the same levels of positivity and positive impact among cancer patients. In another study done by Mo & Coulson (2014) on the efficacy of online support groups through the lens of empowerment it was shown that there can be some problematic factor, but the overall findings suggested that online support groups can be empowering to individuals with HIV/AIDS. Specifically, regarding chronic pain, there is a lack of studies done regarding the efficacy of online versus in person support groups. However, one study done by Mariano et al. (2019), researched the differences between online group teletherapy and in person group therapy for individuals with chronic pain which suggested that online group teletherapy may be equally as effective as in person group therapy, but indicated that more research would be needed for a full adequate assessment.

The social support systems that this review will be discussing are pain management programs (PMPs), healthcare provider (HCP) led, and HCP facilitated groups which fall under the more formal form of social support mentioned above. Chronic pain support groups (CPSGs), depending on the group, could be either the informal or formal form of social support. Support groups in general (PMPS, HCP led, HCP facilitated, and peer led) have been shown to be very effective in accepting disability, overcoming fears, and providing a safe place for learning (Cowan, 2011; Finlay et al., 2016; Finlay et al., 2018; Lefley, 2009).

Pain Management Programs vs Healthcare Provider Led Support Groups

Firstly, a PMP is a formal, educational group that is run by a team of healthcare professionals in a healthcare setting such as a hospital or clinic. PMPs are very education oriented, focusing on giving the patients many different techniques and methods to combat their pain. To join a PMP, most often a client must be referred to by their doctor. Oftentimes this referral comes after a patient has been struggling to find an effective pain management technique that works for them. PMPs can be inpatient or outpatient, but either way is a time intensive commitment (Mayo Clinic, 2020). For example, the Mayo Clinic PMP called the Pain Rehabilitation Center (PRC) is a three-week intensive program (Mayo Clinic, 2020). The impact of such an intensive commitment impacts the patient both socially and financially.

Outside the cost of the PMP, there is still a heavy financial burden on the patients due to missing work, the cost of housing, food, and gas. Similarly, the patient leaving their own space and their support system to go to this type of treatment can cause a negative impact. The Mayo Clinic PMP uses a cognitive behavioral therapy approach to chronic pain education, pain medication management, psychology, physical therapy, biofeedback, occupational therapy, and group pain education sessions; additionally, the PRC employs training and practice in meditation, yoga, relaxation, and physical movement (Mayo Clinic, 2020). While most PMP have a follow-up aftercare support group that helps remind and reinforce behaviors, this type of support group might not always be accessible due to funds, since PMP and their aftercare programs are usually very expensive (Cowan, 2011).

Like a PMP is a Healthcare Provider (HCP)-led chronic pain support group (CPSG). Unlike a PMP, which is run by a team of providers that can offer individualized support, an HCP-led CPSG is led by one provider who organizes and leads all groups activities (Finlay et al., 2018). The goal of an HCP-led CPSG is to provide education along with social support in a formal medical environment. An example of an HCP-led support group would be group therapy in which there is a therapist that leads discussion and allows people to share at specific points (Cowan, 2011). An HCP-facilitated group is organized more by the clients, and the clients may also help decide what kind of topics are covered in the session (Finlay et al., 2018). This type of group is more empowering to the client, however, is still moderated and ran by the healthcare provider (Subramaniam et al., 1999). Research has shown that healthcare provider involvement in a support group setting has been shown to alter the overall behavior and culture of the group (Shepherd et al., 1999).

Both HCP-led CPSGs and HCP-facilitated CPSGs are widely regarded as the most recommended option for support groups due to having both a clinical and social aspect to them (Finlay et al., 2018). These types of groups are also the most common type of CPSG due to the natural progression from doctor’s office, which prescribes a treatment program (a PMP) who then prescribes a support group (Finlay et al., 2018; Finlay et al., 2016). This smooth transition has been noted by healthcare professionals and consequently, many PMP programs prescribe aftercare programs that fall into the category of an HCP-led CPSG. HCP-led and HCP-facilitated CPSG are suited more for people with chronic pain who are still learning about their diagnosis and looking more for definitive treatments and medical advice. The biggest criticism of the PMP and HCP-led support groups, in general, is that they are often too broad and do not adequately go into depth about things that participants need to learn about in order to improve their situation since the HCP must make their recommendations generalizable due to the variety of individual situations or they tend to steer away from topics that may cause certain people to be uncomfortable such as sex (Cowan, 2011). However, research done by Stevinson et al. (2010) in the UK has shown that there is little difference between HCP led or facilitated groups and peer led support while studying cancer patients.

Peer-Led Chronic Pain Support Groups

Peer-led support has been shown to be effective for other medical diagnoses, but little research has been done on the subject regarding chronic pain (Stevinson el al., 2010; Tregea & Brown, 2013). Peer-led support groups consist of individuals who have lived experiences with chronic pain creating a space for others with chronic pain to feel comfortable sharing and talking about their experiences. Peer-led CPSG are usually led by a committee or a core group of members who take ownership of the group (Cowan, 2011; Finlay et al., 2018; Subramaniam et al., 1999). Unlike the other support groups this article has discussed, peer-led groups are a place to share experiences in a setting where significant emotional support can be provided (Cowan, 2011; Finlay et al., 2018). Peer-led support groups are not meant to offer medical advice, but many peer-led support groups invite guest professional speakers to talk on specific subjects that the groups would like to know more about.

Due to the nature of peer-led support groups, there is a lot of variances in the structure they provide. The structure of these peer led groups can vary greatly from group to group since the structure is determined by the group (Finlay et al., 2016; Finlay et al., 2018). Group structures vary by need, so some groups may benefit most from an online support group while others benefit more from an in-person structure. The structure differences can also be seen in the frequency of the meetings, some meet rigidly every week while others may find that a once-a-year, weekend retreat-type format works best supplemented with online or small group meetings. Since the transition to a peer-led group from a PMP is not a natural one, there is very little research on what makes a peer-led group successful.

Peer-led CPSG are different, however, as there are no steps available to assist someone in creating a peer-led CPSG. While PMPs tend to prescribe an aftercare HCP-Led support group after completion of the PMP, patients are given little to no information regarding peer led support options as a method of pain management. There are ways for individuals with chronic pain to go about starting their own peer-led CPSG without having first been in a PMP or an HCP-led CPSG, but those resources are limited to, according to this researcher’s findings, the American Chronic Pain Association (American Chronic Pain Association, 2021). Even with help from an HCP starting a peer led CPSG requires a lot of time and effort to learn from trial and error what works and what doesn’t work.

The American Chronic Pain Association does have resources available to their members regarding pain management tools, communication tools for individuals with chronic pain, survey responses, and membership testimonies but nothing available to the public regarding how to begin and run a chronic pain support group (American Chronic Pain Association, 2021). In collaboration with Stanford University Division of Pain Medicine, the American Chronic Pain Association produced a 212-page resource guide for individuals with chronic pain that reviews different beneficial therapies for managing chronic pain (American Chronic Pain Association & Stanford University Division of Pain Medicine, 2021). This resource guide spends one page discussing chronic pain regarding social support (American Chronic Pain Association & Stanford University Division of Pain Medicine, 2021, p.33) and a one paragraph subsection titled "Chronic Pain Self-Management

Program" (American Chronic Pain Association & Stanford University Division of Pain Medicine, 2021, p. 44). The American Chronic Pain Association is a beneficial public resource for individuals with chronic pain.

In peer-led support groups, the group members completely control the way they organize and facilitate their group. With shared workload, the British members of the Finlay et al. 2018 article expressed that their self-confidence had grown as they felt able to get involved in choosing the direction their support group went. Finlay et al. (2018) dubbed this feeling the "ownership snowball" in which pride, ownership, and commitment of the group grew as they became more involved in the direction of their support group (p. 855). Research done by Taylor et al. (2019) suggests that involvement of group activities and feeling a sense of belonging in those activities are critical to the efficacy of peer led support groups. One participant from the Finlay et al. (2018) study claimed that diversity in ability within the group was a huge contributor to the ability to share the workload and become successful. The American Chronic Pain Association acknowledges the importance of the ownership of a peer-led chronic pain support group and encourages individuals living with pain to find an American Chronic Pain Association group to join or start one if there isn't one available to them (American Chronic Pain Association, 2021).

Cowan (2011) suggests that peer-led groups are a must for chronic pain management due to their ability to allow people to regain their identity through others like them. This phenomenon has been referred to as finding 'pain friends' (Finlay et al., 2018) or 'comparative friendship' (Finlay et al., 2016). Pain friends allow participants to feel at ease just being in a room full of people who understand what they are going through (Finlay et al., 2018). Those with chronic pain often express that there are few people in the world who understand what it is like to live with pain 24 hours a day (Finlay et al., 2018). They suggest that ‘normal’ people do not understand how to behave or assist them and can ask insensitive questions or make them feel small and inconvenient. People with chronic pain have asserted that there is an unspoken bond with other individuals living with chronic pain. In Matthias et al.’s 2016 study on the topic of chronic pain self-management among veterans, they discuss the importance of making these personal connections. This study makes the indirect comparison between the similarity between how veterans feel being a room full of other veterans is nearly identical to the connection that individuals with chronic pain identify with other individuals with chronic pain (Matthias et al., 2016). Like individuals with chronic pain, the veterans in Matthias’ study allude to the unspoken connection between all veterans by virtue of all having served in the military.

This same connection is represented in the chronic pain community and can be shown through the Finlay et al. 2018 study where participants identified as “all in the same boat” even though they all faced different diagnoses and came from various socioeconomic backgrounds (p. 853). This sense of collective identity with any member who walked in the door was something that could not be replicated with ‘non-pain friends’ (Finlay et al., 2018). In such situations, the participants would not need to explain why they cannot sit down at that moment or why they need to leave a gathering early. Another article by Finlay et al. discusses the phenomena of downward social referencing where individuals with chronic pain finally felt as though they were in a room with people who have similar or worse levels of pain (Finlay et al., 2016). Downward social referencing has been shown to boost self-acceptance and self-efficacy (Finlay et al., 2016). This type of unspoken comradery has such a large impact on people with chronic pain that it has been mentioned in some way or another in every article on peer-led chronic pain support groups that this review is assessing (Cowan, 2011; Finlay et al., 2016; Finlay et al., 2018; Matthias et al., 2016; Subramaniam et al., 1999).

Cowan (2011) goes on to explain that peer groups are consistently undervalued by people who see disability from a medical model perspective of needing to ‘fix’ or ‘medicate’ for ‘normalcy’ while, in most peer-led support groups, there is more of a feeling of ability versus disability. These participants focus on what they can do and learn that their chronic pain did not take away their self-identity, only changed it. The participants learned to find their new identity as individuals who could be functional with their chronic pain (Finlay et al., 2018). Working with others who have a similar pain experience has shown to lead individuals to greater acceptance of their own pain and situation (Matthias et al., 2016). The peer-led group from the Finlay et al. 2018 study was able to support each other while they were each on their own journey for their self-identity and on the way, they found a communal identity that created strong bonds.

With both identities, participants claimed to have found both self-confidence as an intrinsic value in themselves as well as understanding and acceptance of their new way of life as a person with chronic pain (Finlay et al., 2018). It was shown that these values helped minimize the side effects of chronic pain and gave the participants better coping skills when they had bad days.

In Finlay et al. (2018) article, discusses the importance of what she calls the “laughter drug” (p. 857). The participants in the study (Finlay et al., 2018) have considered keeping their humor as the linchpin to their success. These participants talked about how they felt their humor was stolen from them and they attribute their success in taking it back to their peer-led group. They felt as though nondisabled people thought of them as dull, humorless, sad people and they found their identities within the peer-led group. The humor was not a byproduct of the group however, it was actively called upon and initiated to allow people to smile and become the “best medicine” (Finlay et al., 2018, p.857). The article from Subramaniam et al. (1999) also agrees and builds upon the “laughter drug” concept and showed both qualitatively and quantitatively that when a group focuses on positivity and empowerment that they are going to be more successful than if they only focused on their condition and their pain, which is seen to be something that a peer-led support group is uniquely qualified for (Finlay et al., 2018, p.857). Participants tended not to focus or discuss the pain itself but preferred to discuss the impact the pain has and focus on how to grow and change themselves to minimize that impact. The group choice to not discuss pain is often made to make the meetings more beneficial but also to make the participants more comfortable by not having to explain their story every meeting.

In a more empirical take, the Subramaniam et al. (1999) article goes more into depth about the participation and outcome of a peer-led group. The study had a small sample size of 13 people and gave a disclaimer that a similar study would have to be done on a larger sample for better data, however they had concluded that the peer-led group was beneficial to the participants in many ways. It concludes that social support in the general sense does not equate to pain-specific social support, but that ‘non pain friends’ were not as beneficial for the participant’s mental health as their ‘pain friends’. The ‘pain friends’ were more beneficial due to their ability to empathize and support each other in a way that they knew would be successful versus ‘non pain friends’ which could not do this as effectively.

The Subramaniam et al. (1999) article also discusses the differences between HCP-led and peer-led chronic pain support groups and concluded that while HCP-led groups are valuable in their own way, a healthcare provider could not adequately give a person with chronic pain the social support they have been shown to need. While HCP-led groups cannot provide the necessary social support, peer-led groups have shown to be able to give valuable chronic pain coping skill education as well as other relevant knowledge that one may believe is only accessible through a professional group. Sharing knowledge and ideas that relate to pain self-management through peer-to-peer learning as well as promoting self-advocacy are some key benefits of peer-led support (Finlay et al., 2016; Matthias et al., 2016). A participant in the Finlay et al. 2016 study makes a point to mention that in the group they often ask if an individual has tried a certain technique or spoken to a certain person for help because “Trust me, we’ve tried absolutely everything there is.” (Finlay et al., 2016, p.671). This quote is quite important since it implies that among all members of the group, they have enough knowledge in the important areas of pain self-management strategies, healthcare resource navigation, and other relevant topics.

Chapter III: Methodology

This study investigated the relationship between membership in a peer-led chronic pain support group and the management of chronic pain. The research is a qualitative study focusing on interviewing current members of a peer led chronic pain support group. This study utilized a grounded theory approach to find themes and connections in the member's various experiences.

Participants, Settings, and Materials

Participants were recruited from an established peer-led chronic pain support group that is based in the Midwest. The criterion for recruiting participants was as follows: they must be current members of an active peer led chronic pain support group, they must have completed a pain management program, and finally they must have at least 7 years of lived experience with chronic pain. Participants were recruited via Facebook post; interview times and other relevant details were communicated via email. Participants were interviewed over Zoom due to the COVID 19 pandemic. The interviews were audio recorded over Zoom. Each interview lasted between 50 minutes to two hours.

Measures

Data collection was done through semi-structured interviews. Each participant was asked a few opening questions that gave insight into their experience, then questions focused on their membership in a chronic pain support group and how this membership has impacted the management of their chronic pain. In general, the following information was obtained: how long the participant has had chronic pain, the original diagnosis that started their chronic pain journey, their chronic pain journey from beginning until their graduation from a chronic pain management program, why they joined/started a peer led support group, how the support group has impacted their relationship with their chronic pain, how their membership in a peer led chronic pain support group has changed how they manage their pain.

Design and Procedure

This study is qualitative in nature and used the grounded theory approach. The goal of this research was to learn more about the relationship between membership of a peer led chronic pain support group and the management of chronic pain. After recruiting members of an active peer led chronic pain support group, they were interviewed individually. The data from the members were coded to look for recurring themes. Once no new themes are found in the narratives of the participants, the data was analyzed to determine what impact membership of a peer led chronic pain support group has on chronic pain management.

Chapter IV: Results

This study used a grounded theory approach to investigate the relationship between membership in a peer-led chronic pain support group and chronic pain management. The participants were interviewed individually within a period of a few weeks. In addition, all participants were interviewed virtually, utilizing Zoom, lasting between 50 to 120 minutes. After the transcripts were created automatically by Zoom, they were then cleaned and verified to match what was said by the participants. Although all names used in this research are fictional, participants created pseudonyms for themselves to protect their identity.

Brackets will be used in quotes to remove any identifying information. Additionally, when participants used verbal intonation to add emphasis, that will be indicated utilizing italics. The phrase 'emphasis added' will be added to the end of the quotation in brackets.

Participants

Demographic variables were collected as reported in Table 1. In terms of gender, 60% were female-identifying, and 40% were male-identifying. Participants' ages ranged from 44-73 years old, and the length of chronic pain reported by participants ranged from 15-48 years. The majority of participants were married (n=3), with partners of the opposite sex, and two were widowed. Each participant has attended at least one pain management program; however, three have been to more than one. While each participant had a unique diagnosis, three participants had chronic pain originating in their backs, and two had severe accidents which led to chronic pain. All participants have been consistent members of the same peer-led chronic pain support group for six and a half years.

Table 1

Participant Demographic Information

Demographic Variables	Felicia	Nay	Kennedy	Tony	Geoff
Age	73	59	44	54	53
Gender	F	F	F	M	M
Length of Chronic Pain	15	22	25	48	15
Original Cause of Pain	lower back pain	lower back pain	Accident - bone loss	Accident- crushed skull	back and neck pain
Occupation	Retired	Out of Work Due to Disability, formerly Hair Stylist	Business Owner	Out of Work Due to Disability, formerly Auto Body Specialist	Career Counselor
Marital Status	M	W	M	W	M
Number of Surgeries/Procedures	21	94	14	192	14
Years Since Most Recent Pain Management Program	7	7	7	>1	7
Number of Pain Management Programs Attended	1	2	2	4	1
Length in Peer-Led Chronic Pain Support Group	6.5	6.5	6.5	6.5	6.5

Note. All variables discussing length of time are measured in years. M indicates married, W indicates widowed.

The final sample included 5 participants who were core group members of a local peer-led chronic pain support group. The group self-reported across participants as having approximately 6-10 “core” group members and up to 75 “outside” members which were clarified by participant Felicia as “Outside just means that they are not with us all the time, some of them come in and out. The core group is always together…” Felicia also clarified that the “core” group members are mostly comprised of the folks that originally came up with the idea to start the peer-led chronic pain support group. One of the things that Felicia mentioned was a key component of "outside members" of the support groups was, "… their home base location is not compatible with where we are for a core group." (Felicia).

Participant Descriptions

Nay was the first participant interviewed. Nay is a 59-year-old female hairstylist who is out of work due to her disability. Nay's chronic pain originated from a steroid injection in which the medical provider did not sterilize the injection site properly and she was diagnosed with p acne thoracic vertebral osteomyelitis which impacted her back. She has had chronic pain for 22 years with multiple additional diagnoses added to the original cause of pain, has attended two different pain management programs, and has reported 94 various surgeries and procedures. Nay is a widow with two children, and she has remarked that they have given her much support through her chronic pain journey.

Felicia was the second participant interviewed. Felicia is a 73-year-old female retired county probation officer. Her chronic pain original diagnosis was degenerative disc disorder which impacted her lower back. Felicia has had chronic pain for 15 years, has attended one pain management program, and has reported 21 various surgeries and procedures at the time of her interview. Felicia states she is married to her "supportive sidekick" and has children and grandchildren in her life.

Geoff was the third participant interviewed. Geoff is a 53-year-old male who is currently employed as a career counselor. His original chronic pain diagnosis was disc herniation in the sacral region of his back. Geoff has had chronic pain for 15 years, has attended one pain management program, and has reported 14 various surgeries and procedures at the time of his interview. Geoff is married to his partner who he has described as "…the most important part of all this…" and has two children.

Tony was the fourth participant interviewed. Tony is a 54-year-old male autobody specialist who is out of work due to his disability. His chronic pain journey was an untraditional one as he reports only remembering life with pain, since the age of six. Given his age, he does not remember what his first diagnosis was, but it was related to sustaining a crushed skull due to a severe injury. Tony has had chronic pain for 48 years, has attended four pain management programs, and has reported 192 various surgeries at the time of his interview. Tony was unable to give a reliable number regarding procedures due to the reportedly sheer amount he had in his lifetime. Tony is widowed and has three children. Due to his reported financial burden of chronic pain, Tony has self-identified as "…homeless until spring. Until I can get back to my camper I'm living couch to couch…"

Kennedy was the fifth and final participant interviewed. Kennedy is a 44-year-old female self-employed business owner. Her original chronic pain diagnosis was osteonecrosis which was discovered after she was in a car accident where her joints dislocated. Kennedy has had chronic pain for 25 years, has attended two pain management programs, and has reported 14 surgeries and procedures at the time of her interview. Kennedy is married with one child.

Analysis of Findings

The final analysis of the data revealed six overall recursive themes: peer group support, the dichotomy of quality of life, self-concept, the impact of healthcare, family and communal relationships, and economic impact. Each of these themes interacted with one another on various levels. Results will be organized by recursive theme, starting with the most prevalent and ending with the least prevalent. Within the discussion of each recursive theme, each axial code will be discussed thoroughly to allow a holistic understanding of the participant's perspectives. Table 2 shows the breakdown of codes on each level: open, axial, and selective.

Table 3 dissects the number of codes found for each recursive theme. Figure 1 shows the percentage of data that each recursive theme holds.

Table 2

Overview of Codes

	Number of Codes
Open Codes	2707
Axial Codes	27
Selective Codes	6

Table 3

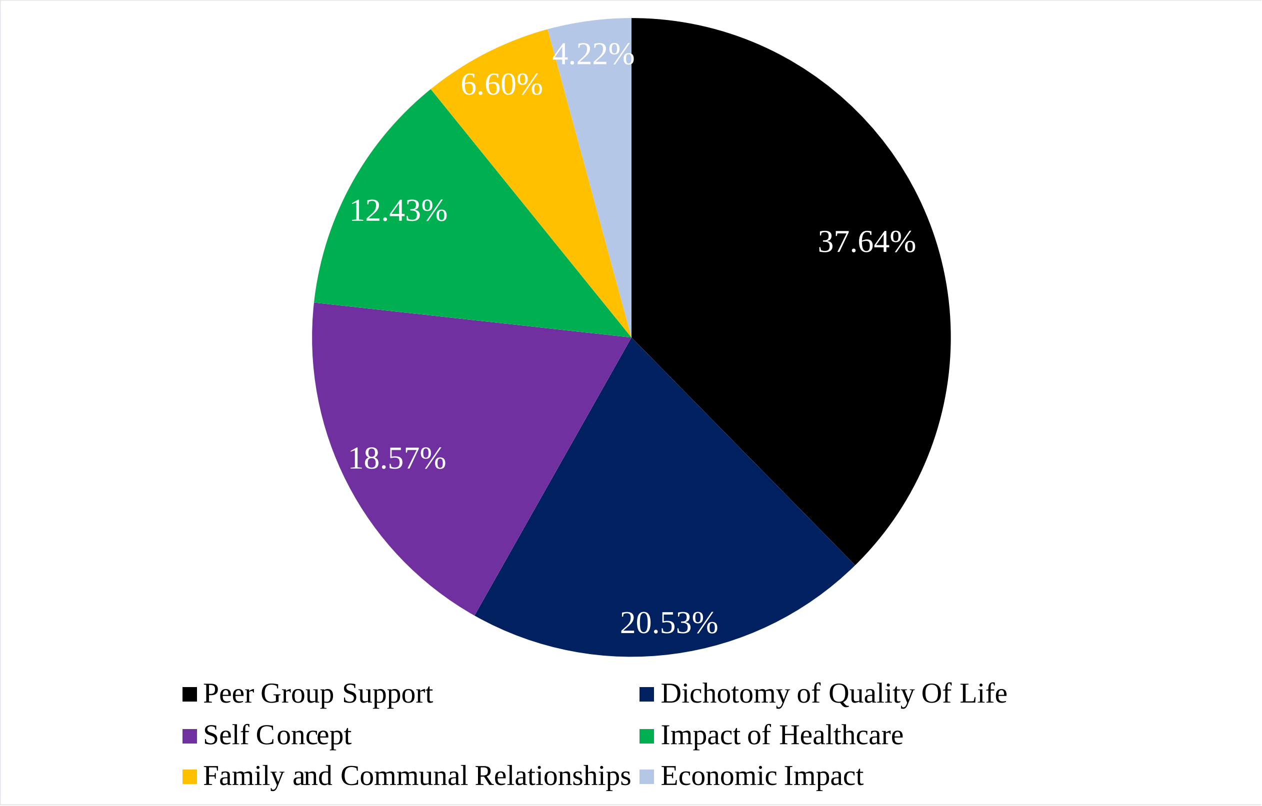
Recursive Theme Codes

Recursive Themes	Number of Codes Found
Peer Group Support	981
Dichotomy of Quality of Life	535
Self-Concept	483
Impact of Healthcare	324
Family and Communal Relationships	172
Economic Impact	110

Note. Table that dissects the open and axial coding can be found in Appendix A.

Figure 1

Percentages of Recursive Themes



This research is utilizing a grounded theory approach which is dependent on coding to ground the emerging theory. The grounded theory method is defined by Walker and Myrick (2006) as a combination of the logic and rigor of systemic quantitative analysis and qualitative methods. Researchers utilizing the grounded theory approach gather data to create a theory versus the quantitative method of starting with a hypothesis and seeking out data to confirm it (Walker & Myrick, 2006). Data analysis in grounded theory takes the form of coding. Coding has three distinct levels, open coding, axial coding, and selective coding. Walker and Myrick (2006) state that this data analysis process “begins with a basic description and moves to conceptual ordering and then on to theorizing” (p. 549). In the open coding process, data is constantly being analyzed and broken down into small, specific, codes (Walker & Myrick, 2006). In the axial coding process, open codes are compared to one another and placed into a larger category of similar concepts. The goal of the researcher in this step is to understand how categories relate to one another and to be able to explain and disentangle the concepts from one another (Walker & Myrick, 2006). Finally, in the selective coding process, axial codes are compared to one another based on relationship, property, and dimension at a more abstract level and placed into larger categories that are centralized around the final core concept that has been identified through the research to create a theory (Walker & Myrick, 2006).

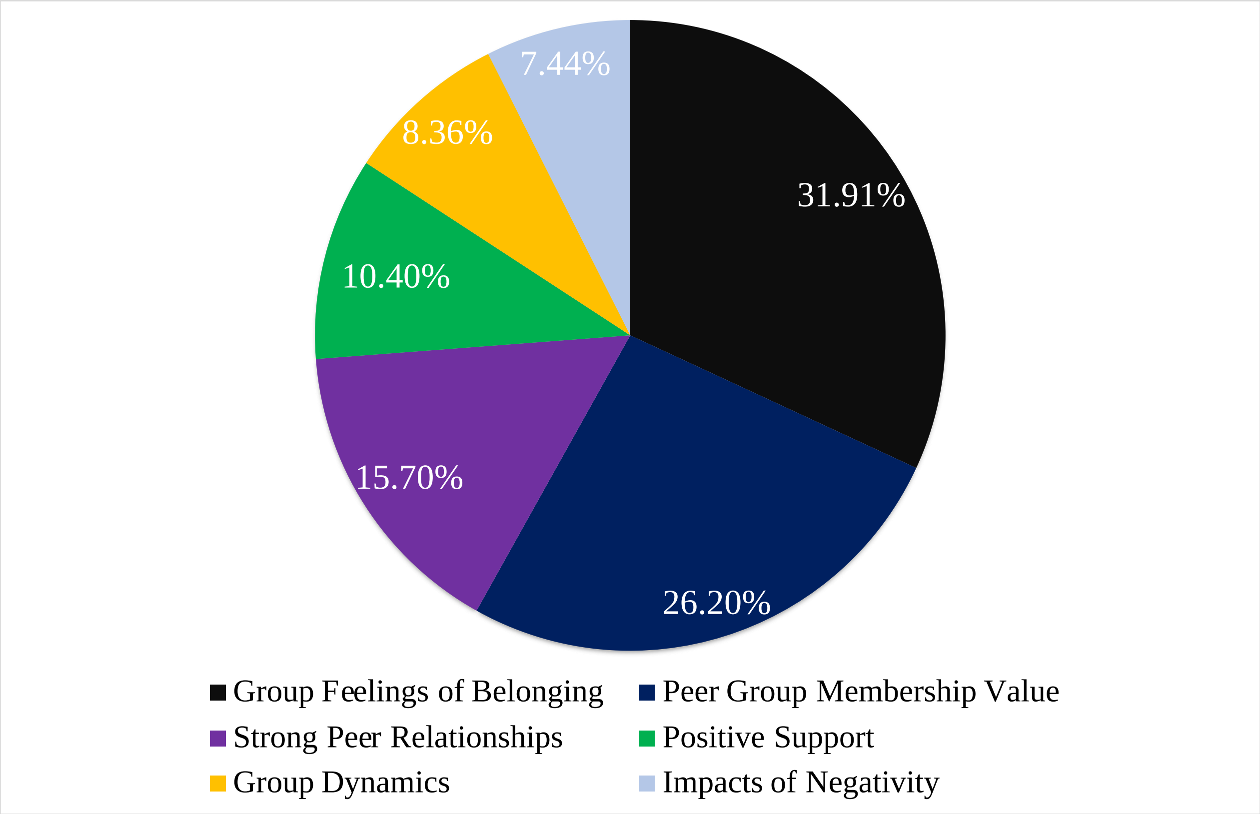
After the completion of the interviews, the researcher went through each transcript, line by line, and created the initial open codes. After the final interview coding was complete and no new emerging codes were found, the researcher took steps to verify the emerging themes and codes through investigator triangulation. Investigator triangulation was done by having two additional researchers confirm findings and give varying perspectives (Carter et al., 2014). This type of triangulation promotes integrating differing perspectives which can identify strengths, weaknesses, and any potential biases that occurred during the completion of open coding (Archibald, 2015). Triangulation started with the researcher and then two other individuals corroborated the researcher’s findings. Two other researchers provided triangulation for this study; one was a seasoned researcher in both qualitative and quantitative approaches and the second was a graduate student who was trained on how to do recursive themes. After triangulation, the researcher began grouping the initial open codes into axial codes which were grouped by having similar themes or concepts which allowed the researcher to see the emerging recursive themes (Walker and Myrick, 2006). After review and removal of non-recursive codes, the axial codes were compiled into the six recursive themes: peer group support, the dichotomy of quality of life, self-concept, the impact of healthcare, family and communal relationships, and economic impact. After completion of the coding processing, this researcher took steps to verify their finding by reaching out to the participants to confirm that the findings were representative of their thoughts and beliefs.

Peer Group Support

Peer group support was identified as the overall approach that was reported as the most successful chronic pain management strategy across all five participants. Additionally, it was the recursive theme that showed up most often in all five interviews and accounts for 37.66% of all codes in the research. Participants discussed the impact of peer support and how it represented a substantial shift in their ability to manage and cope with their chronic pain. The axial codes, or subordinate themes, that make up the recursive theme: group feelings of belonging, peer group membership value, strong peer relationships, positive peer support, group dynamics, and impacts of negativity. The axial codes are shown in Figure 2.

Figure 2

Peer Group Support Axial Code Breakdown



Group Feelings of Belonging. This subordinate theme represented 31.91% of the discussion of peer group support. Participants highlighted the importance of feeling like there were others like them, who had similar experiences as they did, regardless of the actual diagnosis that they have. “When you go [to the peer-led support group] everybody’s got the same kind of issues or a different issue, but it just made us feel like we were a part of something again.” (Tony). For some of the participants, this was the first time they felt validated in their experiences as a person with chronic pain.

> …for the first time, you’re realizing that you have people out there in the world that look like you, that are going through your problems… For the first time, you have

> somebody who has the same things you have, and again it’s not to say that our medical conditions are the same, because they are not, but, you know, all of a sudden you have someone who understands. (Kennedy)

Social hardships, financial hardships, relationship hardships, familial hardships, and sexual hardships were all-recursive examples from participants about topics that the other members of their peer group understood where other people, including doctors and family, did not. “You have somebody who understands the social hardships, that understands the relationship hardships, that understands all of that, so it can kind of feel like you found your people, by design” (Kennedy). The feelings of belonging and understanding that the group fostered created a strong support system that participants identified as a safe space to be vulnerable and to get non-judgmental support. “… understand the safety of these people. To be able to say what you want, and you know nobody’s going to judge you and they’re going to understand you…” (Nay). Furthermore, participants talked about specifically how this safe and non-judgmental space impacts their pain self-management.

> … when I have an issue or something, I usually call the [group] because we know how to deal with it, and you know they can talk you through without using the p-word all the time, or you know the right words or the right triggers… (Tony)

Participants also discussed the impact of altruism in the group, where the support group members would show unselfish concern for the welfare of other members of the group. This theme was recursive among all participants. They talk about how altruism is one of the key factors that allow the group to be successful.

> … we check up on each other, and you know when we don’t hear from somebody for a long time, we figure something’s up and so those calls are made. You know, if I’m turning inwards and having a rough time of it, I will get at least one phone call, probably three or four, and I’ll get texts from everybody. (Geoff)

Nay discusses a specific instance of group altruism where she was hospitalized for an extended time during the holiday season, mentioning specifically that she spent both Christmas Day and New Year's Day in the hospital. She goes on to discuss that where her own family didn't take time to connect with her while she was in the hospital during these important days, the peer support group took time out on Christmas Day to spend some time with her via video chat.

> … they played a game with me and everything … it was a major *major* surgery that was awesome for me, I mean, they thought to do that for me because somebody must have been in that position and knew that that's what could help me … that's something that I'll never forget that they did for me. That was huge *huge huge*. [emphasis added] (Nay)

All participants discussed specifically how impactful it was to have people in their lives that wanted what was best for them, and who understood their experience without having to explain their situation. Both Felicia and Geoff discussed how they struggled with the social obligation to stay and participate in social situations with non-peer relationships even if they needed to leave to manage their chronic pain. They both discuss how in their group, there is no social obligation like that, the group just understands because they have similar lived experiences.

> I don't want to ruin a group setting or a social setting for other people. With the [group] they carry one, they understand, they accept. They are not going to let my leaving affect the group. (Felicia)

Additionally, Geoff talked about how the group prioritizes the individual members to take care of themselves in whatever way is beneficial for them, "… well in our group, you just go because we understand, there's no judgment, you've got to go and do you". Through this quote, it is seen that Geoff emphasizes the importance of participants doing what is best for them in the moment, whatever that may look like.

Communal coping was also a theme that came through in each of the participants' narratives. They report that having a group of peers who have lived experiences with chronic pain has been beneficial not only to their pain management but to their lives. Geoff talks about how his pain management has improved due to working together with the peer support group to unlearn negative coping skills and implementing positive reframing. All the participants discussed that communal coping was how they realized that having a peer support group would be a beneficial step in the management of their chronic pain. Nay recollects the situation:

> [group members] said that they got more out of meeting for dinner after [the medical treatment program] …. And being grouped up together and talking to people, that was more beneficial for them than it was to walk through the pain management things again. (Nay)

Creating a safe, judgment-free space that promotes and prioritizes the well-being of one another with peers that understand each other’s lived experiences seems to be the most impactful part of the management of pain by utilizing social support for these participants.

Peer Group Membership Value. Of the conversation regarding peer group support, 26.2% revolved around the value of peer group membership. Participants found many aspects of their membership in a peer-led chronic pain support group valuable; these aspects can be condensed into three main categories: educational growth, social-emotional growth, and influencing individual growth. Participants reported that the group’s peer-to-peer knowledge network, that there were no topics that were off-limits for discussion, and their dedication to having “learning experiences” (Felica) during their group meetings were all identified as key aspects of group membership that they valued. This educational growth is something the group finds comes very to their group and has a strong impact on each one of the participants. Every participant that was interviewed discussed the importance of being able to bring problems and situations to the group to access the accumulated experience of everyone in the room. Felicia gave an example where, on the advice of the group, she purchased a refrigerator with the freezer on the bottom, she goes on to say, “but when I share something I can’t do, one of the [group] has maybe an idea of how to do it … again, that was an idea from the [group].” (Felicia).

Many participants said that this peer-to-peer knowledge network was more helpful for them than the medical team that they previously relied on. Nay gave an example about a time when this was the case for her:

> … there is somebody in my group that has a spinal cord stimulator and he gave me some of the most genuine information about getting one … [the pain management program] had ambassadors … that you could call and [the ambassador] couldn’t even answer half of my questions, whereas this other person in the group he was like ‘this is what you need to know and it’s not going to be written in any of these pamphlets… (Nay)

However, it wasn’t only the peer-to-peer knowledge network that the participants credited for their educational growth. Participants directly discussed the importance of the group having open conversations about potentially taboo topics. Participants described the topics of group conversations as “not filtered”, “can be about anything”, and “nothing is out of line”. Felicia wryly stated, “… what is shared in that group would probably put any doctor panicking running out of their office ‘no no no no no you can’t share that!’”.

Moreover, it was also the active seeking out educational experiences that 60% of the participants mentioned contributed to the value of the group. These educational experiences, or “learning experiences” as Felicia put it, are sought out by the group to expand their knowledge and help them cope with their chronic pain. Some examples given of these educational experiences were learning about “the pain cycle”, “nutrition guidance”, “alternative life decisions for the hospitals and what we are willing to accept” as well as writing their obituaries and funeral preparation. Felicia discusses that, while these might sound morbid, they are good ways that the group has found to lessen the stress for their family members and encourage autonomy among the group members. But not all examples given were directly related to pain and emergency scenarios, “… we’re going to do a real crazy one this time to show us that exercise doesn’t have to be ‘1-2-3-4 breathe’, no that’s not what it has to be. We are going to learn to belly dance." (Felicia). Kennedy talks about the educational aspect of the peer group as well, “… [group members] are trying new things, learning new things, reading new things, you know, looking at the medical literature so there is all of this that ends up happening … your tools grow and change and increase over time…”.

Peer group membership value was also shown to impact the participants' social-emotional impacts. 80% of the participants discussed how the peer-led support group provided them with emotional support for both situations relating to chronic pain and situations that did not. Emotional support was defined by many participants as having someone to be able to talk things through with, to “bear souls” as Geoff put it. Tony describes the emotional support the group gives him as supporting him in day-to-day living, giving him “strength” when he needed it. Felicia says, “As we share our stories … emotionally they are heavy. They are sad. [The group] is accepting. [The group members] are loving and instructive.”

Of those interviewed, 80% talked about the impact that the group's encouragement had on both their pain self-management and their lives. Encouragement was described as, "giving me the strength and willpower" by Tony and Nay explains it as her group members telling her she can do things she didn't think she was able to. Creating an emotionally supportive and encouraging space for the members has had a great impact and can be seen from this quote from Geoff that encompasses both concepts:

> After I was done with my timeline it felt like there was a big empty spot in the middle of me where all that anger went and … our group has allowed me to not have that spot fill back up. (Geoff)

Of the participants, 60% discussed their feelings of trust and the importance of trust as a key-value to the group membership. Appreciation of the group was also another social-emotional value that was touched on by all participants but can be summed up in this quote from Tony, "I mean there ain't a day or a night that I don't wake up in the morning or go to bed at night thankin' God for the [group]".

Downward social comparison was identified by 40% of the participants as a value of being a member of the chronic pain support group. Geoff talks about this feeling and how it has impacted his outlook on his chronic pain:

> I think going to our groups reminds me how good I have it … it puts the perspective on, you know, the pain that I have because I know my friends have it worse … being able to put into perspective what's going on and how I'm feeling and remembering, yeah, I got it bad, but I don't have *that*. [emphasis added] (Geoff)

Geoff discussed further that his "seminal moment" of his chronic pain journey was his experience with downward social comparison where he realized he "didn't have anything" in comparison to his peers. He realized that when others felt the same, he finally felt as though he belonged. Felicia also talks about her experience with downward social comparison and how it impacts her experience with her pain:

> …one of my favorite sayings is ‘I’m not as bad as they are’ and I know they point at me and say the same thing. However, if I can get feeling ten percent better because someone feels worse than I do, and not feel *guilty* about it…isn’t that a support on its own? [emphasis added] (Felicia)

This allowed both Geoff and Felicia to be able to put their pain into context, to remind themselves of the true state of their chronic pain instead of allowing themselves to continue to catastrophize their situations.

Finally, this concept of “boundaried altruism” was outlined by Finlay et al. in their 2018 study. 60% of the participants discussed their feelings of boundaried altruism. The support group is designed to give advice and support to one another, however, this concept of boundaried altruism gives more nuance to the previously discussed altruism where the group will support and encourage, but not push you past what they believe you can handle. Nay says:

> …when you talk to someone in our group it's just ‘okay, we are okay. Now you can do this.’ … they just understand, they don’t push you to the point you get aggravated but push you enough … to go in the right direction. (Nay)

Felicia explains that the group tries not to put their expectations on anyone, “I try not to make my expectations their journey.” This gives more nuance to the idea of altruism in the group environment as it allows all these social-emotional group values that the participants have identified to be put into practice without pushing individuals too far out of their comfort zone.

Individual growth was the final subordinate group, this group encompasses the group-influenced growth that the participants identified as an important aspect of the peer group membership value. Every participant talked about group-influenced growth, which included specific conversations on accountability and critical peer feedback. Group-influenced growth encapsulates a change made as a direct effect of group membership. Geoff talks about how the group “changed how I operate, how I see life, how I talk to other people”. He goes on to talk about how in social settings he has come to be more understanding of both his limitations and others as a direct influence from the group. Felicia discusses that the group “really brought home” to her the importance of taking care of herself and her own needs, no matter how strange those needs may seem to others without chronic pain. Nay shared that the group pushed her to stop isolating herself when the pain got worse, and their constant support allowed her to reach out for support instead of hiding away. Tony attests that having the group there, coaching him, and helping him keep his attitude positive are things that allowed him to grow. Kennedy talks about the group that has supported her in utilizing and becoming more knowledgeable in various tools that have supported her growth and have supported in her “evolution” that she says couldn’t have done on her own.

However, participants noted that not all group-influenced growth was identified as positivity or seen as cheerleading for each other. 60% of participants talked about how the group held them accountable for their choices and wouldn’t let them “get away” with things. The ability of group members to be able to confront each other on hard topics was seen as not only a strong value of the group but also something that was expected. Confrontation with negative behaviors was often seen as just as important as paise and support for positive ones. Geoff states, “…they’ll call me out on [negative pain management behaviors] and I kind of expect that.” He gives an example further on about how the group utilizes humor occasionally to soften the severity of the confrontation, “… it could be somebody taking medication and then somebody else saying ‘yeah well you spend 50 grand to get over that. That is an expensive pill, are you sure you want it?’”. With a laugh, Tony recalls that group members are not afraid to hold him accountable with this imitation of one of his fellow group members, “God damn, you know, Tony, get your ass up and do it”.

Additionally, 60% of participants mentioned at least one instance of their peers giving them direct, critical, feedback. With the expectation of accountability that has been established in this group, this level of critical feedback was shared as a positive value of group membership. When discussing how the group interrupts negative talk, Geoff talks about how the group does not shy away from critical feedback on each other’s actions in an example he gave:

> [a member of the group] called me once and he was afraid to tell everyone what he had done. He was working on something, and I said ‘man, that’s who we are. If we work and it leads to pain that’s on us, right? It’s not on the injury, it’s not on the project, we made that decision.’ (Geoff)

This level of critical feedback allows group members to see their actions and emotions through the eyes of their peers in a blunt way, which is closely associated with the expectation of holding each other accountable.

Strong Peer Relationships. The next subordinate theme of peer group support is the strong peer relationships that have been shown in this research. 15.7% of the peer group support conversation is related to the importance of peer relationships. The participants shared their experiences establishing and nurturing peer relationships, however specifically all the participants shared a common theme of these peer relationships starting as unexpected connections that were developed through chance and good timing at either the pain management program or the follow-up program, they attended months later. These unexpected connections, especially the ones that were established in the pain management program, were united by both a strong shared identity and shared experiences. Geoff states, "… we blew past [friendship] on the third week of [the pain management program] right. We ceased becoming just people we happened to know". Many of the participants met after their first aftercare program to have an impromptu dinner together, some of whom already knew each other and others who they'd just met that day. Tony describes the situation "A group of, I want to say there was about 12 of us, we walked down to the local bar/restaurant, we sat around the table, and we just started, 'hey do you have this issue?' 'yep'".

These unexpected connections started to grow, and the participants discussed the establishment of these peer relationships during the pain management group and beyond. Nay discusses that she started to connect to the peer group's Facebook page, taking the next step to connect with these peers she had met originally at the pain management program. Nay says, "I started to really connect with these people, and I liked most of them, you know". Felicia remembers the moment that the other core group members reached out to her to form the peer support group, establishing a peer relationship, "When I was approached by a few of those participants [asking] did we want to have dinner once every three months and just get together and talk…" she shared that she believes she was one of the first people to accept the offer and start to build those peer relationships. Kennedy discusses how immediate her realization that the impact of peer support had on her chronic pain when she was just barely establishing these relationships, "… we discovered pretty immediately that those times that we were spending in the evening together… we started treasuring that as its own part of the program".

Building these peer relationships, all participants noted, was integral to their success in the support group. In this period where the group is starting to create these bonds, they mostly attribute finding a shared identity amongst each other, group understanding of their experiences, group encouragement, and the group altruism and boundaried altruism as the building blocks that forged their strong peer relationships. These relationships have led to a strong sense of community within the group, something all group participants spoke of. This quote from Felicia encompasses the various statements that the group gave, "[a support group] takes, well, as they say, it takes a village to raise a child, well it takes not as big of a village … to help support a person with chronic pain". Members of the support group have identified each other and the community they built as the most impactful aspect of their chronic pain management, some talking about the impact of the Facebook group, text messaging, and video chats to connect with the group.

However, these participants all talked about the relationship evolving a step further than strong peer relationships and building community and discussed how their group has become a chosen family through the years. This dynamic was highlighted by participants, defined as "it's different [than anonymous support, it's a family"(Geoff), "it's a level of relationship that has … allowed my quality of life…to increase" (Kennedy), "these people are more my family than my family is for sure"(Nay), "I mean the [group] replaced my blood family…" (Tony), and "…we'll be there for each other forever" (Felicia). As some of these quotes show, this chosen family that evolved from the support group provides the group with a strong bond that not only improves their quality of life and relationship with their chronic pain, but also is strengthened by mutual "genuine love" (Geoff), positivity, and identity.

Geoff, who discussed the idea of chosen family in depth, said, "…my group has become a second family frankly… I call people from there my sister or brother … we are talking about a group of people that we have *chosen* to make family…" [emphasis added]. In this quote, Geoff emphasized the importance of the choice aspect that is attached to viewing the group as family. This connects with what other participants have alluded to regarding the voluntary aspect of group participation.

Positive Support. Positive support, which represented 10.4% of the discussion on peer group support, was identified as being another key theme that supported the peer support group's success. Positive support is defined as the overall affirmative encouragement, supportive validation, and genuine happiness that was cultivated by the group to altruistically support one another. The positivity that was fostered by the group, the happiness that individual participants experienced due to the group, and the overall positive impacts that the group has had are reportedly key aspects of what made the peer support group so effective. Many of the aspects that the participants identified as the group fostering positive support were themes that co-occur within the peer group support selective code. Research says that pain is both a physical and emotional experience and that positive affect, in this case, positivity and happiness caused by the peer support group and is shown to be significantly beneficial to chronic pain management (Finan & Garland, 2015). This corroborates the participants' perspective that positivity is a key aspect of their group that supports their pain management journey. Members talked about positivity extensively in various capacities, but all agree that it was an important thing that their group emphasized.

Happiness was another aspect of positive support that a few participants highlighted as impactful on their chronic pain journey. Nay and Kennedy both talked about how the group was able to bring happiness to them, and Nay even went so far as describing the experiences of just waiting for the group video chat meeting to start as, "… I'm sitting in, ready, and I'm excited you know, I'm excited to see these people". Each member talked about the positive impacts that the group had on their experience extensively, whether that was the happiness and laughter they brought or just keeping the group space and discussion positive. Aspects such as creating bonds strong enough to call family, feeling empowered by doing things previously thought to be unachievable, supportive and positive phone calls from group members outside of established group meetings, and spending celebrations together were all identified by participants as instrumental to contributing happiness to them. Kennedy summarizes her and her peer's thoughts by saying, "…I don't know if…there's any facets that haven't most positively impacted me…".

Group Dynamics. The positive impacts of peer group support are not only on the social-emotional aspects but also on the functional dynamics of the group, which makes up 8.36% of the peer group support conversation. This section discusses the participants' discussion on the logistical aspects of peer-led support groups as well as aspects of the group itself that make it successful.

Participants reported that, before the COVID 19 pandemic, they used to meet once every four months with one larger event a year that they label as a "reboot". The group participants discuss that they have various members that live in different states and that distance is a strong contributing factor to how their group meetings are laid out. Now, after the cultural shift toward utilizing video conferencing tools, the peer support group meets every Sunday via video conference software. This Sunday meeting is referred to by some participants as “[the] family zoom” and has been discussed by most participants as a time to “check-in” with their group.

The retreats that they plan, the “reboots”, were described by Nay as “an amazing amount of work, I mean I couldn’t believe we were collating and stapling and everything”. Nay also talks about what the typical reboot looks like, “… we got up at the same time, we all ate together, then we had our ‘classes’ and everybody participated…”. Felicia, while describing the group's various educational experiences which typically occur at these retreats, talks about how the reunions were typically, “…long weekends, like a Thursday through Sunday…”. Geoff talks about how sometimes these annual events turn into a destination vacation listing places both locally and places that required air travel to go to, especially when going to visit other group members in other states.

The participants struggled to agree on what group leadership looked like from their perspective. Some identified “mama” or “mom”, the oldest member of the group, as the leader. Others identified that there was no distinct leader because they all bring various skills and goals to the group making a communal leadership style the most appropriate description for their group. Some of these varying perspectives on leadership could be connected to certain individuals having a peer role model. Only two participants discussed having a peer role model, but the discussion around it identified Felicia or “Mama” as a peer role model. To this researcher, the leadership theme that comes through in the group is that the “core” group, as identified by Felicia, is the main leading body of the group based on what the participants were discussing. Felicia talks about how the “core” group pulls the “outside” group in, “…so the core group sets things up and opens it up to the outside group” (Felicia). This concept of a “core” group represents the participants' thoughts on the consistency of group members. While some participants, like Felicia, talked about pulling in the outer group from time to time, other participants, like Geoff, highlighted the stability they find in their core group members and appreciated the small turnover rate.

Participants noted the were multiple key facilitation techniques that the group attributes to their success. Kennedy identifies their time in the same pain management program as a reason that they have been so successful, due to being educated in certain agreed-upon standards set forth by the program so that there is a predetermined theoretical framework, a “set of understood values”, for them to approach situations that may come up. Kennedy brings up the concern that if there were members who were in a different pain management program, they might come up with a different framework that could disrupt communication and understanding within the group.

Nay identifies encouraging mindfulness and honesty as ways that the group facilitates their meetings. Setting a timer was a facilitation example she gave if the group had a concern that someone might monopolize the group time. In addition, she remarked that honesty would be key for maintaining their group environment, telling people if they are out of line, and holding them accountable for their actions. Nay adds that redirection is a tool that the group has implemented into their facilitation techniques as they can support group members.

As previously mentioned, altruism has been identified as a pillar of this group and highly impactful for their chronic pain self-management, but four participants have taken the concept a step further and talked about the importance of altruism in the group dynamic. Geoff identified that his chronic pain management skills included the idea of selflessly helping others in his group. Tony had this to say about the importance that altruism in the group, "…get that group of people … that no matter what they love you for who you are and for what you are…". On this same concept, Nay talks about individuals who come to the group and abuse the altruistic nature of group members by coming and taking up all the group's time with a discussion of themselves without giving to others in the group. She recognized this as highly negative, and it was not only identified as disrespectful to the group but also as taking advantage of the group for their own selfish needs. From the information presented, it seems that this altruism is a cornerstone of their group dynamic.

However, even though they identify their helping skills and selflessness, they don't pretend to be trained medical professionals. Geoff recognized that the group is not licensed to educate in chronic pain when he spoke about his thoughts as to why peer-led support was not encouraged in the pain management setting, he said, "[if he was in control of the pain management program] what I wouldn't want is to have people who weren't trained, weren't versed, in what we're trying to teach… I would want a licensed [practitioner] from my facility leading your group". Nay talks about how when the group discusses their pain, any new conditions, or situations that "… nobody's trying to diagnose me, you know, they are trying to be there for me". Kennedy shares the sentiment discussing that "… we are not trained to be care advocates…" and "none of us are certified professionals". This group sets a defined boundary about the role of the group as a peer knowledge network and not medical advice or consultation. Felicia talks about how important it is for potential new group members to understand that the group the boundary when they show interest in the group, "…people need to be in a place where they can accept support, that they [can] trust a non-medical professional to help them on a chronic pain journey…" She goes on to talk about how the group functions on trust and is not held to privacy laws, like HIPAA, since they are untrained. Felicia mentioned that this specifically could be a turn-off for new members.

Group participation was another key concept that was highlighted as important to maintain the current group dynamic. Nay was the dominant voice on this topic as she discussed that member participation and how they participated was very impactful to the dynamic of the group. She says, "…. when we do get together, it's like, everyone is helping, no one is sitting there watching". Nay also talks about the intense collaboration that is required in creating and implementing their retreats and the group involved in both the planning and the retreat itself. Felicia identifies participation as simple as sending a text message to a group member or posting on the group's Facebook page.

Nay highlights that one of the key aspects that makes group participation important is that everyone comes to the group with different skills. She talks about group diversity saying, "we all have different strengths, we all have different things to bring to the table". She goes on to talk about how each member can utilize their strengths to contribute to the group, allowing them to feel worthy of the work that the others contribute and validate their membership.

Impacts of Negativity. The final axial code that showed up in the conversation about peer group support was the impact of negativity on the group. This theme showed up the least, amounting to only 7.44% of the conversation. The group identified negativity as something infectious, spiraling the conversation into one full of complaints and negative perspectives. Nay identifies negativity as a very easy mindset to slip into, especially when surrounded by negative peers. Geoff mentions that when members start to complain in group meetings, it can quickly spiral into what he identified as a “bitch fest”.

Due to this, the group focuses on disrupting negative talk. Strategies identified in this process are, “redirection”, and “laughter”, limiting the amount of time discussing negative topics like pain or circumstance, “shutting down” negative spirals, and even supporting the individual in finding a different group to be a part of. Additionally, there are strategies to avoid negative talk before it happens, like avoiding triggering words or phrases like “pain” or “how are you feeling” which were explained to bring the group member’s attention to their pain. Geoff gives some more insight to this, “I would certainly rather hear about how life is going in all facets rather than just, you know, ‘[I] tore up my shoulder again I can’t believe this’ and going on for the next 45 minutes”.

A strong recurring concept that was discussed by four out of the five participants was negative peers. The discussions around these group members revolved around the idea that they were disruptive, self-absorbed, and inconsiderate.

> … there’s some people are just so negative and no matter what you do they’re going to be negative, and everything is terrible…the food, the chair, you know, anything… They are just negative people and it’s hard to deal with people [that] are all about themselves... (Nay)

Many of the individuals that members identified as negative had traits that directly oppose the key values and dynamics of the group. Tony discussed how this type of group members “…don’t want to make the effort…” and are “…complaining and whining…”, returning to previously discussed topics such as the importance of altruism and disrupting negative talk. Nay used the word “taker” to describe these peers, “…they take everything out of you and drain you…”. This mirrors other discussions on the topic of negative peers, that these negative group members specifically weren’t adhering to the group value of altruism.

Felicia and Nay both shared experiences with a negative peer who was previously a member of the core group, but due to breaches in trust, not accepting group member feedback, and interfering with member’s educational and personal growth she was no longer welcome in the group. Felicia talked about how they “interfered with everyone else’s recovery/acceptance … we were concentrating too much on her and her inability to take care of her mental health that goes along with chronic pain”.

Geoff discussed how impactful negative peers were and how they shaped his experience in his first post-pain management program healthcare provider-led group:

> [a woman attending the group] started to cry and for the next six hours, she cried through everything. If we had a conversation where each of us had to say something, and we each took a minute, she would take 15 [minutes] because she couldn’t get through anything because she cried. [the healthcare provider group] was $3,000 for the day…plus hotels and I probably said 15 minutes’ worth of stuff the whole time and listened to crying for four and a half hours. (Geoff)

Not all the previously discussed negative talk came from negative peers and it is something the participants themselves can struggle with. Participants have discussed that negativity is very easy to fall into and they support everyone in disrupting it.

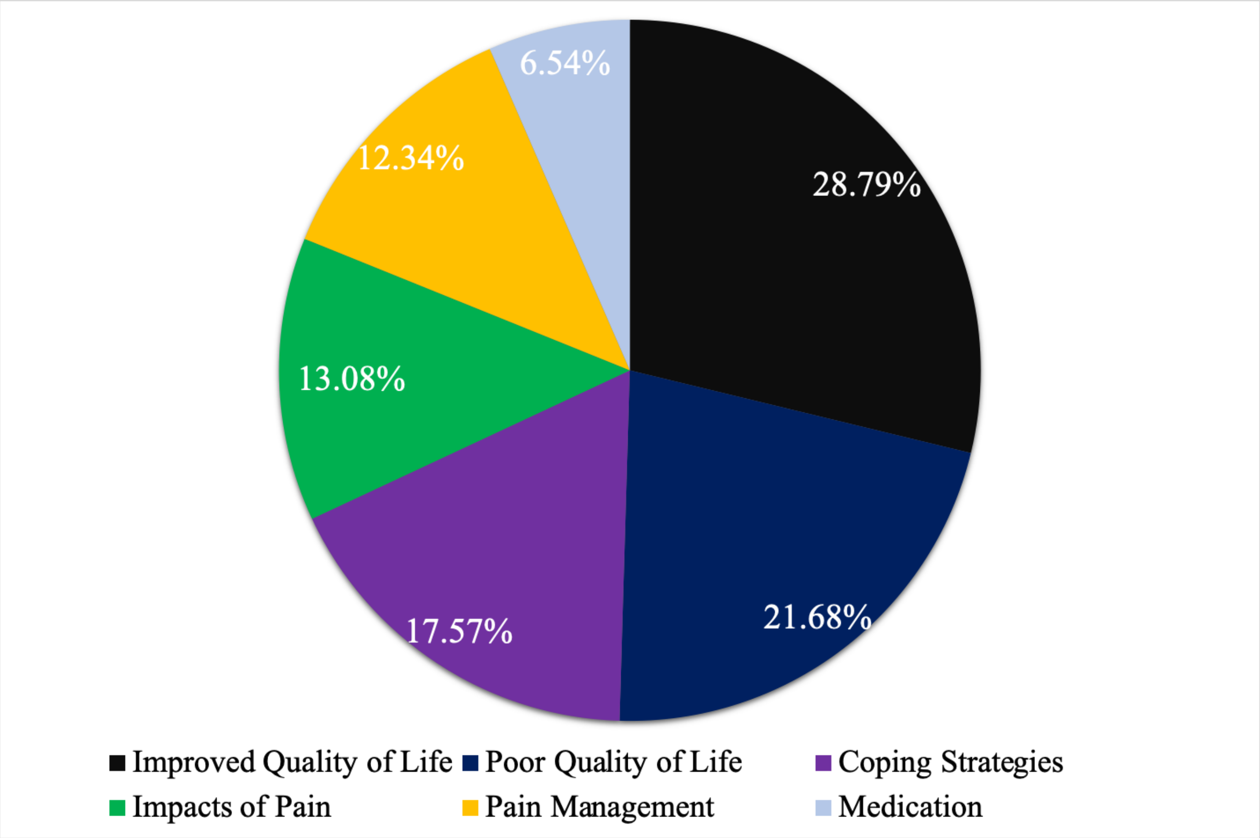
Dichotomy of Quality of Life

Quality of life was the second more frequently occurring theme, accounting for 20.54% of codes in the research. This selective code covers both sides of the clear dichotomy that emerged during the conversation, talking about both the inherently poor quality of life that comes with having chronic pain as well as the improvements in the participants’ quality of life. The axial codes that make up this selective theme fall into one of these subordinate categories.

The axial codes: poor quality of life, impacts of pain, and medication, make up the discussion on poor quality of life, and the codes: improved quality of life, coping strategies, and pain management make up the discussion on improved quality of life. The axial codes for this recursive theme are shown in Figure 3.

Figure 3

Dichotomy of Quality-of-Life Axial Code Breakdown



Poor Quality of Life Resulting from Chronic Pain. The research showed that 41.3% of the discussion on quality of life revolved around the poor quality of life due to chronic pain. This subsection of the recursive theme contains three of the six axial codes present and shows the scope of impact that chronic pain has on the participants involved in the research.

Poor Quality of Life. The axial code, poor quality of life accounts for 21.68% of the discussion regarding poor quality of life. Four of the participants describe having an unknown or idiopathic diagnosis as severely impacting their quality of life. There were seven instances in Nay's transcript where she describes not knowing why she was experiencing pain. She discusses feeling as though "…there wasn't anybody who could help me…" until she found the source of her pain. Unlike Nay's experience, some still haven't been able to find the source of their pain. Kennedy discusses her chronic diagnosis is labeled as idiopathic, "…they can define what is occurring, but they can't tell you why…". The lack of answers, participants mention, can be exhausting and negatively impact their quality of life.

In addition to having pain from unknown sources, the four participants who had their onset of chronic pain before their retirement age talked about the impact chronic pain has on their work-life, forcing them to work through pain daily. This concept of working through pain impacted participants differently based on the kind of career the participant had. Nay and Tony, who were formerly employed as a hairstylist and an autobody specialist respectively, both had to stop working due to the physical toll their jobs took on their bodies. Not only does lack of work cause a reportedly significant impact on one's financial situation, but participants have also connected it to isolation and feeling as though they were losing their value. Tony talks about a cycle that has occurred in his experience when he would work to "…not be such a financial burden on [himself]…" only to cause more pain and problems due to his body "…end up tearing itself apart" and then he would need to pay for more medical assistance which he would work to pay for it. Nay identifies a similar theme. On the other side, both Kennedy and Geoff work in office environments that require a mostly sedentary work environment that is less hard on the body. Kennedy directly related poor quality of life to this concept, "…you're having poor quality of life so [the] chances of you being able to maintain a solid work history, job attendance, functionality, and all of that starts to get impacted as well…". The overwhelming report from many participants was, that just keeping up on their health was directly negatively impacting their quality of life, i.e., hospital visits, traveling to see doctors, working to pay for necessary procedures, coordinating their own care, etc. Kennedy put it bluntly, "…if it not impacting your quality of life, you're not in chronic pain…".

The social isolation that was identified in the discussion of working through pain was a concept that was shown through all the participants' narratives, but most prominently in Nay and Tony's narratives. Nay says that due to her pain, "...I didn't want to be around people, you know, I became very much a hermit…" and later said, "…the worse I am the more isolated I want to be…". Felicia satirically states, "…again, what social life did I have?". Geoff talks about not realizing how socially isolated he was while he was in the throes of chronic pain, but "looking back on it" he identified that he did struggle with social hardships. Kennedy discussed how financials can play a part in social hardships if she can't afford to go out which would dramatically impact her quality of life. Tony talks about how isolation was a coping mechanism of his before his pain management program experience, "If I didn't have to deal with people, I didn't have to explain to them what was going on or how I felt…".

Kennedy also talked extensively about social hardships, talking about how being the "flakey" friend was common due to canceling plans often due to pain. "…so then, of course, you know, you have less people calling", a concept which showed up in other participants' narratives as well. Participants identified that losing relationships is a part of living with chronic pain. Tony discusses this concept when he says, "…it gets to a point where you don't get invited over to this place, because 'I don't want him to fall in *my* yard'…" emphasis added. In addition, Nay talks about the loss of her partner, a significant relationship loss, as a major impacting factor to her poor quality of life and her social isolation. Nay says "…losing my husband and, you know, having small kids, it's just like 'whoa here I am on my own'…". Furthermore, the neglect of family is a significant aspect of social isolation and a strong contributor to poor quality of life, as reported by participants. Three participants discussed family neglect in their experience with chronic pain, all of them talked about how it had a serious impact on their quality of life and their self-concept. Nay shared an instance when her family did not think to visit her in the hospital during the holiday season and went on to express feelings of frustration with them but also feelings of inferiority in herself.

Being isolated from others can not only impact mental health but also physical health if a person requires daily support due to their pain. This lack of independence was reported as negatively impacting their quality of life. Nay talks about how she would find her daily support needs in her daughter and talks extensively about how she wishes for the mother/daughter dynamic, where she can care for her daughter and not the other way around. Felicia also talks about being dependent on daily support "…[I] really couldn't go anywhere on my own…". She identifies driving, grocery shopping, and cooking explicitly as things she would need daily support with, impacting her independence "… [the kitchen] was a mess unless my husband or child would help clean [the dishes] up".

The social pressure that came with being a person with chronic pain is also something that four participants took note of in their narratives. The antithesis of the group altruism discussed in the last section, the group discussed that there were various social pressures and obligations that they couldn’t fulfill due to their pain, causing them to make a faux pas at that moment. This can be summarized by a quote from Felicia, “I always felt compelled that I had to stay to the end [of social gatherings] … my own children [would say] ‘We were playing a game! What do you mean you have to go home?’” This obligation to prioritize the social cues of the event rather than their health is another example of the poor quality of life that comes from chronic pain.

Each of the participants also discussed how explaining their situation repeatedly was exhausting for them. This concept of story trauma, the retelling of traumatic events, was a common thread in the narratives. Kennedy discussed that talking about one’s pain journey was a key concept in the pain management program the group members attended. She identified this aspect as “…potentially could be negatively impacting or positively impacting [on one’s chronic pain] …”. Geoff talks about his experience with the “timeline” activity that the pain management program gave people the option to do. He described the experience of the timelines as others hearing one’s “…innermost trials and tribulations and the anger that came along with it…”. Nay shares that in a different pain management program she attended, she was required to share her timeline with a group she didn’t feel comfortable with, and she said she, “…felt miserable…” about the whole situation.

Finally, the loss that comes with chronic pain and the mourning that goes along with it is another key concept that goes into the poor quality of life axial code. Two participants directly talked about their feelings of loss of purpose or loss of passion that came with their chronic pain. Geoff talks about how, after a severe fall that impacted him both physically and mentally, he made the hard decision to quit playing a sport that had been a strong passion of his for decades. This decision was so impactful for him that he says, “I remember, specifically remember, the last time I put hockey skates on.” He goes on to talk about how he wouldn’t let himself miss the sport because he knew that he wouldn’t be able to play again due to his chronic pain. Nay speaks on a similar feeling caused by the inability to continue her career due to her pain, “I still feel like I need a purpose, because … working was, it is, my joy. It’s my hobby. It’s my interest. It’s all I want to do and, you know, I can’t do it anymore.”.

Four of the five participants spoke about mourning their loss of ability due to their pain. Felicia, who spoke about her “extreme” love of music, shared about a time when she and her husband went with friends to a concert in the park, “even though I was sitting on a very good chair with pillows all around me, I went home. I couldn’t stand it anymore”. She goes on to share that she was in tears along with her friends and husband who shared her heartache. Geoff discusses his experience having to transition out of playing athletics, where he took on other “more social” roles in the realm of sports so he could still be involved without playing. Kennedy puts it plainly saying, “this is a grief process”, she proceeds to talk about how challenging it was to internalize and reprocess the idea that one’s life can’t go back to the way it used to be.

Impacts of Pain. The impact of chronic pain is another significant theme that is shown in the conversation on quality of life, consisting of 13.08% of the discussion. This axial code falls into the category of poor quality of life as participants explained the control that pain has had and will continue to have on their lives.

One common topic discussed by all participants was the uncontrollable nature of their pain. Felicia gave an example of the scope of just how uncontrolled her pain is, "…I stubbed my big toe, well my big toe hurts *and* my back hurts and then my shoulder hurts because those to hurt, and then my hip hurt. It is a vicious cycle…" [emphasis added]. Nay shares her experiences with the severity of pain, "I couldn't sleep…I couldn't sit, I couldn't walk…". She went on to talk about how the pain would just keep coming back no matter what she did to alleviate it, something that many of the other participants echoed. Kennedy spoke on the consistency of her condition describing the pain as something she experienced, "…daily, hourly, minutely…". This consistency is put into perspective in this quote from Kennedy:

> …it's just so damn hard to maintain [one's chronic pain], it is a lot of work to try to live as a functioning human being, emotionally, mentally, or otherwise, and at the same time manage that level of constant issues screaming at you all day long… (Kennedy)

Geoff spoke about his pain, likening it to a family member, "…the pain got to a point where, because we kept adding things to it, it was, you know, part of the family, part of something to deal with everyday…". He talks about his pain as if it were alive, comparing it to various things, a "mini-tornado", "ants are marching", and as seen in the previous quote, "part of the family". Geoff went on to explain that even after the pain management program the pain was still ever-present, "…our pain didn't stop when we left [the pain management program], you know, we all had something added on … and it causes more pain and more pain and more pain…" Kennedy spoke on this lack of a "…at this point in my health, a large portion of what I have is not fixable…". This concept of not having a solution or no longer holding any hope for a "fix" is something that many other participants discussed.

Tony talks about how he ended up wheelchair-bound due to the severity of pain he was experiencing, “The pain got to a point where I was just pretty much couch ridden or in wheelchairs…”. He wasn’t the only participant whose mobility was impacted by the severity of their pain; Felicia and Nay both had mobility aids before they attended the pain management program. Nay shared that her pain got to such a severe point that her daughter pushed her to the pain management program in a wheelchair, “…the only way I could be pain-free was to lay down flat, but how do you live like that, right?” (Nay). Felicia reported arriving at the pain management program dependent on using a cane, “…I walked with a cane and really couldn’t go anywhere on my own…”. All participants discussed the various impacts that their pain had on them. Kennedy expressed that when her chronic pain started, she had difficulties talking, breathing, and eating. Similarly, in Nay’s experience, breathing was significantly impacted by her pain “…especially if you have back pain…you have a tendency not to even breathe deep enough because it hurts.”.

Felicia shared that her pain can significantly impact her mood, “…there are days I can be really snappy, really crabby, and it’s not personal on any level, it is just the way my body is acting that day.”. Geoff talks about how his pain directly impacted his anxiety which caused his mental health to suffer. Additionally, Geoff talks about explaining to others that there are gaps in his memory due to his pain and co-occurring diagnoses, something that Kennedy mentioned in her narrative as well. “What I remember is emotion, and I remember emotion usually pretty clear and then I fill in the rest with pictures I’ve seen or stories that are told…” (Geoff).

Expressing the severity of these impacts, Tony said, "…you can't move, you can't work, you can't do this, can't do that…". Nay also talks about how, because of her pain, she was stuck in her home, isolated from family, friends, and work. "[Pain and anxiety] caused, we'll just call it 'difficulty' at home and work…" (Geoff). Nearly all participants talked about the financial impact of pain as something that was a strong contributing factor to their poor quality of life. The overall economic impact will be discussed further in depth.

Pain was also identified as a strong limiting factor for participants, both socially and functionally. Geoff talks about how there were points when he couldn't drive due to his pain limiting his range of motion in his neck. He also talks about how his pain severely limited his ability to play sports, which was a significant social aspect of his life. Nay and Tony both were unable to continue working in their careers due to their pain, limiting not only the key social factors that work provided for them but also limiting resources such as financial security and their ability to achieve their personal career goals and fulfill their passion for their work. Felicia talks about the physical limitations of pain she experiences, for example, the inability to grocery shop on her own because she struggled to lift the groceries in and out of the cart.

Medication. Participants also discussed the impact that medication had on their quality of life, which accounted for 6.54% of the conversation on quality of life. Four of the five participants spoke about their dependence on medication and the impact that it had on their lives. Tony shared his experience with dependence on pain medications, "…it seems like you're popping pills more … they'd give you pills upon pills because they'd probably get rid of the pain…". Geoff recalled when he attended the pain management program, that he was sorted into the 'addict' group because he was dependent on a pain relief medication to manage his pain. Nay talked about how, when she attended the pain management program, she was surprised at both the number of pain medications she was on and how long she had been on them. "… [the doctors at the pain management program] said … my body was dependent on [the pain medications], so it was really, *really* hard to get off…" [emphasis added]. Felicia talks about how, like the other participants, she did not realize that her dependence on pain-relieving mediation was negatively impacting other aspects of her physical health until her enrollment in the pain management program. "I was only making myself worse. I was allowing muscle tone to go away, and I didn't have enough muscle tone to keep me upright.". She talked about how her medication impacted her quality of life, "I slept through most of life".

Many participants shared that they were overmedicated before they attended their first pain management program. Felicia talked about her experience obtaining pain medication, "…I could have any med I wanted in any quantity I wanted". Kennedy shared that her perspective of pain medication is that it is a "go-to" for most doctors when presented with a person with chronic pain, confirming Felicia's statement. Tony explained that after he started to get off some of his medication, he was seeing things much clearer and was able to understand and appreciate non-pharmacological methods of pain maintenance. And while Geoff shared that he had only one medication going into his pain management program, he was still told that he needed to be tapered off his medication.

Pain medication has also been described by three participants as "limiting". Felicia talked about how, because of her pain medication, she was unable to drive. Kennedy shared that "…it's very difficult to be a functional human being and complete your job, and have relationships, and live your life if you are on the level of narcotics that we generally get prescribed”. Tony was sure to emphasize that his pain medication limited his ability to see the world.

Improved Participant Quality of Life. Improved participant quality of life made up over half (58.69%) of the dichotomy of quality of life. This subsection of the recursive theme contains three of six axial codes present and shows the clear development of the participants' quality of life.

Improved Quality of Life. Participants discussed how various aspects played into improving their quality of life. Of the dichotomy of quality-of-life selective theme, 28.79% of the conversation surrounded the improved quality of life axial code. Quality of life, a more ambiguous topic, has been shown through context by participants to have started improving after their first pain management program and only progressed in improvement when they became members of the peer support group.

Kennedy talked about how her quality of life began to improve when she stopped looking for a “fix” to her pain, “but we’re instead [of a fix, focusing on] ways that are going to make my pain take up less of my life”. She goes on to talk about how acceptance that her pain will always be present and aiming more on removing her focus from her pain to her life has been integral in her quality-of-life boost. Kennedy continues to discuss the importance of not only acceptance of the pain, but acceptance of self and her limitations due to pain. Her experience in the peer group drastically reduced the number of times that she would have gone to a medical provider for support, saving her money, time, and physical wear and tear on her body from travel. She also identifies that the feelings of belonging that the group cultivates and the shared identity that the group has found have made her feel validated and supported, directly impacting her quality of life.

Nay spoke on the change in her quality of life, “[before the peer support group] was a horrible time in my life and I got through it and my life is definitely better…”. She shared that enjoying the little things in life that spark joy for her, like watching television and paying a little extra for cable, were strategies she learned for improving her quality of life from the peer support group. She went on to echo Kennedy’s sentiment that once she learned to accept her pain and “…accepted that it’s okay, that it’s going to be what it is…” she felt that her quality of life improved.

Felicia talks about how the peer group’s Facebook page has improved her quality of life through laughter and photos of the others that show improvement. Like Nay, Felicia said, “it’s okay to be happy and find pleasure in everyday things”. Felicia herself talks about how the smallest things, like a bird landing on her deck, allow her to appreciate the small things and take meaning from them. She shares photos of these small things to the Facebook group to support others who may be having a bad day, supporting her quality of life and the quality of life of other group members. She stated, “my quality of life has improved drastically” regarding implementing things she has learned over the years through the peer-to-peer knowledge network. Felicia also identifies that after she joined the peer support group, she started “enjoying vacations more” because she is learning to appreciate the things around her and make the most of the frequent stops that her pain requires on road trips. Playfully, Felicia said that “I am going to go boogie boarding next winter…should I, do it? Maybe not. Do I want to do it? Damn betcha. Will I, do it? I’m gonna try…” showing that her life won’t be dominated and controlled by her pain. She states, “We can have quality of life, even with chronic pain, we just have to learn to modify it and moderate it”.

Geoff shared that his quality of life was also significantly impacted by the peer group. He talked about how he has “…gone places and seen things that I would never have done…not just going and visiting but actually doing things, you know, when I go places”. He talks about how the group has normalized pain for him, allowing him to feel comfortable “hurt[ing] in public”. Seriously, Geoff explained that “the group has changed my life and, frankly, the life of my family…” showing the scope of the progress of his quality of life. The peer group, Geoff attests, is not only key to managing his pain, but also is what allows him to live his life to the fullest,

Tony shares that the coping skills he learned from both the pain management program and his peers in the group have impacted his quality of life positively. He also talked about how the peer group has significantly impacted his quality of life through his mood, encouraging laughter, “…giggling and laughing was actually better for you than sitting around pouting and moping all the time.” He talks about how the group, “brings out the fun in life again” which supported his pain management as well as his life outside his pain.

Something that was also seen by all participants as having a positive impact on their quality of life was keeping up hope. Each participant talked about their hopefulness, all of them spoke of the hope that becoming a part of a group of peers gave them for their future. One participant’s reaction was nearly euphoric with disbelief at how the group impacted their hope for quality of life. Other participants found hope externally from the group, Geoff talks about finding hope through his partner and hoping to improve for her. Kennedy spoke about the hope she started to cultivate after her quality of life started to improve, changing the pessimistic outlook she adopted after the onset of her chronic pain. “I would say that I *am* better today, and I never expected to have that. I expected it to be static, it’s not” [emphasis added] (Kennedy). Felicia found her hope after the pain management program after she began to see improvement and started to see that could have a life outside of her pain, something that Nay echoed in her narrative as well. Felicia believes that the group is built on hope, “[the peer support group] is built on trust, faith, and a little bit of hope…”.

Change had another positive impact on the participants' lives, the idea that they were metamorphosizing into individuals with not only good quality of life but also people who were no longer controlled by their pain. All participants discussed this concept of their metamorphosis. Nay identified moments where she realized that she could do things she previously thought were impossible with her chronic pain. She went on to talk about how the change in her confidence was another aspect of the personal metamorphosis she experienced through her chronic pain journey, impacted by both the pain management program and the peer support group. She talks about the metamorphosis that she underwent through membership in the group, “they pulled me out of my shell”. Nay goes on to give examples of their influence that sparked the changes she saw in herself, taking trips and reaching out for support instead of hiding away. She gave the group credit for the change that she saw in herself outside of group events as well, choosing to do some crafts versus wallowing in her pain. Having these more effective coping skills is what she indicates transformed her quality of life.

Kennedy goes on to give the scope of the changes she experiences after joining the group, specifically listing quality of life, social relationships, and intimate relationships as things that were changed for the better due to the peer support group. “[these things] changed to a level that’s difficult to communicate exactly how much has changed”. She continued to talk about how the changes weren’t always back to the way things were, “when I say [the peer support group] gave me my life back, I don’t mean my life is like it was before because that’s gone … I mean it gave me my quality of life back”. Kennedy talks about how the group itself calls for evolution in its members since it is an ever-changing toolbox of varying experiences, coping strategies, and knowledge.

Felicia talks about the physical changes as well as the mental and emotional changes that she has experienced during her chronic pain journey. The removal of her cane from the providers at the pain management program was one of the first big changes where she realized her capability. In her changes, she started to take more pride in her appearance after a provider asked, “how I would feel better when I looked like I didn’t feel good”. This indicated a perspective shift for Felicia that impacted her quality of life. The metamorphosis that Felicia identified was not only in herself, but she said that she could see the change in their quality of life on the faces of her group members in their before and after pain management photos.

Geoff indicated more instances of metamorphosis than any of the other members. He talks about how there was a pivotal moment after the medical treatment program that acted as a six-month follow-up for the pain management program saying that the group changed his life by inviting him to participate in the peer group. “This group has changed me as a person, I’m not sure what I would be like if it wasn’t a part of my life.” (Geoff). He identified the biggest changes in himself as becoming more tolerant of others since others were tolerant of him. He also said that the group changed his previously low-risk stay-at-home life into one with more experiences and adventure, affecting not only him and his quality of life but his partner and children as well.

Tony shared that it wasn’t until he started with the peer support group that he started doing exercises that allowed him to shed his mobility aides. With the peer group's influence and support, he made a commitment to himself that he would be able to walk and was able to follow through with it, losing 140 pounds and being able to walk without a wheelchair, walker, or cane. This impacted Tony’s sense of self and his quality of life, allowing him to remove the visible cues of his pain.

The removal of negative coping skills was something that participants noted as also very impactful for the improvement of their quality of life. Felicia used her cane as an example of a coping skill that hurt her, rather than helped her, and the removal of her cane positively impacted her quality of life. Geoff talked about his pain medication was a negative coping skill for him and getting off the medication considerably benefited his quality of life. Tony echoed Geoff’s thoughts on the medication being a negative coping mechanism for him and the significant impact that getting off the medication made for him.

One significant concept that came out of the research was the concept of laughter, which was directly correlated by four out of five participants as a considerable positive force on their quality of life. Tony discussed that laughter was something that would allow people to keep on going during the times when their pain was severe or if they were going through difficult times. Felicia learned that laughter during chronic pain is ok, alluding to the fact she felt a stigma as a person with chronic pain to be serious.

> I got a recipe card folder from [one of the group members] and we decided all of the recipes in it were [going to be] pornographic recipes … talk about laughter! I can still look at some of those recipes like ‘Santa’s Jelly Fingers’ and do nothing but laugh. (Felicia)

Nay reiterated Felicia’s sentiments regarding the stigma against laughter, even though it was so impactful to her quality of life. Nay continued to discuss the connection she saw between successful pain management and laughter:

> …laughter is a huge part of it, we could just text each other, and our group, and, you know, just one little quote or something … and you’ll start laughing and it’ll just bring you up, you know, definitely change your mood completely … it definitely takes a lot of the pain away… (Nay)

Felicia, when responding to a question that asked about what aspects of the peer support group had most positively impacted her, said, “…laughter…lots of laughter”. She goes on to share that she didn’t think that laughter would be something she would experience after the onset of her chronic pain, but now, “…it’s something I look forward to….”

Geoff identified the humor aspect of the group as “gutter” humor and “gallows” humor. He defined this humor as to how the group made fun of each by acknowledging the things they were seeing (i.e., surgery scars) and that those things did not matter to them. By using humor, they were able to confront the negative self-image the group member held and change the distorted thinking that kept them from embracing their disability identity. An example Geoff identified was, “…there’s nothing out of line which probably means some of the humor goes in those directions.” Geoff noted that the group's tendency to tease one another and have the jokes land was something that impacted not only their quality of life but their perspective of self. Nay echoed this concept saying, “…we laugh about it because what else, you know… I have to because otherwise you are crazy, you know, so you laugh about it”. In a phrase of summation, Felicia stated, “if you don’t laugh or smile, you don’t have quality [of life].” Not only was laughter strongly indicated as a way of improving quality of life, but it also was identified as a method to redirect the mind away from their pain. “Can you really feel [your pain] when you’re laughing? You can’t” (Felicia). Tony, Geoff, and Nay each in turn shared the concept that laughter was integral in their ability to redirect their thoughts from their chronic pain.

Coping Strategies. Going into more depth on coping skills, which made up 17.57% of the conversation on quality of life, participants noted significant skills they either learned from the peer group or refined during their membership. Three participants talked about how light exercise or movement was a strong coping strategy for their pain. Nay talks about how, initially, exercise caused her to worry about her pain flaring up, but in fact, it supported her in managing it. Felicia also spoke on this concept, explaining that originally the pain management group was where she started to do exercises that would strengthen areas that were in pain. She credits the peer group to find more engaging ways to move for her health, like belly dancing. Tony talks about utilizing both the exercises he got from the pain management program and peer advice to start regaining his mobility.

Task modification is another coping strategy that four participants mentioned using. Task modification is described by participants as changing the methodology of a task to ease the strain on their bodies. The ability to do tasks that were previously too hard on their bodies was key for the participants. Nay and Felicia gave specific examples of task modifications they use in their everyday lives. Felicia replaced her refrigerator with a model that has a freezer on the bottom so she could reduce the number of times she bent over to look in the refrigerator. Instead of pulling the vacuum back, she learned from the peer group that she should wheel it back in the upright position to lessen the strain on her back and arms. Nay shares that she learned in the pain management program functional skills like how to better hold the garbage can to roll it out on the street. Kennedy shares that task modification is a “logistical” way to manage your chronic pain “… you can modify [tasks] so that you can do more of it…”. Task modification can also look like changing one’s role in an organization to one that is more accessible for their pain like Geoff did in the world of sports once he was no longer able to play, “…I had to replace the actual playing with … more social stuff on the outside…”.

Task moderation is something that only a few participants discussed in their narratives. Kennedy explained that moderation is something she typically uses when she is unable to modify the task. “Another way to address something [if it couldn’t be modified] was to potentially do less of it”. She gave the example of choosing to go to work for two hours instead of six, moving away from the ‘all or nothing’ mindset that Kennedy had a negative association with. Felicia also talks about moderation, in conjunction with modification, as a strong coping strategy that she uses frequently. She identifies that moderation can be challenging because not doing a task can start to cultivate feelings of guilt, however it is still a skill she uses to be mindful of her pain and her limits.

An additional coping strategy that the participants indicated positively impacted their quality of life, is redirection. Participants describe redirection as the process of focusing their mind on something other than their pain to lessen the impact their pain has on them, Kennedy identified redirection as “probably the most prevalent” coping strategy, a sentiment that many other participants agreed with her, Nay calling the coping strategy the “biggest thing” in her pain management toolkit. Kennedy went on to say that when there are no other stimuli, her pain becomes magnified because it is nothing to distract her from it. Geoff talks about distracting himself, primarily through laughter and socializing with the group, to cope with his pain. Tony talks about how he distracts himself with volunteer work when he can, and it helps not only with his chronic physical pain but his mental health and overall quality of life as well. Nay listed coloring books, doing crafts, watching funny videos, and even planning events as examples of redirections she uses. Felicia finds her redirections through jokes in the Facebook group and organically finds small things throughout the day, like birds on her deck. On the altruistic side of the discussion of redirection as a coping skill, Tony said, "If I can make somebody laugh for 30 seconds then they forgot how bad they hurt for 30 seconds…" emphasizing again one of the key pillars of the group's foundation.

Positive reframing is another coping strategy that was frequently reported by participants. The participants describe positive reframing as changing one's mindset about a challenging thing (i.e., chronic pain) into a more positive and healthy way of thinking. Kennedy shares her personal reframe for her pain, "…you're not going to find the thing that's going to make it go away, so if you take this perspective and realize, okay well, you have this thing and view it as its own" she went on labeling positive reframing as an "academic argument of semantics" but yet still attests to its efficacy. Felicia gave us an example of positive reframing, instead of viewing her need to get out of the car and stretch often during road trips as a negative time-wasting activity, she says:

> Quite frankly, I'm enjoying vacations more because I'm finding some really strange things to look at, I mean, when was the last time you went and saw the Paul Bunyan statue, or the green giant, or a roadside museum? Those are things we do now. (Felicia)

Nay gives an example of a positive reframe she uses when she overworks herself, causing her pain to flare up, “I say ‘you know what? I accomplished it. Right, I’m going to suffer for it, but I accomplished it…”. Tony identified that sometimes positively reframing one’s thoughts can be hard, “…it’s not fun getting your mind off of what you’re thinking or what you’re feeling inside and hurting…” but he also said that the emotional and behavioral shift that comes with the change significantly impacted his quality of life.

Occasionally, positive reframing can go hand in hand with religious views. Both Geoff and Felicia discussed their connection to religion in their narratives, but Felicia directly connected her experience as a person of faith as something that supports her in positively reframing situations and improves her quality of life. “I felt that, maybe, I was the blackbird and God’s cardinals were telling me that I was okay.” (Felicia).

Pain Management. The last axial code that falls under the dichotomy of quality of life, is pain management which represented 12.34% of the conversation on the recursive theme. While pain management falls under the improved quality of life side of the dichotomy, there weren’t many recorded instances of pain relief. Common methods for pain relief (i.e., medication, surgery, etc.) may no longer be options for the participants, either by choice or by doctor’s orders. Kennedy, as mentioned earlier, talked about how a “fix” for pain is something that the group doesn’t focus on and accepts themselves and their pain where they are at. However, Nay expressed that she found some pain relief by utilizing a spinal cord stimulator that a group member suggested would benefit her. Felicia shared that she has found some pain relief through utilizing cold packs in the locations of her chronic pain, “and all of a sudden, the other serious pains are not there”.

While pain relief is not common, pain reduction strategies are, with each participant identifying at least one strategy of pain reduction they experienced to be successful. Felicia talks about finding pain reduction with pain medication and exercising for one hour every day, however, in her experience, the pain it reduced was the acute pain, not the chronic pain. This sentiment was echoed by Tony in the narrative, that pills were effective but not effective enough to be a lasting method of pain reduction. Nay identified a few pain reduction strategies, including laying down flat and focusing on her breathing, which she discussed as not being sustainable for consistent pain relief. She also identified laughter, a mental pain management strategy, as something that "…definitely takes a lot of the pain away". Geoff said that acupuncture was a pain reduction strategy that he found worked for him short term. Acupuncture was one of many pain reduction strategies that Kennedy uses to maintain her quality of life, in addition to yoga, meditation, nutrition counseling, and "various levels of chiropractic care". Overall, there are ways that the participants identified to reduce their pain, but none of which they found to be sustainable.

There are various pain management strategies that participants noted throughout their narratives, most of which have already been covered in previous sections. Participants highlighted redirection, laughter, positive reframing, exercise, task modification, and task moderation as pain management strategies they use, but all emphasized social support as the most effective pain management strategy for themselves. "My chronic pain management is my group, and my group is my chronic pain management…" (Geoff).

Other pain management strategies that were mentioned were the "8/8/8" rule, Tony described it as "eight hours of rest, eight hours of relaxation, eight hours of sleep". Geoff explained that some pain management strategies he uses are taking naps, stretching, or calling up one of the peeps for support. He also spoke about remembering to care for his mental health as a pain management strategy, “Mental pain is as bad for me as anything else…”. One strategy that Nay highlighted was having a “difficult day box” where she keeps mementos of positive memories and, when she is having a difficult day, she can go through the bag and smile remembering positive experiences. Kennedy shared that cognitive-behavioral therapy was a key pain management strategy of hers, “your words can impact how you feel, how you feel can impact how you think, and … it’s just a cycle.”. While other participants alluded to not using the word ‘pain’ by calling it the “p-word”, Kennedy spoke on why this was a pain management strategy she subscribed to:

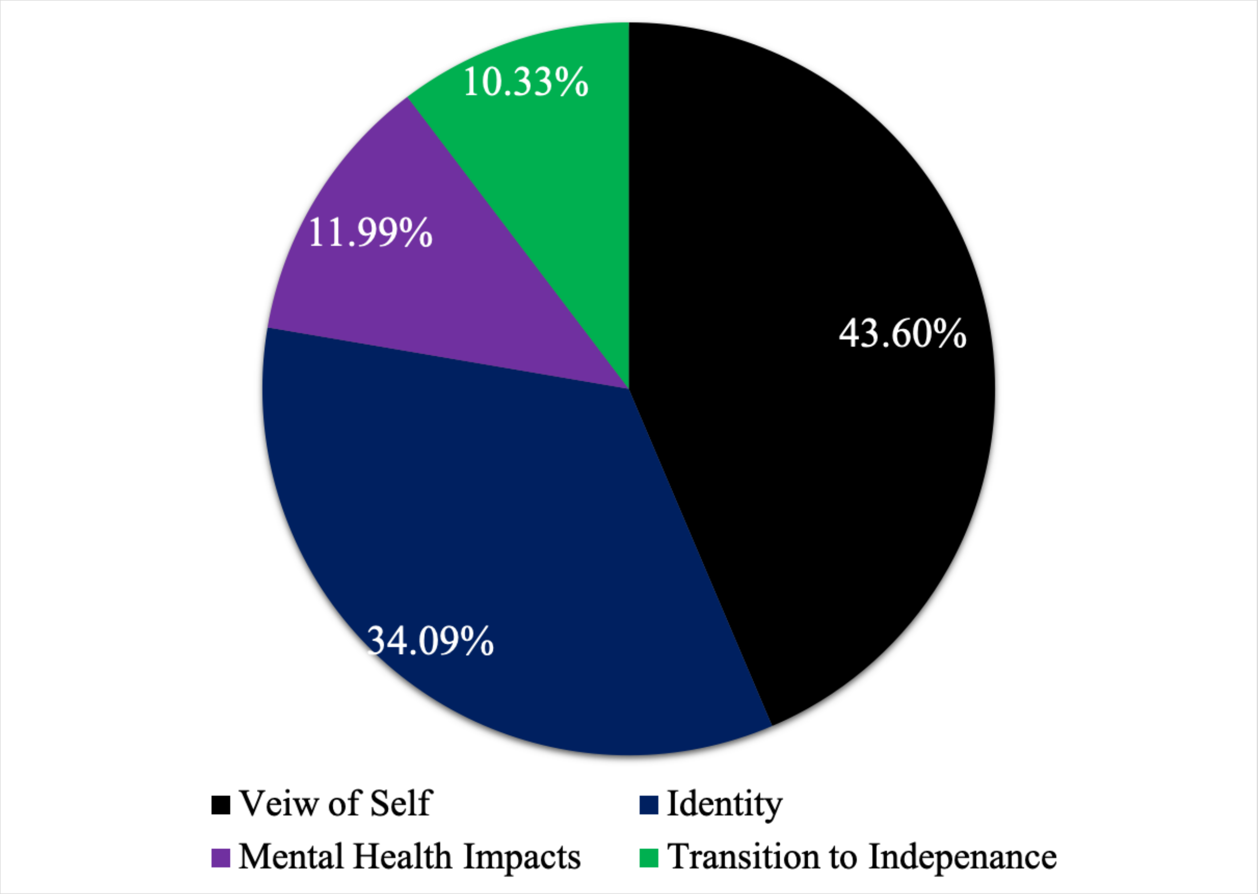
> we don’t use the word pain…because when someone says ‘I’m in pain’ we all have a super negative association with that, your body starts to focus on it and the emotions focus on it, then it becomes more stress which then of course … magnifies all of that. So, we don’t say we’re in pain, we say we are having some discomfort… (Kennedy)

Self-Concept

Self-concept was the third overall recursive theme, accounting for 18.54% of all codes found in the research. Participants discussed how impactful their self-concept was to their pain management and how the peer support group has impacted their view of self. This recursive theme was built on four axial codes: view of self, identity, mental health impacts, and transitioning to independence. The axial codes for this recursive theme are shown in Figure 4.

Figure 4

Self-Concept Axial Code Breakdown



View of Self. Participants' self-concept has been reported to be significantly higher due to their membership in the peer-led chronic pain support group. View of self-accounted for nearly half (43.69%) of the discussion on self-concept. Participants shared how their self-perspective changed and adapted through their various experiences. For most (n=4) participants, their view of themselves and their chronic pain started strictly adhering to the medical model of disability. The medical model of disability says that disability is a defect in the human body that needs to be altered, cured, or removed to have a favorable quality of life.

Felicia shared the development of her perspective of self and that she struggled to get out of the medical model of disability mindset:

> …I always tried to find a fix for me, before [the pain management program], even after [the pain management program] there still had to be a fix out there, [but] with the peer group I accept that there is no fix for me. (Felicia)

Kennedy shares that the medical model of disability was something that she learned and experienced through her medical providers. She discussed that she often felt as though there is a strong push for her to be medicated for her disability calling it a "…hammer nail situation that most doctors go to…". Geoff shared that he was so enveloped in the medical model of disability that when he attended the pain management program all he wanted to do was leave, "I just felt like I was going into something that was, you know, B.S. You took care of [chronic pain] with a neck surgery, this hunky-dory … breathe, breathe, breathe stuff, that wasn't how I operated.". Tony often used the word "normal" to describe individuals without chronic pain and referred to himself as a "cripple", this shows that he has not fully embraced a disability identity and still views himself as something that needs to be fixed like the medical model of disability purports.

Geoff and Tony recalled that before they attended the pain management program and before their membership in a peer-led support group, they didn't realize the severity of their conditions. Geoff indicated that he felt that he had less ability than others, but he didn't realize how his pain had been impacting nearly every facet of his life. Tony, who has had chronic pain for 88% of his life said, "I had [pain] for so long that I just thought it was part of it, you know, up until, like, you know a couple of years before [the pain management program]". This realization of severity skewed their perspective of self and was turned upside down through attendance in the pain management program as well as through their membership with the peer-led group.

Imposter syndrome was also a concept that a few participants talked about. Nay and Geoff both shared that they doubted their belonging in the pain management program after comparing themselves to others in the group. Nay felt as though she was the only one who wouldn't be able to find success in the program, but that others expected her to be. She shared about her first few days in the pain management program, "…when I went to the first [couple days of the pain management program] …sometimes people were dancing like what the heck, this is not where I belong, I have pain and these people are dancing…" Geoff shared that during his time in the pain management program, his imposter syndrome was at an unprecedented high.

> Well, I'm around all these people that have all this *stuff* you know… I saw a guy with a full fishing tackle box full of medication and a guy with a rolling suitcase full of medication, I had *a* bottle. [emphasis added] (Geoff)

He went on to say that he was always hesitant to share his pain experiences because others had it so much worse. "I just kind of felt like I was whining, to be honest, I mean there are people there that had to wear helmets because their medication was so strong, they couldn't stand, and I had one little bottle." When the group shared the morphine equivalency units of their current medications, Geoff shared that there were individuals in the program that had morphine equivalency units upwards of 1400, while his morphine equivalency unit was 4. He shared that it was challenging to experience that level of imposter syndrome while in the program, however, he notes that his experience with the peer group has made him feel validated in his pain and a strong contributor to the group, however, his imposter syndrome has not fully left him.

When the view of self among participants began to positively increase, they internalized the need for self-care and were able to set boundaries with those around them. Four of the five participants discussed setting boundaries with others and themselves because they were putting their well-being and pain management first. Kennedy talks about setting boundaries with herself through task moderation, she reports that she will function better if she limits the number of occasions where she does something strenuous and she tries her best to hold herself to that boundary. Felicia shared that she now sets boundaries for herself in social settings when she needs to leave to take care of herself. She shares that often, non-peer social events will try to push her boundaries and try to pressure her, while the peer group respects her boundaries and encourages all members to focus on themselves and their self-care. The group itself, according to Felicia, sets boundaries for the members so that negative or disruptive peers understand the expectations of the group. She lists honesty and trust as a few of the hard group boundaries for members. Felicia also reports that the group practices setting boundaries not only with each other, family, and friends but also with medical providers.

Geoff identifies that setting boundaries and keeping them was a strength of his, and his membership in the group has reinforced this behavior. Nay, who spoke most frequently about setting boundaries, explains that this was not always a strength of hers. She explained that she would feel guilty changing plans with her friends who did not have chronic pain, but after becoming a member of the group she shares that she has been more confident in asking people to reschedule if she is unable to go out due to her pain. "…if we have to change [plans], we have to change them, you know, and people understand things like that…" (Nay). She shared that because of the pain management program and the group, she has realized her ability to set and keep boundaries with her family, friends, negative group members, and herself.

Each participant spoke about their experience with the realization of their capability. Things that might have never been plausible for them had become feasible due to the support of the group. Nay credits the pain management program for originally opening her eyes to what she is capable of physically, "… [the pain management program] showed me that I could do way more than I thought I could do without having, you know, a big issue…". Nay talks about how the support group has allowed her to realize that she is capable of even the things that the pain management program told her she may not be able to do. Like Nay, Geoff and Felicia attributed the beginning of their realization of capability journey, to the pain management program, but the peer group is what fostered that development for them. Geoff, like most of the others, identified traveling long distances and doing activities that he would have not previously considered doing due to his pain as some of the ways that the support group has impacted his perception of his capability. He also realized that he was more available than he previously thought regarding his mental ability to hold himself accountable for his actions and to reframe his thoughts. Felicia attributes the full realization of her capability to the support group, "…there are very few things we *can't* do if we are careful…" [emphasis added].

Kennedy shares that the group "…gave me my life back…" because she could do many of the things that she attributed to improving her quality of life. She goes on to say the biggest realization she had was that she is stronger than she had ever anticipated after her diagnosis.

Tony shared that his biggest realization of capability was just realizing that he could be a part of a support group like this, be an active and contributing member and support others in their pain journey. He goes on to talk about his realization that he could make changes to his condition, he could take steps to improve himself, significantly impacting his self-perspective.

Self-efficacy is the belief in one’s ability to perform specific activities and skills. Participants discussed how their fear paralyzed their self-efficacy, believing that it would do more harm or injury to their bodies. However, individuals attributed an increase in self-efficacy to the peer support group. Group members challenged the participants' distorted belief system which was life changing. Tony showed examples of high self-efficacy when he made a goal to be able to walk again and was able to fully succeed in that goal, losing 140 pounds and no longer using a mobility aid. Participants also attributed some increase in self-efficacy to participating in the pain management program. Kennedy showed high self-efficacy as well when she shared all the different tools that she used to manage her pain which she learned from both her peers in the support group as well as from healthcare providers in the pain management program. “We have to pull ourselves out” (Felicia). The peer support group changed participants’ belief in themselves to make positive changes and to support them in realizing their capabilities.

Confidence was another key view of self that four participants mentioned. Each participant who discussed confidence shared that they felt the group supported them in building their confidence. The idea that the participants felt as though they could trust in and rely on themselves while also feeling self-assured in their abilities is key for their view of self. Many of the participants' comments that showed their growth in confidence were attributed to the group building strong peer bonds, the shared communal identity that they are all in together, and the group encouraging each other in hard times. Nay said, "…the support group has given me more confidence that I can [manage her chronic pain] …".

Closely connected to setting boundaries, autonomy which was discussed by four participants is another view of self that was reportedly augmented by participation in the peer-led chronic pain support group. Participants felt like they could finally make a decision for themselves based on their own goals through encouragement and validation from the peer support group. Nay spoke about how she has started gaining more autonomy for herself, not only medically, but also within her family dynamic, so she can regain some of her role as a parent to her daughter. She felt comfortable doing things the way she wanted to do them and not obligated to follow a certain medical path or suggestion from those who helped take care of her in the past. Felicia talks about how she takes steps to be autonomous by being able to decide on her own "alternative life decisions". She gave examples of choosing if she would allow her chest to be cracked open or if she would allow them to "zap" her heart in a medical emergency. Geoff talked about his autonomy in his work life, choosing if he was going to overextend himself, "…if the answer is yes, then when I was done, I hurt like a son of a gun, but I didn't blame my shoulders, I didn't blame the doctors… I was able to say, 'okay I over stepped'..."

Self-concept was the fourth highest out of 144 open codes identified through the research and across all five participants. Participants shared their self-perspectives, some being positive and self-assuring and others being more critical or outlining a weakness. These codes show that the participants connected their strengths and weaknesses, outside of pain management and the peer support group, to their overall perspective of self. These windows into their self-concept allowed the research to be able to apply these self-reported personality factors to the data and draw more accurate conclusions throughout the research.

Identity. Identity made up 34.16% of the conversation on the participants' view of self. There are many aspects of identity that the participants covered, finding a shared identity with their peers, developing their own identity as people who have accepted their chronic pain, their acceptance of their disability, and finally regaining their identity.

Shared identity was strongly expressed by participants, the idea that everyone in the group views each other as all in the same situation regardless of if the situations are similar or not. "…we are all in the same boat… everybody's in the same boat…" (Nay). Through this shared identity, group members reportedly more effectively supported one another, having experienced similar situations on various levels. "[living with chronic pain] requires support to continue to do it, and that support can only be provided, in some ways, by people who understand it." (Kennedy). This sentiment was repeated by each participant when discussing shared identity. Group understanding, as discussed earlier, impacts the group's shared identity according to participants, as it is easier to identify with someone who has similar experiences. Felicia and Kennedy both underline the similarities they found, listing off social, relational, financial, personal, familial, and sexual hardships that they found connected them. "…we're all equal because we're all going through the same depression, financials, you know, struggling with medications and all that stuff…" (Tony)

The group felt enough shared identity to start calling each other a family, to choose to be closest to each other over their blood relatives. They have all heard each other's innermost struggles and moments of suffering and have found a kinship within each other after hearing the others have had similar experiences with them. Participants discuss that they feel similar to each other even though they come from drastically different walks of life, their shared experience as individuals with chronic pain bonded them deeper than any other shared experience any participant could think of. This concept is encapsulated by Kennedy in saying that the "difficult journey" that is chronic pain was something that one would no longer need to walk alone since the peer support group was all on the same journey, again, regardless of each member's diagnosis. Tony shared that "…it brings you back to making you feel that you're not in this world on your own…". They have all encountered the same stigmas as well, as Kennedy shared "There are things that all of us experience… I mean *all* of us in the support group have had, I've had, since the beginning that either weren't addressed or weren't medically verified…" [emphasis added]. Finding that others have similar experiences, for example, symptoms that a healthcare provider might have brushed off, would account for another shared experience amongst group members and "starting to see all the threads that connect [the group]." (Kennedy).

The group thinks of each other as equals, even though they all have different diagnoses and different lived experiences, "…nobody in our group is any less than anybody else in our group…" (Geoff) and "…the medical impetus for our chronic pain was very different for all of us, [but] there were so many aspects that were similar" (Kennedy). The fact they all went to the same pain management program impacted their shared identity as well since they all had a base shared experience to bind them together, Kennedy shared that she experiences her connections with peers "…bolstered by having similar experiences and going through [the pain management program] together… [peers in the pain management program] could identify with your experience and you could identify with them…". "…we all struggle, but we all do it…" (Tony).

Since the pain management program, the group has created shared experiences that cultivate their shared identity, even more, traveling together, creating their pain retreats to learn more about pain management strategy and other topics that they find important to their identity as individuals with chronic pain. Nay discussed that the inside jokes were an example of a pain management strategy that was developed over time since they came from years of shared experiences with the peer support group. Felicia uses the words "our" and "we", "…. we have to take care of our needs…", and "… we saw ourselves as we really are…" bringing the group into a collective identity with shared experiences. Tony shared that he always lets the group know when he is having a procedure or a surgery because, "…they understand, they can relate, and without that part right there, *them*, it's lonely you know?" [emphasis added].

The participants also discussed their personal identity development in addition to the shared identity they cultivated. Participants shared that they were continuously developing a richer sense of understanding of themselves within the context of their chronic pain. Many participants connected their identity development journey to other aspects of the group, including communal coping, the peer-to-peer knowledge network, group understanding, and group altruism just to name a few. However, the aspect that participants correlated with their personal identity development most was the shared identity that they were developing in tandem with their identity.

The participants, who all have shared that they view each other as a family, have had their own identities evolve because of the close bonds they have with one another. The creation of a bond so deep they consider each other's family came with a strong shift in personal identity for each participant. Geoff talked about how the peer support group has impacted his identity, learning that both his chronic pain and the peer support group are "…always a part of who I am…". He goes on to talk about how, because of the peer support group, he has started focusing on himself more, "…I'm focused on me and whatever you do is on you, and it changes how you look at life when you start thinking about it that way". Kennedy talked about learning and growing with the group impacted her own identity as one that was okay to evolve and didn't need to stay stagnant. Nay shared that making her choice to turn to the peer support group instead of going back to the pain management program was something that impacted her identity. She started giving herself grace when her pain is bad because she was starting to improve her perspective of her self-worth and learn that it was okay to not have answers regarding her pain, all of which she directly attributed to the peer support group. Tony talked about how his identity as a person with pain started to grow when he realized that he wasn't alone in his experience, it showed him that there was an opportunity for a future for him. This sentiment was shared by Kennedy. Geoff shared that a huge identity shift for him was releasing the anger he had been holding onto over the years, and he credits the group with the fact that his anger hasn't returned.

The participants discussed that learning to accept their disability was not only crucial to their individual identity development and cultivating their shared identity, but it also was impactful to their pain management strategies. With the chronic conditions of the participants, many of them explain that there is no “fix” for them, so they have to accept their condition, accept that this is their life. “…we know this condition is not going away and it’s not going to change...” (Kennedy). Geoff said that his identity as a person with chronic pain improved through his acceptance of his disability. Felicia shared that her identity was also shaped through accepting her disability, that her needs as a person with chronic pain were not only valid but important. She explained that one of the tenants of the group is acceptance of disability, “…you can’t be looking for a fix anymore, you have to accept that you have chronic pain”. Nay summarizes her thoughts which parallel those of other participants, “I’ve accepted it’s okay, it’s going to be what it is … acceptance is a big part of it to have…”.

Kennedy explained that acceptance isn’t an easy path, “…ultimately, [coping strategies and pain reduction strategies are] not going to solve your problem which makes [acceptance] difficult…”. Nay explained that the hardships do not disappear once you have accepted your disability, “…I still have all these things that are in my life…”. However, Kennedy shared that not only did accepting her disability impact her self-concept and self-esteem, but it also significantly improved her quality of life. “…when I said that [the peer support group] gave me my life back, I don’t mean my life like it was before, because that is gone, that’ll never be me again, and the scars of what was and has been, physical and otherwise, are just a part of who I am.” (Kennedy). Geoff mirrored Kennedy’s sentiment, “sometimes [acceptance] going to suck”. Tony shared that he sees his pain and accepting his pain as something that he “…just gotta keep plugging away at…”.

Each participant mentioned at least once that, due to the peer support group, they feel as though they are regaining their identity. Nay shared a moment where she was seeing strong improvement in her ability through her coping skills and pain reduction strategies where she finally felt like herself, saying, “This is me.”. When the peer group encouraged her to grow with them, Nay talks about feeling more herself. Kennedy talks about how the group allowed her to accept her ever-developing personal identity as a person with chronic pain as her own. Geoff explained that he started regaining his identity after he lost some of it to his chronic pain, “I am not my pain. Right, I have pain. I’m going to have pain, for the rest of my life, but you’re not *that* …” [emphasis added]. Geoff went on to talk about how he isn’t sure what his life would even look like if the group wasn’t a part of his life. Felicia said that she can see the differences in the faces of both herself and her group members from before the pain management program to during the peer support group, and that difference underlies regaining their identities from their chronic pain. Tony shared that the feeling of belonging he had was so strong that it helped him regain his identity and his worth because he belonged somewhere again.

Mental Health Impacts. Of the conversation on self-concept, 11.80% was dedicated to the mental health impacts that the participants brought up. The mental health impact of chronic pain has been discussed before in this research, but there were many nuances on mental health that participants noted across narratives. The feelings of stress, shame, fear, and disappointment are often strong contributors to an individual’s mental health status which directly impacted their perspective of self. Participants showed examples of this in multiple instances.

Overall, only two participants directly addressed the relationship between their pain management and their mental health. Geoff notes that his mental health can cause a flare-up in his pain, “…mental pain is as bad for me as anything else…”. He goes on to give an example of a situation that took a strong emotional toll on him, and what would have happened to his pain if he didn't have the peer support group in that situation:

> [if he hadn't reached out to the group for support] what would have happened is my pain stuff would have jumped, I'd have been terrible the next day, I'd have this hurt and that hurt, and I might not have gone to work… (Geoff)

Geoff shared that he isn't the only one in the group whose pain is tied to their mental health, "…imagine being around a bunch of people who, when they are stressed, hurt…". Felicia also talks about her mental health and how she has taken to doing her make-up and her hair every day to her mental health and, indirectly, her pain "on my bad days, if you look good, you feel good.".

While not all participants discussed overarching ideas of mental health and the impact it has on their chronic pain, four participants spoke directly about feeling shame. For most, this was in the context of feeling ashamed of their chronic pain. Nay shares that she wants to become a mother for her daughter since she feels that her daughter took care of her and not the other way around. "I wanted to get my mom role back because my daughter became my mother … I want to be the mom again, I don't want to have her taking care of me, I want her to have a life" (Nay). Felicia discussed taking care of a child, "I would get out of bed when she came home from school, and when I put her to bed, I would get back in bed.". Felicia also outlines her personal feelings of being ashamed of not living up to her own, and others, expectations. For her, guilt and shame stemmed from putting her needs first and setting boundaries in social settings. Tony shared his feelings of shame when discussing losing his house due to the financial impact of chronic pain. He goes on to identify feeling ashamed of his pain, hiding it away from others, and feeling shame for being "weak" because of it. The sentiment of being ashamed of experiencing pain in public was something that Geoff also discussed in his narrative. Geoff went on and identified his shame of not being the husband and father he would have liked to be, due to his pain and that his wife had to take on most of the responsibilities with the family.

Stress was discussed by three participants. Kennedy shared that having pain is stressful but its nature. Nay identified stress when she started the pain management program, she noted that her blood pressure was “super-high” and was having physical manifestations of that stress (i.e., sweating). Geoff identified anxiety that came with experiencing financial hardships, and that it was closely associated with his feelings of fear, “…there is fear involved [in having financial hardship], there’s waiting for the other shoe to drop, and there was anxiety…”.

Fear was discussed by two participants. Nay shared her fears regarding attending the pain management program, “…. I thought for sure I was going to have a heart attack…”, she said that on her first day there were so many changes and new people which intimidated her. Nay gave an example of her fear of having not knowing what the source of her pain was after two or three weeks of trying to get answers, “…I had tears rolling and, you know, the nurse, the X-Ray tech, or whatever, she says oh don’t worry it’s not going to hurt, and I said, no if this doesn’t come out with the answer, I’m crazy…”. Nay also mentioned that she had some fear before her first trip with the peer support group, saying to herself, “…what the heck am I doing…”. Geoff shared his fears about financial insecurity due to the financial hardships that came with chronic pain, but he also shared the fear he felt during the pain management program when they put him into the addict section of the group. “…they put me in the addict section, which scared me…”.

Nay and Geoff were also the only participants to share their experiences with catastrophizing. This cognitive distortion is something that the participants acknowledged by example, how they very quickly jumped to the worst-case scenario. Geoff gave an example of catastrophizing which shows how easy it can be to focus on the negative which decreases one's mental health:

> …if I can't drive because I can't turn my head, I don't think 'boy I can't drive' my focus isn't on that. My focus is, I can't turn my head, and I can't turn my head because there is this block and the block hurts so now, all of a sudden, I can't drive because I hurt… if you follow the rabbit hole all of a sudden, I'm blaming not driving on being hurt. (Geoff)

Nay's examples of catastrophizing were more subtle, talking about how she feels that things never go right for her, "…normally people go in for an appendix [removal] and they … come out outpatient, no, not me. I had to stay overnight for two nights and leave with a drain…nothing goes easy for me…".

Disappointment was another code that only showed up within Nay and Geoff's narratives. Nay shared that she felt disappointed coming out of the pain management program. She'd expected to be able to utilize all the skills and strategies she learned, but it was all much harder for her outside the program which "…busted my bubble a little bit…". Geoff shared his disappointment in the follow-up medical treatment group that was a day-long refresher course for their pain management skills, which was hosted by the same place where they had their pain management program. He shared about a woman who monopolized everyone's time and he was looking forward to being able to check in with people and learn more, but the program did not go the way he had hoped.

Transitioning to Independence. The transition to independence, which made up 10.35% of the conversation on self-concept, allowed the participant's self-perspective to grow alongside their quality of life. Each participant shared their experiences transitioning from dependence to independence. Kennedy defined her transition from dependence to independence as finding ways to make her pain take up less of her life. Tony felt that he was becoming more independent when he started to get off his medications. His transition to independence could also be seen in his lack of need or want for a healthcare provider's support, "…you know, we do fine without the medical thing…". Felicia notes that the day the providers at the pain management program took her cane away was a key moment on her journey to independence. Geoff talked about how reaching out to his group members and not needing an appointment or a prescription and being able to go and live his life were both indicators of independence. Nay credited her transition to independence as one that was marked by her developing stronger self-confidence and self-efficacy.

On the path to independence, there were moments when the participants identified that they were unaware of the impact of their medical decisions. Nay, Felicia, and Tony each spoke about a medical treatment that they agreed to which negatively impacted them, however they took their scenarios as a moment for growth. Felicia and Tony both outlined that they were unaware of the impact that their pain medication had on their bodies. Felicia went in-depth to explain that the pain medication she was utilizing was significantly impacting her system and did not realize she wasn't strengthening her body daily, leaving her weak and out of balance. Nay delineated her experiences with being unaware of the impact of the medical decisions she made, explaining that medical professionals had left significant choices to her without giving her enough information for her to make an informed decision. Because of this, these three discuss independently taking steps for their health outside of the healthcare field.

A part of the transition that three participants identified was disillusionment. For Nay, she was disillusioned by her diagnosis, often in her narrative were phrases like "…this can't be happening…" and "…I didn't realize…" that show her deconstruction of her perspective of the medical model of disability and coming to terms with it. Felicia notes her disillusionment when she realizes she could keep her balance in her first few days in the pain management program, which was a turning point for her when she realized her capability. Geoff's disillusionment surrounded his realization that his quality of life was so poor when he was in the throes of chronic pain.

Shock was something that showed up in three participants' narratives. Geoff expressed shock when he realized the extensiveness of the pain management program, indicating that he laughed out loud when he heard it would be a 27-day program and initially refused the treatment. He also described feelings of shock when he was sorted into the addict section of the pain management program as well as when he was given his morphine equivalency units describing himself as "stunned". Kennedy articulated her moments of shock in herself and the change she has seen in herself after membership in the peer-led support group. She also expressed shock when she realized that she was holistically improving through the peer support group. Nay identified as being shocked at the improvement she made throughout the pain management program, feeling confident in her ability to change her situation.

Felicia and Nay both talk about being critical of themselves and how that has impacted their self-concept to transition into independence. Both women shared that they have been critical of themselves when they struggle to moderate their activities that they know will cause their pain to flare up. Nay specifically highlighted the challenge that it was to balance working, especially because of the personal and financial fulfillment she gets from it. “…[I] kinda reprimand myself for overdoing it because I know that’s not something I should do…” (Nay). Due to the imbalance that Nay’s work has on her life, it challenges her independence. This severely impacts her self-confidence and financial security. Felicia also shares that she has been critical of her own needs in the past and through her transition to independence, she has been able to accept her needs and has given herself more grace.

In the many transitions that participants discussed, starting the pain management program, ending the pain management program, and starting the peer support group, three participants identified certain challenges that came along with it. Nay shared that her transition into the pain management program was intensely challenging, going from her life of pain to a program where “…you’re going to be there for three weeks, you are going to go from eight to five, and you’re going to be sitting up straight…” (Nay). Nay identified that as “…very hard for me”. Felicia also discussed the transition into the pain management program as significantly challenging, explaining that they took her previous coping strategies and supports, like her cane, away from her.

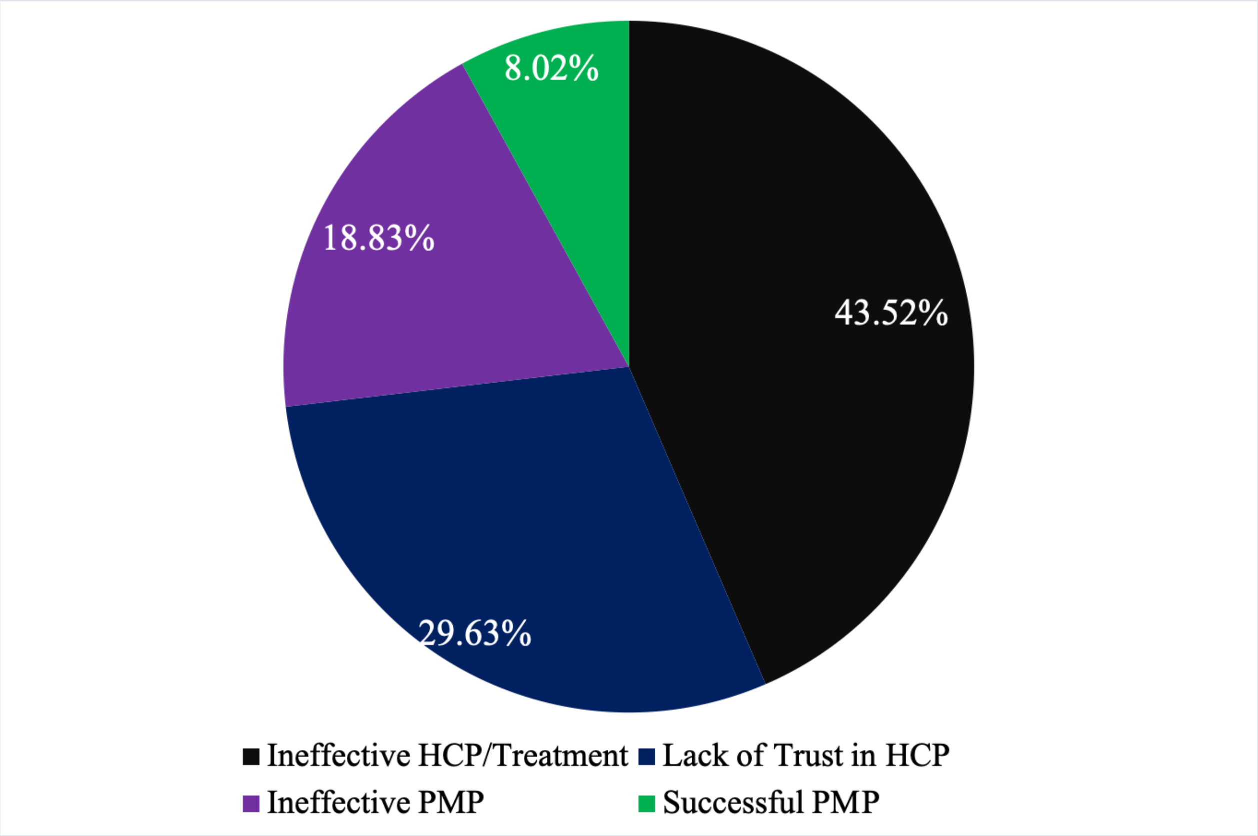
Kennedy shared that the transition from the pain management program back to her home life was an extreme challenge. She delineated that, while the tools and strategies given by the pain management program had been significantly impactful, the transition home was incredibly challenging as the usability of the tools given by the program were not realistic for everyday use in tandem with managing her child, her career, and her spouse. “…you tried to back and integrate what *was* your life into [pain management strategies given by the pain management program] and some of the pieces don’t fit anymore…” [emphasis added] (Kennedy). This sentiment was echoed by Nay and Felicia, “…when I came home [from the pain management program] was difficult…” (Felicia).

Impact of Healthcare

The impact of the healthcare industry was the fourth overall recursive theme, accounting for 12.43% of all codes found in the research. Participants shared their experience with the healthcare industry and how that influenced their choices to create a peer-led support group. They give their unrestricted perspective on the healthcare industry and how it handles patients with chronic pain. This recursive theme was constructed on four axial codes: ineffective healthcare provider/treatment, lack of trust in healthcare providers, ineffective pain management program, and successful pain management program. The axial codes for this recursive theme are delineated in Figure 5.

Figure 5

Impact of Healthcare Axial Code Breakdown



Ineffective Healthcare Provider/Treatment. Most of the codes shown in this recursive theme fall under this axial code, making up 43.52% of the conversation about ineffective healthcare providers/treatment. Each participant shared their own experiences with ineffective healthcare providers and ineffective treatment, some of which were inherent to the experience with individuals with chronic pain, and others were identified by participants as healthcare provider inadequacy.

All five participants identified that throughout their chronic pain journey they experienced inconsistent healthcare. This was frequently due to needing to see specialists for their various concerns and is, subsequently, a natural impact of having chronic pain. However, Kennedy states plainly the concern that lies within inconsistent healthcare:

> …none of [the healthcare providers] talk to each other, so if you're seeing your, you know, acupuncturist, if you're seeing a counselor, if you're seeing…your general doctor, your surgeon, all of those people operate separately… a person who struggles with chronic pain is, on various levels, trying to coordinate your own care and none of them being sufficient enough on their own to fully give you much relief…" (Kennedy)

Nay discussed that because her original doctor could not figure out her diagnosis, she ended up going to many different providers to help her. She reported that her original provider said, "…I just don't know what to do with you…" before she went to another provider. Geoff shared his experience of being passed from healthcare provider to healthcare provider until he was referred to the pain management program. Kennedy, who has been to two pain management programs, discussed her experience in her second program which had her meeting with "multiple therapists and counselors…[and] neurologists…" daily. Tony and Nay had also been to multiple pain management programs, all three identified changing methodology and healthcare providers for each program they attended. Nay specifically mentioned transferring from the pain management program, where she worked with a counselor, to having to find a new one at home when she left.

Felicia shared about her original visit for chronic pain started with a prescription for pain medication and then a referral to "…physical therapy, then to a surgeon who sent me to more physical therapy…then more CAT scans… between all of the doctors I could have any med I wanted in any quantity I wanted”. This shows that not only is inconsistent healthcare problematic for their quality of care, but also the patient’s health. Tony shared that he had a similar experience, “…all the doctors without a thought, ‘yep here’s pills’…”. Geoff shared that he has been to “plenty” of healthcare provider offices for chronic pain and he wasn’t once referred to find a peer support group, which led him to believe that the providers did not think about the best way to support his pain but only the best place to “fix” his pain, not caring about him in the process.

Kennedy also discusses in-depth that she often moves from provider to provider because their specialty no longer works for her pain. This inconsistency, she went on, can not only impact the quality of care but can also impact her financially. “…one of my five neurologists turned to $600 an hour…”. Geoff shared this financial concern about attending different groups after the pain management program.

Each participant has had experiences with ineffective treatments. Most often, participants identified a treatment as ineffective if it did not change their pain levels or impact their quality of life for the better, while still being financially and logistically plausible. Kennedy explains that finding many treatments ineffective is inherent to the condition of chronic pain, “…it is a part of the condition that either there is not a solution for it, or the solution is inadequate for some reason”. As mentioned earlier, Kennedy believed that healthcare providers tended to look for a “fix” which she identified as a part of why many treatments were ineffective. “…there’s just not anything out there that is going to remove those conditions…having all these inadequate tools, none of which are working together…”. She outlined two factors that she felt caused ineffective treatment amongst individuals with chronic pain, "…I think pain is not addressed as an issue…[also] it's overmedicated…". Tony shared that his experience with medicating his chronic pain was ineffective, causing him to lose significant quality of life even if they did manage his pain. Nay listed various experiences, like biofeedback, that she found to be fully ineffective.

Kennedy shared that the knowledge sharing factor of treatment, before the peer support group, was ineffective since it caused severe financial impacts and was logistically unproductive. She explained that seeing a provider and asking a question could have a significant financial impact, in her case approximately $600, especially if the question turned out to be something she did not need to be concerned about. She went on to explain the logistical difficulty of getting into a provider which, in her experience, could take up to three weeks to ask questions or get a professional opinion. Geoff discusses this idea as well, "…if I had to call and be put on hold to talk to the person who leads the group … by the time they got back to me, the moment will have passed…".

Nay shared that her experience with the healthcare provider ran support group that acted as a follow-up treatment for the pain management program was that it was a "…complete waste of time…" Tony echoed Nay's sentiments, as well as Kennedy's thoughts on the importance of financial feasibility, when he said, "[the follow-up program] was $3000 for six hours of sitting in a room and throwing a question in a hat and *maybe* get them answered… it really didn't help us…" [emphasis added]. Felicia shared that most of the topics she wanted to learn about weren't even touched on in the follow-up program's "standard lecture". She said, "I maybe got one or two things out of [the follow-up program] …" and went on to directly compare how much she learned and collected from an hour and a half dinner with her peers. Geoff shared that he found the follow-up program to be incredibly useless saying, "…that was a horrible, very expensive, deal…".

Kennedy shared that she felt that the pain management program was ineffective in its own right, giving unrealistic treatment plans to follow at home. Many other participants shared her sentiments, and this research will go more in-depth about the topic of ineffective pain management programs.

There were also mentions of treatments that exacerbated the pain of the participant. Felicia discussed that being medicated only made her condition worse since she lost muscle tone which resulted in the lack of strength to keep her standing without the use of a mobility aid. Nay gave an example of this as well, "…every steroid shot and everything that I was getting, trying to reduce the pain … they said it was like adding kerosene to a fire…".

Some aspects of this recursive theme, participants noted, were directly due to the negligence of healthcare providers. Of the participants, four of them have reported some experience with negligent care from a provider. Tony felt that being overmedicated for his pain was significant negligence. Geoff had his vocal cords cut during neck surgery, an extreme moment of negligence. Nay had a similar experience through a surgical procedure in which the healthcare provider failed to get her informed consent and left her with severe scarring on her ovaries and bowels. The diagnosis that started Nay's chronic pain journey was caused by deviance from the proper procedure on the end of the healthcare provider who did not clean Nay's skin thoroughly enough before an injection.

Oftentimes, the side effects of negligent care were just as impactful to the participants as the original negligence. Nay, Geoff, and Felicia all found that there were severe side effects to the negligent care they experienced. Felicia found that her over prescription of pain medication caused her to sleep for extended periods, significantly impacting her quality of life. Because the healthcare provider was not preparing the injection site properly, Nay ended up with a significant bacterial infection that was shot into her spine and was the cause of the onset of her chronic pain. Geoff's autoimmune disorder, celiac disease, went unnoticed by healthcare providers for years, while it exacerbated his chronic pain and gave him acute pain regularly.

The female-identifying participants all reported healthcare providers dismissing their diagnoses. Kennedy shared that when she shared her symptoms with healthcare providers, they did nothing to address them for her since it was "…not something that was medically verified as a part of the [pain management] program…". Nay shared that she had to take strides to convince her healthcare providers to take her complaints of pain seriously, "I kept telling them I got pain and they're saying, 'you don't'…". Felicia has a situation that was similar to Nay's, having to convince a healthcare provider that she was in pain, "…I had a doctor that told me, 'You can't be in that much pain, you're laughing'…".

Some participants (n=3) identified that they experienced pressure from healthcare providers to get a specific treatment for their pain. Kennedy, Geoff, and Felicia each identified that they had this experience. Kennedy shared her experience generally, explaining that "…the doctors want…to correct whatever is wrong…", however, she goes on to share that with idiopathic conditions that goal leads to potentially unwanted medical interventions. Geoff, who expressed that he felt pressure to attend the pain management program, shares that, overall, he is glad that he attended the program, but felt like it wasn’t a choice not only from the healthcare provider's pressure but also from his partner's encouragement.

Nay shared the most feelings of pressure for treatment as is seen through quotes like, “…everybody was telling me to fuse 12 vertebras….” and “[healthcare providers] first told me that ‘you’re going to go to this program’…”. It was clear in her narrative that Nay internally struggled initially regarding attending the pain management program for a variety of reasons, one of which was the pressure she was getting to attend. Nay also identified that the pain management program pressured her and the other members of the peer group to not follow through with forming the peer support group, however, Nay said, “…but we did it anyway and it worked out great…”. Nay was also one of the participants in the study who has attended more than one pain management program, but she expressed pressure to attend the second program she attended by her disability insurance since they offered financial support to pay for it.

Nearly all the participants, four of five, expressed feelings that their healthcare providers were unprepared to treat patients with chronic pain. Geoff identified that healthcare providers were unprepared to have open discussions about the real-life impacts of chronic pain, like sex. “… [conversations about sex] would be squashed, you know, that’s inappropriate conversation.” (Geoff). Kennedy shared her candid feelings about healthcare providers who care for those with chronic pain, “So, I think pain as a condition and information about that is nowhere where it needs to be for people in chronic pain. Doctors have less training [in chronic pain] … than I’ve had when I went through the pain management program...”. Tony shared bluntly that he felt as if some of the healthcare providers he went to were still “practicing” medicine.

On a similar thread, every participant identified that, from their perspective, healthcare providers just did not understand their situations. Felicia connected her perceived healthcare provider lack of understanding to their unpreparedness to treat individuals with chronic pain. She went on to say that their lack of understanding about what supports individuals with chronic pain needed was a key aspect of the healthcare provider's unwillingness to promote or refer out to peer support groups. This sentiment is mirrored by Geoff and Kennedy. Geoff continued the concept, saying that healthcare providers believe themselves to be the experts, but he indicated that this wasn’t the case. Kennedy confirmed this sentiment, “…doctors [for the pain management program] were getting 60 hours of training in chronic pain and we had 120 hours of training in chronic pain [through the pain management program]”. She shared that “I don’t know of any healthcare providers who ran the support group, any of the panel of doctors who were a part of the support group who had ever had chronic pain…”.

Kennedy discussed the mental load that came with trying to explain her condition to someone, healthcare providers specifically, who has never experienced chronic pain before, and depending on those same people to answer her questions on her pain contributed to losing faith in healthcare providers. Another example that she gives of the lack of awareness that healthcare providers have regarding functioning with chronic pain is the unrealistic treatment plan she left the pain management program with:

> [the tools the pain management program gave] were tools that if you did nothing else all day from eight to six but manage pain, you could squeeze in all of these things but that’s not what our lives look like, it’s not what anyone’s life looks like…(Kennedy)

Tony expressed that individuals with chronic pain needed to be understood, but he felt that the healthcare industry only focused on controlling them. Geoff shared this perspective, giving an example of discussing topics that impact individuals with chronic pain and suggesting that those topics would not be tolerated in a group environment even though they are the reality for many people with chronic pain. Kennedy shared that she felt that healthcare providers tend to jump directly into trying to “fix” her condition, not understanding that the majority of people with chronic pain are in situations that cannot be changed.

Nay shared that healthcare providers didn’t understand things that were important for individuals with chronic pain, like peer support and building relationships with each other, like the peer-led chronic pain support group. Kennedy reported that the reason healthcare providers wouldn’t refer individuals with chronic pain to peer support is that “…it isn’t well understood, it can’t be endorsed by a medical program…”. Every participant discussed the healthcare provider's non-referral for peer support. Tony passionately shared about how important it is to get others with chronic pain involved in a group, comparing it to other common supports in organizations like “ladies aid in church”. Nay shared that the pain management program was “not happy with us exchanging numbers … this is not what they expect, you know, this is not what they suggest we do…”. Felicia identified that since pain management programs will not promote or allow the development of peer support groups that is probably why peer-led support groups are so rare. She went on to say that it would make sense that the clinic could not share patient information with other patients, but she could not understand why the program would not allow her to collect numbers on her own. Kennedy defined the peer group as "…something not espoused by the program…" and admitted she did not know why other than it isn't extremely well researched.

Geoff explained that peer support was not encouraged outside of the pain management program, no one in the program suggested making interpersonal relationships with others in the group. "…in fact, when one of our group [members] tried to go back to the [pain management program] to talk about [peer support options] and they were shut down". Geoff theorized that one of the reasons that the pain management program did not encourage peer support is for their financial gain.

> the clinic that I went to runs 40 people through the program every day all year long… by not even presenting [peer support] as something that's possible, I would bet that the recidivism rate is 25% higher than it needs to be… (Geoff)

Kennedy shared that she was able to go back and talk to some groups at the pain management program, but ultimately the program decided that "they couldn't afford the time" to have the peer group come and share their experience. She said that she got a lot of positive feedback from people in the pain management program when she went originally and she thinks that the program would benefit from adding a peer aspect to their training, "if they're not willing to commit an hour to [the peer support group], there's very little chance they're willing to commit more of their program to make it a reality."

Lack of Trust in Healthcare Providers. Across all participants, there was an underlying theme of struggling to trust that their healthcare providers had their best interests at heart. Lack of trust in healthcare providers made up 29.63% of the total conversation regarding the impacts of healthcare. The participants' perspectives on healthcare providers strongly impacted their experiences in the healthcare setting and, for many, it was a strong influencing factor in their membership in the peer-led support group.

Nay shared that she has experienced many doubts about the success of treatments given to her by healthcare providers, showing her hesitation in trusting them and the efficacy of their methods. She gave an example of when she was originally deciding to attend the pain management program, she strongly doubted the ability of the program to take her pain away and take her off medication, she reenacted her shock "…I was like 'are you *kidding*'…" [emphasis added]. Kennedy also shared her doubts that the treatments and tools she was getting would be successful. After she had begun to accept that her chronic condition was a permanent fixture in her life, she found that she was "trained" to be searching for a cure, always searching for the next thing that could help. She reports that she stopped believing healthcare providers when they had ideas for a "fix", "…I didn't expect improvement…", but she reported improvement through the peer support group. Doubting success can lead to rejecting treatment as it did for Nay who rejected a suggestion from her provider because she doubted the success of the treatment and her provider did not inform her of the consequences of rejecting the suggested treatment.

One common topic that was discussed by many participants was the mistrust that developed when the pain management program refused to promote peer support. Geoff shared that, from his perspective that the mindset that someone with a chronic condition would go to other resources other than healthcare providers for support "scares the establishment". Many of the participants felt that this information was withheld from them and found themselves fortunate that they were able to come together naturally, an opportunity that many other graduates from the pain management program did not have. Geoff and Tony both discussed that they felt this came from a place of fear, from the healthcare industry's fear of losing control which fostered a strong sense of mistrust within the two men. Tony bluntly put it, “I think they’re trying to control [support groups], they see it as a medical [thing]…” he went on to discuss that the group members see the support group as a way of life, not a medical treatment. “…with the HIPAA rules and [the pain management program rule against starting peer support groups], you know, they got to control you and we don’t need controlling. We need help and understanding” (Tony).

Geoff discussed the legal implications of healthcare providers wanting control, saying that they most likely fear a lawsuit if they do not have control over the places that they are referring people to. Tony ties this fear of control into the reasonings behind why the pain management program will not allow the peer group to come to talk to current patients. Geoff explained that, from his perspective, the lack of referral to peer support was either a “follow the money moment or … healthcare wanting control…”. Geoff neatly tied the two concepts together saying, “the idea that there’s a group out there that can have success that’s not under [the healthcare industry’s] thumb, by not having someone in charge, [the healthcare industry] can’t charge them money to come to a group then…” he went on to say that, with this logic, it would be “financially foolish” for the healthcare industry to promote peer support.

The severe impact of the cost of pain management rehabilitation in tandem with the seeds of mistrust that had been sown within participants created two codes in the research, perceived healthcare provider loss of profit and perceived healthcare provider prioritizing money over health. Kennedy and Geoff discussed these concepts thoroughly between the two of them. Kennedy, who identified the cynicism in her statement said, “Ultimately, I don’t think [peer support groups being referred by the healthcare industry] is going to work, you can’t make money off of it…”. She went on to discuss that “change follows money” and there is not much money in researching peer support groups because the industry cannot capitalize on it. She is strongly believing that even though peer support groups in other capacities (i.e., Alcoholics Anonymous, Narcotics Anonymous) have shown to be significantly impactful, they will not be implemented due to the lack of profit the industry could make off them. Geoff explained that the significant cost of the follow-up healthcare provider-led program, $3,000 per person for six hours, is “…the hospital putting value on their time…” and with how costly they value their time, it is seemingly hard for Geoff to see their intentions as purely altruistic. He goes on to illustrate the amount of money the program takes in, putting himself in the place of the healthcare industry:

> If I can get $3,000 per head and I can get 15 people in the room, then I’m pulling $45,000 in for six hours. Why in the world would I encourage them to go someplace else? And, if I’ve got 40 people in [the pain management program] at any one time, two people come and two people leave every day, all year long, I’m not only doing one of those days, I’m probably doing 15 of those days, maybe 20 of those days, now how much money are we talking about? Why in the world should I encourage [peer support]? (Geoff)

Geoff explained that due to costs, the industry’s unwillingness to promote peer support, and the ineffective nature of the follow-up healthcare provider-led group, the recidivism rate for graduates of the pain management program is much higher than it needs to be. This identifies that, from his perspective, the healthcare industry is prioritizing money over the health and wellbeing of its patients. Geoff and Felicia both outlined feelings that went so far as to suggest that healthcare providers take advantage of individuals with chronic pain that come to them for support. Geoff's feelings of individuals being taken advantage of mostly circled back to his previous points regarding healthcare providers prioritizing money over the wellbeing of their clients, and some people need the tools that the pain management program teaches so they are willing to do in debt to get the support. Felicia said that people who come to the group have a hard time trusting non-healthcare providers to help them with their pain, indicating that healthcare providers have conditioned their patients to question the work of non-professionals. Kennedy acknowledged that the current healthcare system was not built for the "greater good" of the client.

Another large reason given for the participants' lost trust in their healthcare providers is that they simply did not have the skills or experience to educate people with chronic pain in their own experience. Felicia suggested that the healthcare providers didn't have the level of altruism that the peer support group had, identifying that the accommodations made for her by the peer group wouldn't be done for her by healthcare providers, "I can't imagine [a healthcare provider-led peer support program] that would work like that". When Felicia had an experience with a provider who questioned if she had chronic pain because she was laughing which fostered the feelings of mistrust, she asked "…what do you know about chronic pain…" after the provider said that. Kennedy believes that there is a "…failure of doctors to recognize, diagnose, and try to treat pain as its own problems…".

Ineffective Pain Management Program. The ineffectiveness of the pain management program and the follow-up healthcare provider-led program has been discussed throughout the research and makes up 18.83% of the conversation surrounding ineffective healthcare providers and ineffective treatments. As has been previously discussed, all participants found that the follow-up program that was a healthcare provider-led group was extremely ineffective. Across all narratives, the only positive aspect that was noted about this program by participants is that it brought the peer support group to life. All participants discussed which discussed the ineffective nature of their pain management program, as a shared experience for them, participants specifically noted unrealistic treatment plans, selective education, and the refusal to promote peer support as key aspects that made their pain management program an ineffective treatment. Kennedy described the pain management program as "… a little bit of a 'no but' situation, like, 'you can't do this, *no, but* you need to do this' … but all that other stuff, that's actually your existence…" [emphasis added].

The unrealistic treatment plans that the pain management program gave to participants were discussed by all participants, describing them as impractical for use outside the pain management program setting. Kennedy explained that learning how to manage pain in the pain management program was "…essentially, you are living in a bubble, all day every day, you do nothing but learn how to manage your pain and live with it…" and did not prepare her about what managing pain outside the program would look like. Every participant in the study said something akin to this. Felicia illustrated Kennedy's point:

> I think they had me scheduled for four and a half hours a day [of pain management strategies]. Well, in that four and a half hours, you have to make meals, you have to do laundry, you may want a social life. None of that was discussed, how to do all of that and still maintain reality (Felicia).

Tony shared that the unrealistic cost was another aspect of what made the pain management program ineffective, but he went on to say, "…the tools don't always fit the right position, where the [group] does…". Unrealistic treatment was not only limited to the post-pain management program, Nay explained that in her second pain management program experience, the healthcare providers took away her attention deficit disorder medications which were unrelated to her pain but impacted her focus and ability to learn.

The participants also discussed feeling censored by or unable to ask questions that were pertinent to their experience with their healthcare providers. Kennedy felt that the selective education from healthcare providers began as early as only getting exposed to the medical model of disability and not learning about alternative methods of pain management. Felicia concurred with Kennedy's perspective, saying that she didn't even know about specific coping strategies until she attended the pain management program. Felicia, Geoff, and Tony each spoke on the selective education that came with being a part of the pain management program and the follow-up healthcare provider-led group. Felicia shared that there were many things that, because of her pain, significantly impacted her quality of life. She listed sex as something that was never discussed in the program even though it is a major aspect of real life. Geoff expressed the same feelings, saying that if he was to bring it up, it would have been "squashed". After meeting with the peer-led chronic pain support group Felicia expressed that she was surprised as to how many coping skills she could have gained through unfiltered discussions.

The final aspect that four of five participants discussed pain management program's refusal to promote peer support. As mentioned above, the participants shared that the pain management program's rules against connecting with peers outside of the program setting were something that they struggled with. Each participant discussed the various significant impacts that the peer support group had on their chronic pain journey and all of them listed it as their primary and most successful pain management technique. This idea that the program refused to promote it, both when they all attended and even after when the group was able to share all of the benefits and their personal success stories, made some participants feel like the program did not even care about the well-being of their patients and did not give them all the tools for success that they could have. This had a strong impact on all of them discussing the ineffectiveness of the pain management program.

Successful Pain Management Program. There were only 26 coded instances found regarding the successful or positive impacts of a pain management program, however, this theme did appear across all five participant's narratives. It made up only 8.02% of the conversation on the impacts of healthcare, however, all participants mentioned at least one successful educational treatment. Kennedy had the most instances where she talked about successful pain management programs. She shared that the pain management program allowed her to "connect the dots" of all the different factors that were impacting her quality of life, giving her more awareness of her situation and, due to that, being able to take steps to address each of those things. Felicia shared that it gave her support with her time management and made her more mindful of herself and how she was taking care of herself. Geoff had only one instance of discussing the successful education treatment of the pain management program, "the pain management program taught me that … yeah, you got stuff. Are you going to hurt? Yeah. Is it the end of the world? No … Here are some tools to deal with it.".

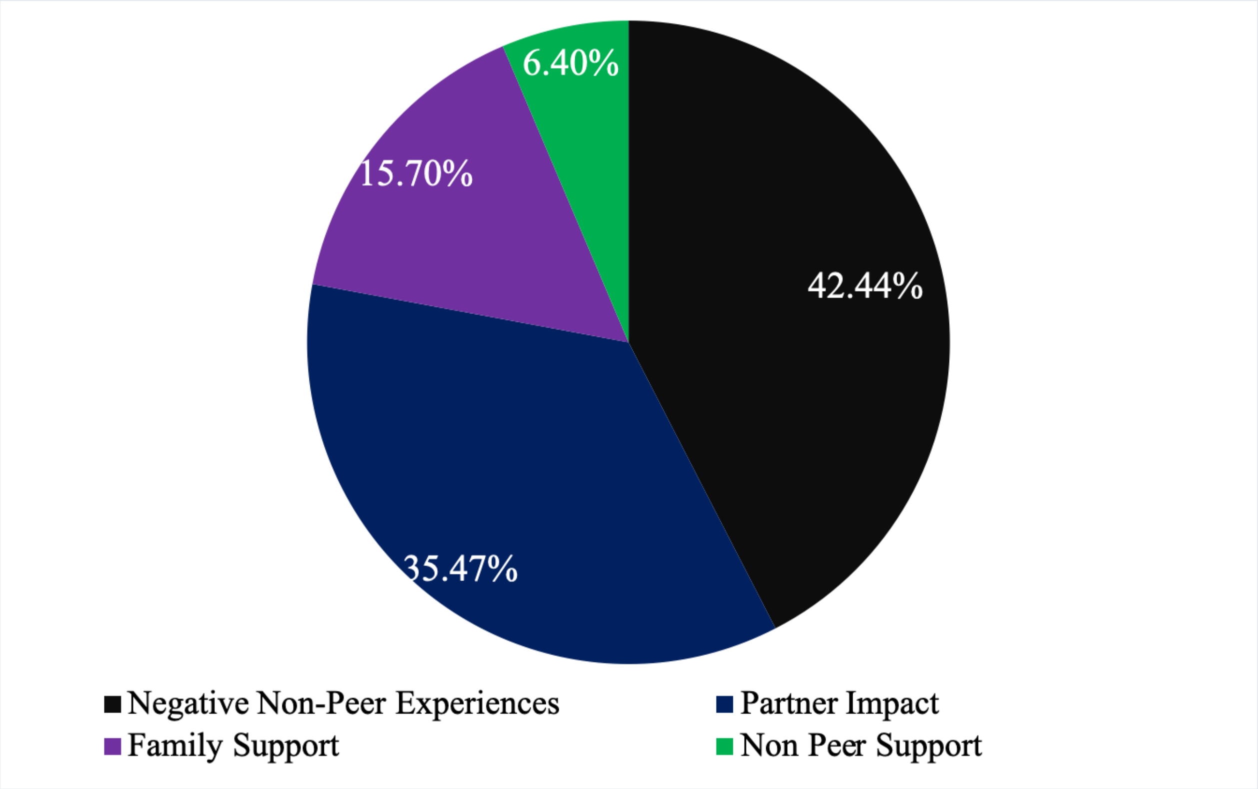
From the research, it seems that many of the participants valued their initial experience with a pain management program. The pain management program in question that all the participants attended was a 27-day-long intensive. This is where many of the participants discussed getting successful educational treatment where they were able to learn more about their pain and how to manage it. Additionally, this program’s goal was to focus on non-medical treatments and weaning participants off their medication. And while this program did allow all the participants to come home with skills that they have kept with them and utilized; it wasn’t free of flaws as discussed above. The peer group cites that going to the pain management program was integral to where they are at now with their pain because it got them started and allowed them to meet one another.

Family and Communal Relationships

Family and Communal Relationships was the fifth overall recursive theme, accounting for 6.60% of all codes found in the research. Participants discussed how the peer support group differed from the average familial or non-peer relationship and how these relationships have impacted their pain management or relationships with their chronic pain. This recursive theme was built on five axial codes: negative non-peer experiences, partner impact, family support, group impact on family, and non-peer support. The axial codes for this recursive theme are shown in Figure 6.

Figure 6

Family and Communal Relationships Axial Code Breakdown



Negative Non-Peer Experiences. Throughout the research, the participants shared various situations that were integral to their experience as people with chronic pain, one of which was negative interactions with people who do not experience chronic pain. This topic made up 42.44% of the overall conversation on family and communal relationships. The key theme here was the lack of understanding that came from people who have never experienced chronic pain and the negative incidents that impacted participants because of it. This non-peer lack of understanding highlighted the importance of having the peer group as a place where the participants felt that they belonged and were understood without question.

The situations that the participants brought up showed an overall lack of understanding for non-peers were various. Tony shared that it is hard to explain what it is like to have chronic pain to people who have never experienced it because they will never understand him, "…I don't know how to explain some of this stuff…" he goes on to share that in 30 days he had "five surgeries and nine procedures" to show that no one with that experience could understand that as just a normal part of life. Felicia felt similarly, "…if you don't have chronic pain, it's really hard to understand…". Nay's narrative mirrored Tony's and Felicia's about this subject, expressing how challenging it can be trying to complain to people without pain about her situation. Felicia shared that she finds it exhausting to be in social settings with individuals who do not have chronic pain because "they look at you [and say] 'you leaving already, are you sick?'". She went on to explain that the social pressure she discussed was nearly always caused by these non-peers, who didn't understand her needs or her boundaries. "… [people] outside this support group don't get it." (Felicia). This is something that Geoff echoed, sharing her perspective that people outside of the group can peer-pressure him to stay when he would need to leave for his self-care. Geoff shared that his own family couldn't fully understand the scope of the bonds that he has created with the peer support group, "…my mother has said, well they kind of fool around and call each other [family]', but that's not it *at all*." [emphasis added].

Low tolerance for non-peers was identified as the result of the constant lack of understanding amongst the participants. Felicia expressed how she can get upset or defensive if a non-peer suggests how or when she should use her coping strategies, "…my hackles go up, don't you tell me what to do…". Along the same lines, Tony talked about his waning empathy for individuals without chronic pain since they will “complain and whine” after getting basic surgery done or experience acute pain that will heal when they are aware of his condition and experiences. Nay shared about her coping strategies for her pain, and she explained her frustration at non-peers criticize her coping skills, “…but *other people*, other people have problems with it…” [emphasis added]. Again, Nay explained that the input of those who do not have pain can be frustrating, going on to give the example of disclosing her disability, which she identified as frustrating because non-peers will “…tell you about 20 other people, because when you got a problem… ’oh I know so-and-so had that’. No, it’s not the same… nobody’s the same…”. Nay continued talking about the overwhelming nature of the unsolicited advice that she gets from non-peers, “…*everybody*, just, *all* the suggestions come, but you know, sometimes they aren’t helpful suggestions…” [emphasis added]. Kennedy explained that many people who do not have pain do not understand that her symptoms cannot just go away or be quickly fixed and cited that they often gave her unsolicited suggestions as well. Nay and Tony expressed that they felt having to field questions from their non-peers was exhausting. Nay shared her experience of coming home from an appointment only to be inundated with questions from her family as soon as she gets home, without a chance to rest. She went on to say that trying to explain to them what the healthcare providers said can be challenging, in addition to having to field the question of “what’s next” from her family.

In addition to this, four participants found that their non-peer support systems experienced allyship fatigue. Geoff said that his non-peer support system expressed exhaustion regarding his pain, saying to him, “…the rest of us don’t know what to do with you…”. Felicia shared that in her experience, even her partner would say things like “…it’s your thing, you don't need me…". Nay expressed how allyship fatigue was a rooting cause of her social isolation, identifying that after having to cancel plans various times due to her pain that "people stop asking". Tony explained that he felt that his friends would stop inviting him over to their houses because they worry about if he will get hurt there. Continuing on this theme, Nay identified that non-peer support changes over time with chronic pain. She explained that the support she got during her first surgery was very different than the support she gets now.

> …like your first surgery, everybody sends you plants, and you get cards, and then when you get to this point it's just like 'oh another surgery for Nay, oh, well yeah sorry for that, you know'. You don't even get a card… I'm not talking about the material things just the support changes… (Nay)

She went on to say that people start to act differently because they don't know what to say, and that is one of the key aspects of the peer support group that is so impactful for her which is the group understanding and not having to explain herself to them. She identified that people feel "tired" of hearing about her situation and chronic pain.

The main misconception of chronic pain from non-peers was recognized by Nay and Felicia as seeing people with chronic pain as lifeless and humorless. Nay shared that when the peer support group visited her while she was in the hospital over the holidays that the staff present were confused at her laughter when she was in immense pain. She went on to say that the idea that people with pain are humorless is a strong misconception about them. "…[we] were always so serious because of all the issues that we have are always so serious that you never give us a chance to just be lighthearted." (Nay). Felicia also shared this sentiment saying, "…yes, we feel [our chronic pain] but we can laugh, giggle, [and] play…".

This plays into the perceived limitations that non-peers have for people with chronic pain. Felicia explained that the misconception that people with chronic pain are serious all the time is a key limitation that others place on the group. She went on to give examples that the group makes strides to be less serious and to laugh and learn new and fun ways to do their exercise and approach life. Tony shared that non-peers perceived him differently, with more limitations, after he shared about his chronic pain. Nay expressed that there were people in her life who told her to "…accept that you can't work anymore and start working on something else…" to which she felt like they were putting their preconceived notions about what people with chronic pain can or cannot do.

Nay, Geoff, and Felicia talked about the clear contrast between peer versus non-peer relationships. In many of the situations outlined in this section, these participants noted how their peers would handle situations better than non-peers did. Felicia noted the differences when she said, "…if [the situation is] I'm tired, I've hit my wall, I'm going to bed, and no one says, 'but wait, we haven't done this or this or this yet, [the support group is] up and giving hugs and saying goodnight…". This outlines the contrast of her experiences with non-peer which historically would pressure or beg her to stay whereas the peer support group would support the boundary she set and wish her a goodnight which strongly underlines the previously discussed importance of group understanding. Geoff told about the same experience that Felicia had with non-peers, identifying the difference as one between the non-judgment of peers and the judgment of non-peers. Nay emphasized the difference in understanding, "…[non-peers] keep asking too much, whereas our group will not do that to you because they've been in the same position…". This stressed the importance of shared identity and group understanding and how non-peers struggle to support participants in these ways causing question fatigue within them.

Nay goes on to describe that she has non-peer friends that she has been close with for over 50 years, but they still can’t give her the understanding or support she needs, she gets that support from the peer group. Geoff shared that a strong difference between his peer and non-peer friends is that he doesn’t feel like he is inconveniencing his peers when discussing anything, he feels as though he can go to them with anything, which wasn’t the case with non-peer friends. “You know when you have a group of people that you can confide pretty much everything in and not have to weigh down the people that have to live with you every day, it changes you as a person.” (Geoff). He shared that the difference he saw between the peers and non-peers in his life was that one was family, and one was friends, “…that’s not something that you … call a buddy of yours …. you’d never make that call [but] you might call your sister…”.

Partner Impact. Of the conversation on family and communal relationships, 35.47% of the discussion was focused on the impact that the spouse of the participant had on their experience. Only three of the five participants are married, while the other two were widowed. Nay, one of the widowed participants, spoke a small amount on partner impact, while Tony, the other widowed participant, didn’t discuss partner impact at all. Felicia and Geoff spoke the most about their partner’s impact on their chronic pain management and on their experience in the support group.

Overall, all three of the married participants and one of the widowed participants went on to discuss the significance and impact of partners in a variety of ways. Kennedy explained that the support group significantly impacted her relationship with her husband, along with all other aspects of her life. Throughout his narrative, Geoff spoke highly of his partner who he indicated impacted him through their support, commitment, and acceptance of him and his pain. He explained that due to chronic pain there were many familial obligations that his partner took on to support him through his pain, allowing him to take care of himself to the best of his ability before the pain management program. He explained that he "…that impact is, I can't explain it…". His partner was part of his motivation to attend the pain management program, which showed the importance of his partner's influence in his pain management. He went on to describe his wife as the "linchpin" in his chronic pain journey. He discussed that his partner supported him through his imposter syndrome while in the pain management program, illustrating their strong commitment to Geoff. Felicia, who did not discuss her relationship in as much depth as Geoff did, explained that her partner was someone that took control of the finances, supporting her by taking responsibilities off her shoulders, exemplifying her partner's commitment. Nay identified her experience with her pain was amplified due to the loss of her husband, "…I'm a widow, so it was like, this can't be happening…".

Felicia talked in-depth about how her partner felt helpless when it came to supporting her pain. "The first time that he was a part of the peer support group, he came wanting to know how to fix me. He wanted to know how he could make me forget about the chronic pain." (Felicia). She identified that her partner was unsure how to help which developed into fear on their end. However, Felicia identified that after her partner sat in on the group, he started to learn more about what type of support she needed and how to support her more. Partner inclusion in the peer-led chronic pain support group was key in supporting Felicia as it allowed her partner to be exposed to the culture they created as well as learn about coping strategies or support skills that would help her. "…we include our spouses because they have to learn how to love with us and not let themselves get pulled into, for lack of a better word, our shit.” (Felicia). Inclusion in the support group led to partner education which Felicia highlighted as key for her and her partner:

> I had seizures at one point in time, well, one of the other spouse's wife had seizures and she’s part of our group. Well, as I had … four while we were together, [the group member’s spouse] taught him how to take care of me and a seizure, which took the fear away from my husband. (Felicia)

Geoff discussed the importance of partner involvement in the support group, describing how his partner learned ways to support him, like using humor to help him redirect even if it is outside her nature:

> my wife is very nice…she is a well-intentioned honorable lady… [the peer support group is] all pretty crass and when she tries to jump in … she’ll come up and say something ridiculous and those moments, when that happens…helps you through a lot of stuff (Geoff).

Partner education and inclusion in the peer support group have shown to be helpful for members showing the scope of impact that the support group has had in their lives. Felicia went on to say that her partner would call other members of the support group to get in contact with her when she was having a rough day, using the peer knowledge network and the group’s altruistic nature to support her. Felicia shared that the partners “learn right along with us”.

The final aspect of partner impact was the unyielding acceptance that the participant’s spouses showed to the participant. Felicia shared that her partner learned to accept her disability through the support group, “he learned that number one, he can’t fix me…”. She identified all the spouses of the group members were “accepting” and “loving”, explaining that “[the spouses] have to accept that they can’t pull us out, we have to pull ourselves out, they can be supportive while we do it…”. Geoff expressed that his partner’s acceptance of him and his disability has been constant since before the pain management program, “she stayed with me, she kept the family together, while I was … overwhelmed with other things…”.

Family Support. Family support covered 15.70% of the conversation and was discussed by four of the participants. Geoff identified family support to be having the group member’s family, their partner, or children, supporting the group member, or reaching out to other group members to help support their spouse or parent. He identified it as “holistic” with the group member’s families being a part of their pain management support and involvement in the group from time to time. This is the type of familial support that Felicia recognized in her narrative as well saying, “My husband would have no qualms calling one of the peer groups and telling them that I needed a kick in the butt…”.

Felicia shared that family support to her was her husband or child supporting her in tasks that she struggled to complete (i.e., the dishes). Nay identified this same kind of family support, sharing that her daughter often took care of her and supported her in her chronic pain journey. Tony shared that “…without [the peer support group], and my one brother, I’d be lost…” he also went on to share that his children were also impactful to his familial support.

Being a parent was another aspect of family support that was identified by participants. Every participant has children, some grown and some still younger, but they each shared that their children were impacted on their chronic pain journey. Tony shared that he often will not even share with his children that he is having a surgery or procedure done, “…they don’t even have to know about it…but I always tell the [peer support group].” Geoff shared that his children have been a motivator for his chronic pain journey, his partner reminding him that “…your kids need you…”. Felicia explained that she was taking care of a child before her enrollment in the pain management program, her voice giving away feelings of inadequacy in her parenting due to her pain. Kennedy expressed that her relationship with her daughter improved significantly due to the peer-led support group. Nay shared that pain had taken her “mom role” away from her, causing her daughter to take care of her rather than the other way around, something that has been discussed previously in this research.

Three participants directly discussed the impact the group had on their families, including their parents, spouses, and children. Nay shared the group interacts with each other’s family on occasion, giving her daughter a look into her life as a member of the support group, “…people will say, you know, ‘oh my gosh your mom is so funny’… and my daughter was like ‘wow, is she really funny?’”. Felicia explained that they have all become permanent figures in each other’s lives, becoming a chosen family, meaning that the group has met their families and their children and formed meaningful relationships with them. Felicia shared that she has gotten gifts from the “children of the group” which extended the umbrella of chosen family for her. Felicia also talks about the harsh realities of the group’s impact on the families, starting up discussions on end-of-life goals and wants so that their families do not have to worry about what they need to do, “…they shouldn’t have to live through more, partake in, chronic pain [after the member passes away], they should rejoice with us, that it’s over…”.

Geoff explained that his biological family, his parents, struggled to understand the place that the group has in his life, not understanding the idea of chosen family. He talks about his partner and children and how they all are passionate about the group and how the group has changed their lives as much as it changed his. “This group has changed my life and, frankly, the life of my family, because we all kind of dig into the group…”. Overall, Felicia identified that the family members of the group are just as much on their chronic pain journey as the group members themselves were, "…they've lived through our chronic pain for a lifetime…".

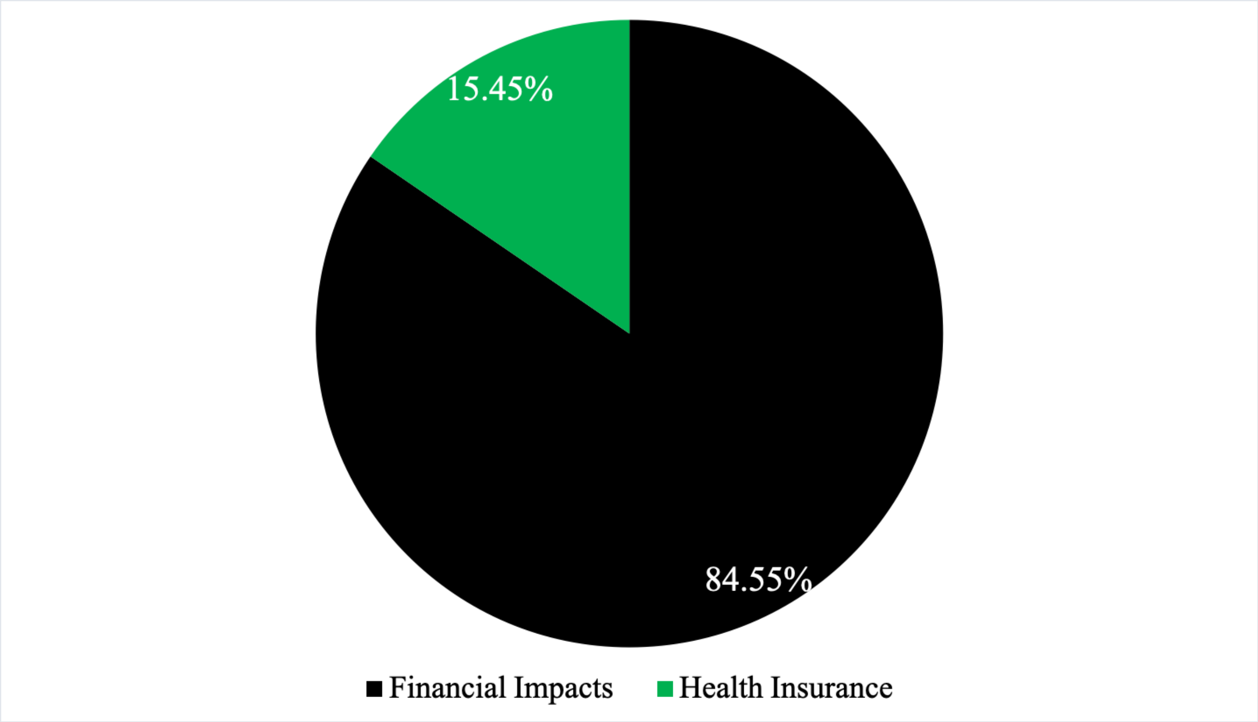
Non-Peer Support. Non-peer support was discussed by four of the participants and it made up 6.40% of the conversation on family and communal relationships. Nay, Geoff, Tony, and Felicia each discussed that while they had negative experiences with non-peers, they still were able to find support through some of their non-peers. Nay explained that establishing non-peer relationships was challenging before her experience with the peer support group but came more naturally to her afterward. Geoff shared that his employer allowed him to take the time off, 27 days, for the pain management program so that he could get the support he needed. His employer said, "I'll cover everything, it won't cost you any time.". Since Geoff could take the time off with full pay and no use of sick time, that helped him offset the financial hardship of attending the pain management program. Tony shared that his non-peer friends threw him a benefit to support him through the financial hardships of chronic pain which "…helped me get through to the pain management program…". Felicia identified that her non-peer friends supported her in her pain, to the point where when she was in pain and crying, they would be crying too. She goes on to say that most of her non-peers will respect her boundaries when she sets them, but not all. She also stated that, in general, she has found that many people, even people she doesn't know, are willing to help her if she asks for it in a "supportive" way.

Economic Impact

Economic impact was the final overall recursive theme found in the research and accounts for 4.22% of all codes in the research. Participants discussed the financial hardships that are essential to the nature of chronic pain and how the peer support group allows them to offset some of that hardship. Economic impact was a theme that showed up as a driving factor throughout the other selective themes. This recursive theme was built on two axial codes: financial impact and health insurance. The axial codes for this recursive theme are shown in Figure 7.

Figure 7

Economic Impact Axial Code Breakdown



Financial Impact. Financial impacts accounted for the majority of the discussion on economic impact, 84.55%, delving into discussions on financial stress, loss of wages, and the positive financial impacts of the peer support group. Kennedy discussed that with chronic pain, all of the hardships she has experienced were interwoven with each other. "…if you are stressed out [about] financial hardships and can't really afford to go do something, would that not then negatively impact your social relationships…?" (Kennedy). She does not see an end to financial hardship being a side effect of chronic pain until there is a drastic change to the medical industry in the United States, which was identified as another stressor since there is no end in sight in her perspective.

Geoff, Kennedy, Nay, and Tony each discussed the significant stress that was caused by the financial hardships that came with their chronic pain. Nay shared that she was working

"70 hours a week" so that she could make ends meet, which significantly and negatively impacted her pain, "…why did I end up with back problems more, you know, of course, because I was working like a crazy person…". Tony shared his financial hardships that followed his chronic pain journey after losing his job due to his disability, "I mean, it drained my 401K, it drained my PPG stock, it drained my savings… eventually… in the past five years, you know, lose my house and everything from it…". Kennedy also shared about her financial situation, "…personally, I have had hundreds of thousands of dollars that I've had to come up with for healthcare provider [costs] and I'm still … paying for [them]". Geoff explained that, similar to Nay, the financial stress of having pain caused him to work a large amount to compensate for the extreme financial burden:

> There's fear involved, there's waiting for the other shoe to drop, and there was the [financial] anxiety, and the easiest way for me to deal with that was to work and get paid … the reason [the financial hardships] weren't insurmountable is that I'd have surgery and I'd sit back for three [or] four days in a row and [then] back to work full time. (Geoff)

Tony explained how losing his job and not being able to work due to his disability has impacted him, "…I'm homeless until spring comes around and I can get back to my camper, I'm living from couch to couch … since late October…". He explains that no job he would be able to find would hire him, even if he could work, "…what job would hire me where I'm doing as much doctor-ing as I am, you don't get that much medical leave…". He went on to say that trying to work just made his medical issues worse, yet he tries to lift the financial "burden" off himself by working, describing the burden as "unfathomable". Nay discussed her experience of being unable to work due to her disability, living on social security disability insurance (SSDI) income, "…I can't live on the disability [SSDI] that I get, there's no way…".

She goes on to explain that this impacted her living situation, moving into a “teeny-tiny house”, because of the extreme loss of wages.

Kennedy explained the significant cost of the pain management program which contributed to her significant financial stress, “For most people, they had to pay a hefty sum to be there…when I say hefty sum, I mean… $12,000 to $30,000, so saying it’s a financial hardship doesn’t really … put it into scope…”. Different participants discussed the financial cost of the pain management program and how it can go beyond the $12,000 to $30,000 that Kennedy said, there is the cost of travel to the program, the cost of housing for the 27 days that the program was since you were not allowed to go home, according to the participants, and the cost of living (i.e., food, drink, toiletries, etc.). Kennedy identified that “…finding a place where you could stay that was more cost-effective…” was a significant financial hardship of attending the pain management program. In addition to the pain management program, each participant shared that for the one day, six-hour, healthcare provider-led group that acted as a follow-up program for the pain management program it was about $3,000, without insurance. Some shared that $3,000 was the high end and others shared that it was the low end of the cost. Tony went on to explain the financial situation for him, just for the follow-up healthcare provider-led program:

> …if you end up with good insurance, I mean, the insurance covers your bills … then you get into a situation where you refinance this to pay for that, but it’s not the medical part of it that is expensive, it’s the traveling … [one would pay for the program] now you got a motel expense, you know, it ends up costing another thousand dollars on top of everything with your food and gas… (Tony)

Geoff shared Tony’s sentiment, saying, “…it was $3,000 for the day. *Three grand for the day plus hotels* and I probably said about 15 minutes’ worth of stuff … I couldn’t for the life of me send that kind of money to do that again…” [emphasis added].

Each participant made note that in the peer support group, while they couldn’t remove all the burdens that the financial hardships brought, they were able to offset some of them. “…I can’t afford to pay a provider to give me the level of support that I get in this peer support group, financially, I don’t have the resources and I don’t know any of us who do…” (Kennedy). Most significantly, Geoff and Kennedy shared their thoughts on how the support group has affected the financial impacts of their chronic pain. Geoff explained that knowing he can turn to the group for support has saved him money by not relying on healthcare providers, “[the peer support group] talk you off the ledge, so you can work the next day, you know? I don’t need to spend $150 an hour for somebody who gets paid to do that…”.

On the same concept, Kennedy discussed that her provider charges $600 an hour and because of the peer support group, she can save that money and turn to them with questions or just somebody to lean on. She shared that the peer support group’s peer knowledge network saves her “tens of thousands of dollars” because she can get the information for free through the group. She went on to explain that “…I can take even $1,000 and go and do something with the peer support group … if I can do that, that’s infinitely less costly and it also doesn’t raise my deductible…”. In a final quote from Kennedy about the positive financial aspects of the peer support group she explained that “the logistical and financial aspects of a peer support being more optimal, you can access it any time…”.

Health Insurance. Health insurance made up 15.45% of the discussion of economic impact, with some participants having more beneficial health insurance and others having less optimal insurance. There was only one participant, Felicia, that discussed feelings of security regarding her health insurance, whereas the rest of the participants shared feelings of stress. Nay shared that insurance was a strong stressor for her when she had to stop working, and since she was a widow, she was not sure where her insurance would come from. She discussed how there were things that she felt that she needed at the time that her insurance did not cover, as well as treatments that were ineffective that it did cover. Tony shared that good health insurance was the difference between general financial hardship and severe financial hardship, and good insurance would "cover your bills". Felicia, who expressed feelings of security with her health insurance, shared that her insurance approved various procedures for her, but it was still a process she had to go through, unsure if they would approve the things she needed. Kennedy explained that she was perceived in many situations as "uninsurable" because of her pre-existing conditions, and if she could find insurance "…[it] had high deductibles and max out of pocket…". She went on to say that with how expensive the healthcare industry in the United States is that there are limits to the procedures and treatments she can do even with her insurance.

Final Analysis of Recursive Themes

This study focused on the relationship between membership of peer-led chronic pain support groups and if there is a connection to higher success in managing chronic pain while lessening the impact on quality of life and the financial impact. This study found that membership in a peer-led chronic pain support group was a more effective approach to pain management than any healthcare treatment, program, or medication regiment. Consistent membership had a significant impact on improving the management of pain which participants reported improved their quality of life: “[the peer support group] really allow me to live my life, knowing that if something goes wrong … where I may have used to reach for a bottle [of pills], I reach for the phone.” (Geoff). Through the research, participants also reported peer-led support as a method of reducing the financial impact of chronic pain. As Kennedy stated, “...a peer-led support group...I can reach out for support and all of that can be at cost... [the support] doesn’t cost anything except for the relationship…”

Cross Analysis of Peer Group Support and Impact of Healthcare

Across all six recursive themes, peer group support and the impact of healthcare had many interesting aspects that showed the direct contrast between what the participants thought were the positive aspects of the peer support group and the healthcare provider care they report receiving. For example, many of the participants found value in being able to discuss any topic in the peer support group, unfiltered, however, they also discussed that healthcare provider ran programs like the pain management program and the follow-up program, that they were unable to ask questions that may have been considered too “inappropriate” by the healthcare provider running the group. Some codes that were found in these two categories are inherently opposite one another, which shows that the value the group brings to the participant is something that they were unable to find in the doctor’s office. Additionally, participants described the peer support group as providing the support that healthcare providers are unable, and from some perspectives, unwilling, to give. The codes that showed the dichotomy best are no taboo topics versus selective education, trust versus lack of trust in healthcare providers, group altruism versus perceived healthcare provider prioritization of money over health, and group understanding versus medical professional perceived lack of understanding.

No Taboo Topics VS Selective Education. The peer group that the participants are members of has a strong culture of no topic is taboo to discuss. They have created an open environment where they can learn from one another about topics that may have a reputation for being unmentionable. This idea of no taboo topics is in direct contrast with the participants' reported experiences with healthcare providers. Felicia talks about this dichotomy, "… there were no holds barred, we could talk about anything, where [at the pain management program] they didn't want to talk about most of that.". This quote hits on the selective education provided by healthcare providers, a restriction of information that could potentially come from seeing chronic pain as a medical diagnosis and not something that impacts every aspect of one's life. "Imagine having a nurse at the front [of the group] and having somebody in the group that you are with a leader, saying 'man let me tell you about my sex the other night' well that would be squashed, you know. That's inappropriate conversation." (Geoff). In this quote, Geoff echoes other participants' perspectives that healthcare providers would not discuss matters that they don't see as relevant or appropriate. This is where the understanding of peers impacts the participants because healthcare providers would perceive discussing these topics as intentionally disruptive, where peers see a genuine question as something that is a real barrier in their lives.

Trust VS Lack of Trust in Healthcare Providers. A key aspect that was identified by participants as an important aspect of membership in the peer support group was trust. This trust has been crucial to the creation of the culture of the peer support group, allowing them to build strong relationships, be authentic, and be transparently honest with one another. Many participants have expressed a lack of trust in healthcare providers over the years after various experiences with the dismissal of illnesses, unrealistic treatments, and being treated like unreliable witnesses to their own condition.

Group Altruism VS Perceived Healthcare Provider Prioritization of Money over Health. There was an underlying theme among all participants that health care recommendations were based on money rather than altruistic intentions to relieve chronic pain. Due to the lack of trust, inconsistent healthcare, and pressure for treatment between the patient and healthcare provider, the altruistic nature and stability of the group allowed them to benefit from the pain management strategies they have cultivated over the years.

Group Understanding VS Healthcare Provider Perceived Lack of Understanding. Participants shared that healthcare providers lack understanding of the scope of impact of chronic pain, citing lack of sufficient training and lived experience as primary reasons and that this lack of understanding significantly negatively impacted their chronic pain journey. Peer group holistic understanding of chronic pain, no matter how different the participant's diagnoses were, was the largest recurring code that showed up in the research. The participants shared that healthcare providers could not understand the social hardships, financial hardships, relationship hardships, familial hardships, and sexual hardships that come with chronic pain, while all those hardships are universal for individuals who have lived experiences with it. Due to the consistent lack of understanding from healthcare professionals, the support group became a safe place for not only validation but also individual growth and acceptance. Group understanding was the largest code in each narrative. "Nobody could help each other more [than the peer support group]" (Nay)

Chapter V: Discussion

Chronic pain is a national public health issue that impacts the quality of life and the economy while disproportionally affecting various communities (Institute of Medicine et al., 2011). There are various approaches to chronic pain management which are effective with varying risk factors. Social support for individuals with chronic conditions is not a new concept but removing social support from the healthcare industry into peer support is uncommon. As a result, many healthcare professionals that work with chronic pain tend to prescribe healthcare provider-led or facilitated support groups versus peer-led support groups. This study investigated the relationship between membership of a peer-led chronic pain support group and chronic pain management. Specifically, this study evaluated peer-led chronic pain support groups to determine whether they are an effective alternative to more traditional chronic pain management methods for quality of life and financial impact.

Summary

This study used a qualitative grounded theory, which found that peer-led chronic pain support groups are an effective approach to managing chronic pain. The overall finding was that participants reported a significant increase in their quality of life and self-concept due to membership in a peer-led support group. At the same time, they were relieving some of the financial burden of chronic pain in a society without universal healthcare.

Overall Impressions of Peer Group Support

Overall, support (37.64%) within the peer group was the most recursive theme reported by participants. Support included many axil codes, which all fit under the umbrella of support received in the group. Participants reported this code as the most successful factor for managing their chronic pain. The sense of belonging from peer group support was critical to the participants' pain management. In addition to the strong peer relationships they cultivated, participants outlined many factors that played into their perceived value of the peer group. Participants discussed the group dynamics that they believed contributed to the support level of their peer group and compared both the positive support from group members and the real negative impacts that occurred in the group. The results indicate that peer group support was the most effective method of chronic pain management for each participant, which indicates that peer support is a viable method for managing chronic pain.

Overall Impressions of Dichotomy of Quality of Life

The dichotomy of quality of life (20.53%) was the second most recursive theme reported. Participants discussed the poor quality of life inherent to chronic pain and the improved quality of life that came primarily from the nature of chronic pain in the peer-led support group. The results in this section support the research conducted by Finlay et al. (2018), highlighting the significance of laughter and improved quality of life through peer support. Furthermore, the analysis supports the theory that the peer-led chronic pain support group improves the quality of life for the participants, supporting them in managing their pain.

Overall Impressions of Self-Concept

The third most recursive theme was Self-concept (18.57%) which participants identified as a critical impact on their chronic pain journey. While participants' self-concept developed, they found more success in their pain management strategies and got more out of the pain management program and the peer support group. All participants reported the development of a shared identity in the peer support group as an essential factor that supported their identity development. Participants recounted embracing this new version of themself by accepting that their disability is just a part of their identity. However, they expressed that they do not allow it to control them as it had before. Within the group, the shared identity allowed individuals with completely different diagnoses and backgrounds to identify each other as family, as the same. Overall, the results showed that the participants' experience with the peer-led support group significantly impacted their self-concept, which, in turn, supported their chronic pain journey. As shown through developing a chosen family and cultivating a shared identity, self-concept also significantly improved the participants' quality of life, positively impacting their chronic pain.

Overall Impressions of Impacts of Healthcare

The impact of healthcare (12.43%) was the fourth most recursive theme reported. The impact on healthcare was an unexpected theme that emerged from the participants' narratives. The participants' significant lack of trust in their healthcare providers and the reported ineffectiveness of healthcare providers and the prescribed treatments were unprecedented in current research. It was clear through this research that the support given by healthcare providers was not nearly as effective or abundant as the support provided by the peer-led support group. Participants highlighted aspects of their experiences in the pain management program as beneficial to managing their chronic pain. Many participants cited the program as a good starting point for their chronic pain journey. However, conversely, many discussed unrealistic treatment plans and the support of selective education within pain management programs.

Additionally, participants were frustrated that the pain management program did not refer them to peer-led support. Participants saw this as withholding a viable treatment option, at best, and maliciously prioritizing their capital gains by creating a pain management monopoly, effectively ignoring their ethical duty for nonmaleficence, at worst. The overall findings concluded that while pain management programs had positive aspects, they were not as effective as the peer-led support group in supporting the participants with their chronic pain management.

Overall Impressions of Family and Communal Relationships

Family and communal relationships represented 6.60% of the recursive themes reported. This theme showed both the negative and the positive aspects of non-peer support, ultimately showing that non-peer support was distinctly inferior to the peer-led support group as a method for managing chronic pain.

Overall Impressions of Economic Impact

Economic impact (4.22%) represented the lowest percentage of recursive themes. This code showed the financial hardships of chronic pain in a country without universal healthcare. All participants discussed this significant financial impact; however, participants working manual labor jobs shared more significant financial hardships than participants working office jobs. The findings indicated that attending a peer-led support group relieved a portion of the financial burden since there were no associated costs to attend. Additionally, the findings showed that while the financial savings from attending the group was not the most prevalent beneficial aspect of the peer-led support group, it was still a significant benefit that participants highlighted.

Benefits of the Study

This study has many benefits for the chronic pain community. Firstly, this study purports that peer-led chronic pain support groups are a viable method of chronic pain management that has substantial financial implications for individuals with chronic pain. Additionally, this study reported a connection between peer-led support group membership and improved quality of life. This grounded theory could significantly impact persons with chronic pain who are financially insecure or socially isolated and give them a fiscally more viable method of chronic pain support that creates a safe place for creating strong peer relationships. Furthermore, the findings of this study show peer-led support as a valuable method of chronic pain management and supports future research on the topic of peer-led chronic pain support groups and their impact on chronic pain. Finally, this study adds more nuance and new information to the current research on peer-led chronic pain support groups, especially in the U.S., where there is no universal healthcare.

Limitations

The small sample size in this study limits the generalizability of the results due to only having five participants. Furthermore, each participant was a member of the same peer-led chronic pain support group, so these results cannot be generalized to other peer-led support groups. This research cannot be generalized to all members of a peer-led chronic pain support group because the participants were all core founding members which could be different than non-founding members. In addition, it is beyond the scope of this study to delve deeply into the family and communal relationships and self-concept that participants noted in their narratives since this study focused on learning about the relationship between pain management and peer-led chronic pain support groups.

Implications for Future Research

The analysis of the data corroborated the findings of other researchers on peer support and chronic pain. However, only small sections of the pre-existing research discussed the relationship between individuals with chronic pain and healthcare providers. Future research focused on the efficacy of peer support with participants who have differing experiences with healthcare providers is recommended. Potentially, peer support would be less than ideal if healthcare providers gave adequate support when patients seek services at the start of chronic pain. The findings of this future research could support the healthcare industry in creating more accessible, both in opportunity and financially, chronic pain management supports for their clients. This study theorized a tentative solution to the national public health issue that supports individuals with chronic pain in relieving the economic impact of chronic pain and increasing quality of life. Future studies could turn to other methods of research to test this theory amongst a broader, more generalizable group.

Additionally, future studies could replicate the theory created from this study to investigate its outcomes in other peer-led chronic pain support groups. The current research on chronic pain documents a clear disproportionate impact that chronic pain has on specific communities in the United States. Future research should investigate the possible efficacy of peer-led chronic pain support groups in managing that disproportionate impact (cite). Additionally, further research could be done on women with chronic pain, as this research showed that only the female-identifying participants reported that healthcare providers dismissed their illness.

The efficacy of peer-led support groups based on specific demographics such as age, gender, and race, would be another step for future research. Five factors of fears of addiction, anger, suicidal ideation, and self-compassion emerged during the coding but were not recursive but should be included in more extensive studies to investigate their impact. Since this research did not have questions structured to focus on chronic pain's mental health impacts, these factors did not show up across participants. However, these would be essential factors to include in future research studies.

References

American Chronic Pain Association. (2021). *Support groups*. https://www.theacpa.org/support-groups/

American Chronic Pain Association & Stanford University Division of Pain Medicine. (2021). *ACPA and Stanford resource guide to chronic pain management: An integrated guide to comprehensive pain therapies*. https://www.theacpa.org/wp-content/uploads/2021/09/2021-ACPA-Resource-Guide-to-Chronic-Pain-Management-v3.pdf

Archibald, M. M. (2015). Investigator triangulation. *Journal of Mixed Methods Research, 10*(3), 228–250. https://doi.org/10.1177/1558689815570092

Benyamin, R. (2008). Opioid complications and side effects. *Pain Physician*, *2s;11*(3;2s), S105–S120. https://doi.org/10.36076/ppj.2008/11/s105

Blau, W. S., Dalton, J. A. B., & Lindley, C. (1999). Organization of hospital-based acute pain management programs. *Southern Medical Journal*, *92*(5), 465–471. https://doi.org/10.1097/00007611-199905000-00003

Boudreau, D., von Korff, M., Rutter, C. M., Saunders, K., Ray, G. T., Sullivan, M. D., Campbell, C. I., Merrill, J. O., Silverberg, M. J., Banta-Green, C., & Weisner, C. (2009). Trends in long-term opioid therapy for chronic non-cancer pain. *Pharmacoepidemiology and Drug Safety*, *18*(12), 1166–1175. https://doi.org/10.1002/pds.1833

Cho, S., Zunin, I. D., Chao, P. J., Heiby, E. M., & McKoy, J. (2011). Effects of pain controllability and discrepancy in social support on depressed mood among patients with chronic pain. *International Journal of Behavioral Medicine*, *19*(3), 270–279. https://doi.org/10.1007/s12529-011-9175-4

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, *41*(5), 545–547. https://doi.org/10.1188/14.onf.545-547

Cowan, P. (2011). Support groups for chronic pain. *Handbook of Pain and Palliative Care*, 639-648. https://doi:10.1007/978-1-4419-1651-8_34

Dahlhamer, J., Lucas, J., Zelaya, C., Nahin, R., Mackey, S., DeBar, L., Kerns, R., von Korff, M., Porter, L., & Helmick, C. (2018). Prevalence of chronic pain and High-Impact chronic pain among adults — United states, 2016. *MMWR. Morbidity and Mortality Weekly Report*, *67*(36), 1001–1006. https://doi.org/10.15585/mmwr.mm6736a2

Driscoll, M. A., Higgins, D. M., Seng, E. K., Buta, E., Goulet, J. L., Heapy, A. A., Kerns, R. D., Brandt, C. A., & Haskell, S. G. (2015). Trauma, social support, family conflict, and chronic pain in recent service veterans: Does gender matter? *Pain Medicine*, *16*(6), 1101–1111. https://doi.org/10.1111/pme.12744

Eccleston, C. (1995). Chronic pain and distraction: An experimental investigation into the role of sustained and shifting attention in the processing of chronic persistent pain. *Behaviour Research and Therapy*, *33*(4), 391–405. https://doi.org/10.1016/0005-7967(94)00057-q

Ersek, M., Turner, J. A., & Kemp, C. A. (2006). Use of the chronic pain coping inventory to assess older adults' pain coping strategies. *The Journal of Pain*, *7*(11), 833–842. https://doi.org/10.1016/j.jpain.2006.04.002

Feldman, E. C. H., Macaulay, T., Tran, S. T., Miller, S. A., Buscemi, J., & Greenley, R. N. (2020). Relationships between disease factors and social support in college students with chronic physical illnesses. *Children's Health Care*, *49*(3), 267–286. https://doi.org/10.1080/02739615.2020.1723100

Finlay, K. A., & Elander, J. (2016). Reflecting the transition from pain management services to chronic pain support group attendance: An interpretative phenomenological analysis. *British Journal of Health Psychology*, *21*(3), 660–676. https://doi.org/10.1111/bjhp.12194

Finlay, K. A., Peacock, S., & Elander, J. (2018). Developing successful social support: An interpretative phenomenological analysis of mechanisms and processes in a chronic pain support group. *Psychology & Health*, *33*(7), 846–871. https://doi.org/10.1080/08870446.2017.1421188

Finan, P. H., & Garland, E. L. (2015). The role of positive affect in pain and its treatment. *The Clinical Journal of Pain*, *31*(2), 177–187. https://doi.org/10.1097/ajp.0000000000000092

Frieden, T. R., & Houry, D. (2016). Reducing the risks of relief — The CDC Opioid-Prescribing guideline. *New England Journal of Medicine*, *374*(16), 1501–1504. https://doi.org/10.1056/nejmp1515917

Galea, S. (2017). *Chronic pain and the health of populations | SPH*. Boston University School of Public Health. https://www.bu.edu/sph/news/articles/2017/chronic-pain-and-the-health-of-populations/

Gil, K. M., Keefe, F. J., Crisson, J. E., & van Dalfsen, P. J. (1987). Social support and pain behavior. *Pain*, *29*(2), 209–217. https://doi.org/10.1016/0304-3959(87)91037-2

Gureje, O., von Korff, M., Simon, G. E., & Gater, R. (1998). Persistent pain and well-being. *JAMA*, *280*(2), 147–151. https://doi.org/10.1001/jama.280.2.147

Hagemeier, N. P. E., PhD/PharmD. (2020). *Introduction to the opioid epidemic: The economic burden on the healthcare system and impact on quality of life*. AJMC. https://www.ajmc.com/view/intro-opioid-epidemic-economic-burden-on-healthcare-system-impact-quality-of-life

Harold M. & Bogduk, N. (Eds.). (1994). *Classification of chronic pain* (2nd ed.). IASP Press. https://www.iasp-pain.org/publications/free-ebooks/classification-of-chronic-pain-second-edition-revised/

Higginson, A., Forgeron, P., Harrison, D., Finley, G. A., & Dick, B. D. (2019). Moving on: Transition experiences of young adults with chronic pain. *Canadian Journal of Pain*, *3*(1), 85–97. https://doi.org/10.1080/24740527.2019.1587707

Huber, J., Muck, T., Maatz, P., Keck, B., Enders, P., Maatouk, I., & Ihrig, A. (2017). Face-to-face vs. Online peer support groups for prostate cancer: A cross-sectional comparison study. *Journal of Cancer Survivorship*, *12*(1), 1–9. https://doi.org/10.1007/s11764-017-0633-0

Institute of Medicine, Board on Health Sciences Policy, & Research, C. C. O. A. P. (2011). *Relieving pain in America: A blueprint for transforming prevention, care, education, and research* (1st ed.). National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK91497/

Kashikar-Zuck, S., Sil, S., Lynch-Jordan, A. M., Ting, T. V., Peugh, J., Schikler, K. N., Hashkes, P. J., Arnold, L. M., Passo, M., Richards-Mauze, M. M., Powers, S. W., & Lovell, D. J. (2013). Changes in pain coping, catastrophizing, and coping efficacy after Cognitive-Behavioral therapy in children and adolescents with juvenile fibromyalgia. *The Journal of Pain*, *14*(5), 492–501. https://doi.org/10.1016/j.jpain.2012.12.019

Kindt, S., Vansteenkiste, M., Josephy, H., Bernardes, S. F., & Goubert, L. (2018). Helping your partner with chronic pain: The importance of helping motivation, received social support, and its timeliness. *Pain Medicine*, *20*(1), 77–89. https://doi.org/10.1093/pm/pny006

Lefley, H. P. (2009). A psychoeducational support group for serious mental illness. *The Journal for Specialists in Group Work*, *34*(4), 369–381. https://doi.org/10.1080/01933920903219094

Mariano, T. Y., Wan, L., Edwards, R. R., Lazaridou, A., Ross, E. L., & Jamison, R. N. (2019). Online group pain management for chronic pain: Preliminary results of a novel treatment approach to teletherapy. *Journal of Telemedicine and Telecare*, *27*(4), 209–216. https://doi.org/10.1177/1357633x19870369

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

Mayo Clinic. (2020). *Pain rehabilitation center - core components*. https://www.mayoclinic.org/departments-centers/pain-rehabilitation-center/sections/core-components/gnc-20481695

McCarberg, B. H., Nicholson, B. D., Todd, K. H., Palmer, T., & Penles, L. (2008). The impact of pain on quality of life and the unmet needs of pain management: Results from pain sufferers and physicians participating in an internet survey. *American Journal of Therapeutics*, *15*(4), 312–320. https://doi.org/10.1097/mjt.0b013e31818164f2

McCracken, L. M., Carson, J. W., Eccleston, C., & Keefe, F. J. (2004). Acceptance and change in the context of chronic pain. *Pain*, *109*(1), 4–7. https://doi.org/10.1016/j.pain.2004.02.006

Mo, P. K., & Coulson, N. S. (2014). Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within HIV/AIDS-related online support groups. *International Journal of Nursing Studies*, *51*(7), 983–993. https://doi.org/10.1016/j.ijnurstu.2013.11.006

National Institute on Drug Abuse. (2021). *Opioid overdose crisis*. https://www.drugabuse.gov/drug-topics/opioids/opioid-overdose-crisis

Rzeszutek, M., Oniszczenko, W., Schier, K., Biernat-Kałuża, E., & Gasik, R. (2015). Trauma symptoms, temperament traits, social support and the intensity of pain in a polish sample of patients suffering from chronic pain. *Personality and Individual Differences*, *83*, 13–17. https://doi.org/10.1016/j.paid.2015.03.036

Shepherd, M. D., Schoenberg, M., Slavich, S., Wituk, S., Warren, M., & Meissen, G. (1999). Continuum of professional involvement in self-help groups. *Journal of Community Psychology*, *27*(1), 39–53.

Smith, B. H., Elliott, A. M., Chambers, W. A., Smith, W. C., Hannaford, P. C., & Penny, K. (2001). The impact of chronic pain in the community. *Family Practice*, *18*(3), 292–299. https://doi.org/10.1093/fampra/18.3.292

Stevinson, C., Lydon, A., & Amir, Z. (2010). Characteristics of professionally-led and peer-led cancer support groups in the United Kingdom. *Journal of Cancer Survivorship*, *4*(4), 331–338. https://doi.org/10.1007/s11764-010-0129-7

Subramaniam, V., Stewart, M. W., & Smith, J. F. (1999). The development and impact of a chronic pain support group. *Journal of Pain and Symptom Management*, *17*(5), 376–383. https://doi.org/10.1016/s0885-3924(99)00012-3

Taylor, I., McNamara, N., & Frings, D. (2019). The “Doing” or the “Being”? Understanding the roles of involvement and social identity in peer-led addiction support groups. *Journal of Applied Social Psychology*, *50*(1), 3–9. https://doi.org/10.1111/jasp.12635

Tregea, S., & Brown, K. (2013). What makes a successful peer-led aphasia support group? *Aphasiology*, *27*(5), 581–598. https://doi.org/10.1080/02687038.2013.796506

van Dyke, B., Kim, M., & Thorn, B. (2018). Longitudinal relationships between perceived social support and quality-of-life among patients with chronic pain. *The Journal of Pain*, *19*(3), S39. https://doi.org/10.1016/j.jpain.2017.12.109

Volkow, N. D., & McLellan, A. T. (2016). Opioid abuse in chronic pain — Misconceptions and mitigation strategies. *New England Journal of Medicine*, *374*(13), 1253–1263. https://doi.org/10.1056/nejmra1507771 von Korff, M., Scher, A. I., Helmick, C., Carter-Pokras, O., Dodick, D. W., Goulet, J., Hamill-Ruth, R., LeResche, L., Porter, L., Tait, R., Terman, G., Veasley, C., & Mackey, S. (2016). United states national pain strategy for population research: Concepts, definitions, and pilot data. *The Journal of Pain*, *17*(10), 1068–1080. https://doi.org/10.1016/j.jpain.2016.06.009

Walker, D., & Myrick, F. (2006). Grounded theory: An exploration of process and procedure. *Qualitative Health Research*, *16*(4), 547–559. https://doi.org/10.1177/1049732305285972

Warwick, R., Joseph, S., Cordle, C., & Ashworth, P. (2004). Social support for women with chronic pelvic pain: What is helpful from whom? *Psychology & Health*, *19*(1), 117–134. https://doi.org/10.1080/08870440310001613482

Young, S. D., Koussa, M., Lee, S. J., Perez, H., Gill, N., Gelberg, L., & Heinzerling, K. (2018). Feasibility of a social media/online community support group intervention among chronic pain patients on opioid therapy. *Journal of Addictive Diseases*, *37*(1–2), 96–101. https://doi.org/10.1080/10550887.2018.1557992

Appendix A: Complete Code Breakdown

Selective Code Total	Selective Codes	Axial Code Total	Axial Codes	Open Code Total	Open Codes
981	Peer Group Support	313	Group Feelings of Belonging	110	Group Understanding
				92	Group Altruism
				46	Belonging
				33	Group Acceptance
				23	Communal Coping
				9	Group Safe Space
		257	Peer Group Membership Value	42	Group Influenced Growth
				34	Peer to Peer Knowledge Network
				27	Peer Support vs HCP Care
				26	Group Encouragement
				21	Group Emotional Support
				19	Trust
				17	Appreciation of Group
				17	No Taboo Topics
				16	Group Accountability
				12	Boundried Altruism
				12	Educational Aspect of CPSG
				7	Critical Peer Feedback
				7	Downward Social Comparison
		154	Strong Peer Relationships	49	Peer Relationship Building
				31	Community
				31	establishing peer relationships
				24	Chosen Family

				19	Unexpected Connections
		102	Positive Support	57	Peer Group Positive Impact
				38	Foster Positive Support
				7	Group Influenced Happiness
		82	Group Dynamics	18	Importance of Altruism
				15	Group Participation
				14	Group Meeting
				12	Group Leadership
				7	Group Facilitation Techniques
				5	Distance
				4	Group Member Stability
				4	Untrained
				3	Peer Role Model
		73	Impacts of Negativity	25	Disrupt Negative Talk
				24	Negative Peers
				18	Disruptive/Self Absorbed Group Members
				6	Contagious Negativity
535	Dichotomy of Quality of Life	154	Improved Quality of Life	57	Quality of Life
				44	Laughter
				32	Metamorphize
				13	Hopefulness
				5	Remove Negative Coping Skills
				3	Euphoria
		116	Poor Quality of Life	23	Social Isolation
				19	Working Through Pain
				16	Story Trauma

				11	Source of Pain Unknown
				10	Loss of Relationships
				10	Social Pressure
				8	Mourning Loss of Ability
				7	Familial Neglect
				7	Loss of Purpose/Passion
				5	Daily Support Dependance
		94	Coping Strategies	24	Positive Reframing
				24	Redirection
				17	Task Modification
				12	Moving for Health
				8	Task Moderation
				6	Coping Strategy
				3	Spirituality
		70	Impacts of Pain	34	Uncontrolled Pain
				15	Impact of Pain
				12	Mobility
				9	Limited by Pain
		66	Pain Management	50	Pain Management Strategy
				13	Pain Reduction Strategy
				3	Pain Relief
		35	Medication	16	Medication Maintenance
				11	Medication Dependence
				4	Limited by Pain Medication
				4	Over Medicated
484	Self-Concept	211	View of Self	60	Self-Concept
				39	Realization of Capabilities

				28	Setting Boundaries
				26	Autonomy
				23	Self-Efficacy
				12	Imposter Syndrome
				11	Confidence
				8	Medical Model of Disability
				4	Realization of Severity
		165	Identity	82	Shared Identity
				42	Acceptance of Disability
				32	Identity Development
				9	Regaining Identity
		58	Mental Health Impacts	16	Shame
				15	Fear
				8	Catastrophizing
				8	Mental Health Impact on Chronic Pain
				6	Disappointment
				5	Stress Manifestation
		50	Transition to Independence	12	Disillusioned
				11	Dependance to Independence
				9	Transition Challenges
				8	Shock
				5	Self-Criticism
				5	Unaware of Impact
324	Impact of Healthcare	141	Ineffective Healthcare Provider/Treatment	34	Ineffective Treatment
				23	Inconsistent Healthcare
				23	Healthcare Provider Non-Referral for Peer Support

				20	Healthcare Provider Perceived Lack of Understanding
				14	Pressure for Treatment
				7	Dismiss Illness
				7	Negligent Care
				6	Side Effects of Negligent Care
				5	Healthcare Provider Unprepared
				2	Treatment that Exacerbates Pain
		96	Lack of Trust in Healthcare Providers	41	Lack of Trust in Healthcare Provider
				20	Perceived Healthcare Provider Prioritizing Money over Health
				14	Doubted Success
				9	Perceived Healthcare Provider Fear of Loss of Control
				8	Perceived Healthcare Provider Loss of Profit
				4	Rejecting Treatment
		61	Ineffective Pain Management Program	21	Ineffective Pain Management Program
				16	Unrealistic Treatment Plan
				15	Refusal to Promote Peer Support
				9	Selective Education
		26	Successful Pain Management Program	26	Successful Educational Treatment
172	Family and Communal Relationships	73	Negative Non-Peer Experiences	38	Non-peer lack of understanding
				11	Peer vs Non peer relationships
				9	Allyship Fatigue

				6	Others Perceived Limitations
				5	Question Fatigue
				4	Misconceptions
		61	Partner Impact	26	Partner Support
				8	Partner Acceptance
				6	Partner Education
				5	Impact of Partner
				5	Partner Inclusion in Chronic Pain Support Group
				5	Significance of a Partner
				4	Partner Feeling Helpless
				2	Partner Commitment
		27	Family Support	9	Group Impact on Family
				8	Parenting
				7	Family Support
				3	Group/Family Interactions
		11	Non-Peer Support	8	Non-Peer Support
				3	Establishing Non-Peer Relationships
110	Economic Impact	93	Financial Impacts	50	Financial Impacts
				30	Financial Stress
				13	Loss Wages
		17	Health Insurance	17	Health Insurance

Appendix B: Recruitment Methods

Posted on a local peer-led chronic pain support group Facebook Page on 10/28/2021:

You are invited to participate in a research study investigating the relationship between peer lead chronic pain support groups and chronic pain management.

About the Study:
Chronic pain is a current public health problem that significantly impacts the United States in various ways and while there are modern pain management techniques, cost, ability, and access can impact their effectiveness. This research will use semi structured interviews approximately 1.5 - 2 hours in length to investigate the benefits of peer support on chronic pain management. Participants will contribute to the knowledge in the field of chronic pain through sharing their personal narrative. The completed study will benefit the field of chronic pain research as well as society as a whole through contributing to the knowledge and forming a theory to use as a starting point for future research. The overall goal of this study is to create a theory about how peer-led chronic pain support group membership impacts the management of chronic pain.

Participant Criteria:
In order to participate in this study individuals must:
-be a current member of a peer-led chronic pain support group
-have experienced a pain management program
-have had at least seven years of lived experience with chronic pain

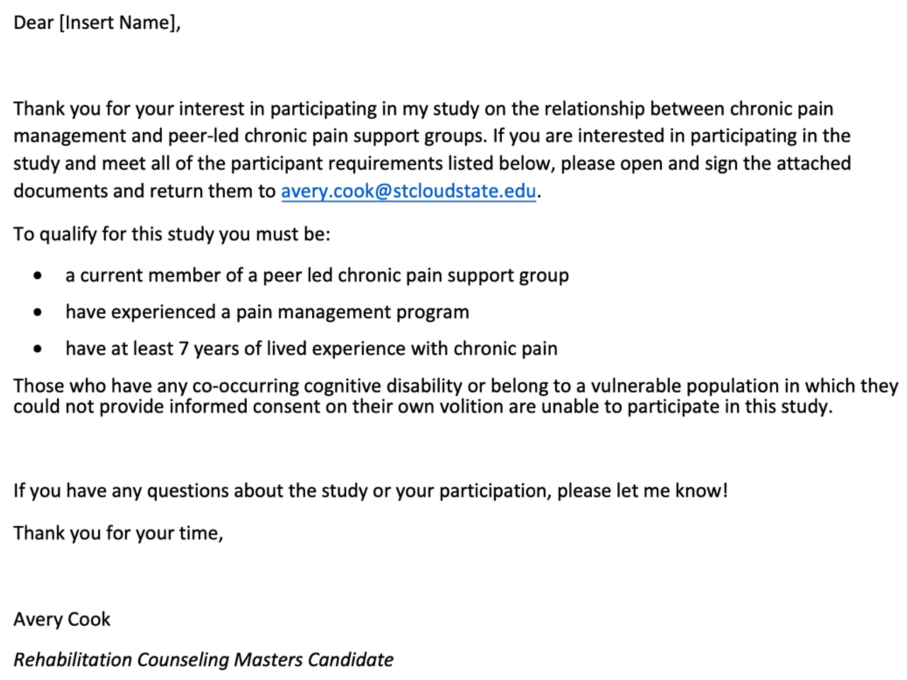
Those who have any co-occurring cognitive disability or belong to a vulnerable population in which they could not provide informed consent on their own volition are unable to participate in this study.

If you are interested in this opportunity and meet the above criteria, please email Avery Cook at avery.cook@stcloudstate.edu to get started.

Thanks!

Appendix C: Email Communication

To participants who inquired about the study:



Dear [Insert Name],

Thank you for your interest in participating in my study on the relationship between chronic pain management and peer-led chronic pain support groups. If you are interested in participating in the study and meet all of the participant requirements listed below, please open and sign the attached documents and return them to avery.cook@stcloudstate.edu.

To qualify for this study you must be:

- a current member of a peer led chronic pain support group
- have experienced a pain management program
- have at least 7 years of lived experience with chronic pain

Those who have any co-occurring cognitive disability or belong to a vulnerable population in which they could not provide informed consent on their own volition are unable to participate in this study.

If you have any questions about the study or your participation, please let me know!

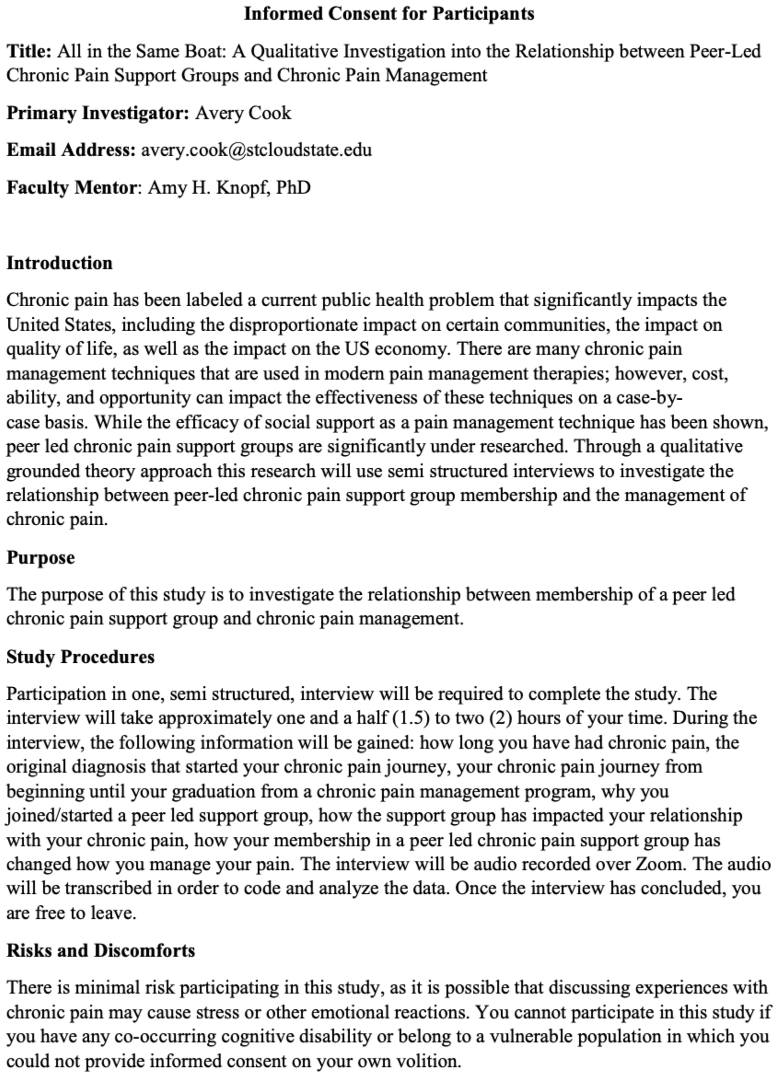
Thank you for your time,

Avery Cook

Rehabilitation Counseling Masters Candidate

Appendix D: Consent and Release Forms

Informed Consent for Participants



Informed Consent for Participants

Title: All in the Same Boat: A Qualitative Investigation into the Relationship between Peer-Led Chronic Pain Support Groups and Chronic Pain Management

Primary Investigator: Avery Cook

Email Address: avery.cook@stcloudstate.edu

Faculty Mentor: Amy H. Knopf, PhD

Introduction

Chronic pain has been labeled a current public health problem that significantly impacts the United States, including the disproportionate impact on certain communities, the impact on quality of life, as well as the impact on the US economy. There are many chronic pain management techniques that are used in modern pain management therapies; however, cost, ability, and opportunity can impact the effectiveness of these techniques on a case-by-case basis. While the efficacy of social support as a pain management technique has been shown, peer led chronic pain support groups are significantly under researched. Through a qualitative grounded theory approach this research will use semi structured interviews to investigate the relationship between peer-led chronic pain support group membership and the management of chronic pain.

Purpose

The purpose of this study is to investigate the relationship between membership of a peer led chronic pain support group and chronic pain management.

Study Procedures

Participation in one, semi structured, interview will be required to complete the study. The interview will take approximately one and a half (1.5) to two (2) hours of your time. During the interview, the following information will be gained: how long you have had chronic pain, the original diagnosis that started your chronic pain journey, your chronic pain journey from beginning until your graduation from a chronic pain management program, why you joined/started a peer led support group, how the support group has impacted your relationship with your chronic pain, how your membership in a peer led chronic pain support group has changed how you manage your pain. The interview will be audio recorded over Zoom. The audio will be transcribed in order to code and analyze the data. Once the interview has concluded, you are free to leave.

Risks and Discomforts

There is minimal risk participating in this study, as it is possible that discussing experiences with chronic pain may cause stress or other emotional reactions. You cannot participate in this study if you have any co-occurring cognitive disability or belong to a vulnerable population in which you could not provide informed consent on your own volition.

Benefits

Benefits from this study include contributing to the knowledge in the field of peer led chronic pain support groups.

Compensation

There is no compensation for participating in this study.

Confidentiality

The confidentiality of the information gathered during your participation in this study will be maintained. Your personal identity will remain confidential. You will not be identified by your name in any published material. All data will be kept in a file cabinet in a locked office.

Voluntary Participation/Withdrawal

Your participation in this study is voluntary. You may decide not to participate or to withdraw your consent to participate in this study at any time, for any reason, without penalty. Your decision whether or not to participate will not affect your current or future relations with St. Cloud State University or the researcher. The study investigator may stop your participation at any time without your consent for the following reasons: if the study is canceled, or for reasons deemed appropriate by the research coordinator to maintain subject safety and the integrity of the study.

Acceptance to Participate in the peer led chronic pain support group study

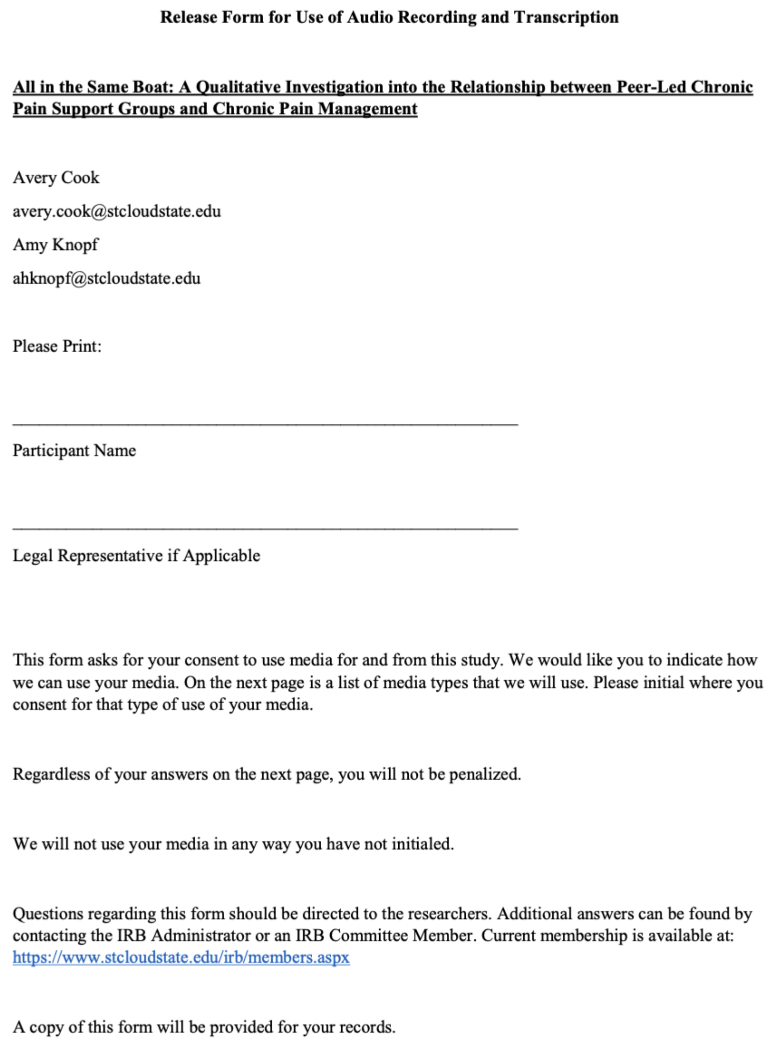
Your signature below indicates that you are at least 18 years of age, you have read the information provided above, and you have consent to participate. You may withdraw from the study at any time without penalty after signing this form.

Subject Name (Printed) ____

Subject Signature____

Date____

Release Form for Use of Audio Recording and Transcription



Release Form for Use of Audio Recording and Transcription

<u>All in the Same Boat: A Qualitative Investigation into the Relationship between Peer-Led Chronic Pain Support Groups and Chronic Pain Management</u>

Avery Cook
avery.cook@stcloudstate.edu
Amy Knopf
ahknopf@stcloudstate.edu

Please Print:

____
Participant Name

____
Legal Representative if Applicable

This form asks for your consent to use media for and from this study. We would like you to indicate how we can use your media. On the next page is a list of media types that we will use. Please initial where you consent for that type of use of your media.

Regardless of your answers on the next page, you will not be penalized.

We will not use your media in any way you have not initialed.

Questions regarding this form should be directed to the researchers. Additional answers can be found by contacting the IRB Administrator or an IRB Committee Member. Current membership is available at: https://www.stcloudstate.edu/irb/members.aspx

A copy of this form will be provided for your records.

Audio; no video	
Consent Granted	Type of Release
	Used by research team to record and analyze data
	Published or presented in an academic outlet (e.g., journal, conference)

Transcription of audio	
Consent Granted	Type of Release
	Used by research team to record and analyze data
	Published or presented in an academic outlet (e.g., journal, conference)

I have read the above carefully and give my consent only for those items in which I initialed.

____ _______________

Participant Signature (if 18 years of age or older) Date

____

Participant Name (Printed)

Appendix F: Interview Guide

Interview Guide:

1. How long have you had chronic pain?
2. What was the original diagnosis that started your chronic pain journey?
3. Tell me about your experiences with chronic pain before the Pain Management Program?
4. Before the PMP did you feel like you had:
    a. Poor Quality of Life?
    b. Financial Hardships?
    c. Social Hardships?
5. Tell me about the impact your Pain Management Program had on you and your chronic pain journey.
6. What did you take away from the Pain Management Program?
7. Tell me about your decision to join/start a peer led chronic pain support group versus a Healthcare Provider ran support group? What were some of the deciding factors?
8. How has the support group impacted your relationship with your chronic pain?
9. Tell me about how your quality of life has changed from before the peer-led support group to after?
10. What aspects of the peer-led support group have most positively impacted you?
11. Holistically, what have been the biggest changes you have seen in yourself and your pain management techniques during your membership to the support group?
12. Peer-led chronic pain support groups are rare, why do you think this method of support is underutilized?
13. In your opinion as a person who has had chronic pain for over 7 years, do you believe that your participation in a peer-led chronic pain support group has positively impacted your chronic pain management? If so, how? If not, explain?

Appendix G: IRB Approval

Approval from SCSU 10/28/2021

Hi Avery,
Your IRB project titled “All in the Same Boat: A Qualitative Investigation into the Relationship Between Peer-Led Chronic Pain Support Groups and Chronic Pain Management” has been approved. Attached is your decision letter.

Thanks!
Candy Swenson
Administrative Director