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Narratives of Chronic Pain After Treatment in Adult Patients

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This is to certify that the doctoral dissertation by

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Abstract

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MS, University of Bridgeport, 1976

BA, St. John Fisher College, 1972

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

In the United States 100 million people live with pain and must negotiate complicated clinical decisions that lead to a variety of treatments to control pain, some of which are effective and some that are not. Social identity theory and attribution theory guided the development of the interview protocol and analysis plan. A qualitative study was conducted to explore the complex nature of living with chronic pain through the narratives of seventeen adults in chronic pain for at least 3 months. Structural and thematic approaches were used to analyze the data. The structural results revealed three groups of participants: those who were pain-free at the time of the study, those using non-opioid medications to manage pain (over-the-counter or prescription), and those using opioid medications. The narratives of chronic pain revealed the shared experience of managing the unpredictable ebb and flow of pain daily. The results also exposed confrontational and stigmatizing experiences with doctors on issues including how to express the severity of pain and request opioid medications. Many participants reported undertreatment for pain. They also noted that anxiety increased pain. All participants experienced stigma associated with chronic pain from sources such as employers, family, and friends. The results suggest that (a) an ecological model is useful for understanding the barriers to pain relief that patients experience, and (b) chronic pain might be better treated as a separate disease instead of a symptom associated with an underlying condition. The results also pointed to opportunities for positive social change including advocating for greater consensus on the definition and treatment of chronic pain, and the utility of a biopsychosocial approach to treat all aspects of the chronic pain experience.

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Dedication

To Cindy, my wife: Her suffering from chronic pain inspired this study. Her strength in the face of adversity inspired awe. During our years together, she supported and encouraged me through the difficult phases of this project. Her courage, honesty, dedication, patience, and support made this study possible.

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Likewise, I would like to thank my male mentors, who helped me learn how to confront and move past my learning disabilities, and male patriarchy. These included: my godfather, Sam Danton; Rev. Ted Hoskins, a minister in the Congregational Church; and various other males, who appeared when I was ready and gave me spiritual and moral guidance. These latter teachers were too numerous to mention.

I would also like to thank Walden University. I would not have been able to do this study without their existence and encouragement. I took their mission to develop scholar practitioners seriously because they took it seriously. In every course, that lesson was a compelling aspiration and guide.

Finally, I would like to thank my mother, father, and my extended family. No matter what problems I gave them during my youth, they encouraged me to develop my wisdom, talent, and ability to communicate. Despite many setbacks, they never gave up the hope that I would become a productive and useful human being.

Their hopes for me remain an ongoing challenge.

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Chapter 1: Introduction to the Study

Pain is the oldest and still the most common reason for seeking medical treatment (Ljungvall et al., 2020; Meldrum, 2003; Prunuske, 2014; Sinatra, 2010; van den Beuken-van Everdingen et al., 2016; Vargas-Schaffer, 2010). Research often uses the terms “pain” and “suffering” interchangeably (Chapman & Gavrin, 1999). The difference between these two terms is critical to the comprehensive understanding of pain. This study was focused on the experience of persistent, chronic pain, defined as pain that continues after treatment for longer than medical providers expect (Gatchel et al., 2014; Siddall & Cousins, 2004; Stones & Cole, 2014). The evidence for the existence of chronic pain is undeniable (Berry & Dahl; 2000; Swan & Hamilton, 2016; Volkow & McLellan, 2016; Wailoo, 2104). This chapter summarizes the current knowledge and challenges in pain research, how this study addressed the gaps in that research, and why addressing these gaps was significant. I then review the research questions and the theories behind the framework of the study. I then consider how those theories supported the research questions.

Background

In the United States alone, 100 million people have lived with chronic pain (Ambrose & Golightly, 2015; Ljungvall et al., 2020; Peppin et al., 2015). The treatment of chronic pain, unlike other physical symptoms, has been fraught with political, economic, and social challenges (Clauw et al., 2019; Nagel, 2016; Treede et al., 2019; Wailoo, 2014). Treating chronic pain exceeded the costs of other common chronic conditions such as hypertension, heart disease, and diabetes (Clauw et al., 2019; Staton et al., 2007). The research estimated these costs to be between 560 to 635 billion dollars annually (Clauw et al., 2019; Gaskin &

Richard, 2012). Yet, despite enormous efforts and expense, medicine needed the research on the patient's voice to develop a more human understanding of the experience of chronic pain (Nichols et al., 2020; Rajagopal, 2011).

There were multiple ways to define chronic pain in the research (Bell & Salmon, 2009; Calati et al., 2015; Garschagen et al., 2015; Heit, 2001; Stubbs, 2016; Werner et al., 2004; Wong et al., 2015). In most studies, chronic pain was considered pain that lasts longer than 3 months (e.g., Clauw et al., 2019; Rivera et al., 2015). By any definition, chronic pain was a complicated phenomenon and difficult to measure objectively (Koyama et al., 2005; Littlejohn et al., 2019; Treede et al., 2019).

There were two main views on treating chronic pain (Nijs et al., 2019; Treede et al., 2019). The first was that chronic pain is a symptom (Dowell et al., 2016; Henry et al., 2015). The second was that chronic pain is a disease (Clauw et al., 2019; Engel, 2012). Henry et al. (2015) stated that treating chronic pain as a primary condition masked the pain and led to increased dosages in pain medications and long-term problems, including addiction. From this perspective, opioid medications should be titrated down and eliminated over time, regardless of whether the underlying, pain-producing conditions had been resolved (Dowell et al., 2016). Collectively these researchers suggested that treating noncancerous pain as the primary goal risked iatrogenic addiction. In this view, the problem was primarily due to over-prescribed pain medications (Dowell et al., 2016). Such research advised limiting or eschewing opioid pain medications, even when the patient complained of pain. It also minimized quality-of-life factors and the possibility of undertreatment (Hoffman, 2016).

Other researchers felt the basis of pain treatment should focus on quality-of-life considerations, not just medication types or dosages (Lynch, 2016; Melzack, 1990; Nijs et al., 2019; Treede et al., 2019). In this perspective, doctors administered pain medications at an effective dose to manage pain for as long as necessary. This control needed to be achieved by whatever means necessary, including the use of opioids (Gourlay et al., 2005; Kumar et al., 2015; Rajagopal, 2011; Treede et al., 2019).

A frequent topic of controversy in the history of pain treatment was the need to confront quality-of-life factors and eliminate needless pain (Nijs et al., 2019). The latest iteration started in the medical community with cancer pain (Katz & Rosenbloom, 2015; Melzack, 1990). Later research supported the idea that pain control should be a primary goal (Bennett et al., 2019; Gatchel et al., 2014; Katz & Rosenbloom, 2015). However, many researchers took issue with the need to control pain as the primary goal in noncancerous, chronic pain (Bhamb et al., 2006; Chaparro et al., 2014; Compton & Volkow, 2006; Henry et al., 2015; Moseley & Butler, 2015).

The epidemiological trend documenting the rise in opiate addiction has further complicated clinical decisions on pain control and polarized the debate (Peppin et al., 2015). The Centers for Disease Control and Prevention (CDC, 2015) reported that, from 1999 to 2014, opioid addiction increased, which caused 160,000 deaths. The CDC report also estimated that there were 1.9 million people who abused or became dependent on opioids in 2013. One theory was the over-prescription of opioid medications caused the rise in opioid abuse (Compton & Volkow, 2006).

Other research suggested prescribers may not be the primary cause of this increased addiction (Finnerup et al., 2015). Sullivan and Levin (2016) stated that more pain-producing conditions became evident as the number of baby boomers with chronic pain conditions increased as the country aged. The authors also noted that this population might have brought a tendency to be more open to the use of medications for pain control. Also, there was little evidence that reducing addictive pain medications would lead to better long-term pain management (Finnerup et al., 2015). Long-term pain management might require a personalized pain genotype, the identification of which needed more progress in neurological research (Bruehl et al., 2015).

Staton et al. (2007) stated that doctors consistently underestimated pain levels among patients who sought treatment and complained of pain. The authors found these differences in perceptions were more pronounced when the patients were from an ethnic minority. Even when the patients participated in detailed questions about their pain, the goal appeared to persuade patients to follow medical advice (de C Williams, 2016; Moseley & Butler, 2015; Zanini et al., 2016).

Stigmatizing systemic, social, and self-shaming judgments complicated pain treatments and undermined adequate control (Monsivais, 2013). Feelings of stigma were present in any disabling, chronic illness, including chronic pain (Jackson, 2005). Pain research often reported stigmatization feelings of chronic pain sufferers (Breivik et al., 2006; de C. Williams, 2016; Slade et al., 2009; Wilbers, 2015). This stigmatization sometimes resulted in self-shaming, perpetuating the problem (Waugh et al., 2014; Werner et al., 2004).

Research on treating pain as a symptom versus pain as a disease created conflicting recommendations on medical treatments (Peppin et al., 2015). These research studies noted a possible increase in systemic stigma from the medical community and society in general (Bennett et al., 2019; Breivik et al., 2006; de C. Williams, 2016; Slade et al., 2009; Wilbers, 2015). Other researchers suggested that the voice of patients was not appreciated (Rajagopal, 2011; Tsao, 2012). More information regarding a chronic pain patient's experience could better illuminate ways to understand and treat the condition (Bury, 2001; Thomas, 2010). A narrative approach might address this research gap (Rajagopal, 2011). Webster and Harden (2013) thought pain was a qualitative experience. They and other researchers recommended narrative analysis as a possible means of rehumanizing the understanding of chronic illness (Bury, 2001; Rajagopal, 2011; Thomas, 2010).

Problem Statement

The persistence of chronic pain changes a person's life and leads to comorbid events, including loss of work, depression, lower quality of life, isolation, and higher medical costs. (Von Korff et al., 2016). There is a lack of consensus on whether these aspects of chronic pain constitute a separate disease that requires its own course of treatment (e,g., Clauw et al., 2019), or if the search for pain's underlying mechanisms should be the primary goal (Vardeh et al., 2016). Further, since pain cannot be objectively measured, the treatment of pain is based on self-report and the judgement of medical providers (Bourke, 2014). Often pain is considered a symptom of an underlying problem (Robbins, 2017). Accordingly, treatment is focused on diagnosing and treating the underlying problem and not concentrating on complaints of pain (Brodal, 2017). What is missing from the debate on how to treat pain is the voice of the patients in chronic pain (Rajagopal, 2011; Tsao, 2012). Some research has tried to address this gap using surveys and focus groups (e.g., Wong et al., 2015). Researchers are calling for more in-depth understandings from the patients' perspectives. In this study I used narrative research to allow the participants to tell the story of their chronic pain experience in their own words. These stories explore the barriers to the adequate treatment of pain and how pain treatment can be improved.

Purpose

The purpose of this study was to explore the complex nature of pain through the narratives of participants who experienced chronic pain. The goal was to collect the stories of chronic pain treatment-seeking, pain relief, and stigma in pain patients. The plan was that these narratives would contribute to a deeper understanding of how pain might be better managed whenever possible.

Research Questions

This study addressed the following research questions and subquestions to draw closure on the identified gap in the literature:

RQ1: What were the narratives of managing chronic pain for patients?

SQ1a: How did these participants describe their experience of access to treatment?

SQ1b: How did these participants describe their experience with the pain management process?

RQ2: What was the meaning of stigma for these participants who used or believed they needed opioids?

SQ2a: How was stigma experienced in the treatment process?

SQ2b***:*** How was stigma experienced with family and other social supports?

Framework

One theoretical framework of this study was social identity theory (Dumont & Louw, 2007). This theory posited social roles could take many forms depending on the perceptions of the individuals within a group (Trepte, 2006). Monsivais (2013) stated that individuals with chronic pain formed their identity within a group according to how openly they expressed their chronic pain feelings. With more severe pain, the author concluded chronic pain was difficult to hide. The result might be a change in social roles imposed by the pain condition.

The change in social roles because of chronic pain invoked another theoretical construct, stigmatization. Some researchers suggested that stigma might result from a changed social role (Jackson, 2005). Much of the research documented the co-occurrence of chronic pain and stigma (de C Williams, 2016; Monsivais, 2013; Slade et al., 2009; Waugh et al., 2014; Werner et al., 2004). Stigma was evident in multiple pain studies, even when stigma was not the focus of the research questions (Breivik et al., 2006; Slade et al., 2009; Sturgeon & Zautra, 2016). The emotional impact of stigma lowered the ability to manage pain (Waugh et al., 2014). There was also evidence of stigma in situations where there was no observable bias (Monsivais, 2013).

A second theoretical framework came from the attribution theory. Attribution theory deals with how people create causal explanations in the absence of objective evidence (Kelley, 1973). Attribution theory helped explain why subjects hid their true feelings and gave a more socially acceptable answer to their doctors (Augoustinos et al., 2014). Also, because there is no objective measure of pain except by self-report, this theory was useful in understanding why patients and doctors disagree about the severity and causes of chronic pain (Staton et al., 2007). Attribution theory also helped explain when the substitution of a causal explanation, imposed without the conscious awareness, created a false memory (Reyna et al., 2016). Finally, attribution theory helped design questions for the structured interview so that the inquiries did not bias the outcome (Douglass et al., 2013).

Nature of the Study

For this study I used narrative research to explore the experience of people who live with chronic pain. Jovchelovitch and Bauer (2000) stated that narrative research was a well-recognized method for documenting shared cultural experiences, particularly illness and persistent pain experiences. Both the subject and the experimenter were active participants in creating a credible account with a beginning, middle, and end (Riessman, 2008). Surveys and case studies removed data from their original contextual relationships and placed them in another context, thus changing their meaning (Maxwell, 2013). Putting the data back into its original contextual relationship is an excellent way to maintain and fully understand the unique experience of chronic pain (Rajagopal, 2011).

For this qualitative, narrative study I interviewed 17 participants with chronic pain with one interview per participant. The participants were people who responded positively to an invitation from a referral source or expressed an interest in participation after hearing about the study's exitance. Each participant signed a written consent before beginning the interviews. The research questions encouraged each participant to tell their pain story in their own words. The data was recorded, transcribed, and then analyzed for common elements. Analysis of the themes for either supporting or disconfirming the research questions followed. These analyses included hand-coding, structural analyses, and computer assisted/aided qualitative data analysis software (MAXQDA™). Participants experiencing chronic pain often shared sensitive topics. Attempts to earn the participant's trust, assure confidentiality, and develop a nonjudgmental, empathic connection were high priorities.

To facilitate trustworthiness, the recommendations of experts in qualitative research guided the creation of the research questions and subquestions (Noyes et al., 2017; Riessman, 2008; Saldaña, 2016; Shenton, 2004). The thematic analysis approach uses structural analysis, theme identification, member checking, and computer software coding programs (Riessman, 2008; Saillard, 2011).

Definitions

The following definitions were terms used in this study:

Abuse of pain medications: This term defines one of the ontologically independent effects of pain medications in the treatment of chronic pain. This term describes when a person takes a pain medication that a doctor did not prescribe, is prescribed for another person, or when a person takes over-the-counter (OTC) drugs beyond the recommended dose without a doctor’s advice (Vowles et al., 2015).

Adverse d*rug* e*vents*: The term applies to all possible unfavorable pain medication outcomes, including side-effects, tolerance, drug escalation, and addiction. (Chapman et al., 2010; Gourlay et al., 2005; Heit, 2001; Vowles et al., 2015).

Addiction: This term is one of three ontologically independent expressions used to define the adverse effects of pain medications. Here it refers to the continued use of a pain medication despite a lack of relief, apparent harm, or a craving for the recreational effects. (Vowles et al., 2015).

Attribution theory: The theory states that a person creates an explanation in the absence of sufficient objective evidence to confirm the conclusion. This term explains how doctors come to erroneous conclusions on treating pain based on their experiences (Kelley, 1973).

Confirmation bias: This occurs when a person overestimates the effects of a given treatment or intervention in complicated situations or treatments. (Stubbs, 2016).

Chronic overlapping pain: With chronic overlapping pain, multiple underlying conditions contribute to the source of chronic pain, making the diagnosis, treatment, and pain relief more complicated (Fillingim et al., 2020; Littlejohn & Guymer, 2019).

Drug escalation: This occurs when the dosage of a drug increases more quickly than recommended by the standard practice to relieve pain (Henry et al., 2015).

Dependence on pain medications: This term is one of three ontologically independent expressions used to define the adverse effects of pain medications. This term applies when the titration or lowering of a pain medication increases severe pain or the inability to manage pain effectively. (Vowles et al., 2015).

Epidemic: The term applied to any medical problem that outstrips existing medical or other treatment resources (Barth et al., 2017; Dowell et al., 2016; Huffman et al., 2015; Penders, 2013; Reuben et al., 2015; Volkow & McLellan, 2016; Vowles et al., 2015).

Face Pain Rating Scale: This scale is the most common method of self-reporting pain. It is a 0-10, Likert-scale with Rating 0 (no pain) to Rating 10 (the most pain possible). Over each rating are hand-drawn faces that represent the increasing severity of pain (Swan & Hamilton, 2016).

Gatekeeper: In medicine, physicians have a dual role of healer and gatekeeper. In their gatekeeper role, they determine access to treatment and medical needs. (Carlsen & Nyborg, 2017).

Iatrogenic addiction: This term represents an addiction that results from the over-prescription of pain medications (Dowell et al., 2016; Higgins et. al., 2018).

Joint Commission: Formerly called the Joint Commission on Accreditation of Health Organizations (JCAHO). The Joint Commission is an accreditor of hospitals and other health care providers. They also are deeply involved in setting standards for pain management (Berry & Dahl, 2000).

Narrative research: This term refers to qualitative research that uses the participant's entire story and breaks the data into themes. After that, the analysis identifies the common themes between participants (Jovchelovitch & Bauer, 2000; Maxwell, 2013; Rajagopal, 2011).

Opioid: Any medication based on morphine or designed to give the same relief to pain as morphine and has proven to lead to addiction in some people (CDC, 2015).

Pain: There was no commonly accepted definition for this term. A lengthy discussion of the definitions of pain is in Chapter 2. The most common meaning: Doctors should allow patients to define their pain (Haylock, 2002; Newton et al., 2013).

Pain model: In the absence of an objective measure or theory of pain, models can organize various conceptions of pain and pain treatment modalities (Engel, 2012).

Pain event: Because the definition of pain can vary from study to study, this term was one way to describe a complaint of pain without accepting any given interpretation of pain (Bourke, 2014).

Pain relief: The term is used when the patient no longer complains of pain. It can also mean a 50% reduction in pain as defined by the patient (Finnerup et al., 2015).

Pain treatment: This refers to any intervention used to relieve pain, regardless of its effectiveness (Wailoo, 2014).

Pain tolerance: This term refers to when a patient self-reports a lower level of pain than expected given the cause (Irving, 1988).

Person-centered care: The term used when treatment included patient values, preferences, expectations, and social circumstances (Brummel-Smith et al., 2016). In areas of long-term treatment, this term is more widely accepted. (Wade & Halligan, 2017).

Propensity scores: This is a method to explore differences in groups with observational or nonrandomly selected data. A propensity score creates a probability that a subject will be in one group or another. This evaluation allows researchers to evaluate whether differences are a result of treatment effects (Luellen et al., 2005).

Pseudoaddiction: The term is used to identify when addictive behavior disappears after reported pain is relieved. (Bell & Salmon, 2009).

Publication bias: The term is used when outside influences affect the number and type of studies done on a topic (Sismondo, 2008).

Quality of life: This term is used when treatment outcomes should consider overall well-being and pain relief in addition to medication types and dosages (Lynch, 2016; Melzack, 1990).

Qualitative trustworthiness: Trustworthiness is a term used by qualitative researchers instead of validity. This term differentiates qualitative study terms from quantitative terms (Roulston & Shelton, 2015).

Referral source: This is a strategy that prevents a researcher from purposefully choosing participants in a qualitative study and potentially introducing biases in the research study. By putting a referral source between the participants and the researcher, participants would more likely reflect the actual topic under study (McLeod, 2017).

Saturation: In narrative studies, saturation occurs when the same data repeats in interviews and no new insights are likely to be discovered. Saturation usually leads to terminating the search for participants (Boddy, 2016; Francis et al., 2010; Mason, 2010).

Social identity theory: Social identity theorists study how a self-concept evolves and internalizes. This evolution comes from the need to develop and preserve a positive self-image when interacting with a social group (Abrams & Hogg, 1988).

Stakeholder: Anyone affected by the pain strategies and treatments of the patient could be considered part of this group. It includes patients, providers, government officials, pharmaceutical companies, family members, researchers, and affected professional agencies (Boswell, & Giordano, 2009).

Stigma: This label describes when repeated experiences of negative bias spoil the social identity of a person (Major et al., 1998)

Suffering: The taxonomic category ranks above physical pain and includes all types of human anguish, not just pain that arises from disease (Nagel, 2016).

Triangulation: This is a qualitative research strategy where a researcher collects data from different sources. This study did not use this technique (Shenton, 2004).

Undertreatment: This is a label used when a provided treatment results in inadequate pain relief and allows unnecessary pain (Peppin et al., 2015).

World Health Organization (WHO) Algorithm: The WHO suggests an algorithm for a step-by-step approach to pain treatment. Sometimes this approach results in prescribing opioids (Ventafridda et al., 1987; WHO, 2017).

Assumptions

I made the following assumptions with this study:

- I assumed a person can better understand the experience of pain by interviewing people who suffer from chronic pain.
- I assumed that despite individual differences, there are some similar situations for people in chronic pain, the exploration of which may help optimize pain treatment.
- I assumed stigma can be a consequence of bias that people with chronic pain experience, and that this experience is likely in social and medical settings.
- I assumed that narrative medicine research can contribute to improving the treatment of disease though a deeper understanding of a patient’s lived experience.

Scope and Delimitations

The following boundaries were inherent in this study:

- While there are similar experiences to chronic pain, the results from this study may not apply to people in acute pain. The short-term duration of acute pain sometimes allows for the enduring of pain until relief comes via healing. Acute pain relief within the period that medical providers expect is not part of the scope of this study.
- The nature of purposeful sampling (where the qualitative goal is to seek participants who share experiences) does not allow for inference to populations not included in the study.
- Due to the locale where I captured the data, the data might have been shaped, at least in part, by the lack of available local, specialized treatments. This concern was addressed in the results.

Limitations

The following were limitations to the study:

- This study depended entirely on the reported experience of the participant. There was no attempt to use information from the participant's medical providers, friends, or family. The study did not use triangulation in any other form to verify the reported experience of the participant.
- While not as easily observable in situations where pain can be lessened or better tolerated, any kind of pain might still generate similar experiences. The research

conclusions of this study might apply to cases where experienced pain is not as severe. Identifying those situations, however, was not a goal of this study.

- Because pain ebbs and flows, a report of pain at the interview may not be consistent with another interview taken later from the same participant. In this study I aimed to find similar experiences between pain participants, not to understand the longitudinal sequala of future pain experiences.

Significance

Considerable literature has documented the propensity to undertreat chronic pain due to: (a) fear of addiction or misuse, (b) fear of adverse effects, (c) lack of diagnostic criteria, and (d) lack of training (Bell & Salmon, 2009; Bhamb et al., 2006; Chapman et al., 2010; Gourlay et al., 2005; Peppin et al., 2015;). Rajagopal (2011) stated that the patient's voice was missing from the treatment debate in all cases. The author further noted that little research examined the patient’s narrative regarding pain relief and the effects of stigma. Such research could deepen the field’s understanding of (a) the consequences of medical decisions to restrict access to pain medications, and (b) the social effects of long-term pain on treatment outcomes (Tsao, 2012).

One goal of this study was to contribute to professional practice by improving compassionate care for patients in a medically appropriate way. Another goal was that this study's results would add to the growing body of knowledge that contributes to a deeper understanding of the suffering of millions of patients who experience chronic pain.

Summary and Transition

Unlike other physical symptoms, chronic pain treatment is fraught with multiple challenges, including high costs. Because there is no objective measure of pain, our measures of pain are usually documented by self-report. Despite centuries of research, there are competing theories as to the characteristics and treatment of pain. The rise in opiate addiction has further complicated clinical decisions on pain control and polarized the debate. Stigma might complicate pain treatments and prolong adequate control.

As a result, more research was necessary for people who suffer from chronic pain. Such research should deepen our understanding of their pain experiences. Pain research also suggested this understanding might be essential to provide optimal care and reduce unnecessary pain.

This study's theoretical frameworks included social identity theory and attribution theory, with the construct of stigma. For the study I had planned to interview 15 participants with chronic pain, but in the end I interviewed 17 participants for the study. They came from people who responded positively to an invitation from a referral source or volunteered after hearing about the study. All responses were recorded and analyzed using techniques consistent with narrative analysis.

Chapter 2 begins with a historical context of the perception of pain. It includes how chronic pain is defined and measured in healthcare. The published literature indicates a lack of consensus on pain measurement, making prevalence estimates difficult. The next section focuses on the treatment and undertreatment of pain, the latter fueled by fears of growing addiction. I also discuss research on bias and stigma towards individuals who suffer from chronic pain and have used opiates for pain relief. I present the theoretical frameworks of social identity theory and attribution theory and describe them in relation to the participants' experiences and how I used them to create the interview guide and analysis plan.

Chapter 2: Literature Review

There exists a large body of research on pain and the treatment of pain (Bennett et al., 2019; Clauw et al., 2019; Littlejohn et al., 2019; Ljungvall et al., 2020; Nichols et al., 2020; Nijs et al., 2019; O'Keeffe et al., 2016; Singh et al., 2016; Schuchat et al., 2017; Tighe et al., 2017; Treede et al., 2019; van den Beuken-van Everdingen et al. 2016; Walther-Larsen et al., 2017). However, there remained a lack of consensus on the definition, diagnosis, and treatment of chronic pain (Bennett et al., 2019; Finnerup et al., 2015; Gourlay et al., 2005; Nijs et al., 2019; Wailoo, 2014). An in-depth review of the literature revealed that there was little research on how individuals with chronic pain struggled with treatment options, got relief from pain, and dealt with the stigma associated with the use of prescription medications, particularly opioid medications. It also indicated a possible need to develop more research on the chronic pain treatment experience to illuminate better ways to understand and treat the condition.

Literature Search Strategy

I used the following databases to search the literature on pain, pain relief, and its outcomes: (a) EBSCO, (b) PsycINFO. (c) PubMed, (d) SAGE Collections, and (e) Science Direct. The major search terms included *addiction, pain, pain models, pain treatment, pain relief,* and *stigma*. I also searched two terms associated with qualitative research: *bias* and *narrative research.*

Due to the complex nature of pain, I used other terms within each major search category to develop a more complete picture of the nature of pain. For addiction, minor search terms included *abuse, DEA, harm reduction, history of opioids, opioids treatments,* and *the War on Drugs*. Pain search terms also included *acute pain, breakthrough pain, cancer pain, chronic pain, costs of pain, depression, neuropathic pain, pain assessment, persistent pain, suffering,* and *suicide*. Pain model terms included searches for *biomedical model* and *biopsychosocial model*. Pain treatment searches sometimes included *alternative therapies, chronic pain treatments, efficacy, Joint Commission, marijuana, opioids, treatment satisfaction, palliative care, quality of life, side effects, survival analysis, treatment compliance,* and *universal precautions*. Pain relief was searched with *inadequate pain management, opioid psychopharmacy, outcome measurement, palliative care, pseudoaddiction,* and *undertreatment*. Finally, stigma searches also sometimes included *disbelief, discrimination, health care encounters,* and *patient-centered care.*

In searching for research bias, I used terms such as *confirmation bias, false memories, hindsight bias, response bias, prejudice,* and *publication bias.* Narrative research included other search terms such as *client satisfaction, illness narratives, qualitative research,* and *qualitative synthesis*.

Given the multiple perspectives on pain and the various interests of stakeholders in the treatment of pain, complex searches for this study were inevitable. Whenever possible, these searches used the most recent citations. Many qualitative and pain treatment perspectives, however, tended to collect in the more distant past. As values changed, attitudes towards chronic pain changed, and this affected the research literature. As I will posit, there appeared to be no consensus in the field of pain treatment.

A Short History of Pain

Meldrum (2003), in a capsule history of pain management, stated that the philosophy of pain dated back at least to the Judeo-Christian religion. The author noted that the story of Job and the Passion of Christ suggested that chronic pain was almost necessary for moral behavior. Meldrum added that early utilitarian philosophers used pain and pleasure as opposing measures to determine good. The author added that doctors in the 17th century viewed chronic pain as a measure of resilience and potential recovery from illness. Meldrum stated that these views started to change with the widespread introduction of opium, beginning in 1680. The author pointed to the later introduction of morphine, an opium derivative, marketed under Heroin, contributing to this change.

Meldrum (2003) suggested the new use of anesthesia during surgery as another influence on the medical view of pain. During this period, when the underlying cause of pain could not be determined, the liberal use of medications to minimize pain was considered standard practice (Bourke, 2014; Meldrum, 2003; Wailoo, 2014). Meldrum further stated that the pendulum began to swing in the opposite direction in the early 1900s, when addiction, psychological treatments of pain, and the development of theories that chronic pain rewired the nervous system appeared. Meldrum added that, during this period, a wide variety of alternatives to narcotic medications were developed, with limited success in the case of chronic pain. After World War II, the suffering of soldiers returning home from the war with refractory, chronic pain conditions began to change medical opinions back to minimizing pain as the primary goal (Bourke, 2014; Meldrum, 2003; Wailoo, 2014).

Wailoo (2014) stated that pain treatment in the next 6 decades was fraught with political, economic, and social challenges. According to the author, since World War II, the societal view of pain could be divided between politically conservative and liberal viewpoints. In the conservative view, pain tolerance was a transformative experience that helped patients become more vigorous and motivated to overcome any disability. Direct treatment of pain, in this view, inevitably led to the overuse of medications, increased government involvement, creeping socialism, and dependency. Wailoo further added, in the liberal view, chronic pain was a significant obstacle to happiness. The author noted that this view posited pain relief as essential to developing compassion, a sense of community, and a quality life. Due to these opposing political views, Wailoo concluded that necessary suffering and unnecessary pain were often not defined by doctors treating patients. Instead, the author stated professional agencies, governmental laws, and the courts usually established these standards.

Bourke (2014), in a book on the history of pain perception, stated that pain historically was a shared experience based on individual and cultural attitudes of what Bourke called a “pain event” (p. 20). Other pain research literature also used adverse drug event terminology when describing pain medication problems (Chapman et al., 2010; Gourlay et al., 2005; Heit, 2001; Vowles et al., 2015). Bourke went on to say that when a person was in pain, there was no way of objectively measuring the experience except by what the person in pain reported and how an observer interpreted that report. The author concluded that this led to a variety of social and medical perceptions of pain throughout history.

Since 2000, the need to aggressively assess and treat pain again came into question (CDC, 2015; Dowell et al., 2016). In an editorial, Robbins (2017) suggested that the treatment of pain as the fifth vital sign, even when a patient did not complain of pain, led to the overuse of pain medications. The author suggested that the increase in fatal opioid addictions coincided with the same period as overzealous pain assessments. Robbins questioned whether there was undertreatment in more than 10% of people who complain of postoperative pain. While the author admitted that the increased emphasis on pain assessments and the increase in opioid addiction might be a coincidence, the use of pain scales in all medical situations has come into question. The American Medical Association (Anson, 2016) and the American Academy of Family Physicians (Lowes, 2016) dropped the advice to use pain scales in routine medical assessments.

The controversy on pain, its costs, and its causes continued to date (Clauw et al., 2019; Finnerup et al., 2015). The National Pain Strategy, a National Institute of Health study on pain, concluded that ongoing research on chronic pain could provide (a) insights on prevention, (b) the best ways to educate patients and physicians, and (c) better interventions for chronic pain (Deacon, 2013; Von Korff et al., 2016). Yet, the complexity of treating chronic pain and the continuing lack of consensus on even the definition or assessment of chronic pain seemed to make that goal elusive (Bruehl et al., 2015).

Defining and Assessing Pain

The dilemmas of understanding pain begin with the challenges of defining and assessing pain (Bourke, 2014; Wailoo, 2104). Often, pain definitions overlapped, contributing to research confusion (Vowles et al., 2015). An old description of chronic pain was an alarm signaling that a biological system is malfunctioning (Haylock, 2002). Another was that it is an objectionable sensory experience, with emotional aspects related to tissue damage or the possibility of tissue damage (Driscoll & Kerns, 2016). Tighe et al. (2015) compared chronic pain to hunger and nausea, which are medical problems with multiple causes manifesting with similar symptoms.

Julien et al. (2014), in a book on psychopharmacology, stated that pain has two broad categories. These categories included: (a) nociceptor pain, where observable tissue damage was evident; and (b) neuropathic pain, believed to be caused by a nervous system dysfunction. When pain disappeared within the expected healing time for the observed tissue damage or diagnosis, doctors defined nociceptor pain as acute pain (Gatchel et al., 2014). On the other hand, when chronic pain persisted, doctors labeled the pain neuropathic (Julien et al., 2014). To include pain where there was no observable biological cause, Brodal (2017) suggested that a reductionist definition of chronic pain focused on specific effects, such as pain scales, cannot fully comprehend a pain event. Instead, the author proposed a third general category of pain called homeostatic pain. In this definition, Brodal suggested the source of chronic pain was a perceived threat to internal hemostasis. The author further suggested that something triggered the pain alarm system, like an automotive theft alarm sounding in the dead of night, but the exact cause may be unknown. Further divisions of these categories into more specific labels often depended on the underlying medical diagnoses.

Acute Pain

Doctors labeled pain from a surgical procedure, recent onset of an illness, or a traumatic injury as acute pain (Sinatra, 2010; Tighe et al., 2015). Qaseem et al. (2017), in an article on the treatment of back pain, defined acute pain as lasting less than four weeks and subacute pain as lasting between 4-12 weeks. If it lasted longer, depending on the diagnosis, it was considered chronic pain.

Johnson (2005) discussed the differences between the two commonly used pain scales. The author stated that one used a scale without rating numbers (visual analog scale), and the other used a scale with rating numbers (numeric rating scale). Drawn faces were an early suggestion for measuring pain in children (Stuppy, 1998) and later added to the numeric pain scale (Flaherty, 2008). Swan and Hamilton (2016), in an instructional essay on pain assessment for advanced student nurses, stated that a face pain scale continued to assess the severity of acute pain. The authors further indicated that it has evolved into the commonly used pain scale because of its 0-10 ratings and illustrations of facial expressions. Swan and Hamilton further stated that, in this rating system, the lowest rating represented no pain, and the highest rating represented the most pain possible. The authors also noted that hand-drawn faces accompanied these numbers, ranging from a smiling face (Rating 0) to a frowning hand-drawn face (Rating 10).

In addition to face drawings, a variety of numeric and visual rating scales assessed the intensity of chronic pain in children (Castarlenas et al., 2017). In addition to numeric pain scales, there were verbal rating scales where children had to pick out a phrase that best described their pain (Miró et al., 2016). Hildenbrand et al. (2016) defined the color analog scale, a 10-centimeter line colored in increasingly deepened red shades to indicate pain intensity. The authors added that a child moved a marker over a line to indicate the severity of pain.

Weissman et al. (2015) found physicians often had to rely on the report of caregivers when people with disabilities were in chronic pain and were unable to report pain symptoms reliably. At times the addition of a supplemental checklist facilitated direct observation. The authors added that doctors depended on this strategy for people with dementia. In older adults, particularly after a fall or a motor vehicle accident, the tendency to become sedentary, even when activity was low before the injury, tended to prolong their recovery (Platts-Mills et al., 2016). Kaufman and Baucom (2014) stated that ignoring these likely comorbid conditions prolonged recovery and called it diagnostic overshadowing.

Meek (2015), in another clinical review on pain assessment for nurses, stated that a report of pain needed to be followed by more in-depth questions. The author further noted that acute pain assessment could use the mnemonic OLDCART: (a) *onset* of the pain; (b) *location* of pain in the body; (c) *duration* of pain; (d) *characteristics* of the pain (e.g., crushing, burning, stabbing, etc.); (e) *aggregating* factors of the pain (e.g., triggers, activities, body positions, events that make the pain worse); (f) *relieving* factors of the pain (e.g., cold compresses, heat, avoidance, and relaxation); and (g) *temperature* (e.g., cold skin, warm skin). Meek further stated that patient-centered care often required an expanded role for nurses, and these assessment skills were within their potential competencies. Several newly developed multimodal pain scales for assessing acute pain also existed but were not yet in everyday use (Tighe et al., 2015).

Chronic Noncancerous Pain

Chronic, non-cancerous pain had many definitions, making it very difficult to assess (Honey et al., 2016). One description was that it was a health disorder that had pervasive adverse effects on patients and their families (Garschagen et al., 2015; Von Korff et al., 2016). Others described chronic pain as a disabling physical condition with several concomitant psychological disorders, including depression, loss of hope, a lack of motivation (Wong et al., 2015), and suicidal feelings (Calati et al., 2015; Stubbs, 2016). The negative impacts on employment, leisure, life goals, and other quality of life supports often appeared in reports of chronic pain (Werner et al., 2004; Von Korff et al., 2016). A fourth definition was that chronic pain differed from acute pain in that it lasted longer than expected to provide a protective function for the body to heal (Gatchel et al., 2014). The patient defined chronic pain by its location and severity as a fifth, older, but still widely accepted definition (Haylock, 2002; Newton et al., 2013). Finally, as stated above, in many studies, researchers defined chronic pain as pain that lasted longer than three months (Vallerand et al., 2015; Von Korff et al., 2016; Vowles et al., 2015).

Chronic Regional Pain Syndrome

Schneider et al. (2015) stated that Chronic Regional Pain Syndrome (CRPS) is a pain disorder that spreads from an injured site to affect a broader region of the body, often limiting itself to one area, such as a limb. While usually starting with a traumatic injury (Type I), the authors stated that the etiology and magnification of its broader pain effect was unclear, as was its sequela. Schneider added that, even when there was no observable injury (Type II), the diagnosis was made by observing: (a) abnormal pain processing; (b) changes in skin color and temperature; (c) abnormal burning sensations, sweating, sometimes followed by chills; (d) edema; and (e) unusual changes in sensory-motor functioning. Carr et al. (2016) believed that CRPS was very complex to diagnose and treat and often resulted in severe pain. The authors stated that early diagnosis is essential to treatment, but the accurate diagnosis often was delayed because it was a diagnosis by exclusion.

Chronic Pain Cancer Related

Parala-Metz and Davis (2013) stated that cancer pain was more difficult to assess than acute pain. The authors posited its presentation varied according to: (a) multiple onsets; (b) varying durations; (c) multiple locations; (d) genetics; (e) medical history; (f) patient mood; (g) patient expectations; and (h) the culture of the patient. Parala-Metz and Davis further stated that cancer pain was usually classified as chronic pain because it often lasted longer than three months. Nonetheless, episodes of acute pain frequently flared up within the course of treatment. These flare-ups were called breakthrough pain (Portenoy et al., 1999; Winiarczyk & Knetki-Wróblewska, 2016). Other authors stated that doctors did not fully understand breakthrough cancer pain, making an effective diagnosis and treatment difficult (Bennett et al., 2019; Mercadante. 2018). Paice et al. (2017) suggested that one way to meet this challenge was to vary pain diagnoses by types of cancers. However, when the authors used only three types of cancers, they found that their criteria applied more generally would cause controversy. This realization led Paice to conclude that their goal of an evidence-based taxonomy of pain based on cancer type would not occur any time soon.

Chronic Overlapping Pain

Fillingim et al. (2020) stated that chronic overlapping pain occurred when multiple sources created chronic pain. The authors noted that chronic overlapping pain was more likely to develop chronic pain's comorbid psychological effects. Fillingim studied various combinations of overlapping pain sources and found they all significantly impacted emotions, which increased overall pain.

Persistent Acute or Chronic Pain

This term became the general term for any pain that continued for longer than a medical provider expected (Gatchel et al., 2014; Siddall & Cousins, 2004; Stones & Cole, 2014). Based on clinical experience, this expectation was usually classified by diagnosis and intervention (e.g., Kainu et al., 2016; Proud & Howard, 2016; Rutten et al., 2016). Higgins et al. (2018), in a meta-analysis, found that persistent acute pain challenged current medical resource allocations, but the research did not support the widespread incidents of iatrogenic opioid addiction. In a later chapter, I will discuss the relationship between persistent pain and addiction.

In summary, pain, acute or chronic, was a condition that most people had experienced. Yet, the idiosyncratic nature of chronic pain (i.e., origins, time frame, and co-occurring conditions) created challenges for researchers to converge on a single definition or assessment process. Complex pain symptoms defied precise diagnosis and assessment, making treatment more difficult.

Prevalence of Pain

The difficulty of defining and diagnosing pain not only negatively affected the ability to determine an accurate prevalence of pain, but it also interfered with indirect epidemiological indicators used to understand the breadth, depth, and severity of a pain "epidemic" (Barth et al., 2017; Dowell et al., 2016; Higgins et al., 2018; Huffman et al., 2015; Penders, 2013; Reuben et al., 2015; Volkow & McLellan, 2016; Vowles et al., 2015). As stated above, treating pain exceeded the costs of other common chronic conditions such as hypertension, heart disease, and diabetes (Moore et al., 2014; Staton et al., 2007). Chronic pain cost estimates ranged from $560 to $635 billion annually (Gaskin & Richard, 2012; Nahin, 2015). Since there was so much variability in the definition and assessment of pain, physicians used their clinical judgment to assess and treat pain (Bhamb et al., 2006). These varying clinical judgments affected estimates of pain prevalence (Paydar et al., 2016). To address these difficulties, pain studies researchers often limited their prevalence studies to subcategories of pain definitions and diagnoses.

Acute Pain Prevalence

The primary complaint in most emergency rooms was acute pain, encompassing 40% of the 100 million people who sought emergency care in a hospital each year (Ahmadi et al., 2016; Sinatra, 2010; Stalnikowicz et al. 2005). Acute pain was also a concern in the 70 million surgeries performed yearly in the United States (Tiege et al., 2015). One study on postoperative pain indicated: (a) 84% experienced pain five hours after abdominal surgery; (b) 92% experienced pain two days after surgery; and (c) 96% of post-surgical patients experienced pain three days after surgery (Singh et al., 2016). Another study stated that 82%

reported moderate-to-severe pain intensity two weeks after discharge (Sinatra, 2010). Lack of aggressive treatment of acute pain often sets the stage for preventing a host of later pain complications--including chronic pain, infection, and morbidity (Nagel, 2016). Tiege et al. (2015) suggested that, despite enormous research, acute pain was still not well understood. The resources were variable, and there was a need to go beyond relying solely on medications.

Chronic Pain Prevalence

By one estimate, in the U.S. alone, more than 100 million people live with chronic pain. Other estimates ranged from 14%-25% of the general population (Peppin et al., 2015; Von Korff et al., 2016). The Center for Disease Control estimated that 11.2% of the general adult population had some form of chronic pain (Dowell et al., 2016). In other countries, chronic pain estimates range up to 8% of the general population (Gilron et al., 2015). In patients over 65, chronic pain estimates range up to over 33% of the aging population (Molton & Terrill, 2014). In a worldwide meta-analysis, chronic pain prevalence increased steadily according to age group, going from 14.3% in young adults to 62% in adults over 75 years old (Lynch, 2016).

Cancer Pain Prevalence

Patients with cancer experienced chronic pain 30%-45% of the time (Fujii-Lau, et al., 2015; Vuong et al., 2016). In advanced cancer, the prevalence of pain rose to 75% (Haumann et al., 2017; Haylock, 2002). In a worldwide meta-analysis, van den Beuken-van Everdingen et al. (2016) stated that chronic pain in cancer patients was evident in approximately: (a) one-third of cancer patients who survived; (b) more than half of the patients during cancer treatments; and (c) two-thirds of the patients with advanced or terminal cancer. Overall, the authors further stated that more than one-third of cancer patients reported their pain as moderate to severe. Research showed that numerous factors affected the perception and sequela of chronic pain management in cancer treatment (Swan & Hamilton, 2016). These variabilities made developing a consensus on the assessment and treatment of chronic pain difficult (Von Korff et al., 2016).

Chronic Regional Pain Syndrome Prevalence

Schneider et al. (2015) found 50,000 new chronic regional pain syndrome (CRPS) cases each year, and a population estimated between 1.5-3.0 million people. Another estimate was the prevalence of CPRS-I (i.e., with injury) was 0.26 per thousand per year (de Mos et al., 2007; den Hollander et al., 2016). Ratti et al. (2015) stated the complexity of CRPS diagnosis made epidemiological estimates unreliable. The authors said that, while CRPS has had various labels over the past century, the prevalence was considered very rare. Ratti et al. (2015) concluded that, with better diagnoses, CRPS was secondary to multiple etiologies. These included: (a) fractures, (b) surgery, and (c) genetic predisposition. Yet, confusion continued in the literature.

To differentiate chronic regional pain, widespread chronic pain, and fibromyalgia, Kim et al. (2012) defined chronic regional pain as existing in a particular area of the body and widespread chronic pain as pain over the entire body. The authors then further differentiated widespread chronic pain from fibromyalgia by looking for 11 out of 18 tender points, often seen in fibromyalgia. In a Korean hospital, the authors found chronic regional pain in 31% of the patients. Kim further found widespread chronic pain in 6.5% of the patients and fibromyalgia in 1.7% of the patients. As in chronic pain, CRPS was challenging to diagnose, treatments lacked consensus, and much more research was necessary to develop practical prevalence guidelines (Ratti et al., 2015).

Persistent Pain Prevalence

Estimates are that approximately one-third of the American population experienced pain at any given time (Driscoll & Kerns, 2016). In the most recent study on pain prevalence, Nahin (2015) extracted data from 2012 medical statistics, taken from 8,781 adults in 17 categories of illnesses likely to produce pain. From that survey, the author estimated that, in America, 126 million patients (55%) were in some form of pain over the previous three months. Also, Nahin further estimated that 25.3 million (11.2%) were in daily pain, and 25.3 million (10.3%) were in moderate to severe pain.

In summary, the prevalence of pain was difficult to determine because chronic pain was difficult to define and assess. Depending on the type of pain, the underlying medical problem, and the population in question, pain prevalence estimates range from 8% to 45%, with vulnerable populations and complex pain ranging as high as 75% (Peppin et al., 2015; Singh et al., 2016; Von Korff et al., 2016). It was the most common complaint when people seek medical treatment (Meldrum, 2003; Prunuske, 2014; Sinatra, 2010; van den Beuken-van Everdingen et al., 2016; Vargas-Schaffer, 2010). It was the costliest medical condition to treat (Moore et al., 2014; Staton et al., 2007). At any given moment, estimates were that one-third of the population experienced various pain (Driscoll & Kerns, 2016). What follows are descriptions of different conceptualizations of chronic pain and how these models contribute to the challenge of appropriate and practical approaches to treating pain.

Conceptual Models of Pain

Biomedical Model

Engel (2012) defined the biomedical model as a factor analytical, reductionist approach to treatment. In this model, chronic pain was a symptom of an underlying disease. The author further stated that chronic pain treatments focused on the underlying causes of chronic pain. This focus tended to ignore any psychological components of the disease. Engel believed the primary focus on underlying causes was using the biomedical model of pain treatment. The author further stated that when physicians thought the etiology of chronic pain was psychological, they often decided that treatment was outside their purview.

In the biomedical view, masking chronic pain by directly treating it led to increased dosages in pain medications and long-term problems, including addiction (Henry et al., 2015). Pain medications offered only temporary relief and, ideally, should be titrated down to zero over time, regardless of whether the underlying, pain-producing conditions were resolved (Dowell et al., 2016). Brodal (2017) believed that this reductionist approach to pain, however, often caused problems when it confused the experience of pain with its biological sources. From a political standpoint, this view was the conservative pain treatment model (Wailoo, 2014).

Peppin et al. (2015) also stated that the strict biomedical model caused systemic problems. The authors felt that medical interventions using this paradigm led to undertreatment and unnecessary pain. The authors posited that with a strict biomedical, the primary focus was on medications and other pharmaceutical industry solutions. Further research indicated that this approach also unintentionally led to a treatment that held out the hope of a magic bullet, encouraging interventions that were too often futile and ineffective (Deacon, 2013).

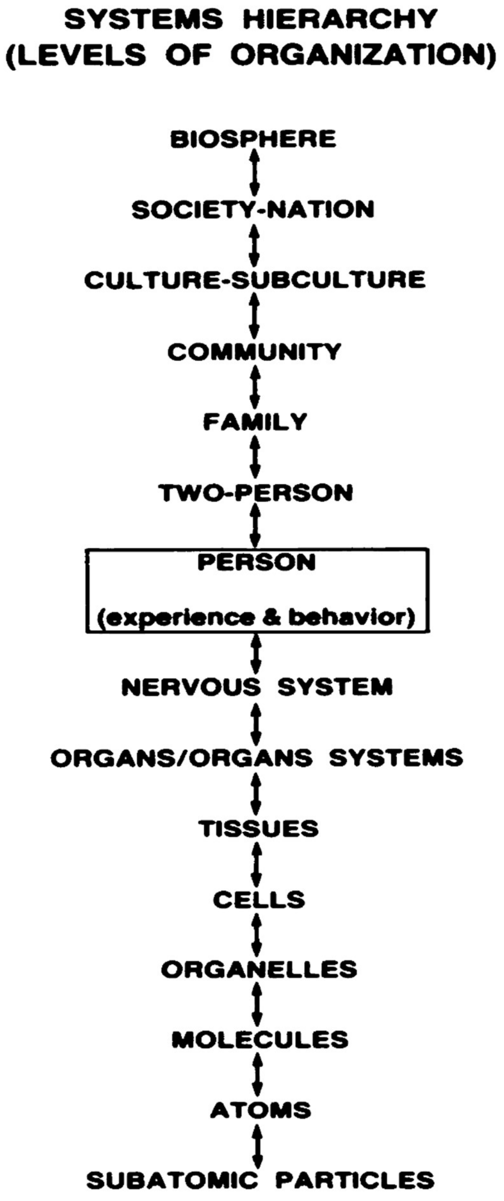
Vardeh et al. (2016), on the other hand, stated that a mechanistic approach to pain offered the best long-term hope for pain control. The authors admitted that most pain management treatments were inadequate. Nonetheless, Vardeh stated an effective intervention might be possible once medicine with an improved understanding of pain mechanics. The authors also pointed out that an enhanced understanding of mechanisms helped address such pathologies as diabetes and peptic ulcers.

Biopsychosocial Models

Engel (1980) contrasted the biomedical model with the biopsychosocial model. In this alternative model, the patient was part of a hierarchy of natural systems with levels ranging from the biosphere to subatomic particles. According to the author, in the middle of the biopsychosocial hierarchy were the patients, including their experiences and behaviors. Engel stated, in place of a reductionist approach, a biopsychosocial model included the feelings of a patient, the doctor-patient relationship, and any information gleaned from any level of the hierarchy that might be useful to the resolution or management of pain (see Figure 1). This model has multiplied into various sub-models regarding chronic pain, with many overlapping aspects, which often varied according to which aspects were emphasized (Quintner et al., 2008).

Figure 1

Biopsychosocial Hierarchy as a Continuum



Note. From "The Clinical Application of the Biopsychosocial Model" by G.L. Engel, 1980, *The American Journal of Psychiatry*, 137(5), p. 537. Reprinted with permission, 6/30/2021 Rightslink® by Copyright Clearance Center.

Biopsychosocial Submodels

Wade and Halligan (2017) stated that the biopsychosocial model's complexity and the lack of a consensus definition of chronic pain had prevented widespread acceptance, despite extensive use of the term in research. Yet, the authors felt its influence was growing, and it appeared to be the basis of what was called person-centered care. In the illness research literature, the various identifiable sub-models that may guide treatment.

Gate Control Model of Persistent Pain

Melzack (1990) first postulated the gate control model of pain during cancer treatment. The author theorized the existence of a gate in the spinal dorsal horn that acted as a switch to turn on and turn off pain before the signal of pain reached the brain. Melzack also theorized that there many ways to close this gate, including relaxation and cognitive interventions. The gate was opened, however, by fear of pain. Only after the adequate control of pain could other interventions work to manage and minimize pain. It put the author in agreement with researchers who believed that pain control needed to be achieved first by whatever means necessary, including the use of opioids. This model treated addiction and adverse side effects as secondary (Bhamb et al., 2006; Chaparro et al., 2014; Compton & Volkow, 2006; Finnerup et al., 2015; Gatchel et al., 2014; Henry et al., 2015; Hoffman, 2016; Katz & Rosenbloom, 2015; Moseley & Butler, 2015). Since then, the gate control theory of pain became a widely accepted theory for pain control in cancer treatment (Katz & Rosenbloom, 2015; Zhang et al., 2018).). Other biopsychosocial models often incorporated this concept (Driscoll & Kerns, 2016).

Complexity Model

Peppin et al. (2015) proposed a new paradigm for pain treatment called the complexity model. The authors stated that the complexity model set goals in all appropriate areas likely to affect pain management and individualized by circumstances. Peppin explained that these areas included: (a) education about pain management, (b) establishing pharmacological goals and medication treatment routines, (c) examining and setting goals around coping, (d) developing individual and social supports necessary, and (e) developing an exercise routine that can exist within the limits of any pain-related disability to increase functioning. The authors stated that these criteria were best accomplished when the related services were under the same organization, working with the same treatment philosophy. Peppin concluded that this model worked collaboratively with the pain patient to address their pain's complex nature, with patient satisfaction as the ultimate goal. In more complex pain management, the authors added that the use of opioids was necessary for patients in persistent, chronic pain. Peppin further stated that a complexity approach must deal with patients for whom medications caused more problems than they solved.

Adjunctive Psychological Model

Jensen and Turk (2014) offered a review of the various psychological treatments used as adjunctive pain management techniques to address non-biological pain and suffering. The authors broke these treatments into four categories: strategies to redefine and cognitively restructure the perception of pain, education on the etiologies and treatments of pain according to the diagnosis, physical exercises and other activities to help cope with pain, and other psychological therapies found useful in lowering the perception of pain. In further research, while helpful, these techniques were not likely to eliminate pain or even adequately manage moderate-to-severe pain without medications (Barth et al., 2017; Passik, 2009). Nonetheless, research shows they have been useful as an adjunct to coping with persistent pain (Ambrose & Golightly, 2015; Berg & Upchurch, 2007; Galvani et al., 2019; McCracken & Gutiérrez-Martínez, 2011; McCracken, 1998; Sirois & Wood, 2017; Vlaeyen et al., 2016).

Neurobiological Model

This model held out the hope that it may be possible to directly measure pain by looking at brain functioning, primarily through brain imaging. It was possible to observe which parts of the brain were active when a person was in pain using fMRI and PET scans (Flor, 2014). Brodal (2017) stated, while there appeared to be an observable pain network, how those areas of the brain interacted, and how it was affected by pain perceptions were not well understood. The author noted the brain activated in regions of the pain network when the patient reported no pain. Brodal further stated that, with persistent, chronic pain, other brain regions, including the cortical gray and white areas, seemed to be affected. The author felt this created the possibility for many false alarms in pain determination, and brain imaging seemed to confuse pain remembered but not felt. Brodal concluded that using brain activation as an objective measure of experienced pain, like blood pressure and heart rate, was not yet reliable as an objective measure. Other researchers stated that this model might offer hope in understanding why some patients could tolerate chronic pain and others could not (Littlejohn & Guymer, 2019; Tracey, 2016).

Defining Chronic Pain as a Symptom or Disease

Engel (1980) was the first to point out that the differences between the biomedical model and the biopsychosocial models. These differences focused on whether chronic pain was a symptom of an underlying problem (biomedical) or a separate disease (biopsychosocial). If it is a symptom, then the underlying problem would be the primary focus of treatments (Raffaeli & Arnaudo, 2017). If chronic pain is a separate disease, a more holistic approach to pain management would be appropriate (Clauw et al., 2019).

As previously stated, Robbins (2017) in an editorial suggested that pain-as-disease models, particularly when a patient does not complain of pain, have led to the overuse of pain medications. The author suggested that the increase in fatal opioid addictions coincided with the same period as overzealous pain assessments. Robbins questioned whether there was undertreatment in more than 10% of people who complain of postoperative pain.

Stanos et al. (2016) stated that chronic pain's complexity involved biological, psychological, and social interventions. The authors felt that primary care physicians, who handle most chronic pain treatment, did not receive adequate training to diagnose and treat chronic pain at this level. Morlion et al. (2018) suggested that chronic pain was a separate disease and changed treatment focus to quality-of-life criteria. Other researchers criticized the biomedical model because it overemphasized medication types and dosages (Melzack, 1990; Rajagopal, 2011). Pain was also sometimes considered the fifth vital sign, like pulse, respiration, body temperature, and blood pressure (Edlund, 2011; Raffaeli & Arnaudo, 2017; Yuen & Irwin, 2005). When long-term treatment results in a lifetime of opioid use but a higher quality of life, by this view, it was considered a fair trade (Kumar et al., 2015; Tompkins et al., 2017).

Treede et al. (2019) described how the International Classifications of Disease (ICD) might better classify chronic pain as a separate disease. The authors hoped that those changes would develop better treatment pathways, improve patient access to biopsychosocial alternatives, and reduce stigma. Treede also stated that opioids might be used long-term safely with some people. As will be seen, there was little access to biopsychosocial treatment in participants interviewed for this study. How the medical community could improve patient access to biopsychosocial treatments under the current classification system will be addressed in the results.

In summary, given the variety of pain models, no testable pain theory, and no objective measure of pain, any given pain model's adoption seemed a subjective choice based on the treating physician's preferences and training. It indicates that treatments that spring from these models have a subjective, interpretive component in assessing and treating pain. This subjective component, and its effects, will be further explored in pain treatments. The next section also discusses the role of pain models in addiction and undertreatment.

Pain Treatments

The ultimate goal in treating pain is to relieve as much pain as possible without causing more harm than good (Schuchat et al., 2017; Coghill et al., 2003; Kahan et al., 2006; Penders, 2013; Sehgal et al., 2012). While there has been considerable research to develop clinical guidelines and best practices, a primary clinician usually makes the risk/benefit analysis in pain treatment decisions (e.g., Dowell et al., 2016; Gourlay & Heit, 2009; Jensen & Turk, 2014).

Two books devoted to educating pain patients provided a fair comparison of opposite approaches to pain treatments. Nagel (2016) focused on the inability of the medical system to fully understand and eliminate pain. The author questioned current medical practices and assumptions. He also encouraged the use of opioids at the outset, if necessary, to successfully manage pain. Over time, Nagel concluded opioids could be reduced and pain better managed, but chronic pain control by any means was the best course. Caudill (2016), on the other hand, while admitting the limitations of current treatments of pain control, seemed to eschew opioids and encouraged pain patients to use non-opioid pain medications and psychosocial interventions to control their pain. In the absence of pain relief, the author prescribed acceptance and continuously challenging the limitations of pain.

In general, the research on pain treatment seemed to chart a middle path, as seen by the World Health Organization (WHO) recommendations and their guidelines (World Health Organization, 2017). Initially, the WHO analgesic ladder was a treatment algorithm urging a step-by-step approach to treating cancer pain that sometimes resulted in using opioids (Ventafridda et al., 1987). Vargas-Schaffer (2010) stated that this algorithm was modified, by WHO and others, several times over the past four decades to include all types of pain. The author said that in every iteration, the fundamental recommendations of WHO remained: (a) start with oral pain medications, (b) give medications at regular intervals, (c) adjust dosage by the intensity of pain, individualize pain treatment, and (d) explain the treatment plan to the patient, the family, and other care providers. Concerns about opioid addiction and how pain treatment should vary by diagnosis sometimes caused variations in the WHO analgesic ladder (Baker, 2017; Morlion et al., 2018).

Acute Pain Treatments

Chronic pain can come directly from the physician's actions when they first undertreat acute pain (Gatchel et al., 2014; Kehlet et al., 2006; Nagel, 2016). Gordon et al. (2016) reviewed 32 questions recommended when addressing acute surgical pain. The survey addressed pain management before, during, and after surgery called perioperative acute pain management. The authors admitted that the evidence for those questions was sparse and based mostly on the reported experience of physicians who treat pain. Kent et al. (2017) postulated that mismanagement of acute pain often results from a poorly defined taxonomy that depends on the intensity of the acute pain and its duration. Instead, the authors proposed a multidimensional framework of pain management, similar to the complexity model.

Khidir and Weiner (2016), in a commentary, discussed the dilemma of emergency room physicians faced when patients complained of severe pain, where they must give treatment under pressure, without longitudinal medical information, and influenced by an ever-changing standard of quality care. For instance, Barnett et al. (2017), citing the recent rise in opioid dependence as justification, did a study on emergency room physicians who prescribed opioids. The study focused on people with Medicare who came to the emergency room and had not used an opioid during the previous six months. Barnett then divided the emergency room physicians into quartiles, with high-intensity, opioid-prescribing emergency room physicians in one quartile. The other physicians ranked in the other three quartiles, with low-prescribing physicians in the fourth quartile. The authors found that the patients with the high-intensity, opioid-prescribing physicians were more likely to become dependent and were more likely to experience injuries within the next 12 months. Barnett acknowledged that their Medicare population studied was predominately older adults and that their findings were correlations. The authors did not report the effectiveness of pain relief, the quality of life of the patients, or why most emergency room doctors in the hospital refused to give any opioid medications. Yet, the subjects in the Barnett study probably knew the hospital was parsimonious with pain medications. In that case, a person in chronic pain might soon learn to go to another hospital or request a particular doctor to treat their complaint. As a result, the patients with the most pain, and the most complex medical problems, might be avoiding low-intensity, opioid-eschewing doctors, leaving them with a healthier population, which could account for the effects.

Cancer Pain Treatments

As previously mentioned, the assessment and treatment of cancer pain was the first use of the WHO analgesic ladder (Bao et al., 2016; Haylock, 2002). Treatment outcomes seemed to be most effective with constant assessment and around-the-clock treatment of cancer pain with medications (Gatti et al., 2014; Haylock, 2002). As previously mentioned, cancer pain was where the medical community first understood the need to recognize and aggressively treat needless pain (Melzack, 1990; Katz & Rosenbloom, 2015). Later research also supported the idea that adequate control of cancer pain must be a primary treatment (Gatchel et al., 2014; Kumar et al., 2015; Radbruch et al., 2013; Seymour et al., 2005). Van den Beuken-van Everdingen et al. (2016), in a meta-analysis on cancer pain, stated that, despite some progress in the past decade, pain in cancer patients remained a problem and needed more research.

Noncancerous Chronic Pain Treatments

The same algorithm as chronic, non-cancer pain guided the treatment of persistent pain and chronic regional pain. Despite its ubiquity, chronic, noncancerous pain remained the most complex and complicated treatment (e.g., Honey et al., 2016; Volkow & McLellan, 2016). Dowell et al. (2016), using a strict, evidence-based biomedical model, believed that opioid medications should be titrated down and eliminated over time, regardless of the resolution of the underlying, pain-producing conditions. The authors stated that titration down, either through persuasion or coercion, provides for the patient's overall health. Dowell allowed exceptions in cancer treatment, palliative care, and end-of-life care. The authors claimed that it risked an increase in iatrogenic addiction if the primary goal of treating noncancerous, chronic pain was pain relief. Dowell defined iatrogenic addiction as an increase in addiction caused by physicians over-prescribing pain medications. The authors postulated that doctors could avoid this increase by prescribing fewer opioid medications as a general practice.

Dowell et al. **(**2016**)** further recommended that doctors assess the risks and benefits of opioid use, though they offered no specific recommendations for determining benefits. By focusing solely on the risks, the authors seemed to support the strict, biomedical point-of-view. However, by giving a palliative care exception, Dowell left room for long-term opioid medication use. Still, the authors did not define when that decision was an acceptable risk. Using this model, many doctors continued to limit or even eschew opioid pain medications, despite whether pain remained severe, quality-of-life compromised, or undertreatment was evident (Bhamb et al., 2006; Chaparro et al., 2014; Compton & Volkow, 2006; Finnerup et al., 2015; Henry et al., 2015; Hoffman, 2016; Moseley & Butler, 2015).

Biopsychosocial pain treatment models viewed opioids and other potentially addictive medications very differently (e.g., Gourlay & Heit, 2009). In some of these pain models, drugs were administered immediately at an adequate dose, for as long as necessary, to manage pain (Kumar et al., 2015; Rajagopal, 2011). Other models followed the WHO algorithm, slowly increased the type of pain medication, and then gradually reduced the drugs to their lowest effective dose (Finnerup et al., 2015; Gatchel et al., 2014). They addressed any secondary problems (e.g., addiction, misuse, tolerance, etc.) through harm reduction programs (Gourlay et al., 2005). These treatment models collectively advocated using quality-of-life criteria rather than an enforced reduction of medications (Kumar et al., 2015; Rajagopal, 2011).

The next section will address addiction and fears of addiction. It will also discuss when patients in pain reported inadequate treatments or researchers found what they concluded was undertreatment. Finally, the section discusses how this lack of treatment may sometimes result from stigma.

Undertreatment of Pain

With no objective measure of pain, factors outside of the doctor/patient relationship influenced the prevalence of adequately or inadequately treated pain (Wailoo, 2014). Peppin et al. (2015), in a commentary, addressed how the expanding population of pain patients often overwhelmed busy primary care physicians and existing pain clinics. The authors posited that the complexity of treating chronic pain led to undertreatment due to: (a) lack of reimbursement for a thorough assessment; (b) lack of physician training, particularly in the psychological effects of pain; and (c) treatment models that focused on procedures and symptoms rather than outcomes. Peppin also concluded that these factors led to the undertreatment of pain.

Gatchel et al. (2014) wrote a commentary on why pain clinics were not addressing the problem of undertreated chronic pain, which they believed was widespread. The authors differentiated between a multidisciplinary approach and an interdisciplinary approach. Gatchel stated that a multidisciplinary approach included different professionals who intervened in other locations, with limited communication and few shared intervention philosophies. The authors contrasted this with an interdisciplinary approach, when all professionals were in the same place, in constant contact, and used the same treatment philosophy. Gatchel admitted that an interdisciplinary approach's upfront costs were higher, and insurance companies tended not to approve these more complex interventions. The authors concluded that this ignored the fact that long-term expenses were much lower in an interdisciplinary approach, and outcomes were better.

Finnerup et al. (2015), in a literature review of 229 studies on the evidence-based treatment for chronic pain, found a widespread lack of treatment. The authors reviewed studies on undertreatment, under-diagnosis, pain treatment effectiveness (50% reduction in pain), and pain treatment costs. Finnerup focused primarily on randomized controlled studies from peer-reviewed journals with estimated effect sizes when that data was missing from the results. The duration of most of the included studies was between 12 to 24 weeks and showed no differences in effectiveness in the medications used for pain control. The authors also found 10% of the research overstated the effects of their pain treatment. Finally, Finnerup found the research standard for properly managed pain (50% reduction) varied according to individual response. The authors concluded there was evidence of unmet need in pain management outcomes.

Breivik et al. (2006), in an international survey of 15 European countries and Israel, also reported prevalent unmet need in chronic pain treatments. The researchers used telephone interviews with over 45,000 individuals experiencing chronic pain, some for over six months. Breivik studied various medication treatments, including NSAIDs, weak opioids, paracetamol, COX-2 inhibitors, and strong opioids. The authors found about 40% of the individuals surveyed still reported inadequate pain management. Breivik also found that moderate-to-severe chronic pain continued to occur in about 40% of adults. The authors concluded that undertreatment was evident in the chronic pain population.

Bhamb et al. (2006) published a survey of 248 primary care physicians on their treatment of chronic pain: (a) what medications they used, (b) what diagnoses necessitated opioid medications, and (c) how they guarded against abuse or other forms of addiction when prescribing opioids. The authors found that doctors said they felt comfortable prescribing opioids during cancer treatment and terminal illness. Breivik found that doctors did not feel comfortable prescribing opioids for non-cancerous pain. The authors found that the primary concerns of the doctors in those situations were ranked: (a) patients were abusing prescriptions, (b) possible addiction, (c) side effects of opioids, (d) tolerance to opioids, and

(e) lack of training on how to choose opioid medications. The authors concluded that there was evidence of untreated pain after treatment.

Bruehl et al. (2015), in an experiment on the treatment of lower back pain, tested a screening questionnaire proposed for use by physicians who hoped to supplement their clinical judgment with objective analysis on the likelihood of later addiction during opioids use for chronic pain treatment. The goal of the authors was to impact the rising rate of opioid abuse. Bruehl hypothesized that their screening questionnaire might predict future opioid abuse because it tapped into individual differences in opioid responses. The authors did find that one group reportedly liked morphine more than other groups with lower scores on their questionnaire. Bruehl postulated that these subjects were more likely to become addicted. However, one limitation of this prediction was that the authors were unable to separate the influence of pseudoaddiction. It was a label Bruehl gave to subjects who had undertreated pain before participating in the study. As a result, the authors could not separate addiction from pain relief in the group that said they liked the medication.

Rajagopal (2011) wrote a commentary on his experience with long-term, refractory pain. As a patient, he endured severe pain until his condition eventually improved, a painful, year-long struggle. As a specialist in palliative care, Rajagopal was shocked when his fellow clinicians ignored treatable pain and seemed not to understand that pain relief was necessary. The author identified six sources of these misunderstandings: (a) a lack of resources, particularly in the developing world; (b) a lack of education in palliative care strategies; (c) government and industry regulations that were too focused on treatment rather than pain relief; (d) fears of addiction; and (e) a systematic lack of understanding by the medical community of the experience of chronic pain. Rajagopal felt that this lack of recognition came from the paucity of research on the experience of long-term, refractory pain in non-cancerous, chronic pain conditions. The author concluded that narrative research on the experiences of chronic pain patients might fill this gap.

Rivera et al. (2015) was a qualitative survey of 3,029 pain patients that focused on the quality of their lives after three months of treatment. The study was limited to patients with moderate to severe pain, with chronic pain duration of up to seven years. The survey measured: (a) ability to self-care independently, (b) participation in usual activities, (c) levels of pain and discomfort, and (d) levels of anxiety or depression. The authors concluded that there was evidence of quality-of-life improvements in approximately half of the subjects interviewed. The lack of progress in the other half showed evidence of undertreated pain. Rivera concluded that the severity of pain and interference with usual activities significantly impacted quality-of-life.

While many doctors expect cancer pain to resolve as the treatment progressed, research showed that from 33% to 45% did not receive adequate cancer pain treatment (Vuong et al., 2016). Other research showed that undertreatment existed at cancer treatment centers even with multiple treatment modalities (Haumann et al., 2017; van den Beuken-van Everdingen et al., 2016). Gatti et al. (2014) found that breakthrough pain was highest in cancer patients who had undertreated baseline pain.

Undertreated, persistent pain also exists in acute pain populations. Undertreated pain was reported: (a) in emergency rooms (Paydar et al., 2016; Platts-Mills et al., 2016); (b) after motor vehicle accidents (Apkarian et al. 2016; Platts-Mills et al., 2016); (c) in hospitals

(Trentin et al., 2001); (d) after major surgery (Singh et al., 2016; Sinatra, 2010); and (e) in outpatient treatment centers (Emilson et al., 2017; Hayes & Hodson, 2011; Kehlet et al., 2006). Undertreated, persistent pain had also been found: (a) in addicts both with and without treatment for addiction (Nordmann et al., 2017); (b) in older adults, particularly in nursing homes (Arnstein, & Herr, 2017; Björk et al., 2016); (c) in people with mental illnesses (Abdallah & Geha, 2017); and (e) in children (Hiller & Suominen, 2017). These data supported Siddall & Cousins (2004) contention that persistent pain caused a separate disease state that could be more serious than the original pathology that caused chronic pain, negatively affecting treatment decisions.

In summary, prior research has shown that the undertreatment of pain was evident in all pain populations. It seemed particularly likely in moderate-to-severe pain, even when the duration of the experienced pain was short. The literature indicated that the propensity to undertreat pain might be due to: (a) fear of medication misuse, abuse, or addiction; (b) fear of adverse side-effects; (c) lack of clear diagnostic criteria; (d) lack of training; (e) pressure from government and professional organizations; (f) social stigmatization of pain patients; and (g) systemic bias in the medical research and practice (Bell & Salmon, 2009; Bhamb et al., 2006; Chapman et al., 2010; Gourlay et al., 2005; Peppin et al., 2015; Rajagopal, 2011). As Wailoo (2104) stated, some of these factors were outside of the typical doctor-patient relationship and were part of the broader social system.

Systemic Factors That Influence the Assessment and Treatment of Pain

A review of the literature revealed a lack of understanding on whether the undertreatment of pain: (a) resulted in needless suffering, (b) was an unavoidable side-effect of good medical practice, or (c) was an interaction of the two that may depend on circumstances or individual responses (e.g., Chapman, & Gavrin, 1999; Chapman et al., 2010). Peppin et al. (2015) stated that these factors overwhelm busy primary care doctors, mainly because of many factors out of their control. The authors said it was relevant to examine the “macro-level” or systemic forces that influence how pain and pain patients are perceived, assessed, and treated.

Fears of Addiction

The epidemiological trend documenting the rise in opiate addiction has further increased the possibility of persistent pain undertreatment (Rajagopal, 2011). As previously stated, the CDC reported that there were 1.9 million people who abused or became dependent on opioids in 2013. From 1999 to 2014, opioid addiction increased and caused 160,000 deaths. Yet, opioid prescription use dropped 13% between 2012-2015, with no decrease in opioid deaths. This result brings into question the causal role of opioid prescribers (Schuchat et al., 2017).

Nonetheless, other studies continued to assert that the over-prescription of opioid medications caused the opioid epidemic (Ballentine, 2010; Dowell et al., 2016). In an epidemiological study, Compton and Volkow (2006) theorized that the increased use of opioids to treat pain caused an increased availability of opioids, fueling an epidemic. While focusing primarily on prescribing physicians, the authors suggested increased vigilance in the use of opioid medications. Compton and Volkow (2006) also suggested increased research on screening and the effects of opioids on brain development.

Henry et al. (2015) studied the increase in opioid dosages for 246 patients treated with opioid medications, termed drug escalation. The authors studied the increased likelihood of addiction resulting from high-dose opioid use versus lower doses. Henry surveyed the hospital records of people given opioids for pain who were naive to opioid medications. The authors defined this as no documented opioid use for the past year. Henry also limited their subjects to those with skeletomuscular pain but no other comorbid, pain-producing conditions. The authors measured dosages in prescription-dose-days to account for participants who took intermittent doses. Henry also measured office visits, emergency room visits, nursing visits, telephone consultations, refill requests, and patient emails. The authors used mixed-effects regression analysis to differentiate the groups who did not have dose escalation from those who did. Once separated, Henry used a Wilcoxon two-sample test for continuous variables and Fisher's exact test for categorical and dichotomous variables. The authors found that subjects identified as having dose escalation were more likely to be substance abusers, had more frequent office visits, and was evident in the first year of opioid use. Henry felt that early escalation of opioid doses in the first year might predict later addiction, but further study was necessary. The authors mentioned, however, that pseudoaddiction (i.e., undertreatment) could also explain those results.

Alternate Explanations for the Rise in Addictions

However, other researchers suggested that prescribers may not be the primary cause of increased addiction. According to Sullivan and Levin (2016), more pain-producing conditions might have resulted from an increased number of older baby boomers with chronic pain. The authors stated that this population could also be more open to using medications for pain control. Also, there was little evidence that reducing addictive pain medication prescriptions would lead to better long-term pain management (Finnerup et al., 2015). Long-term pain management might require a personalized pain genotype, the identification of which needed more progress in neurological research (Bruehl et al., 2015).

Exaggerated Fears of Addiction

Vowles et al. (2015), in a meta-analysis, documented the overlapping definitions in pain research and the tendency to overestimate the prevalence and severity of increased social problems with opioid use. According to the analysis, the author concluded that only three terms used in the research were distinct and measured different pain medication problems: (a) misuse, where the patient used medications in a way not prescribed by a doctor (e.g., taking pain medication given to a spouse); (b) abuse, where the patient used a drug in a medically unintended way (e.g., taking prescription medications for recreational purposes); and (c) addiction where pain medications were repeatedly taken, or craved, despite apparent harm and no medical benefit. Vowles et al. (2015) postulated that using non-overlapping definitions would eventually bring consensus to the prevalence, treatment, and pain management outcomes.

In a classic study, Heit (2001) stated that only two in ten patients (20%) on long-term opioid medications became addicted when treated with opioids. Another 20% had side-effects associated with the long-term use of opioids. The author called these secondary conditions adverse drug events. The author stated that addiction prevalence data conflated these secondary conditions with addiction. Opioids could be safe long-term for the remaining 60% in noncancerous, refractory pain. Not adequately controlling persistent pain would relegate these patients to needless suffering and unnecessarily lower their quality of life. (Chapman et al., 2010; Gourlay et al., 2005; Kumar et al., 2015; Rajagopal, 2011; Vowles et al., 2015).

Robins et al. (1974) in a classic study on addiction among veterans returning from the Vietnam War found that heroin use, which was considered an epidemic among Vietnam veterans in 1973, dropped from 60% to 10% one year after returning home. The authors found that among those who continued to use heroin, they had a high probability of addictive behaviors before being deployed. In a follow-up lecture, Robins (1993) stated that the data from his previous study had withstood the test of time. No other factor explained the result except that using heroin does not lead always lead to addiction. Treatment outcomes involving the use of long-opioids for pain control backed up this conclusion (Kumar et al., 2015; Passik, 2009; Rajagopal, 2011).

In summary, while the rise in addiction is undeniable, its true causes are in question. Sanctioning doctors and prescription monitoring programs may result from an over-simplified understanding of the complex nature of pain and its treatment. Changing population characteristics (aging), cultural changes in the acceptability of medication for pain, and the promotion of opioids by pharmaceutical companies for use for conditions and symptoms not appropriate for opioid use may all contribute to the current U.S. opioid controversy. The rise of heroin and opioid addiction, particularly in older and Caucasian demographics, may not be caused primarily by the over-prescription of pain medications. For a more in-depth exploration of why the medical community needs a more comprehensive understanding of chronic pain and its confusion with other types of suffering, we must consider other factors.

Effects of Bias on Pain Treatment Decisions

Chapman et al. (2013) defined explicit bias as a consciously expressed stereotype that may be partially true for a group but does not predict the characteristics of any particular member of that group (e.g., men like watching sports). The authors stated that bias could be positive (e.g., rich men make good husbands) or negative (e.g., rich men make untrustworthy sexual partners). Chapman defined implicit bias, on the other hand, as an unconscious belief often denied by people who hold that belief. It was only evident through actions or decisions (e.g., I believe women can be as good as men, but I have never met one I would hire). In healthcare research, training controlled much of explicit bias. Yet, implicit bias has been documented and may be prevalent (Zestcott et al., 2016).

Systemic Pain Bias

Berry and Dahl (2000) stated that one professional organization that addressed persistent pain was the Joint Commission, formerly known as JCAHO. The authors stated that, at the turn of this century, the goal of the Joint Commission was to address the prevalent undertreatment of both acute and chronic pain in all clinical settings and includes: (a) emergency rooms, (b) post-operative care, (c) burn centers, (d) cancer treatment, (e) outpatient centers, (f) primary care offices, and even (g) at-home care. Berry and Dahl concluded that these standards would address unrelieved pain costs and that appropriate pain management was a right, not a privilege. Baker (2017) stated that, over the next 16 years, the perception of undertreated pain versus addiction evolved into the current controversy. During that period, the author contended, the focus of the pain research shifted from undertreatment and became: (a) moving away from narcotic pain medications, (b) improving quality of life factors in pain management, (c) developing non-narcotic pain medications and nerve blocks, and (d) developing psychosocial pain treatments.

Baker (2017) stated JCAHO remained concerned about the prevalence of undertreatment. The author concluded that the accrediting commission kept four recommendations: (a) engage all stakeholders, including the patients, in determining standards; (b) anticipate, monitor for, and address unintended consequences; (c) ensure that the survey algorithms of the JCAHO continually test against a focus on easily measurable observations that negatively influence quality outcomes (e.g., the sole use of rating scales); and (d) keep survey standards abreast of the most recent research. Baker showed that JCAHO had yet to achieve its goal to treat pain relief as a right. So unnecessary pain may still occur if physicians limit themselves solely to the biomedical model to treat pain.

Government Influence on Pain Bias

On the other hand, the federal government significantly influenced the perception of a causal link between addiction and prescription pain medication abuse (Cole, 2011). Hari (2016) stated the first federal agency charged with enforcing the laws against narcotic drugs was the Federal Bureau of Narcotics. The author added that it replaced the agency designated to enforce the prohibition of alcohol in the 1930s. Hari also said that, from its very inception, this replacement agency deliberately promoted racist arguments. The current federal drug enforcement agency, called the Drug Enforcement Agency (DEA), continued racial biases in drug enforcement, with drug arrests and people imprisoned for drug offenses focused mainly on blacks and Hispanics (Bobo & Thompson, 2006). It helped create the school-to-prison pipeline, incarcerating minorities, and low-income individuals, while being more lenient with others who committed the same offenses (Ruiz, 2016).

In addition to the CDC issued guidelines against the long-term use of opioids, Tran et al. (2017) posited that the Federal Drug Administration (FDA) had a role in creating rules designed to prevent opioid abuse. The authors pointed out that the biggest, recent change in regulations was the rescheduling of hydrocodone from Schedule III, a drug with limited abuse potential, to Schedule II, one of high abuse potential but still medically useful. The authors described other FDA inspired changes that so far have had only modest effects included: (a) warning labels on medications with abuse potential; and (b) promoting computerized risk management databases that monitored who was prescribing and who used potentially addictive prescription drugs.

Windle (2016) said efforts to curb opioid use showed the government appeared to be firmly on the side of controlling the opioid epidemic by restricting medical prescriptions. The author openly questioned whether the federal government had tipped the scale on the perception of persistent pain patients. Windle documented that various government agencies, whose goal was to stigmatize, and sometimes criminalize, the use of painkillers, and how it worked against agencies concerned with quality-of-life and pain relief (e.g., JCAHO). The author further stated that this was difficult for nurses at the frontlines of pain control and trained to be patient-centered. Windle concluded that advocating for pain relief often puts nurses at odds with other hospital and governmental authorities.

Other Organizational Sources of Systematic Bias

Sismondo (2008), in a meta-analysis, contended that the pharmaceutical industry created publication bias, often intentionally, because it resulted in higher profits. The author stated that pharmaceutical companies accomplished this through ghost management, where unacknowledged advisors designed studies, edited the reports, and then promoted the results. Sismondo also stated that ghost management: (a) tended to attract more future funding; (b) marginalized non-aligned academic researchers; (c) skewed the number of publications in the direction of new, expensive drugs favored by the industry; (d) made it more likely to earn FDA approval; and (e) tended to hide side effects, contravening research, or possible alternate treatments. It supported and gave some context to the later assertion that pain research was too focused on medication treatments (Peppin et al., 2015).

Eaves (2015) did a qualitative study on how people with chronic pain used OTC analgesics to mitigate their chronic pain rather than more effective prescription medications when in moderate-to-severe pain. The author found that advertising from drug companies was a major contributing factor in the inappropriate use of OTC analgesics. Eaves (2015) stated that advertising was also responsible for perceiving these drugs as harmless, further stigmatizing opioids as a possible good alternative. As such, the author contended, their use was often not discussed when seeking medical advice for pain, even when dosages were critical to an accurate diagnosis and the possibility of drug interactions. Eaves stated that the reasons for not using prescription medications include: (a) saving more effective medications for more severe pain; (b) feeling that prescription medications masked the chronic pain and made monitoring pain difficult; (c) concerns about tolerance; (d) fears that prescription medications would impair ability (e.g., thinking, driving, operating heavy machinery, etc.) and (e) concerns about addiction. The author concluded that these were why people used OTC medications in larger dosages than recommended, sometimes to the point where they could harm.

Cooper (2013a) did a literature review on the abuse of OTC medications in general. The author found that the problem was international in scope and little understood. A qualitative study by the same author, done on people who believed they could become addicted to OTC drugs, found: (a) while admitting their addiction, OTC drug abusers differentiated themselves from addicts who used prescription drugs or illegal drugs; (b) those who self-identified as addicts had formerly used prescription drugs for the same condition; (c) codeine was the drug most often mentioned in OTC addiction, but Cooper indicated other possibly addicting OTC drugs (e.g., pseudoephedrine, diphenhydramine; other cold remedies, etc.); and (d) those self-identified with OTC drug addiction tended to avoid treatment because they felt their addiction was more acceptable (Cooper, 2013b). Cooper (2018) later asserted that OTC addiction was real, tended to be ignored, and was not completely understood. Chhatre et al. (2017) said OTC drugs might be responsible for the general increase in older adult addiction. Stone et al. (2017) also stated that misuse was in the older populations, with drug interactions was the most common form of misuse. Other research found that differing adverse effects of various analgesics might confuse the user. This misunderstanding appeared to involve the method the FDA used to label the impact of several types of OTC pain medications and their side-effects, particularly for older adults (Ryan et al., 2016).

Meier (2018) documented evidence that drug companies lied about the addictive nature of their opioid medications. The author contended that drug companies knew their medications were addictive as soon as 1996. Nonetheless, these companies promoted their pills as less addictive to doctors until 2007. Meier found that early on, federal government employees discovered this deception but were told by upper Bush administration officials in the Department of Justice (DOJ) not to pursue an investigation. Instead, the author stated that Perdue Pharma, convicted on one charge of misbranding, blamed the promotion on a few rogue employees. The resulting fine was a fraction of the profit Perdue made over the years of its legal challenges.

Sources of Pain Bias from Healthcare Providers

Staton et al. (2007) found that the increased costs for treating chronic pain may be due to its ubiquity. The author further stated that this ubiquity could be based in undertreatment. Using the 0-10 rating scale for pain, Staton independently asked patients to rate their pain. The authors then asked the treating physician to rate the chronic pain of the same patient. When there was a 2 point or greater difference, Staton labeled it as a disagreement. The authors found that doctors consistently underestimated the intensity of pain in their patients with chronic pain. The authors concluded that the factors that drove this underestimation included: (a) lack of doctor training, (b) not appreciating the emotional aspects that may exacerbate chronic pain, (c) fear of side effects or addiction, and (d) the clinical judgment that complaints of pain were malingering. Staton found regular disagreements between doctors and patients regardless of gender, ethnicity, or income level.

The authors added that chronic pain perception differences often appeared when the patients were from an ethnic minority.

Bell and Salmon (2009) looked at pseudoaddiction (another label for undertreatment) and bias. In a meta-analysis, the authors also found a reluctance of doctors to prescribe opioids. Bell and Salmon stated that three factors were behind this reluctance: (a) lack of physician training; (b) prejudices against the use of opioids to treat pain (opiophobia); and (c) government legal restrictions on the use of opioids even when clinically necessary to control pain. The authors also found that pseudoaddiction was applied when treating white people with opioids but less often used when treating minorities, particularly black patients, with similar afflictions.

Althubaiti (2016) addressed the problem of confirmation bias in medicine. The author stated that confirmation bias was when decisions were made according to the medical provider's presumptions, opinions, or predilections. Althubaiti went on to state that confirmation bias was possible in any medical decision that required judgement. The author stated that confirmation bias was best controlled by always acknowledging the possibility of bias, being objective with evidence, accepting to advances in thinking, and taking into account contradictory evidence.

Publication Bias in Pain Research

Calati et al. (2015) did a literature review of research on the relationship between suicide and severe pain. The authors searched 159 studies in MEDLINE and PsychINFO until 2015, with 31 articles meeting their search criteria. Calati reviewed studies on both chronic and acute pain. The authors also researched various types of suicidal actions, including ideations, suicidal plans, attempts, and completions. Calati commented that underestimating chronic pain may affect suicide rates.

Calati et al. (2015) did not attempt to change their conclusions based on the possibility of confirmation bias. The authors' primary judgment was that, as the severity of the pain increased, the likelihood of suicidal behavior also increased. Calati suggested more studies on why some people resisted severe chronic pain and others did not. A later review indicated confirmation bias in suicide pain research, and the relationship between suicide and chronic pain was more substantial than reported (Stubbs, 2016).

Some researchers discounted research that did not use quantitative, randomly controlled studies (e.g., Vowles et al., 2020; Dowell et al., 2016). Others discounted pains studies that had small effect sizes (Finnerup et al., 2015). This judgment tended to exclude all research based on narrative and other qualitative methods. Yet, quantitative studies on pain based their numbers on statements extracted from surveys and pain scales. (e.g., Wong et al., 2015), which could be quantifying qualitative self-reports.

In summary, bias was a conscious or unconscious prejudgment based on stereotypes instead of experience, observations, and facts. It had multiple sources, and it was complicated to address. However, unaddressed, it could stigmatize people in persistent pain. Bias in pain management research resulted from: (a) mutable definitions of pain, rating scales, and surveys that do not fully reflect the experience of pain; (b) treatments that vary by the pain model used; and (c) bias, whether implicit or explicit. Limiting information to evidence-based studies with the scientific patina of quantitative statistics did not seem to add anything to our understanding of pain. One area that could increase our awareness of chronic pain would be to examine the feelings of stigma and the effects of bias on pain patients.

Role of Stigma

The study of stigma has a long history in social psychology, particularly on the effects of social isolation (Cacioppo et al., 2015; Hawkley & Capitanio, 2015; Oliveira et al., 2015). Major et al. (1998) defined stigma as a social identity spoiled by repeated negative bias experiences. The authors contended that a negative social identity affected the reputation and treatment of a person or group.

Jackson (2005) wrote a comprehensive essay on why chronic pain sufferers, despite their ubiquity, posed a threat to a cultural definition of social order. In ordinary, face-to-face encounters, the author stated that chronic pain sufferers learned to hide their affliction because they might be disturbing and threatening to other people. Jackson postulated that stigmatization was expected, even among chronic pain sufferers who negatively judged others in chronic pain. The author further suggested this stigmatization resulted from the pain sufferers' changing social roles that might put them in social limbo between their former and current social classifications. Jackson concluded this uncertainty was threatening because the sufferer's social role was no longer easily understood. The author labeled this social displacement due to these uncertainties as liminality.

Monsivais (2013) studied 15 Mexican American women who experienced persistent, chronic pain. The study focused on stigma in three forms: (a) social, (b) self, and (c) systemic. The author also added perspectives on how their culture and gender roles influenced Mexican American women. Monsivais postulated that chronic pain's invisibility made it more challenging to fulfill traditional roles expected of Mexican American women. The author concluded that this lack of understanding in their support system created family, work, and medical treatment problems. Monsivais added that Mexican American women (and women in general) learned to hide their pain, avoid complaining, and overexert (at least in terms of their disability). The author also contended that women avoided people who were likely to judge them, including medical providers. Monsivais stated that the resulting stigmatization potentially prolonged their healing process and prevented good outcomes. The author concluded that to prevent stigma, treatments needed to involve the patient by understanding how stigmatization causes harm. Monsivais also postulated that such an understanding might give medical personnel the ability to ameliorate those causes instead of unintentionally making them worse.

As stated above, in a telephone survey of over 46,000 subjects, including 15 European countries and Israel, 40% of the subjects reported undertreatment and stigma (Breivik et al., 2006). In qualitative research that explored the role of exercise in treating chronic lower back pain, subjects reported stigmatization in every focus group (Slade et al., 2009). De C Williams (2016) did a topical review of stigma when treating pain in clinical settings. The author stated that research showed subjects reported stigma due to undertreatment and lack of proper assessment. De C Williams further noted that many other studies on treating chronic pain showed stigma reports. The author also noted that little research looked at the causes of stigma or how to alleviate stigma. The author also felt that stigma was less likely if the patient complied with medical advice. De C Williams found that questioning, or failure to follow, medical advice opened the patient to increased prejudice and stigma. The author also found bias in that pain should be short-term, based on an observable physical disorder, and fixable. On the other hand, De C Williams concluded that persistent pain was suspect and often stigmatized.

Werner et al. (2004) conducted a qualitative study on ten women with persistent, chronic pain who recounted their feelings of self-shame and the experience of stigmatization. The study documented their attempts to: (a) negotiate care; (b) deal with the prejudice of family, friends, and acquaintances; and (c) deal with their self-shaming. The authors concluded that these were characteristic results of stigma. Werner further found that the woman tended to distance themselves from others experiencing pain and often said that talking about chronic pain was boring. The authors theorized that this allowed them to avoid any discussion regarding the psychological causes of pain and its social stigmatization.

Wilbers (2015) conducted a qualitative autoethnography of her experience supporting her mother, who lived with persistent, chronic pain for 14 years due to a degenerative spinal condition. The author stated that, as the disease progressed, opioid medications became the only effective treatment. Wilbers described: (a) multiple episodes of stigmatization of her mother; (b) difficulty getting effective treatment; (c) unfounded accusations that her mother was an addict; (d) multiple instances of negative feedback from the author’s students, friends, family, doctors, and even randomly encountered strangers when she discussed the situation with others; and (e) multiple occasions where there was fear that the doctor might take away her mother’s medications and leave her mother in despair. The author concluded that her mother was stigmatized and presented with unneeded stress. The weakness of this study: These experiences might have been an outlier case of chronic pain management.

Waugh et al. (2014) studied 92 adults with persistent, chronic pain who answered a questionnaire on their negative experiences with stigma. The authors differentiated between social stigma, structural stigma, and internalized stigma. Waugh found that internalized stigma, defined as expecting to experience stigma even in the absence of any environmental triggers, was the predominant feeling expressed. The authors concluded that internalized stigma was a factor in treating chronic pain and needed to be addressed concurrently with all medical interventions.

Wong et al. (2015) conducted multiple surveys on 178 Chinese chronic pain patients' quality of life, some suffering from persistent pain for up to 10 years. According to the authors, Asian clinics differed culturally from western clinics. Asian patients tended to use more passive coping methods, which means they were more likely to accept medical advice without question. The subjects in Wong were also less likely to have the same doctor over time, as their doctors often changed from visit to visit. The authors concluded that the severity of pain and anxiety/depression were most likely to predict lower patient satisfaction and quality of life. Depression and lower patient satisfaction, either caused or exacerbated by stigma, had deleterious effects on medical treatment outcomes (e.g., Phelan et al., 2015)

In a review of the narrative literature on pain, Newton et al. (2013) studied the effects of disbelief on stigma. The authors used the term delegitimation, defined as when medical professionals did not believe reports of pain. Newton found five sources of this phenomenon: (a) felt stigma even in the absence of anything said by the doctor; (b) biological explanations used to disconfirm reports of pain; (c) challenges to the personal integrity of a patient; (d) gender and ethnic stereotypes; and (e) accusation of psychological problems, particularly interpreting pain reports as psychologically-based complaints. Other research showed disbelief was evident beyond the doctor/patient relationship. It appeared in different kinds of relationships, including friends and family (Armentor, 2017). Research showed that even when medical providers closely questioned their patients about their pain, stigma was still a potential problem. In those instances, the goal appeared to persuade patients to follow given medical advice even when it did not conform to patient beliefs (de C Williams, 2016; Moseley & Butler, 2015; Zanini et al., 2016).

In summary, stigma was evident in various pain studies, some even when it was not the focus of the research. The emotional impact of a chronic pain condition lowered the ability to manage pain. The internalized effects of social stigma added to the adverse consequences of chronic pain, even when there were no bias reports. Logically, if physicians used a strictly biomedical model to treat pain, and they too often ignored emotional factors, it may create an increased possibility of stigma and the undertreatment of unnecessary pain.

Theoretical Frameworks

The development of the methods and analyses in this study followed two theoretical frameworks, social identity theory and attribution theory. These two theories explained the changes in the self-concept of chronic pain suffered and possible sources of stigma.

Social Identity Theory

Social identity theory evolved in the early 1960s from Henri Tajfel, an experimental social psychologist dedicated to making social psychology less reductionist (Dumont & Louw, 2007). It postulated that social identities evolved from the need to develop and preserve a positive self-image when interacting with a social group (Abrams & Hogg, 1988).

The accentuation principle often defined social roles. Here individuals may take many forms of social identity within a group, according to their immediate perceptions (Trepte, 2006). Augoustinos et al. (2014) stated that no one theory defined all types of attributions. The author went on to say current research on social identity theory was better able to explain accentuation, bias, types of prejudice, and the formation of social identity.

Monsivais (2013) applied social identity theory to understanding how individuals who live with chronic pain see themselves compared to others. The author stated that individuals with chronic pain identify within a group according to how openly they express their illness to others. The author also said moderate-to-severe chronic pain was difficult to hide. Monsivais concluded that this could result from a change in social roles imposed due to the pain condition.

Sturgeon and Zautra (2016), in a review of research on resilience to pain, stated that both physical pain and social pain shared pathways of the brain pain network. The authors labeled social pain as anxiety that came from social isolation and stigma. Sturgeon and Zautra speculated that addressing social isolation and other adverse social effects common to pain patients would increase resilience.

Sheedy et al. (2017), in a mixed design on the factors that promote resilience to pain, found several negative experiences related to an inability to cope with chronic pain. The authors stated these experiences included: (a) losses due to chronic pain (e.g., the failure to resume previous activities; work/money losses; loss of ability to self-care, etc.); (b) experiencing adverse social events due to pain (e.g., loss of friends; disbelief when they express pain; loss of social activities, etc.); (c) loss of a sense of self (e.g., lowered self-esteem; lowered self-confidence; spoiled reputation, etc.); and (d) more negative mood including increased anger and intolerance to minor stresses. The lowering of resilience to pain and the effects of stigma and disbelief on chronic pain seemed to have similar antecedents (e.g., de C Williams, 2016; Waugh et al., 2014).

Attribution Theory

Augoustinos et al. (2014) stated that attribution theory, a form of social identity theory, dealt with how people created causal explanations in the absence of objective evidence. Despite years of research, the author concluded that the literature revealed competing theories about why people make causal explanations when the facts are not known or even knowable. Augoustinos identified the problem as being within the research itself. The authors stated that attribution researchers had trouble distinguishing the actual responses from response bias, where the subjects hid their true feelings and gave a more socially acceptable answer.

Since it is not possible to measure chronic pain except by self-report, attribution theory was useful in understanding why patients and doctors disagreed on the severity and causes of persistent pain (Katz & Rosenbloom, 2015; Newton et al., 2013). Being under pressure by their professional organization and governmental agencies to reduce opioid prescriptions, attribution bias could also explain why doctors sometimes chose treatments that were self-serving (Coleman, 2011; Macciocchi & Eaton, 1995). These factors could be added to stigma and bias concern advocates of the humanization of pain treatment have regarding systemic undertreatment of chronic pain (Baker, 2017).

Narrative research is also affected by another aspect of attribution theory, hindsight bias (Groß et al., 2017). Roese and Olson (1996) defined hindsight bias as an after-the-fact judgment of a past event, introducing new knowledge not available at the time of the decision. More than just the recall of an event, it is a substitution of a new causal explanation imposed without the narrator's conscious awareness. Sometimes this created a false memory (Reyna et al., 2016). Hindsight bias might guide an interviewer in determining the difference between a false memory, a truthful memory, and a fabrication (Volbert & Steller, 2014). Douglass et al. (2013) stated false memories tended to affect eyewitness accounts of a crime. The authors noted that these mistakes included: (a) using questions that lead the witness; (b) frequent interruption of the account; (c) using closed instead of open questions; and (d) not listening to facts that seem unrelated to the question asked. These issues were similar to those raised by expert narrative researchers (Riessman, 2008; Saldaña, 2016).

Role of Narrative Medicine in Pain Relief

Jovchelovitch and Bauer (2000) stated that narrative research was a well-recognized method for documenting shared cultural experiences, particularly illness and chronic pain experiences. The authors felt that both the subject and the experimenter were active participants in creating a credible account with a beginning, middle, and end. Maxwell (2013) stated that surveys and case studies removed data from their original contextual relationships and placed them in another context, thus changing their meaning. An excellent way to maintain and fully understand the chronic pain experience was to put the data back into its original contextual relationship through the use of narrative (Rajagopal, 2011).

Tsao (2012) suggested that one of the reasons for the undertreatment of persistent pain was that the patient's voice was missing from the treatment debate. The author stated that the field currently needed a deeper understanding of: (a) the consequences of medical decisions to restrict access to pain medications; (b) the reasons why doctors do not fully understand persistent, chronic pain and tended to dislike treating it; and (c) the social effects of long-term pain on treatment outcomes. Jurecic (2012) stated that misunderstanding a pain patient's experience commonly occurred in the medical literature. The author felt that this lack of understanding was because of the hermeneutics of suspicion. Jurecic defined hermeneutics as the willingness to listen but a readiness to maintain doubt. The author stated that illness narratives have a long history of being discounted. Also, advances in medical technology often created a historic distance between patient and doctor (e.g., Newton et al., 2013). Insurance companies and the profit motive discouraged comprehensive doctor/patient contact and limited the ability to converse in depth (Larsen, 2016).

Jurecic (2012) stated that misunderstanding the experience of a pain patient usually left patients at a loss, especially when they had a complicated medical condition. The author said that unanswered questions about their prognosis, sometimes not fully understood by anyone, created suspicion and distrust. Jurecic posited that if one could put illness narratives back into their previously important role in the healing process, it could rehumanize pain treatment. The author further asserted that narrative research gives satisfaction and complete the meaning of the illness experience. Jurecic also stated that narratives were a check on dehumanizing technological approaches to treatment. Finally, because they were accessible to the average person, the author believed that personal stories could become an agent of social change both in the doctor/patient relationship and for social stigmatization as a whole. Jurecic concluded that narrative research would add the voice of the patient and deepen our understanding of how pain treatment might improve. When this voice is missing, doctors might find themselves in the gatekeeper's role instead of their preferred role of healer (Carlsen & Nyborg, 2017).

Summary and Transition

The study of pain and pain perception has varied throughout history, mainly due to the lack of objective measures and the subjective nature of the experience. Nonetheless, research also showed that persistent pain was undeniable. In response, various conceptual models of pain promoted different treatments of pain, which led to controversies. According to some researchers, this controversy led to the undertreatment of pain, fueled by fears of addiction to pain medications, particularly opioids.

These controversies led to variations in how patients in pain were perceived and treated by the medical community. Research also showed that the lack of an objective measure of pain might create circumstances where medical decisions could be affected by bias and stigma. The perceptions sometimes led to undertreatment, mainly due to a reductionist approach to chronic pain that focused on the underlying causes instead of its experiences.

The theoretical frameworks of social identity theory and attribution theory were used to understand how bias, particularly implicit prejudice, and confirmation bias, can unintentionally create stigma. This stigma might prolong suffering and sometimes caused undertreatment, particularly in cases of complex pain. Also, the literature supported the idea that to re-humanize treatment, the field needs more research that included the voice of the patient. Surveys and questionnaires were previous attempts to add the voice of the patient into the treatment process. Without the context of their reports, however, what people in chronic pain experienced was lost.

Chapter 3 presents the research design and rationale, including how the narrative approach plays a role in the research questions. This chapter also presents my experience in caring for a spouse with persistent pain, its effect on my role as a researcher, and other trustworthiness issues. The methodology section includes the rationale for participant selection and my data analysis plan. The chapter ends with my procedures for complying with Institutional Review Board (IRB) requirements and my strategies addressing ethical concerns.

Chapter 3: Research Method

The purpose of this qualitative study was to explore the complex nature of pain through the narratives of people who experienced persistent, chronic pain after treatment. In this research, I collected stories of chronic pain, treatment-seeking, pain relief, and stigma. The results were narratives told in the words of the participants. By looking for common experiences, I attempted to develop a deeper understanding of how the participants, their families, and their providers might better manage chronic pain.

Research Design and Rationale

What was missing from the literature was a deeper understanding of how individuals with persistent, chronic pain experienced treatment, relief, and stigmatization. The research needed more information about chronic pain experiences to illuminate better ways to understand and treat the condition. In brief, chronic pain was considered a qualitative experience (Penney et al., 2016; Webster & Harden, 2013). There was a growing interest in using narrative analyses to rehumanize the understanding of chronic illness (Bury, 2001; Thomas, 2010). The research suggested that a narrative approach might address the gap in chronic pain understanding (Rajagopal, 2011; Tsao, 2012).

Eaves (2015) stated that narrative research was a well-recognized method for documenting shared cultural experiences, particularly illness and chronic pain experiences. The author said that both the subject and the researcher were active participants in creating a credible account with a beginning, middle, and end. Eaves concluded that an excellent way to maintain and fully understand the chronic pain experience was to collect the data as it occurs in its actual contextual relationship using narrative research.

Riessman (2008) stated that the stories people told themselves created social identities that were often fluid. The author noted that narrative research was the study of information that created a given outcome, meaning, or social identity. Riessman suggested that a narrative researcher intended to learn about an experience in all its details. The author added that a sequenced narration was the best approach to analyze this experience. Riessman believed that examining themes over multiple, independent stories makes it possible to identify common experiences of participants.

Riessman (2008) further stated that a narrative method looked at the whole story and its themes, not just the common details broken into fragments. The author believed a grounded theory analysis, with coded narrative fragments, sometimes left out the context. Riessman added narratively organized ethnographic studies only focused on the interpretations of the researcher. They missed the experience of the participants and their surrounding culture. The author also believed that other qualitative research forms, such as hermeneutics, semiotics, discourse, and conversation analysis, offered some narrative research elements. Yet, Riessman suggested the narrative approach was more crossdisciplinary and gave a broader picture of the lived experience. Narrative research also tended to offer a more comprehensive understanding of the social identity of pain patients and the consequences of such an identity (Bury, 2001; Frank, 2015).

Research Questions

This study addressed the following research questions and subquestions to draw closure on the identified gap in the literature:

RQ1: What are the narratives of chronic pain management in patients?

SQ1a: How do these participants describe their experience of access to treatment?

SQ1b: How do these participants describe their experience with the pain management process?

RQ2: What is the meaning of stigma for participants who use or believe they need opioids?

SQ2a: How is stigma experienced in the treatment process?

SQ2b: How is stigma experienced with family and other social supports?

Role of the Researcher

Riessman (2008) recommended that a qualitative researcher's primary goal was to find recurring patterns in independent narrations without creating a bias. The author stated that the participants might simply give information the researcher appeared to expect in a poorly designed study. As a result, even though interviewers were the cocreators of the narrative, Riessman believed that their influence over the story content should be minimal. Therefore, in this study, the pain stories were in the first person and used words chosen by the participant. My role as the researcher was to mostly listen, clarify when necessary, prompt if the narrative faded prematurely, and allow for tangents. Such an approach allowed for analysis of the style of the story as well as its content.

Putting an illness into a narrative may also have a beneficial effect on the participant's ability to cope with their pain by giving their experience more profound meaning and supporting a positive social identity (Thomas, 2010). Creating an empathetic narrative during the 4 years of caring for my spouse with refractory pain gave us both an experience of this beneficial effect. It increased our ability to cope with my wife's pain and allowed her to manage her pain, using more biopsychosocial strategies. As her pain management strategies progressed, she started a garden, did regular exercises, became more involved in church and community activities, incorporated meditation into her daily routine, and tried to increase her circle of friends. Friends and medical providers often commented on her improved ability to manage her pain over the years.

For the first 2 years of my wife’s pain experience, however, I felt multiple doctors were dismissive of the amount of pain she suffered and often left her pain undertreated. There were several confrontations with various doctors who described my wife as: (a) being an addict, (b) exaggerating her chronic pain due to mental illness, or (c) as intentionally malingering. Two years later, my wife’s underlying medical conditions progressed to where medical tests confirmed her reported pain. Also, due to my review of the pain research, I was better able to understand why some physicians decided to undertreat. In these discussions, I was able to offer research-based alternative points-of-view. After my wife received regular opioid medications, my conversations with prescribing doctors became less contentious, particularly with her primary physician. Nonetheless, it still appeared that my wife's pain continued to be ineffectively managed, intermittently, during numerous hospitalizations.

In a typical hospital admission, an emergency room doctor ordered an opioid pain medication that adequately treated my spouse’s pain. Once admitted into a hospital bed, however, my spouse often called and said that the hospital physician discontinued her previously prescribed opioid medication with no explanation. Instead, the hospital substituted Tylenol and ice packs. After multiple calls and complaints, sometimes a third doctor would reinstate the opioid, though by now, my spouse was in agony for hours. Even then, her prescribed opioid was only at half of its regular dose. Still later, sometimes days later, and after further complaints to the hospital, the dosage would be increased to an adequate level—but not always. The problem with this dosing approach, and its negative consequences, existed in research on unnecessary pain during cancer treatment (Melzack, 1990).

Despite our best efforts, these undertreatment experiences during hospital admissions happened so often that my wife loathed going into a hospital. Yet, her frequent kidney infections, the danger of sepsis, and her numerous vertebrae compression fractures remained a concern. I worried that avoiding the hospital was a risky choice. The ordeal of my wife, the lack of definitive answers, and the conversations I had with doctors over the years, was the inspiration for this study.

These experiences might raise questions about the trustworthiness of this study. The extensive and sometimes contentious history of caring for my wife might have created a bias for reaching conclusions. Roulston and Shelton (2015) gave six suggestions for managing bias in qualitative analysis: (a) acknowledge interests of the researcher and how it might influence data analysis, (b) reflect on how closely the data stays within the range of the research questions, (c) examine how the data elicited differences from researcher expectations, (d) reveal what data surprised the researcher, and (e) explain how the conceptualizations of the researcher changed the throughout the study. I used all these guidelines in my data analysis.

I used six suggested steps to minimize other trustworthiness threats: (a) become involved in the phenomenon on a long-term basis; (b) develop rich, detailed data; (c) solicit feedback from people within the phenomenon; (d) use a variety of participants under different circumstances; (e) look for negative examples (e.g., where there was no use of addictive medications, yet participants managed their pain effectively); and (f) use numbers appropriately in qualitative research (Maxwell, 2015). Another strategy I used to minimize possible threats to trustworthiness was recognizing how personal experiences with the topic can be an attribute for qualitative researchers (Patton, 2002). Finally, in the selection of narrative themes, it was essential to examine multiple perspectives. These perspectives included: (a) participants who refused or severely limited pain medications, and (b) attempts to balance, complete, and fairly represent multiple points-of-view (Shenton, 2004).

I did not use triangulation, where data collection entails different methods (Shenton, 2004). Data came solely from the narrations of the participants, with me as the sole data collector. This data was available, though, both in raw and coded form, for any committee member to examine. To increase trustworthiness, I used member checking (Varpio, 2017). Feedback also was continuously solicited from doctors, other treatment professionals, individuals with chronic pain not in the study, and other acquaintances who showed interest. After I stated that I was not a medical professional during these discussions, I freely gave any helpful information I could offer.

Finally, I recognized that my experiences with pain management were both an asset and a drawback. It was an asset because I was already deeply involved in the phenomenon. It was a drawback because it opened the possibility of bias. Because of trustworthiness issues, I addressed: (a) implementing what research suggested would minimize bias, (b) following suggestions from expert qualitative researchers, and (c) bringing in different points-of-view in the selection of participants when it was possible.

Methodology

Target Group

Participants had to meet the following criteria: (a) be 18-years-old or older, (b) be able to express the details of their condition, (c) be able to consent to the study, (d) respond to a formal invitation to participate from a referral source or approach me and volunteer, (e) had experienced their pain for 3 months or longer, and (f) experienced persistent, chronic pain daily or regularly. These criteria gave the participant adequate experience with current medical treatments, chronic pain limitations, and increased participant selection trustworthiness.

Sampling Strategy and Criteria

Participants came from a convenience sample those who responded positively to the distribution of an invitation from a “referral source” or who approached me and volunteered after hearing I was doing a study on chronic pain. Possible sources of referrals included: (a) local health vendors (e.g., health food stores); (b) sponsors of local health management classes; (c) acquaintances of mine who encountered people with chronic daily pain; (d) people with whom I had an established relationship and who knew others in chronic pain; and (e) snowball sampling where people I had interviewed referred others in chronic pain. Referral sources did not choose participants. They only forwarded invitations to their contacts without further influencing the choice to participate. The invitee contacted me a self-addressed, stamped envelope (SASE) included in the referral packet. They were also able to contact me by phone or email to find out more about the study and to decide to participate. See Appendix A for a sample of the referral packet.

There was no attempt to limit participants who were unhappy with either their doctor or their treatment regimen. Neither were those participants excluded. There was a purposeful attempt to solicit participants from minority groups. Monsivais (2013) stated that bias was evident in chronic pain management. The author questioned whether minorities had increased difficulty seeking treatment for chronic pain.

Sample Size and Saturation

The number of participants was planned to be 10-15 individuals. Previous narrative research stated that this was where saturation tended to occur (Boddy, 2016; Francis et al., 2010; Mason, 2010). The final sample size was 17 individuals. Saturation had two considerations: (a) theme saturation, where new interviews reported no new themes; and (b) meaning saturation, where up to nine of the most frequent themes were assessed for consistency of meaning (O’Reilly & Parker, 2013). If either of these criteria had shown a lack of saturation, I would have increased the number of participants. Since there appeared to be saturation, the search for participants ended. All participants received a written report summarizing the results.

Instrumentation

The semi-structured interview questions attempted to encourage the participants to tell their pain experiences in their own words (See Appendix B for the interview script). Several books influenced the selection of interview questions. These books focused on helping people with refractory pain organize their thoughts, understand possible treatment options, and consider alternative approaches to dealing with pain (Caudill, 2016; LeFort et al., 2015; Nagel, 2016).

During data collection, I informally interacted with other people in chronic pain and who showed interest in sharing their experiences with me. These informal interactions provided shared experiences like the formal participants, despite different diagnoses and circumstances. Finally, this instrument initially evolved from an attempt to meet the requirements of an advanced course on qualitative analysis techniques. The early version of this instrument produced hours of recorded data from three individuals who voluntarily allowed me to interview them regarding their chronic pain as part of my course assignments. This study did not use any of those data.

During the interviews for this study, I inquired as to: (a) their gender, (b) age range, (c) reasons for chronic pain, (d) region of the country, (e) medications used, and (f) length of time in chronic pain. I did not ask these questions directly. Instead, I hoped the data would occur naturally during the narration. If they did not, these queries followed what appeared to be the natural end of the narrative.

The semi-structured interview introduced enough flexibility to answer the research questions but kept the narrative in the subject's words. I was a skilled interviewer and ensured that all participants had the same interview questions. Such consistency allowed for better comparisons of narrations. The semi-structured interview questions did not change as the data taking progressed. Nonetheless, I sometimes rephrased the questions to deal with any context or culture-specific issues that arose during the interview. To add to the trustworthiness of this study, I informally interviewed doctors who treat pain. I looked for: (a) their opinions on how they dispensed pain medications, (b) any questions they had about the experience of chronic pain, and (c) if they would be interested in being a possible referral source for other participants.

I obtained certification to teach courses on the self-management of chronic illnesses. These courses were through a local hospital and its patient education program (Nathan Littauer Hospital, 2012). Self-Management Resource Center (2018) developed the program. Teaching these courses gave me further experience in the field of treating chronic pain.

Procedures for Data Collection

The primary interviews occurred by phone through a computer conferencing website. Before beginning the interviews, all participants gave written consent, sent to me by the included SASE. The interviews took between 20 to 60 minutes. An audio recorder provided by the website recorded all questions and responses. This recording was then transcribed into a word processing file by computer through a transcribing website. I later checked the accuracy of the transcriptions using the tools provided by the transcription website. No one else had any access to the data.

Since the interview was online, the participants chose the location for the interviews that provided for confidentiality and comfort. The time of the interview was by mutual agreement. After 17 interviews, the study reached saturation criteria, and the interviews ended. All participants received a summary of their narration sent for member checking.

Data Analysis Plan

The overall approach to data analysis followed the guidelines given in Saldaña (2016): (a) similarity, themes that seemed congruent with logical expectations of the research questions; (b) difference, themes that were not able to be predicted from the research questions; (c) frequency, how often either kind of themes occurred; (d) sequence, the order in which particular recurring themes tended to occur; (e) correspondence, how often the themes tended to occur with other kinds of everyday life events; and (f) causation, where the emergence of one theme seemed to cause another. As data emerged, they were both hand-coded and coded by a computer program. The themes of the second and third analyses answer the research questions. Also included were results from discrepant cases. The CAQDAS software chosen for this analysis was MAXQDA (Saillard, 2011). Data analysis was reviewable, both in its raw and coded form, by any committee member.

Issues of Trustworthiness

This study addressed trustworthiness by following the recommendations of Saldaña (2016): (a) increased credibility using prolonged contact, saturation, reflexivity, and peer review; (b) increased transferability with detailed, thick descriptions and using a variety of referral sources to distribute invitations to enhance variation in participant selection; (c) while not using triangulation, I used member checking; (d) a detailed process of the study allowed future researchers to repeat the study; and (e) increased confirmability by using the words of the informants when identifying themes and making conclusions. As stated above, the data, both raw and coded, were saved and were available for any committee member review.

Ethical Procedures

All data were kept confidential. Identifying information was stripped from the narrative. I was not in a power relationship with any possible participant because I was retired from full-time employment. Some of the participants who responded to the invitation came from family, friends, and acquaintances. All these participants experienced persistent pain and responded to a request from a referral source or approached me and volunteered to be part of the study once they heard about it. I kept confidentiality from other acquaintances and family members unless I had written permission to share the interview information. As stated above, I stripped all identifying information from the narrative and gave each narrative an identifying number. I kept all confidential information on my computer with restricted access, and I kept paper records in a locked box file in my home office. These data will be stored safely for the next five years.

There were no external organizations that needed IRB approval to interview participants. Written consent was reviewed and signed before the interview began. After they signed, each participant received a copy of the consent agreement. If any participant was reluctant after giving initial consent or expressed a reluctance to continue, I took the first no as an answer. The results reflected the number of participants not completing the application. Any information gathered to that point was eliminated from the final analysis.

Participants experiencing persistent, chronic pain were from a vulnerable population. Interviews certainly involved sensitive topics. High priorities included earning the subject's trust, assuring confidentiality, and developing a nonjudgmental, empathic connection. The approach helped participants develop a deeper understanding of their situation and learn better-coping skills (Charon, 2001). If an interview produced distress in any subject, I would have referred the participant to a trained clinician or other support sources. This resource was not requested or appeared to be needed.

Summary and Transition

This study explored the complex nature of pain through the narratives of people who experienced chronic pain after treatment. I addressed my experiences with caring for a spouse in chronic pain and its possible effects on the study's results. The target group was adults who experience persistent, chronic pain daily, or almost daily, for three months or longer. An online audio recorder website recorded the entire interview and protected confidentiality. A second online service transcribed all audio recordings into word processing files. Using the tools of this second website, I checked those files against the audio recording. The number of participants was 17 individuals. I obtained written consent for other ethical concerns, kept all data confidential, stripped identifying information from the narrative.

In the following chapter, I describe the participant pool and the procedures for analyzing the data. The results are presented and organized by research question. Discrepant cases and findings are discussed, and the efforts to maintain trustworthiness are evaluated.

Chapter 4: Results

The purpose of this qualitative study was to explore the complex nature of pain through the narratives of participants who experienced chronic pain and received varied treatments for it. This exploration collected participant stories of chronic pain, treatment-seeking, pain relief, and the experience of stigma. There was a growing interest in using narrative analysis to rehumanize the understanding of chronic illness (Bury, 2001; Thomas, 2010). Prior research revealed that patients' voices were missing from the literature, and narrative research was an excellent way to gain access to these to better understand chronic pain (Eaves, 2015; Rajagopal, 2011; Tsao, 2012).

This study addressed the following research questions and subquestions:

RQ1: What are the narratives of chronic pain management in patients?

SQ1a: How do these participants describe their experience of access to treatment?

SQ1b: How do these participants describe their experience with the pain management process?

RQ2: What is the meaning of stigma for participants who use or believe they need opioids?

SQ2a: How is stigma experienced in the treatment process?

SQ2b: How is stigma experienced with family and other social supports?

For the study I used two different methods to analyze the results. One was a structural analysis that grouped participants according to the strategies they used to manage pain. The second analysis examined how the results addressed the research questions and themes that all participants shared. This chapter covers the setting and demographics of participants. It details how I collected and analyzed the data. Finally, how I systematically explored the themes that resulted from those analyses.

Settings

The primary interviews were by phone through a computer conferencing website. I used website tools to record and transcribe all interviews. As promised, no one besides me had any access to the raw data. The participants chose the location for the interviews based on their sense of confidentiality and comfort. The time of the interview was by mutual agreement. After 17 interviews, the study reached saturation and the interviews ended. Because the last four interviews produced no new themes or experiences, this met the requirement for saturation (O'Reilly & Parker, 2013).

There were a few problems with the member check. The member check plan was to summarize the interviews and write the synopsis in the third person. All identifying details were eliminated or changed, as planned. However, the COVID-19 pandemic posed a few problems with sending the summaries to the participants. The first attempt was to email a password-word protected file to each participant. Most participants could not open this file even after they received the password. The modified member check plan sent each participant a printed file created using pandemic-safe protocols of a mask, gloves, and tape to seal the envelope. This modification delayed the final data analysis, but participants who responded to the member check requested only minor changes. Three participants did not respond.

Demographics

Of the 17 participants, 10 were women, and seven were men. Because the interviews were by phone, there were no restrictions on location, a possible concern before the study began. All participants were American citizens. All were Caucasian, but three were born in Lebanon. Eleven participants lived in my local area, Gloversville, NY. There were two participants from the Northeast. Finally, there were four participants from the Southeast and one participant from the Southwest. As described in Chapter 3, my intent was to recruit participants from my geographic area. Yet, in the final sample, six participants were nonlocal. Table 1 displays the age range, diagnosis, and primary means of managing pain for each participant. A pseudonym identified all participants.

Table 1

Demographic Characteristics of the Sample

Pain group	Participant	Gender	Age Range	Diagnosis
Pain gone				
	Ralph	male	65-74 years	Herniated disc back/neck
	Peter	male	25-34 years	Torn ACL
Nonopioid				
	Justin	male	18-24 years	Back pain
	Bill	male	45-34 years	Back/knee pain
	Ada	female	25-34 years	degenerative spine
	Sally	female	65-74 years	Cyst at the base of the spine
	Vito	male	25-34 years	Ehlers-Danlos syndrome/arthritis
	Mada	female	25-34 years	Kidney Transplant
	Rita	female	65-74 years	Neck/leg pain
	Dina	female	55-64 years	Shoulder dislocated
	Jean	male	65-74 years	Spinal stenosis bone spurs/bulging disk
	Rachael	female	74-85 years	Arthritis
	Caity	female	65-74 years	Stenosis in the spine
	Nija	female	65-74 years	Arthritis
Used opioids				
	Ben	male	45-54 years	Degenerative bone disorder
	George	male	35-44 years	Kidney transplant/arthritis
	Mary	female	65-74 years	Ruptured a disk in back

Data Collection

The target group was adults who were: (a) 18-years-old or older, (b) could express the details of their condition, (c) were able to consent to the study, (d) had experienced their pain for 3 months or longer, and (e) experienced persistent, chronic pain daily or regularly. These criteria gave participants adequate experience with current medical treatments, and chronic pain limitations and insured trustworthiness in participant selection.

As previously stated, most participants came from a purposeful sampling of adults who responded positively to the distribution of an invitation from a referral source. Also, some participants came from people who volunteered after hearing about the study. Furthermore, a few participants came from snowball sampling of those interviewed. All participants then contacted me to answer any questions, signed the necessary consents, and made an interview appointment.

The original data collection protocol was modified when people who heard me speak about this study approached me and asked if they could participate. The original data collection plan did not anticipate such a qualification for participation. The modified data collection protocol added this qualification after IRB approval (Walden University IRB approval number 04-19-19-0116261). Once individuals qualified, the interview protocol went as planned. Eleven people handed out invitations and were not participants. These referral agents distributed over 75 invitations. Of the people who received invitations, 15 people responded positively, and five others approached me after hearing about the study. Of those interviewed, five participants agreed to contact other people they knew who were in chronic pain, and these snowball referrals had three positive responses.

In every referral packet, there was a letter describing the study, Of the 20 people who filled out the necessary paperwork, 17 set up an interview appointment, and three did not.

While I had not anticipated that some participants would be pain-free at the time of their interview, it did not disqualify them from the study if they were previously in pain for 3 months or more. Two participants reported they were pain-free. Concerns of a study limitation due to limited medical services in my surrounding community were unfounded. Participants included individuals from other parts of the country (see Table 1). Some received advanced treatments specialized for their diagnosis and were provided pain management treatments not available in my local community.

The semistructured interview protocol did not vary for any participant. After expressing interest and signing the consent, every participant received a phone contact that answered any questions and set a time for the interview. A computer conferencing agency recorded phone conversations. Afterward, an online service transcribed the data using computer algorithms into a word processing file. I then used the tools at the transcription site to check the transcriptions against the audio. As a result, I was the only person who had access to any form of raw interview data.

Structural and Thematic Analysis

I used two different approaches to analyze these data. I used a structural analysis to explore the difference between three groups: (a) participants who were pain-free at the time of the interview, (b) participants who had chronic pain but did not use addictive medications, and (c) participants who used potentially addictive drugs to manage their chronic pain. The thematic analysis answered the research questions by exploring common themes discovered through computer-assisted qualitative data analysis software.

Structural Analysis

I first analyzed all transcripts through a structural analysis by hand from the transcribed interview data. The resulting documents were chronological pain stories for each participant. The results of the structural analysis revealed the narrative organization of all pain stories. Each had a beginning, middle, and end. This analysis revealed that, while there were numerous similarities among narratives, the experience of chronic pain was idiosyncratic but was able to be grouped by the way the participant chose to manage their pain:

- Pain free. Participants who experienced chronic pain for 3 months or more, but the pain had resolved.
- Nonopioid pain management. Participants who did not use opioids or addictive pain medications regularly.
- Used opioids or other addictive medications. Participants who used opioids or an addictive medication as their primary pain management strategy.

The resulting structural differences are in Table 2. Later, these documents were the source of a synopsis that was sent to each participant as a member check.

Table 2

Participant Differences in *Their Primary Pain Management Strategy*

	Pain free	**Did not use opioids**	**Used opioids regularly**
Access to treatment	Had little trouble accessing treatment.	Had some trouble accessing treatment.	Remained worried about access to treatment
Managing the ebb and flow of chronic pain	Typical ebb and flow pain management	Ebb and flow of pain difficult on some days	Ebb and flow of pain difficult daily
Discussions about addiction	Did not have a discussion about addiction with a doctor	Had minor discussions about addiction with a doctor	Felt they had to prove they were not an addict when with a doctor
Use of opioids	Avoided opioids and other addictive drugs	Avoided opioids and other addictive drugs	Embraced opioids and other addictive drugs
Beliefs about opioids and addiction	Believed opioids always led to addiction	Believed opioids always led to addiction	Believed opioids sometimes led to addiction
Experience of stigma from medical professionals	Experienced little stigma after being pain-free.	Experienced some stigma from medical professional	Experienced major stigma from medical professional
Experience of stigma from others	Experienced little stigma from others after being pain-free.	Experienced some stigma from family and friends	Experienced major stigma from family and friends

The results of this analysis also revealed fundamental structures that affected: (a) access to treatment, (b) daily planning to manage pain, (c) how often they experienced stigma from doctors, and (d) how often discussions about addiction arose during medical appointments. The most dramatic differences were in the group who used opioids or another potentially addictive medication to control pain. These differences are described below and supported with text from participant transcripts.

Access to Treatment

Access to treatment for chronic pain varied according to the primary way participants managed their chronic pain:

Pain-Free

The following participants who had resolved their chronic pain seemed to have little difficulty accessing medical treatment. Peter said,

> I did go to doctors and orthopedists. I went … several times to orthopedists. I … got a prescription every time for physical therapy. I also … brought up Active Release…. My doctor … said she had heard of it. And that was really helpful.

Ralph said, “I go see my family practitioner. He checks up on me…. I got blood pressure and cholesterol problems.”

Non-Opioid Pain Management.

Some participants who used OTC medications and other strategies to manage pain had little difficulty seeking treatment but sometimes felt medical interventions did not help. Rita stated,

> Because I was terribly under impressed [with my treatment]. It was not helpful. I thought it might have been sciatica. They said it wasn't. They didn't really tell me what it was. They didn't seem to know what it was. I went to the pain clinic, initially, I saw one doctor. Then they had made up a follow-up appointment. And he, all of a sudden, had quit and I saw somebody else. And then that person left. They did recommend physical therapy. So … I went back. I went to PT. And they did various exercises for probably a couple of months, maybe … two to three months. And it didn't do one single thing … it didn't seem to have any rhyme or reason to it. And I would do the PT and it wouldn't have any kind of an impact, whether I did it or not. So, after a couple months … I just told them it's not making a difference. It's not doing anything. It doesn't seem to make one bit of impact … So, I stopped going.

Sally said,

> And people thought it was sciatica, but it was not sciatica. So, I was going to physicians to try to get a diagnosis. I went to an orthopedic [doctor] and I went to a chiropractor to try to deal with it. And I finally ended up at a neurosurgeon's office. And he was the physician who was able to help me the most, at least, in diagnosing what I had. Through all the tests, through the years, I had MRIs. And they showed a huge cyst in the base of my spine. It was, I think, 3 centimeters long, or something like that, in size. And what the neurosurgeon said, because he did a contrast MRI … [was] that [the] cyst is leaning on nerves in the base of my spine. And it's developed a kind of place where it sits in my pelvic area.

Used Opioids or Other Addictive Medications

Participants who used opioids regularly were apprehensive that their next doctor visit might result in losing their most effective pain medications. Mary said,

> She's a PA and when I asked for a refill of the Soma [Carisoprodol], the head doctor in the practice put a note in my chart, "Get her off of this…. She should not be taking that all the time." And I panicked and I said … what am I going to do? I do not take it for pain management, I take it for my bladder. So, she [my PA] advocated for me.

George commented,

> I mean, they did do the tests, but when things were coming back negative, they sent me to a rheumatologist. But my blood tests were coming back almost negative. I didn't have … arthritis. But they said it wasn't what was causing my issues. But again, they didn't know really what to do because pain management as a thing wasn't really popular. And every time we mentioned it, [the] docs … [said] "No, no, no. You got to go see a specialist." But never point me in the right direction.

Managing the Ebb and Flow of Chronic Pain

All participants had to manage both mild pain days and days that were more difficult. However, the intensity and frequency of these experiences varied according to the primary strategy used to manage chronic pain.

Pain Free

For the pain-free participants, managing pain was mostly just a problematic memory. Peter said,

> I have like soreness after working out, but it's within normal limits. So, right now my pain is no worse than it was before my injury because I have a flat foot on my left foot. And that's always had some soreness to it. But it hasn't really been a problem ever. It was pain within normal limits for what I was used too.

Ralph stated, “The first episode of pain, with all those pills, was gone by … September 25th, 1998. I'll never forget it…. That's 21 years ago…. And four years after that … I was [ultimately] without pain.”

Non-Opioid Pain Management:

For participants who use OTC medications as their primary medical intervention, there were difficult days and some more easily managed. Rita said,

> It hurts every day. But sometimes it tends to be worse. Sometimes when I'm sitting at the computer working … I … take an Excedrin…. Or I might have to lay down if my back is in spasm for a little while … or to put heat on it. [Yet] I do the same things, whether I'm in pain or not. And it doesn't stop me from doing any activities. But … sometimes I just have to sit and rest. And … occasionally go out and do things. But what really starts to bother me is … in the evening, when I'm watching my granddaughters.

Rachel stated,

> I know when I start hurting that I just have to take more breaks. I have to sit down in between while I'm doing outdoor work or whatever I'm doing and kind of relax. And put more stuff on [OTC topical medications]. And then wait a while and then I go

> back to try to finish the job if I can. Whether it's mowing or trimming or painting or whatever I'm doing or washing floors or whatever.

Mada said,

> The only medication I can take is Tylenol. Well, no matter what happens, even if I got sick, like now, I'm not allowed to get out of the house a lot because my immune system is very weak…. So maybe the pain is less [since my liver transplant] it's like 80% less. But the pain in my kidney now, sometimes it's crazy because it starts from that from the lower back all the way to the shoulder…. So, it's going to be a bumpy road. But I'm going to be strong enough for it. I passed through a lot of pain. I'm learning to pass through more if I actually get to a point where I'm going to be painless, completely painless.

Used Opioids or Other Addictive Medications

For participants who used opioids or other addictive medications, difficult days appeared to be more likely and more frequent. George said,

> So, when I wake up in the morning, that's usually when it's at its peak. Because I've been lying down and sleeping. And I wake up and everything is just hitting me at once. Just getting out of bed is like a job…. Sometimes … it's not worth it…. I'm just going to call in…. As soon as I get up and move, and I start moving the joints a little bit, I have to get hot water on me immediately…. I am almost in tears sometimes because it's so bad. I run my hands … [under] hot water so those things start moving…. I get in the shower … [and] let all the heat do what it's got to do. And then … as I am moving, it feels like everything is just like punching me and stabbing me at

> once. I'll take some medicine in the morning. I'll finally get to work…. then once my pills start kicking in … it takes the edge off just enough so I can function. It's not that the pain disappears. It gets to the point where I could actually do my job without really showing them I'm [in] a little bit in pain.

Ben stated,

> In a lot of pain? Well, it's pretty much every day that I come home from work … I come home … my hips are sore. It's hard to fall asleep because I can't sleep on my back. I don't sleep on my stomach. So, I kind of jump from side-to-side and my hips are always sore. Feels like I got hit with a baseball bat, sometimes. And this is very uncomfortable.

Discussion About Addiction with Doctors

While addiction was a concern for all participants, it most often became an issue during a medical appointment if the participants were using an addictive medication to manage their pain.

Pain-Free

Doctors sometimes offered addictive medications to participants during their time with chronic pain. One participant used them, but neither participant felt they were useful. In response to a question if he had ever had a conversation with any doctor about addiction, Peter said, “I don't think so. No, I haven't really had any problems with substances.” Ralph stated,

> The last doctor I saw [while I was in pain] … told me there was nothing he could do for me except for keep giving me pain pills. I said they're not working. They just said, well, there's nothing we can do.

Non-Opioid Pain Management

Even when participants refused addictive medications, they still had to deal with the possibility that they were secretly harboring a desire for an addictive drug. Dina said,

> Yes, they dismiss what I'm actually telling them because they think I'm only there looking for them to give me a pill--until I got really upset. Like I didn't even ask for a pill. And in prior years, in another instance, I went to a neurosurgeon and he said to me, "We don't write pain pill prescriptions." And it was the first time meeting him. And truly, what he said to me was very offensive. Because I never asked him for a pain pill, never implied I wanted one. And he directly looked at me and told me that. Like he thought that's what I was there for.

In response to a question as to whether he ever had a conversation with any of his doctors about addiction, Justin stated, "Yes. Usually, depending on like the medications that they prescribed. Just … [be] careful on how much you take or whatever … because certain medicines can be very addicting compared to others." When it was suggested that he did not take them, he replied, "That was the hydros [hydrocodone]."

Used Opioids or Other Addictive Medications

When participants used additive medications to control their pain, they often had to prove that they are not an addict, or they might lose their pain prescriptions. Ben stated,

> So now I am to get this young doctor. Now I've got to sit here and tell my whole story again and they don't like giving medicine … because everybody's acting like … there's a bigger epidemic or something. You know, they don't want to give anybody any pain medicine anymore. And it's like you've got to be kidding me. You don't know my story. The only thing you see is that there's a chart saying, hey, he's been on this medicine a long time. Why is he on this medicine?

George said,

> But every time I got a new doctor and they saw [Dilaudid] it raised red flags on their end ... they immediately … say, "Let's get you off of this." And I'm … looking at them saying, that's not going to work. We've done this before…. And doctors are very scared to write a prescription for that type of med. And I mean, I understand, but when you get a person that's on it for a reason, there's a difference.

Believed More Medical Intervention Would Help

Even when participants had a bad experience with doctors when managing their chronic pain, a strong faith in medical interventions remained, for the most part. With participants who used addictive medications, however, their faith usually contained a dose of skepticism.

Pain Free

Pain-free participants had positive things to say about medical intervention. Peter said,

> [My doctor] was pretty validating. I felt like she was letting me know that she was listening. She had an excellent bedside manner. And she also was she was really well

> trained. Her background was in sports medicine. And she knew a lot of people who got surgery and people who didn't get surgery.

Nonopioid Pain Management

Despite having some difficult experiences with chronic pain and doctors, participants in this group maintained their faith in medical interventions. Sally said, “I go to the doctor for my annual physical…. And so, I'm sure that he would order pain medication for me, but I have not asked for it.” Caity stated, “I go to a fabulous [doctor] group…. So, I went there and … when I walked in, he said, ‘Well, I can tell you right away what you have.’ My experience with that doctor was just phenomenal.” Vito said, “My doctor was a really good doctor, and she worked at the [nearby clinic] ... I buy … [OTC medicines] at the store. Bill stated, “I haven't had a bad experience with a doctor. Other people have had bad experiences with doctors. But I've always been fortunate. My family has also been very fortunate not to have really negative experiences.” Ada said,

> But I really think I am lucky, and I'm blessed that at least for the conditions I have are treatable. Worst case scenario was the surgery. Of course, it gets irritating here and there. Like, the days when the pain is really bad. But I'm so thankful because I really think it could be worse. And I remain motivated to do my part, to do what I can to prolong whatever it is that's degenerating my spine. We'll find that out soon, hopefully. And I'll do my part, as much as I can, like I said, and the doctors will do… theirs. I've seen a lot of doctors, in different states and different countries, try[ing] to get as many opinions as I can. And, recently, I kind of realize that they all have the same thoughts each time. The same advice on what to do next.

Used Opioids or Other Addictive Medications

Participants in this group liked their doctors but seemed worried about the future treatment of their chronic pain or a change in provider. Ben stated,

> I'll be meeting my new doctor and I don't know how keen they are to giving me pain medicine … he did run bunch of tests and, [made] sure that I'm taking my medicine and … not abusing them … and I tested out fine…. And it's kind of scary, at the same token … because what I [was] used too … [was] a great doctor. He even told me things like, “I'm an old school doctor…. I know what it's like to be a laborer.” He knows how many surgeries I've been through.

Mary said,

> I had to have the battery replaced [in my spinal column stimulator] but … things didn’t work right, so they ended up doing the whole thing over. So, that one lasted until the battery ran out in May of 2009. Then it was replaced, and it’s been a miracle until last year when I felt my whole back of my shoulder and my ribs was burning and on fire ... they told me I had a broken rib, they told me I had shingles … and finally, last December, I convinced them to do a myelogram … and it showed that the implant had shifted…. So, I had to wait to get that approved. In February, they replaced … [and] they revised it … and I begged them, please, the battery has already outlasted its lifetime, it’s going to die. And they said, no we are not going to do it. Well, two days after I got home, the battery died. So, I had to go back May 2nd and have the battery replaced. So … they think they know everything about it, and they don’t know a thing.

George stated,

> I was hoping a different doctor would say or do something different. And the general practice doctors, of course, [said] they don't know, but they pointed me in a direction. Usually starts as rheumatology first … but when I get there, I talk to the rheumatologist and they say, no, you need to see a pain specialist. Well, the military works in mysterious ways. It takes months … to get into the doctor. And when you finally do get there, it starts all over again. The pain doctors even went, “Well, let's try to see if it's a rheumatology thing.” But they don't listen to you. So, it's like a giant circle. That tells me either they don't know about it or they didn't care.

Believed Addictive Medications Always Led to Addiction

Participants who were not using addictive medications did not state that they felt the need for those medications. Some reported that they would refuse if offered. Participants using addictive medications, however, felt that their medications were essential.

Pain Free

Pain-free participants believed that potentially addictive pain medications should be avoided and usually led to addiction. Peter said, “I've never smoked marijuana in my life. I know I get stomach trouble when I drink alcohol. So, I think I was fine with meditation because that's the healthy way to get a buzz for me, not for everyone.” Ralph said,

> There were times that I thought maybe I would double dose, but I wasn't that type of person. Even though I was in pain, they told me I had to take one tablet every six hours and that's what I took. I would just have to suffer if it didn't work because I knew of addictions, and I didn't want it. I might become addicted. I guess even with

> these new drugs that they got out there, it doesn't take long to get an addiction to them. And then you go through some major side effects. And I didn't want to do that.

Nonopioid Pain Management

It was a similar reaction with participants who used OTC medications to manage pain. Rachael said,

> [Interviewer asked, “And do they [doctors] ever talk about other meds you could take?”] No. Not really. Just the basic ones as you need them. That's all. Nothing strong. [Interviewer, “They don't talk about any stronger meds?”] No. No. And that's okay because I to go the natural way. Or, like now, the biggest thing is the CBD, the rub. I have the rub, and I have the drops. I have to take them every day.

Dina said,

> And I opted to not take them [Percocet] because I didn't want to cause another issue for myself. So, I didn't take … [as much] from the second day after the surgery. I didn't take them regularly … And then I would only take one a day, or one in the evening when I tried to sleep. Or when I really couldn't stand it, I would take one. Probably not even every day, but just at the point from not being able to stand the pain.

Sally said,

> He was the one that offered me pain medication. He said it's just … going to be there. If you want and I'll give you pain medications. I said, no, I don't want it … He offered me gabapentin … Not any of the opioids or anything like that. [Interviewer asked, “If he had offered you the opioids, would have taken them?”] No.

Used Opioids or Other Addictive Medications

Participants using opioids and other addictive medication believed the drugs were essential to their pain management. There was also no indication of abuse. Mary said,

> After the head doctor said to stop prescribing addictive medication, my PA talked to him and said, “Listen, this girl needs this. She’s not taking it for pain management. She is taking it for her bladder because she is allergic to everything.” So, she advocated for me. And I was afraid [I’d] have [to] switch doctors because the doctor I was going to left. And…[once] they put me in [another] practice [and they] said, “I’m not giving you this Altram. You’re a drug addict and you need to … take pain management and get off of it.” I switched doctors.

George said,

> And so, they said they put in my records for a pain management-type thing, that [Dilaudid] is the only thing that would work. But like I said, it's not that I got suggested to a pain management specialist. It was, “Let's try things to see what works.” And that was like [the] E.R. doctors … every time I got brought into the emergency room for something. It just became a routine. I had like, they call it a cocktail. It's just like different types of little meds. And then they give me the big juice med, that's what I call it … And sometimes it was a full … juice-wise, which is straight in [intravenous injection]. So, it immediately it takes effect, all the way up to 2 milligrams … I did not take Dilaudid today. Like I said, on good days, I'm able to take … Tylenol, about a thousand milligrams…. It's not that I don't. They were expecting me to come in every month or so and get refills. What it ended up being

> every six to eight months I got refills. And, you know, it got down to the point where I was taking only so many meds or so many times, they knew I was not one of those [addicts].

Stigma from Doctors and Medical Professionals

Stigma during medical treatments was common, but the experience varied by the strategy the participant used to manage chronic pain. Twelve participants experienced stigma during medical treatments. As will be seen, even when stigma was not experienced during medical appointments, all participants in chronic pain experienced stigma from some source.

Pain Free

Participants who were pain-free experienced stigma as a problematic memory. Peter said,

> Yeah, my orthopedist said that I should be running. This was the first one I saw in 2016. And he said I should be running after I got like the boot. And … he said … Your leg is strong. You should be running in like three months.” And I think that was a very unhelpful comment. Even though I respect his expertise, he definitely was helpful in a lot of ways. But this … was unhelpful. And, when I thought I should be running in the summer later, I injured myself. So, it was not solution focused.

Nonopioid Pain Management:

Stigma occurred even when a participant would refuse addictive medications. Dina said,

> [One doctor] basically dismissed my pain when I was telling them what I felt and the pain that I was in. He just kind of laughed it off and said, "Oh, I've had five shoulder

> dislocations like whew, that's nothing. What are you worried about?” And I assured him that if I was not in pain I wouldn't be there.

Caity said,

> [The doctor said,] “You know maybe I'll send it to [another doctor] and let him evaluate.” And then he said, “Why aren't you fat?” And I said, “I beg your pardon?” He said, “Ninety-nine percent of the people who come in here with knee problems are fat.” And I said, “Well, I suppose I'm not fat because I eat right and exercise. But, you know, injuries are caused by all sorts of things.”

Mada said,

> And [the case manager] said, “We know that there's something wrong with you. But it's not to that [much of an] extent. There's a lot of people more sick than you.” And … and she did not put herself in my shoes. And I actually told the doctor …. Even if I wasn't in pain, she should take it into consideration. [My test] results were scary. My liver started forming very bad cells. They were scared of cancer…. And I used to go nuts [when anyone mentioned I was not sick enough].

Used Opioids or Other Addictive Medications

Participants who used addictive medications were most likely to experience stigma during medical appointments and had the most to lose. Mary said,

> I have been called a doctor hopper because I kept trying to find someone to help me. And it is just, there very few doctors that I trust. I feel better now than I have in a long, long, long time but it is never going to all stop hurting.

Ben said,

> I did have a doctor visit with an on-call doctor, the one who was covering for my doctor. I had a different procedure done and he started giving me the business about me being on my medicine for so long. He's like, "Oh, you shouldn't be on it…. You know you should go see an orthopedic doctor." And I'm like, "Dude you don't know anything about me…. you know, I don't drink. I don't do anything. I pretty much just take my meds and that's it. You know I'm a laborer. I've worked hard all my life. I still have one leg longer than the other. And I'm in constant pain." And he just wasn't even trying to hear me … and I'm like, well I'm glad he's not my permanent doctor.

Stigma From Family and Friends

Even when stigma was not reported from medical professions, all participants reported experiencing stigma from other sources. These sources included family, friends, and casual acquaintances.

Pain-Free

Again, when pain-free, stigma from friends and family were often just a bad memory. Peter said,

> In terms of my friends, a lot of them didn't necessarily wait up when I was trying to come along with them to class. And I didn't really complain about pain with friends so much. But I did complain about pain when I was with family. And they wanted to do something, and I wanted to rest. Like my parents don't take themselves too seriously but they do like to hurry a lot…. I don't exactly remember what he said. I remember the attitude of feeling rushed. I think it was the essence of it was that he

> was feeling burdened … And one of the issues was that I was taking breaks when I was doing well. Whenever I walked somewhere … I would sit for like maybe 30 to 60 seconds.

Non-Opioid Pain Management

In this group, stigma from friends and family could be avoided by merely hiding pain or refusing to discuss it. Bill said,

> But it's very aggravating … because as soon as I take Tylenol, one of my coworkers at work … [begin] joking about it, because I was having a lot of pain. And we're allowed to sleep at work when we don't have any calls because … the ambulance service … and the trucks are all taken care of…. So, I'm like, "Yes, this will take about 15-30 minutes and then I might try and fall asleep." So [a coworker] had to joke it … "Oh, yeah … here's Bill. He'll take some of this Tylenol in 30 mins and fake snoring sounds." Pretending like, as soon as the medicine gets in my mouth, I'm out like a light.

Caity said,

> When I was 24-years-old, I had been married for six months, [and] we were cross-country skiing with a group. And I was staying with this horrible husband that I divorced way too late, and I should have done it sooner. And my feet just went out. And I put my hand down and catch myself. And when I got up, I said I thought … I broke my arm. And he [husband] said, "You can't have broken your arm. You just put it down in soft snow." I said, "Honestly, I think I broke my arm…." My husband was an alcoholic…. And he said, "Well, let's just get a beer and maybe it'll feel better.

> And then if not, we'll go home." So, he had a beer and I said, "You know … honest to God, I broke my arm." And he said, "You can't [have]. But if you're gonna be a booboo, we'll go home." So, I went home and I cooked … and served dinner and washed the dishes and complained about my arm. And [he said] "So … since you're complaining all the time, I will take you to the hospital….". So, we got to the hospital. They said, "You did indeed break your arm. But it's more complicated than that. You need to see an orthopedic surgeon…." Of course, the orthopedic surgeon was closed on Monday. So, I saw him on Tuesday. And he went apoplectic because I had a bone tumor and it had eaten my bone away … And, because I broke it, it pierced the tumor. If the tumor was malignant, I was in deep … trouble. Especially since it had been now a day and a half…. And I saw a specialist in these sorts of tumors…. And he said he couldn't believe I had no pain leading up to it…. Well, everybody has advice. Everybody has a doctor. Everybody has, "You know, what I did?" Everybody has an authority of some sort. And some of that's comforting. And some of that's just like eye-rolling….

Used Opioids or Other Addictive Medications

In this group, attempts to protect their most effective pain medication was to deal with the appearance of an addict and sometimes hide their pain. Yet hiding their chronic pain was often difficult. George said,

> Sometimes my friends here at work think it's fake, that I'm trying to get out of stuff…. I've had … people pulling me aside, saying … that I'm a shammer and I just want to get out of work. Because … like a lazy person and I just want to get out and

> go home. So, we call them shammers. [Interviewer … how did that make you feel?] Well, mainly angry because of my history with the military. I've never been that person…. But also freaked out that I'd be labeled [with] higher-ups with military promotions, awards, things like that. Because … you do so much in your career, all of a sudden, you're labeled as a shammer.

Ben said,

> My friends understood it [but] my family maybe not so much. Everybody had the attitude that well you had the surgery you should be fixed you shouldn't have any pain. And … that's not true … they don't live with it. They don't understand … you're constantly walking crooked…. My family just didn't get it. They didn't understand…. "Why are you in pain?" And I'm like, "Well … I don't know. Maybe because I was cut open so many times…." I had to work for a living and unfortunately hard labor is hard labor…. And then having a disability definitely didn't help.

Discrepant Cases and Findings

Despite the many underlying similarities, confirmability was evident because there were also striking counterexamples not anticipated by the research questions. These included faith healing and chronic pain unexpectedly vanishing and then returning. Ralph said,

> I believe in Jesus and my brother Phil. He was a born-again Christian who was a Baptist minister he laid his hands on me and asked Jesus to take away my pain and heal me. And I stopped taking all my narcotics except for Celebrex…. And I was able

> to do things I wasn't able to do before…. [Now] I come home and I sit down, eat dinner, and sit and watch TV and I'm normal. I've been normal now for 10 years.

Rita said,

> And then at some point, it [the pain] kind of just disappeared. Now, once in a while, it will recur, but it's much more mild … actually this winter, it kind of recurred, but it's much more mild and it doesn't really bother me very much.

Thematic Analysis

A thematic analysis was employed to explore common experiences across interviews. This thematic analysis used both a hand analysis and MAXQDA (Saillard, 2011). The themes discovered through this second analysis answered the research questions. These themes are summarized in Table 3.

Table 3

Summary of Themes for Research Questions

Theme	Example Quote
Research Question 1	
Good pain days.	A good day would be I wake up and it feels good and… I'm very motivated… (Dina)
Difficult pain days.	So, I did go through to the hospital. I was hospitalized for two weeks because I have jaundice and chronic hepatitis…. (Mada)
RQ 1, Subquestion 1a	
Multiple Doctors and Uneven Outcomes	But I just feel like they've always said there really was nothing that… they could do. So, I don't even bother with it anymore. I don't even bother discussing it. I just figured, what are they going to tell me? Ice and take pills… and I already know that. (Jean)
RQ 1, Subquestion 1b	
Very Severe Pain	It's [when] I have to take something for the pain. I would have to put … cold and hot compression on my neck. It depends on how bad the pain is. But at times it's so bad, I mean, I cannot even hear anything. That's how bad the pain gets. And other times … I just have to do breathing and stretching. And I try to do a lot of mind over matter. (Ada)
Anxiety and Pain	I was a constant, stressed-out mess. And I have subsequently learned that complicates every physical thing I have …. And I was sad about that … but my pain has always been worse when I'm discouraged. (Caity)
Biomedical Treatment with Biopsychosocial Elements	I was having a lot of pain. I was still trying to … do things that help me like remain satisfied with my life. Like I was meditating daily and that seemed to help. I was still doing pretty well in school. I think I actually was very involved with school because it was a good distraction from my anxiety about like reinjury and pain. (Peter)
Research Question 2	
Social Identity and Liminality	But a lot of times they just said it was not a real thing. It's in my head. Or I was a hypochondriac. Or, you know, we can't find any physical thing that caused this pain. So, it's not a real thing …. (Geroge)
Evidence of Resilience	One time, a couple of years ago, when I was having that hip issue and I was going to go horseback riding. And my one relatives … who tends to be negative, said, “Don't go. Maybe you shouldn't go.” And I said, “No way. I'm going to go. I don't care. It hurts anyway. I might as well go and have fun.” Which I did…. I had a blast and it was fine. (Rita)
RQ2 Subquestion 2a	
Stigma from Medical Professionals	“Are you visiting your psychiatrist recently?” Because I have a psychiatrist. “No … I'm just telling you that I'm in pain, and you guys have to do something about it….” Because I felt like they were taking it in such an easy way. (Mada)
RQ 2 Subquestion 2b	
Stigma from Family and Friends	Of course, that hurts because everyone keeps teasing me about I need to go in bubble wrap and stuff. They don’t understand…. I haven’t done any of this stuff on purpose. I didn’t have plans to hurt my back in nursing [school]…. (Mary)
Self-stigma	I do whatever I have to do for whatever work … because I need to work. And, like I said…. I'm too young to be treated like an invalid. And I don't want that. So, I just kind of pretend I'm okay most of the time. (Jean)

Research Question 1: The Experience of Chronic Pain

The most common theme was managing days when chronic pain was less intense and days when the chronic pain was more severe. The goal was to find a balance where the chronic pain was still present, but participants could still function. Participants used various idiopathic strategies to achieve this goal.

Good Pain Days

These days were sometimes the result of adequate pain management strategies. Other times, relief appeared to be a matter of luck. Dina said,

> A good day would be I wake up and it feels good and … I'm very motivated…. you just have an outlook where you're ready to go. You're not exhausted…. you just feel light. In the mornings, [if] you wake up and there's that pain or that constant nagging discomfort, then you're almost defeated before you start….

Ada said,

> A typical day now is studying in the morning. My first few hours in the morning are always spent studying. I do gym after that. I finish any errands I have after that. Either I come back to studying or I've been looking for work recently. I started volunteering teaching, right now, teaching adults.

Rita said,

> I'm sitting at the computer working, which I was this morning. So, I took an Excedrin. I take an Excedrin every day. There's … never a day when I don't take an Excedrin. Because it does help take the edge off. But when it's really bad, I might have to take two. Or I might have to lay down if my back is in spasm for a little

> while. And that helps, or to put heat on it. And I put heat on sometimes. Other than that, there's nothing different. I do the same things, whether I'm in pain or not.

Difficult Pain Days

Sometimes, difficult days resulted from anxiousness, over-doing a task, or meeting otherwise everyday demands of life. Other times, there was no predicting or explaining days with more pain. Mada said,

> So, I did go through to the hospital. I was hospitalized for two weeks because I have jaundice and chronic hepatitis…. So, I got out of the hospital and everything was fine. I lived my life normally again. And then in 2013 … the pain started. And … I had to go through … six years until 2020, when I had my liver transplant.

Ada said,

> When somebody is in pain, it can be difficult … to get doctors that understand you…. [And] then I didn't want to go. I told my mom, I give up on going to doctors…. So … [it’s] the same way a woman meets the man of her dreams. It was the doctor of my dreams. He understood exactly what I was talking about.

Research Question 1, Subquestion 1a: Access to Treatment

While the experience of going to the doctor varied by the primary pain strategy used, many participants spoke of hiding pain from doctors. Also, regardless of pain strategy, pain management often had multiple doctors, and it sometimes did not improve treatment.

Multiple Doctors and Uneven Outcomes

Even when a participant could find a doctor who would treat their chronic pain, this often led to numerous referrals and uncertain outcomes. Sally said,

> It's a local physician. And so, I'm sure that he would order pain medication for me, but I have not asked for it. He knows what I have. He's gotten all the reports from all the physicians…. He's a GP, so he's not going to know anything to do with it.

Bill said,

> I am probably supposed to get a yearly checkup, at least for the fire department's sake and haven't gotten one yet. It's a whole time issue. And I'm kind of afraid of what they will say about my knees. And that [I] might not be able to work anymore. And I know that I'm very capable of working. I'd just go out and do it. So, I'm a little concerned what they might say [something] about my knees. I really never got up to getting a physical done.

Justin said,

> [Interviewer, "And how do you feel when you leave the office of a typical doctor visit? Do you feel like something has happened or you've been helped?"] Not really, because … they tend to just tell me … [to] take pain meds [OTC] and stuff like that … Not too much physical activity. And because that's something that I already know and already do.

Jean said,

> I'm not a complainer. You know, I may go in and speak of this or that. But I just feel like they've always said there really was nothing that … they could do. So, I don't even bother with it anymore. I don't even bother discussing it. I just figured, what are they going to tell me? Ice and take pills … and I already know that. So why waste their time and mine? It's a kind of forgotten thing.

George said,

> So, I went from being seen and cared for very meticulously prior to my transplant and after my transplant. And then I was put on to a transplant kidney specialist that's not part of the surgical team…. And I see him for literally five minutes…. “Your blood test looks great… your meds look fine. Let's get you set up for a rheumatologist.” Well, I've seen rheumatologists for the last couple of years. And I keep getting the blood tests. It's not that. So. he can't figure it out because if it's not the kidney problem, it's not the meds I'm on from the kidneys. He doesn't know what to do for me. And only knows what to do is point me towards a rheumatologist. [Finally, the doctor says] “Do you have any questions?” [I replied] “I have joint pain, or I have this pain … I need to take care of it to see what it is.” And he kind of scratches the head… “I don't know what to do for you, it's a pain thing. I'm not the pain guy….”

Research Question 1, Subquestion 1b: Experience with Pain Management.

The success of a given management strategy also depended on idiosyncratic factors plus the severity of the pain. If the chronic pain was too severe, most pain management strategies failed. All participants reported incidents where there might have been an improvement in the managing of chronic pain. This outcome might indicate possible undertreatment, though no participant used that term. The next chapter will address undertreatment in more detail.

As participants experienced more anxiety, they seemed to experience more pain. All doctors appeared to use the biomedical model. On their initiative, some participants found other treatment strategies useful as supplements.

Very Severe Pain

Severe pain days were often commented upon by all participants. If the pain was too severe, participants tended to stay home when they could. Dina said,

> A bad day? [I] just get my coffee. Sit down. Turn on the news. Maybe just … take some Tylenol and putter around my house. I feel like doing something, but I don't feel like doing something. My mind says I do, but my body says no … I'll just sit back down … and watch … TV … [then] get up and … pace in the house. Like I'm uneasy or antsy. I'm bored. But you don't know what to do with yourself.

Peter said,

> If it were like eight out of ten, it would probably mean that I'm going to have difficulty getting to the kitchen. I would stay in bed longer. I would probably be just worrying, at that point, and not really able to … do much about my pain.

Ada said,

> Poor pain days is when I tried to go to the gym, and I can't. And if I push myself, I can only do very, very basics. Maybe just a little bit of walking. It's [when] I have to take something for the pain. I would have to put … cold and hot compression on my neck. It depends on how bad the pain is. But at times it's so bad, I mean, I cannot even hear anything. That's how bad the pain gets. And other times… I just have to do breathing and stretching. And I try to do a lot of mind over matter.

Anxiety and Pain

Anxiety reportedly increased pain. For some, decreasing anxiety was a psychological intervention in pain management. The next chapter will discuss anxiety management and its implications for pain treatment. Caity said,

> I was a constant, stressed-out mess. And I have subsequently learned that complicates every physical thing I have.… And I was sad about that … but my pain has always been worse when I'm discouraged. If I feel like somebody is listening to me, and that there is light, not necessarily at the end of the tunnel, but there's something I can do. There is some responsibility I can take to make this better … then I can endure it.

Peter said,

> Oh … my physical therapist told me. It was a mixture of the nerves, the physical nerves firing a whole lot when stimulated. And that my pain was also making me more anxious. And anxiety adds to the perception of my pain. So, it's more like I was used to feeling pain for so long that like even resting my leg at an angle was enough to stimulate a pain response…. I was concerned about my anxiety.

Nija said, “But … the one thing I have noticed that stress a lot adds [to] the pain. So that's one thing I'm sure of. And I was kind of surprised when the doctor told me that.”

Biomedical Treatment with Biopsychosocial Elements

Participants who received medical treatments for chronic pain had doctors who used the biomedical model. Yet, some participants found elements of the biopsychosocial model to manage pain. Ada said,

> Yesterday, I was in a yoga class and I try to incorporate yoga as much as I can. I try

> to do as much meditation as I can at the house, while I'm at home or outside. Once in a while, I go on a retreat for a couple of days, just to … regenerate your inner drive, the mind, the body and all of that. All those have helped.

Peter said,

> I was having a lot of pain. I was still trying to … do things that help me like remain satisfied with my life. Like I was meditating daily and that seemed to help. I was still doing pretty well in school. I think I actually was very involved with school because it was a good distraction from my anxiety about like reinjury and pain.

Caity said,

> I really am very happy. And so now I'm back hiking and doing yoga and kayaking when the weather is conducive. And … [I] got rid of the boyfriend that didn't like a handicapped woman in his life. And I also attribute a lot to counseling because I was just buckling under the stress. And that was a big help. I did that for maybe two and a half years in the middle of the back saga.

Research Question 2: Meaning of Stigma

The experience of stigma was also idiosyncratic but had many similarities.

Social Identity and Liminality

Whenever possible, participants avoided talking about their pain with people who might not understand or judge them. Other times, trusted people provided social supports that enhanced the ability of the participant to manage pain. Dina said,

> [Interviewer: So how do you feel about the fact you have to hide your pain from people?] I don't know. I guess I never really thought about that. I just don't want to be

> Debbie Downer. So … in the moments that I'm with people … not particularly my family or sisters, but say my friends, just … being around them and hearing their goings-on and feeling a part of that … is actually uplifting for me. So … I don't talk about my pain. If they ask me … I'm just very vague about it. Most of the time … I want the positive effect of their company.

Bill said,

> Frustrating. I grew up in a house where my dad was in the army. My mom was a nurse and they made light of everything like, "Oh, it's not really that bad…." I've had several injuries as a kid. So, I … [just] shrug it off …. So, yeah, it's frustrating.

Sally said,

> They didn't notice [my pain] and I don't complain about it … I mentioned it a couple times to some friends, and [now] I just don't bring it up…. It's not a topic of conversation. Some people occasionally … know I have … pain. They'll ask me about it. But, normally, it doesn't come up … sometimes my family, like my older sister, may ask me. "How is it?" And I'll say, "Well, it's just there. I mean, it's not any worse, any better." You just handle it.

Rita said,

> I don't think they realize I'm in pain. I said something to my son a couple of weeks ago. I don't think they realize I'm in pain because I don't talk about it or complain about it … when it gets really bad, I'll [sometimes] complain about it….

George said,

> I'm saying … [that] they're very afraid to do [any medical intervention] … because

> they're not pain specialists…. But a lot of times they just said it was not a real thing. It's in my head. Or I was a hypochondriac. Or, you know, we can't find any physical thing that caused this pain. So, it's not a real thing….

Jean said,

> Well, just very old, very helpless, very useless, very not contributing. When I was on disability and then I wasn't working, I felt horrible. Because … I wasn't bringing any money in…. when I stopped doing the work that I was used to, and wasn't making as much, I just felt … just so limited. What can I do now? You know, I used to be able to do anything. And now my options are, I've got to pick and choose whatever. And I'm not good at that kind of work. The work I'm good at, I can't do now. So, what am I gonna do? So, kind of scared.

Evidence of Resilience

There was also evidence of resilience in most participants. Resilience was apparent when participants reframed their pain as an experience where they had functional or psychological control. This evidence was more noticeable when participants faced with everyday stressors or unexpected events or changes. Rita said,

> One time, a couple of years ago, when I was having that hip issue and I was going to go horseback riding. And my one relatives … who tends to be negative, said, “Don't go. Maybe you shouldn't go.” And I said, “No way. I'm going to go. I don't care. It hurts anyway. I might as well go and have fun.” Which I did…. I had a blast and it was fine. As a matter of fact, for some reason … doing that horseback riding that day actually helped. My hip felt better for a couple of days. I don't know if it was just the

> fact of sitting in the saddle.

Mada said,

> I'm a person that never actually talks about pain. They [my family] used to feel that without me saying [it] … And they used to know whenever I'm in pain, [when] I need to be alone. [Or] I need to speak. They were not [the] kind of people that [say], "Oh, my God, why are you calling us? Why aren't you answering, blah, blah, blah?" No, they always were there. They never left my side … And my mother played a very big role, and all my family did. But my mom was number one.

Sally said,

> I've taken ibuprofen. I've taken Excedrin. Those are the two main pain medications. They don't really affect it. But I think that's more psychological, for me to be able to take something. But sitting for long periods of time and driving really was the worst. And I was on the road a lot for the last three years. So that was really the worst time. And now that I'm back in the office [and] sitting is really doing it to me. I have no pain at night … sometimes I don't notice it as much as other times. Sometimes it's really difficult to handle. But … there's nothing you can do about it. So, I just handle it.

Research Question 2 Subquestion 2a: Stigma Experienced During the Treatment Process

Stigma from Medical Professionals

All participants reported the experience of stigma in a variety of ways, though not always from medical professionals. Mada said,

> "Are you visiting your psychiatrist recently?" Because I have a psychiatrist. "No … I'm just telling you that I'm in pain, and you guys have to do something about it…." Because I felt like they were taking it in such an easy way.

Justin said, "There is one doctor that I went to and he had, jokingly …said, 'You might just be faking it ....' But … I came there in real pain. I don't need you to joke about it…."

Research Question 2 Subquestion 2b: Stigma From Family, Social Supports, and Self-Stigma.

Many participants also expressed being shamed by others, mostly from people they knew. Even when participants attempted to hide their pain from strangers and other acquaintances, stigma from family and friends was evident. Sometimes, though, it appeared unintentional.

Stigma from Family and Friends

Peter said,

> I was upset and frustrated with how [my father] expressed his emotions. But he wasn't making me or forcing me to carry things. I am grateful he stopped when I told them how I was not comfortable with helping out. He didn't force me to do things. He just wanted me to do [more] things.

Caity said,

> And I have never, ever forgiven my friends, that I hike with. Because they all trooped off [when I was injured and could not walk]. And there were just … two frail people [left] who felt sorry for me and just cheered me up. But all my friends just marched off and then it started to rain. So that was an incredible two hours.

Mary said, “Of course, that hurts because everyone keeps teasing me about I need to go in bubble wrap and stuff. They don’t understand…. I haven’t done any of this stuff on purpose. I didn’t have plans to hurt my back in nursing [school]….” Justin said, “There have been times during physical activity where I have to take a break because my back hurts. And, you know, people are rag on me. But nothing serious because they know that I do have back issues.”

Self-stigma

When describing their chronic pain experience, self-shaming was common. It often took the form of not wanting to be a burden or be labeled as a complainer. Often these participants hid their pain whenever possible. Racheal said, “[You are depressed] but you just push yourself because … there's no one else to do anything. And you just have to take care of him [her husband] and that's all.”

George said,

> Mentally, not good. Yeah, physically, obviously still hurting, but mentally it was very frustrating. I caused a few ruckuses every now and then. Like I'd go up the chain [of command]. But I felt, I don't want to use the word helplessness and bad, but it was helpless…. I can't do anything about it. I just got to trudge on and just deal with it. But it was to the point where mentally I felt drained. I felt lonely about it. You know, my wife, she couldn't do anything. She just said, well, let's go see a doc cause she's not a pain person. She just knows what I was doing every morning. But it felt like this can't be it. Someone's got to know about this stuff. Because I wasn't the only one…. There's a lot of military men and women and spouses that are going through

> something like this with no answers.

Jean said,

> Well ... one day … they'll say, oh, your back's bothering you today, isn't it? And … I just brush it off. I don't want people feeling sorry for me. And I don't want to be treated any differently. Especially at my work. I'm not a complainer or anything. I do whatever I have to do for whatever work … because I need to work. And, like I said … I'm too young to be treated like an invalid. And I don't want that. So, I just kind of pretend I'm okay most of the time.

Evidence of Trustworthiness

Credibility

The recommendations of Saldaña (2016) guided the establishment of credibility. There was prolonged contact with the data. I did four separate analyses: a) the review of the computer-generated transcripts against their audio recording, b) a structural analysis of the transcripts to organize the pain stories into chronological narratives, c) a computer analysis of the transcripts to identify experiences in common; d) a member check using a synopsis of each pain story to insure accuracy and record any developments, and (e) identification of counterexamples not anticipated by the research questions.

By including two extra participants in the study than planned, I found evidence of saturation. The last four interviews reported no new experiences. Also, participants were able to be grouped according to their primary pain management strategy. Despite any differences, however, the sequala of the pain processes management of most participants was similar.

For the member check, each pain story was re-written in the third person. I password protected member check files and then emailed to each participant with 2-step certification over the phone to unlock the file. Most participants, however, were unable to open this file. In a second attempt, I sent printed synopses to each participant prepared using COVID-19 safe protocols. The responses to these synopses included only minor changes that did not change any themes. Three participants did not respond to the second member check, but the other 14 members usually stated that the synopses accurately described their chronic pain experience.

Transferability

The commonality of the experiences of the participants despite having different diagnoses, ages, pain management strategies, and circumstances was evidence of transferability. For instance, most participants had to start each day while still in bed. During this time, they planned how to approach the expected demands of the day, plus how they might pace themselves to manage their pain and still achieve their daily goals.

Dependability

In my proposal, there were concerns that the contentious history of caring for my wife might have created biases for reaching conclusions. I followed Roulston and Shelton (2015) six suggestions for managing bias in a qualitative analysis, which included: (a) acknowledging interests of the researcher and how it might influence data analysis, (b) reflecting on how closely the data stayed within the range of the research questions, (c) examining how the data elicited differences from researcher expectations, (d) revealing what data surprised the researcher, and (e) explaining how the conceptualizations of the researcher changed the throughout the study.

All participants met the following criteria: (a) were 18-years-old or more; (b) were able to express the details of their condition; (c) were able to consent to the study; (d) responded to a formal invitation to participate from a referral source or who approached me and volunteered; (e) had experienced their pain for three months or longer; and (f) experienced persistent, chronic pain daily or regularly. These criteria ensured that the participant had adequate experience with current medical treatments. It also confirmed that the participants had experiences with ongoing pain limitations.

Participants were not limited to those unhappy with either their doctor or their treatment regimen. Neither were those participants excluded. There was a purposeful attempt to solicit participants from minority groups. Monsivais (2013) stated that bias was evident in chronic pain management. He questioned whether minorities had increased difficulty seeking treatment for chronic pain.

Confirmability

The reflexivity evident in the multiple exchanges between the researcher and all participants indicated confirmability. In these exchanges, participants sometimes reflected on how their participation in the study changed their lives. As Rita put it,

> [K]nowing I was going to be doing this interview about pain, made me realize … I get cranky because … I'm so tired. All I want to do is lay down because my neck is hurting, or my back is hurting. And … if the kids … need things … I want to be able to be there for them without getting cranky about it.

Evidence of Ethical Procedures

All data were kept confidential. Identifying information was stripped from all narratives. I was not in a power relationship with any possible participant because I was retired from full-time employment. Some of the participants who responded to the invitation came from family, friends, and acquaintances in persistent pain. All participants responded to a referral source request or approached me and volunteered. I kept interview data confidential, even from other acquaintances and family members, unless I had written permission. Each narrative had an identifying number and a pseudonym. I stored the personal information on my home computer or in a locked box file for paper records.

Summary and Transition

This study interviewed 17 participants regarding their experience of chronic pain. All participants interviewed were able to describe their experience with pain and their access to treatment. The most common themes revolved around managing pain with different strategies daily to retain/aspire to a quality of life worth living. Most participants experienced stigma in various forms. Stigma came from people they knew, mostly medical professionals, family, and friends.

For participants not using addictive drugs, a brief discussion on addiction occasionally occurred during medical meetings. For participants who used opioids, however, these meetings were challenging and often produced anxiety. These challenges remained ongoing.

Common themes were identified through the structure of the interviews and how participants answered the research questions. The evidence for these themes came from exact quotations. The themes showed that pain management was idiosyncratic to the individual, though there were many similar pain experiences. The data demonstrated trustworthiness. There were both common themes and unexpected experiences that were not anticipated by the research questions. The data achieved saturation because the last four participants interviewed added no new experiences to the data. Reflexivity was evident because of the multiple exchanges between the researcher and all participants. Finally, there was evidence of transferability because all participants had no difficulty answering the questions and creating a narrative with a beginning, middle, and end.

Chapter 5 presents how the study's results compare to existing research and how the results might point to a possible synthesis in pain conceptualization. I describe how these results point to the need for psychological interventions to help people in pain, regardless of severity or diagnosis. This chapter also discusses other implications of the findings, and the need for future research. The conclusion discusses study's potential to impact social change.

Chapter 5: Discussion, Conclusions, and Recommendations

In this qualitative study I explored the complex nature of chronic pain through the narratives of adults who experienced it for 3 months or more. The primary focus was to investigate whether exploring the voice of pain sufferers would deepen the understanding of the experience of chronic pain and improve treatment (see Eaves, 2015; Rajagopal, 2011; Tsao, 2012).

Key Findings

I conducted a narrative analysis, and 17 participants were interviewed. The results were generated from both structural and thematic analyses. The structural analysis revealed distinct groups (pain-free; nonopioids to manage pain; opioids to manage pain), and the thematic analysis identified 12 themes to describe the nature of their pain experience and how they experienced stigma both in treatment and in their social interactions with family, friends, and community. These findings supported the need for a biopsychosocial approach to chronic pain treatment. The results also seem to align with the approach that chronic pain treatment is better addressed as a separate disease rather than a symptom of an underlying problem. Finally, the results showed that insights can arise from the narratives of people experiencing chronic pain.

- There were dramatic experiential differences among participants who used opioids or other potentially addictive medications to manage their pain. Yet, there were also striking similarities in the experiences of all participants with chronic pain.

- All participants discussed needing to balance the ebb and flow of chronic pain. Their goal was to find a balance where their chronic pain was still present, but the participants could function. Participants sometimes received medical help in developing their pain management strategies. More often, the participants developed unique pain management strategies with only occasional guidance from medical professionals. The resulting pain strategies were often idiosyncratic.
- All participants responded affirmatively to the questions about good days and bad days, but the reasons behind their comments varied considerably.
- Most participants reported that anxiety increased their pain.
- Most participants had a story of experiencing stigma when doctors dismissed their pain or experienced stigma from medical professionals. Other sources of stigma included family, friends, and casually encountered strangers. Participants also reported feeling self-ashamed about their pain and their attempts to participate in everyday life.
- There were instances of discrepant cases, where two of the 17 participants were pain-free at the time of the interview. In one case, this was due to extensive physical therapy. In the second example, pain relief came through faith healing.

Interpretation of the Findings

The results reflected many findings in the research on chronic pain. Overall, the wide variety of treatments may reflect the lack of consensus on the definition of chronic pain and treatment found in the pain research (Bourke, 2014; Wailoo, 2004). A comprehensive listing of how participant reports matched those found in existing research is in Appendix E.

Some of the experiences of participants seemed to fit into three categories: (a) pain-free participants, (b) those who did not use addictive medications to manage pain, and (c) participants who used potentially addictive medicines regularly. Yet, all groups had numerous experiences in common. For example, reaching out to their physicians and medical professionals often resulted in recommendations for medications, surgery, or physical therapy (Peppin et al., 2015). As described earlier in Chapter 2, the biomedical model has a minimal repertoire for treating chronic pain. Participants reported feeling frustrated and sometimes despondent (Jurecic, 2012). For example, when an on-call doctor suggested Ben reduce his medication because he had been on it too long, Ben responded, “You know I'm a laborer. I've worked hard all my life. I still have one leg longer than the other. And I'm in constant pain.” Nonetheless, the doctor continued to dismiss his pain.

Most participants had little more than a casual discussion with doctors regarding addiction. The interaction was more confrontational if participants took a potentially addictive drug, or their doctor concluded they wanted one. Commonly it was opioids, but it was also benzodiazepines or other kinds of anxiolytics. Such participants felt they had to prove a negative (i.e., demonstrate that they were not abusing medications). After they found a doctor willing to prescribe their medications, there were ongoing concerns that a new doctor would refuse to prescribe the potentially addictive drug. Yet, no participant who used potentially addictive medicines to control pain appeared to be abusing those medications. George reported, “But a lot of times they [the doctors] just said it was not a real thing … I was a hypochondriac. Or, you know, we can't find any physical thing that caused this pain.” These findings were consistent with published literature showing that using addictive drugs did not always lead to addiction, and opioids can be useful in managing long-term pain (Chapman et al., 2010; Gourlay et al., 2005; Heit, 2001; Kumar et al., 2015; Ljungvall et al., 2020; Rajagopal, 2011; Vowles et al., 2015; Wilbers, 2015)

Balancing the Ebb and Flow of Chronic Pain

While every participant reported experiencing an ebb and flow of chronic pain, they reported various approaches to finding a balance. The data showed that nearly all 17 participants felt that their daily activities influenced their chronic pain (see Appendix E). OTC treatments were popular supplemental pain management approaches and were often used in combination with other therapies. Also, OTC medications were preferred and used more frequently than prescribed medicines (Eaves, 2015). This preference could be because opioids were not available to most participants. Yet, 14 of the 17 participants felt that using opioids would lead to addiction and said they would refuse those medications if offered (Bruehl et al., 2015).

Biopsychosocial strategies (Engel, 1980) were used as supplemental pain management strategies and included: (a) limiting or modifying daily tasks (Jensen and Turk, 2014); (b) regular exercise (Slade et al., 2009); and (c) cognitive-behavioral techniques including mindfulness, meditation, or psychological counseling (Sheedy et al., 2017; Sturgeon & Zautra, 2016). Often, the participants developed their own pain management strategies with only occasional guidance from medical professionals. Most participants believed that their daily activities influenced their pain experience (Rivera et al., 2015).

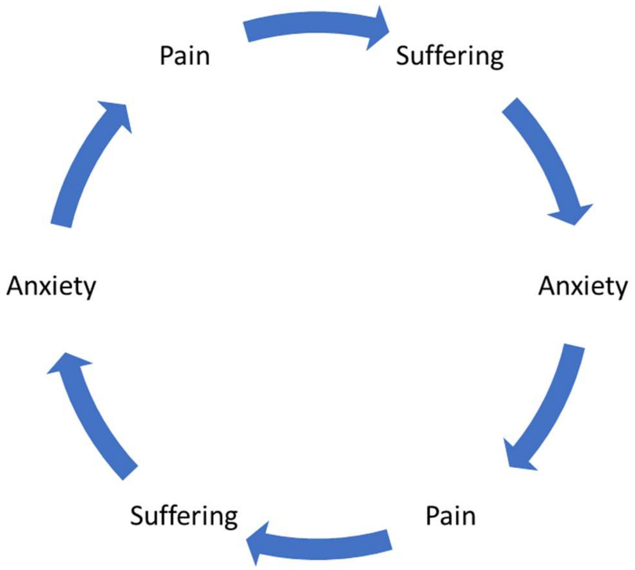
Anxiety and Pain

Increased pain seemed most significant when anxiety negatively affected social identity (Major et al., 1998). It was particularly evident when participants reported embarrassment at not maintaining their previous level of functioning. As they lost friends, jobs, and spouses, their self-esteem suffered. When perceptions became internalized, participants often seemed to blame themselves for their predicament (Monsivais, 2013). So, from a psychological point of view, finding a way to prevent self-shaming and reduce anxiety, in general, seemed to be a point of possible psychological intervention to improve pain management.

Over time, anxiety had a cumulative effect on pain (Ljungvall et al., 2020; Palmeri, 2016; Wong et al., 2015). As this cycle progressed, chronic pain sometimes increased beyond what medical professionals would expect (Kaufman & Baucom, 2014). Anxiety was often evident in the reports of pain by participants. These reports could explain the findings that doctors often felt that patients exaggerate their chronic pain feelings (Staton et al., 2007). Figure 2 shows the escalating nature of anxiety and pain over time, as expressed in the participants' narratives.

Figure 2

The Relationship between Anxiety and Pain Severity



Note. This figure graphically illustrates the cumulative effect of anxiety, pain and suffering. As chronic pain continues, it creates anxiety, and this increased overall suffering. If left unattended, anxiety can increase overall suffering, leading to further interventions for adequate pain management.

Undertreatment Was Evident

All participants struggled with pain management. In the literature, this is identified as undertreatment, and it was a frequent topic in the peer-reviewed literature on pain (Abdallah & Geha, 2017; Arnstein & Herr, 2017; Björk et al., 2016; Breivik et al., 2006; Clauw et al., 2019; de C Williams, 2016; Hiller & Suominen, 2017; Kehlet et al., 2006; Nordmann et al., 2017; Paydar et al., 2016; Platts-Mills et al., 2016; Peppin et al., 2015; Rajagopal, 2011; Trentin et al., 2001; Wailoo, 2014). Ten participants in this study explored biopsychosocial techniques for pain management (e.g., yoga, exercise, meditation, diet), yet they reported little support from their treating professionals other than agreeing with the effort. Other participants did not report the need for biopsychosocial strategies (see Gourlay & Heit, 2009). Nonetheless, their regular reports of severe pain suggested whether a more comprehensive, physician-directed approach might improve treatment outcomes. This study's findings concurred with the literature in that many of those participants would refuse stronger, potentially addictive medications even if offered (Bruehl et al., 2015). However, three participants found opioids and other addictive drugs essential to their functioning (see Ljungvall et al., 2020; Rajagopal, 2011).

Often, when pain could not be relieved, the participant stated they would "push through the pain." The success of this strategy depended on pain severity. If the pain was too severe, this strategy usually failed. However, almost as often, many participants responded with resilience and an openness to better pain management. In this study they reported: (a) ignoring the pain and continuing with a planned activity, (b) intentionally lowering their anxiety through reframing; (c) seeking counseling; (d) reaching out to family and friends for support; (e) changing their physical environment; (f) testing whether they could expand their exercise regime even when it might increase their pain; (g) warning supervisors of their limitations and asking for an accommodation; (h) challenging any pain medication to see if they needed it; (i) getting training and taking college courses to find employment more compatible with their limitations; (j) taking time to engage in favorite activities; (k) increasing exercise even if it risked short term pain; (l) confronting medical professionals when they exhibited bias or stigma; (m) fighting for the right to continue employment after their chronic pain became an issue; and (n) exploring cognitive-behavioral therapy and mindfulness strategies (see Ambrose & Golightly, 2015; McCracken,1998; Rupp et al., 2004; Sheedy et al., 2017; Sturgeon & Zautra, 2016; Wong et al., 2015).

Four participants hoped their next medical intervention would stop their pain forever. The rest of the participants accepted that they might be in pain for the rest of their lives. Those participants seemed less hopeful about their future and more resigned to their fate.

The Experience of Stigma

Most participants had a story where a doctor dismissed their pain (Coleman, 2011; Katz & Rosenbloom, 2015; Macciocchi & Eaton, 1995; Newton et al., 2013; Roese & Olson, 1996; Waugh et al., 2014). While seeking medical treatment, the reports of stigma did not seem to be limited by gender, age group, or geographic location. Other than stigma from medical professionals, many participants expressed being shamed by others, mostly from people they knew, including self-shaming (Abdallah & Geha, 2017; Armentor, 2017; Hiller & Suominen, 2017; Monsivais, 2013; Waugh et al., 2014; Werner et al., 2004; Wilber, 2015). Despite these experiences, 8 of the 17 participants expressed faith in their doctor to manage their pain. The other nine participants felt that their doctor was no longer helpful or was never beneficial in their pain management. Yet, these participants still sought medical intervention for other medical problems.

Theoretical Analysis of Findings

The methods and analysis were guided by social identity theory, attribution theory, and the construct of stigma. The results of the study also revealed the relevance of barriers to treatment, and the idiosyncratic use of biopsychosocial approaches to managing pain.

In social identity theory, the experience of liminality (as described in Chapter 2), was defined as the consequences associated with changes in a person's social role that resulted in feelings of being in limbo. Expressions of hopelessness (e.g., regret at losing a vital employment role or internalizing experienced stigma), were examples of liminality (Jackson, 2005). In addition, hiding their real feeling of pain to protect a former social role could be considered a part of the liminality experience (Monsivais, 2013). Other statements included: a) feelings of helpless; b) being frustrated with the limitations of pain; c) feeling left out of recreational and routine activities; d) hiding feelings of pain from friends to prevent pity; e) being fearful of the future because of their chronic pain; f) saying few people understood or empathized with their pain complaints; g) being worried about limited employment opportunities; and h) expressing fears of being labeled an addict (Cacioppo et al., 2015; Carlsen & Nyborg, 2017; Hawkley & Capitanio, 2015; Major et al., 1998; Monsivais, 2013; Oliveira et al., 2015; Sturgeon & Zautra. 2016) The uncertainty produced by stigma and chronic pain exemplifies how people move through the liminal state in negotiating their social identity and seeking help (Dauphin et al., 2020).

Attribution theory was useful in understanding why patients and doctors disagreed on the severity and causes of persistent pain (Carlsen & Nyborg, 2017; Katz & Rosenbloom, 2015; Newton et al., 2013). As described in Chapter 2, attribution theory is useful for understanding the circumstances under which people attribute a cause to self or something else. In this research, patients described how doctors refused to attribute their pain experience to a condition or symptom when the sources of the pain could not be detected by biomedical means. Doctors were more inclined to attribute the reports of pain to exaggeration, personal weakness, or seeking addictive drugs. Attribution theory also explains why participants hid their pain from doctors and medical professionals (Jackson, 2005; Monsivais, 2013; Waugh et al., 2014; Werner et al., 2004; Wilbers, 2015).

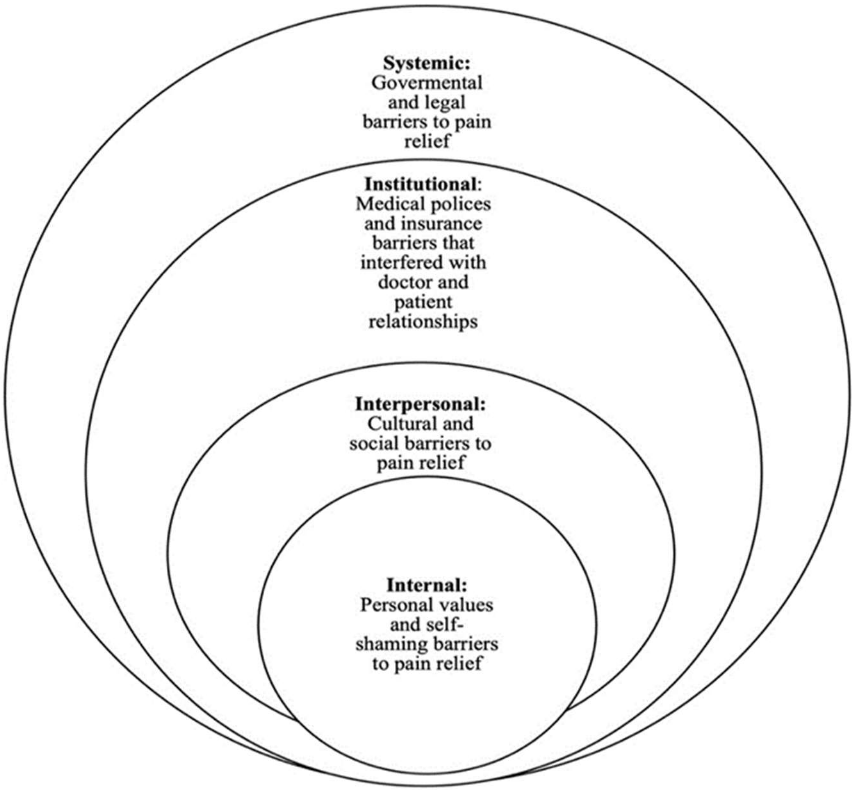
The construct of stigma was explored from multiple perspectives. The sources of stigma were varied and reflected the sources of stigma found in the research (Bell & Salmon, 2009). Participants report the experience of stigma from: (a) doctors (e.g., that they were complainers or seeking more drugs); (b) from family and friends (being ostracized from family and friends for “not keeping up” or being limited from activities by pain); and (c) self-stigma (feelings of being punished, feeling hopeless and unworthy of support, feeling responsible for their pain). These examples of stigma are consistent with other studies (Dauphin et al., 2020; Jackson, 2005; Major et al., 1998; Werner et al., 2004).

Emergent Ecological Model of the Barriers to Pain Relief

A surprising and consistent set of experiences that were described by participants were the barriers encountered while accessing treatment and support. These barriers included: (a) governmental and legal barriers to pain relief such as laws that prevent doctors from making an independent decision on pain treatment; (b) institutional and administrative policies that interfered with doctors and patients relationships, including a lack of insurance reimbursement when pain relief programs were available; (c) interpersonal barriers including biases encountered during the ordinary course of social interactions with friends and families; and (d) internal barriers including personal values, self-shaming, and the inability to accept the limitations imposed on the participants by their chronic pain (Littlejohn & Guymer, 2019). This emergent model is conceptualized in Figure 3.

Figure 3

The Levels of Bias that Create Stigma and Other Barriers to Pain Relief



Note. Adapted from "Five Mind-Blowing Realities About Race (That White People May Not Know)." By M. Lietz, 2018, August 27, *Emmanuel Gospel Center,* https://www.egc.org/blog-2/2018/5/23/3u8bsicsasybnnco5bea7vculw6m9s

The Need for a Biopsychosocial Approach to Pain Management

On the biomedical side, Carlsen and Nyborg (2017) said that these barriers often force doctors into restricting access and treatment, information, and alternative services outside of the biomedical model. The authors also noted that the gatekeeper's role often conflicted with the ability to be a healer and sometimes left their patients angry and confused. Furthermore, Carlsen and Nyborg suggested that these barriers seemed to be more a matter of biomedical tradition than evidenced-based practices more consistent with a biopsychosocial model. It was noted that in this study, while all participants received standard biomedical treatment when they sought help, many tried to improve on that treatment by searching out biopsychosocial therapies on their own. The result was a panoply of different outcomes and idiosyncratic solutions to the management of their chronic pain.

Limitations of the Study

This study provided a snapshot of the experience of chronic pain for participants who were in chronic pain for three months or more. Credibility was established using two kinds of data analyses, member checks, and identification of discrepant cases. There was also evidence of saturation because the last four interviews did not contain any reports of new experiences.

Efforts to enhance transferability allowed readers and future researchers to understand and use the results to do further research (Shenton, 2004). Methodological details of data collection and analysis followed well respected qualitative procedures (Riesman, 2009).

Dependability was evident because my interests and potential biases were stated. The data stayed within the range of the research questions. Participants met all selection criteria. These criteria ensured that the participant had adequate experience with current medical treatments and experiences with ongoing pain limitations. Participants were not limited to those unhappy with either their doctor or their treatment regimen. There was no attempt to determine what would happen to these individuals over time.

Confirmability was evident in the reflexivity due to the multiple exchanges between the researcher and all participants. In these exchanges, participants sometimes reflected on how their participation in the study changed their lives. My analysis did not differentiate the person who is abusing an addictive medication from those who require addictive medicines to control their pain.

Recommendations

Evaluating the sequelae and effectiveness of non-pharmacological chronic pain treatments presents several problems (Clauw, 2019). Such future studies would be especially complicated if they relied solely on evidence from randomized controlled trials. Shadish (2011) stated the concerns with RCT studies when evaluating observational data include: (a) ethical considerations of waitlists and no-treatment controls, (b) the divergent outcomes of subjects who have varying diagnoses and differing levels of pain severity, (c) the lack of consistency in the treatment strategies used with observational data, (d) the lack of consensus on desired outcomes and the inability to measure those outcomes objectively, and (f) the difficulty of controlling research bias.

There is also limited value to relying on solely qualitative studies on the chronic pain experience to compare any pain management method of effectiveness. Noyes et al. (2017) proposed qualitative evidence synthesis as a supplement to deciding the comparative value of any pain management intervention. However, the authors further suggested that this method may not be adequate to make such a decision without using a quantitative approach.

Instead of relying on RCT studies and the limitations of qualitative meta-analysis for evidence of chronic pain effectiveness, future researchers could use propensity scores. Guo and Fraser (2014) stated that propensity scores are a second-best choice when RCT trials are neither ethical nor feasible. This lack of feasibility is often the case with observational data.

Due to the lack of objective measures in determining pain, the idiosyncratic nature of chronic pain strategies, the varying diagnoses of pain sources, and the likelihood of bias from multiple sources, propensity scores may prove a better research strategy (Devilly & McFarlane, 2009). There is considerable research on chronic pain using this kind of analysis (e.g., Teh et al., 2010).

As previously mentioned, this study was a snapshot of the experience of chronic pain to date. Of the participants interviewed, 15 still needed to manage their pain daily. What happens to these individuals over time? How effective is their treatment? What are the sequelae of the experience of pain management?

As previously mentioned, one way to study the sequelae of chronic pain management is to use propensity scores. It statistically divides subjects into groups and is considered the best second choice when RTC designs are not feasible. Such a method can use data readily available from anonymous quantitative medical records or other sources. It can also employ Quality of Life measures and other accepted measures of pain's known comorbid measures. Such scales may result in a more useful measure of pain severity. While any given scale may not be a fully effective method of measuring pain, multiple measures might be more helpful. Future researchers can use a mixed methods design to combine a qualitative evidence synthesis with quantitative data. Such research might provide us with insight into the usefulness of non-medical strategies for improved pain management, including online education, support groups, and cognitive-behavioral therapy or other kinds of psychoanalysis.

Implications

In addition to more research, effective change requires further training not usually provided to medical professionals. Medical policymakers and legislators are encouraged to investigate how the War on Drugs harmed the doctor/patient relationships without effectively addressing the opioid epidemic. If protocols to treat pain and addiction become more humane and used addictive medications when necessary, it may provide a better alternative to refusing medicines in chronic pain patients. The problem of drug addiction has increased despite laws trying to control the medical use of these medications. The four decades of failure using the criminal justice system and subverting the doctor/patient relationship requires exploring other approaches that may have better results. (Maté, 2008)

Another policy recommendation is to explore how harm management strategies might help treat both conditions when people are in chronic pain and abusing addictive medications (Gourlay et al., 2005). When addictive pain medications are necessary to manage persistent pain, harm reduction programs are another option to treat drug misuse and addiction (Ivsins, 2019; Maté, 2008).

There is ample evidence in the data that cognitive behavior therapy, particularly contextual behavior therapy, helps to manage pain (Sturgeon & Zautra, 2016; Sheedy et al., 2017). Sirois and Wood (2017).stated that positive psychology health improved physical pain management. The authors also stated that these capabilities are underutilized in the treatment of chronic pain. Treede et al. (2019) recommended changes on improving chronic pain diagnosis. The author speculated that utilizing new ICD codes might encourage reimbursement for psychological therapy.

While the efforts to provide new diagnostic codes for chronic pain are welcome, they are not necessary for insurance reimbursement, and are not widely accepted. As a possible alternative, the DSM-5 (2013) has redefined Somatic Symptom Disorders. It now includes Psychological Factors Affecting Other Medical Conditions (316, F54). This diagnosis would allow insurance reimbursement for the mental health treatment of the psychological effects of chronic pain. Helping people cope with the impact of psychological suffering is the primary focus of psychologists and other mental health therapists.

Conclusion

This study supports the research that inadequate pain treatment springs from several sources and include: (a) lack of physician training; particularly in the psychological effects of pain; (b) treatment models that focused on procedures and symptoms rather than other comorbid factors (i.e., the biomedical model); (c) lack of reimbursement from insurance companies for biopsychosocial treatments of pain; and (d) fears of addiction from pain medications whose proper use is not fully understood. Outside of the doctor/patient relationships, other factors that influence the adequate treatment of pain were biases that include: (a) pressures from government regulations and professional organizations; (b) social stigmatization of pain patients; (c) systemic bias in the medical research and practice; and (d) prejudices that are internalized and promote hopelessness in patients with chronic pain.

This study also shows that when medical professionals confine their treatment to the biomedical model, people who suffer from chronic pain will seek out biopsychosocial pain treatments on their own, resulting in idiopathic therapies and outcomes. The study also supported using opioids and other addictive medications long-term as safe for some people, as some research suggested.

Finally, this study suggests that the regular inclusion of psychological and other adjunctive therapies for treating chronic pain might address the lack of consensus on chronic pain treatment. The tools for such inclusion, including how one might obtain insurance reimbursement, already exist. However, further study on the sequela of chronic pain treatment may be necessary to win wider acceptance. These results support the Joint Commission's goal to address the prevalent undertreatment of chronic pain in all clinical settings.

Too often, doctors who want to be healers must take the role of gatekeeper. They must defend a system where their treatment decisions are restricted. They must maintain patient trust and still explain why their patients must endure pain that too often is unnecessary. They must face chronic pain management's complexity and overcome the psychological effects of stigma in their patients and their own implicit biases. In the primary care office, where most long-term treatment of chronic pain occurs, they must perform this difficult task in the time allotted by their practice requirements. A biopsychosocial model's necessary treatment may be asking too much of the current medical system as it exists. More research will be needed to win acceptance of the benefits of biopsychosocial treatment. These benefits include reducing the costs of unrelieved pain, encouraging doctors to be healers instead of gatekeepers, and encouraging more patient-centered pain treatments. The medical community and greater society can rehumanize pain management and promote the right to better pain management as fundamental to the care and well-being of those who suffer from chronic pain.

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Appendix A: Referral Packet

Hello,

Thank you for considering participation in my study on chronic pain. You were given this invitation because one of the people who agreed to help me find participants felt that you might be a good person to interview. What I hope to hear is your pain story, from beginning to present, in your own words. After that, I will compare what you said to what others told me. I expect to interview 15 people and to look for similarities or differences. Anything said to me will be kept confidential, even from the person who gave you the invitation.

The reason this invitation did not come directly from me is because my thesis committee felt that my experience with caring from my wife's chronic pain might negatively influence my choice of participants. By putting another person between me and my participant recruitment, they believe it would add trustworthiness to the study. This is also why we will conduct this interview by telephone, by appointment, through United Conferencing, a computer conferencing organization. This organization will record the call, transcribe what was said, and send the results to me. This organization agreed to keep your confidentiality. The results will be stored in locked file on my computer. All recordings will be given a number and any identifying information will be stripped from the narration.

If you wish to participate, contact me in any of ways listed below. Also, read the consent form and, if you agree and understand it, sign it. Then send if back in the pre-paid envelope provided. Alternatively, if you have a email signature, I will send you a computer version.

Thank you for considering participation.

Matthew Vittucci, MS, ABD

PhD Candidate Walden University

CONSENT FORM

You are invited to take part in a research study on what it is like to be in chronic pain. This is because you identified yourself as a person in chronic pain for 3 months or more. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part.

This study is being conducted by Mathew Vittucci, a doctoral student in the clinical psychology program at Walden University. You might already know the researcher in another role, but this study is separate from that role.

Background Information:

The purpose of this study is to compare the experiences of different people in chronic pain without judgement. It is hoped that the study will reveal experiences people with pain have in common. I am looking for how people describe their pain, what they tried to relieve their pain, and how chronic pain affected their well-being. It has been reported in research that people in chronic pain feel that telling their pain story without judgement has helped them better cope with their pain.

Procedures:

If you agree to be in this study:

- You will be asked to tell your pain story, in a face-to-face interview, from its start until now.
- Your words will be recorded by an audio recorder and transcribed into a word processing file. All identifying information will be stripped from this file and it will be given a unique number.
- This interview should take 60-90 minutes and will be done in an area that is private and where you feel comfortable.
- In a second face-to-face interview, you will be able to see the transcript of your story. You can make corrections, add more information, or even decide the you no longer want to be part of the study. You can also talk about any feelings resulting from being in the study. I may also ask for any background information that will be kept out of the transcript and used for anonymous participant profiles (gender, age group, ethnicity, social relations, etc.). Again, identifying information will be kept strictly confidential.
- If necessary, a third session may be needed to add any new information, make changes you feel are necessary, or add to any further experiences that occurred after participating in the first two sessions. This information may be done by phone, computer, or in a third face-to-face interview, depending on your preference.

Here are some possible sample questions. They will only be used as prompts. Your pain story may be told as you see fit:

- In your own words, tell me your pain story. When did it begin?
- Describe for me a typical day with your chronic pain?
- Did it affect your employment or your employment goals?
- How did your friends and family respond to your pain?
- Let’s discuss your relationships with doctors.

Voluntary Nature of the Study:

This study is voluntary. You are free to accept or turn down the invitation. No one will treat you differently if you decide not to be in the study. If you decide to be in the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

This type of study involves some risk due to minor discomforts because the feelings discussed are emotional and private. If you choose to share a sensitive topic (i.e., that could trigger emotional distress, depression, etc.), and need more help, I provide contact information for further support. Being in this study should not pose a risk to your safety or wellbeing. It is not intended to be a replacement for regular counseling or doctor visits. Yet, as stated above, may people find that telling their pain story without judgement, in their own words, helps them understand their experience more completely. Often, they are better able to describe it to doctors, family, friends, and acquaintances. In addition, it sometimes helps them identify ways to better cope with their pain.

Payment:

There is no payment for participation. You may keep, however, a copy of your pain story as transcribed. A summary of the results will also be mailed to you if you complete the study successfully.

Privacy:

Reports coming out of this study will not share your identifying information. I will not use your personal information for any purpose outside of this research project. Your transcribed story will be kept secure by an identifying number in separate files. Identifying information will be kept in another file with a security code to prevent unauthorized access. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You may ask any questions you have now. Or, if you have questions later, you may contact me via email.. If you want to talk privately about your rights as a participant, you can call the Research Participant Advocate at my university at 612-312-1210. Walden University's approval number for this study is **2019.04.19** and it expires on **07-2034-5.**

Obtaining Your Consent

If you feel you understand the study well enough to decide about it, please indicate your consent by signing below.

Printed Name of Participant ____________________

Date of consent ____________________

Participant’s Signature ____________________

Researcher’s Signature ____________________

Contact Information

In the course of this study, I may have to contact you for several possible reason. This information will be kept in a place that is separate from your Pain Story. It will be destroyed after the study is completed and you have been informed of the results. A phone number or email is preferred. Please fill this out and send it in with your Consent Form.

Name____

Address____

Phone ___________________________________(optional)

Email ___________________________________(optional)

Best way to contact _________________________________

Best time to contact ____________________________________

Thank you.

Matt Vittucci

Just fill out this form and sign the consent form. Then send this page and the last page of the consent form in the SASE. Keep the numbers for the Conference Center handy for the interview. If you have any questions, feel free to call me at 607-287-2084.

Appendix B: Script for the Interview

As we already discussed, the purpose of this study is to explore, in your own words, your pain story. As a reminder, everything you tell me will be kept confidential unless you tell me something that would be an imminent danger to you or others. I am recording this with an audio recorder to make sure I do not miss anything you said. This recording will be kept confidential, and your real name will not be associated with this recording or any other document except your informed consent form. Do you understand what I just said? Do you agree?

1. In your own words, tell me your pain story. When did it begin?
2. What was your life like before your chronic pain began? Can you describe for me a typical, ordinary day?
3. Describe for me a typical day with your chronic pain?
4. Tell me about your course of treatment. When did you first go to a doctor? What was suggested? How did you feel about those suggestions?
5. Then what happened? Was there a turning point, getting much better or much worse, in the management of your pain? Or has your pain been consistent since it began.
    a. Were there activities you did more frequently or less frequently?
    b. How did it affect your employment or your employment goals?
    c. How did your friends and family respond to your pain?
    d. What was said?

   e. How did that make you feel?

6. What is your day like when the pain is well managed? Describe a typical day of good pain management?
7. What is your day like when the pain is poorly managed? Describe a typical day of poor pain management?
8. Let’s discuss your relationships with doctors. Tell me about your relationship the current doctor who prescribes (or would prescribe) your pain medications.
9. What happens now during a typical doctor visit?
10. How do you feel when you left that office?
11. How does that doctor assess your pain?
12. How does that doctor manage your meds?
13. What was said?
14. How did that make you feel?
15. Describe for me what happened during your worst doctor visit.
16. How did you feel when you left that office?
17. How did that doctor assess your pain?
18. How did that doctor manage your medications?
19. What was said?
20. How did that make you feel?
21. What happened during your best doctor visit? How did you feel when you left that office?
22. How did you feel when you left that office?

23. How did that doctor assess your pain?
24. How did that doctor manage your meds?
25. What was said?
26. How did that make you feel?
27. Have you ever had a conversation with any of your doctors about addiction?
28. What was said?
29. How did you feel about the conversation?
30. How did it affect your treatment?
31. Is there anything else you'd like to tell me about your pain story or your experience of pain in general?
32. Do you know anyone else who might be interested in telling me their pain story?
33. Demographics: Gender _______ Age range______

    Diagnosis of pain condition: _____________________________________

    Medications used: ____

    City/Region: _____________

    Length of time in chronic pain: ______________

Referral: ____

Appendix C: Coding Scheme

No notes were taken during the interview. Instead, raw data was captured solely by use of an audio recorder. The recording was transcribed into a Word file only by me. These transcriptions were checked for accuracy and stripped of any identifying information unintentionally recorded. The first analysis was a structural analysis and was done by hand coding. The second and subsequent coding reviews were done with the help of MAXQDA, a qualitative computer program (Saillard, (2011). As stated above, the coding scheme looked for: a) similarities; (b) differences; (c) frequency; (e) correspondence; and (f) causation (Saldaña, 2016). The resulting data from the second and third analyses related to the research questions in the form of themes. Since there were discrepant and unexpected results, and the last four interviews contained no new experiences, saturation was reached, and no additional participants were added.

Appendix D: Permission to Reprint

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Appendix E: Participant Topics Found in Research

	Research		Ralph	Peter	Justin	Bill	Ada	Sally	Vito	Mada	Rita	Dina	Jean	Rachae	Caity	Nija	Ben	Geroge	Mary	
	Topic	Citations	No Pain		No Opioids												Used Opioids			Frequency
Research Question 1	Under treatment/ pseudoaddiction	Abdallah & Geha, 2017; Arnstein & Herr, 2017; Apkarian et al. 2016; Björk et al. 2016; Emilson et al., 2017; De C Williams, 2016; Hiller & Suominen, 2017; Kehlet et al., 2006; Nordmann et al., 2017; Paydar et al., 2016; Platts-Mills et al., 2016; Peppin et al., 2015; Wailoo, 2014; Rajagopal, 2011; Breivik et al., 2006; ; Trentin, et al., 2001	X				X	X	X	X	X	X	X	X	X		X	X	X	13
	Pain Influenced by Activities	Rivera et al., 2015	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	16
	Role of narrative in pain relief	Jurecic. 2012; Maxwell, 2013; Newton et al., 2001; Rajagopal, 2011; Tsao, 2012									X									1
Research Question 1-1	Resilience and Anxiety	Sheedy, et al., 2017, Sturgeon & Zautra, 2016, Wong et al., 2015		X			X	X	X		X	X	X		X	X	X	X	X	12
	Stigma and self-shaming	Breivik et al., 2006 Jackson, 2005; Werner et al., 2004; Wilber, 2015; Waugh et al., 2014						X	X	X	X	X	X	X	X		X	X	X	11
	Role of exercise	Breivik et al., 2006; Slade et al., 2009		X	X		X	X	X	X	X	X	X		X		X			11
	Used Psychobiosocial	Engel, 1980	X	X	X		X	X		X	X	X			X				X	10
Research Question 2	Liminality and chronic pain	Cacioppo et al., 2015; Hawkley & Capitanio, 2015; Jackson, 2005; Major et al., 1998; Monsivais, 2013; Oliveira et al., 2015; Sturgeon & Zautra. 2016	X	X			X	X		X	X	X	X		X	X	X	X	X	13
	Stigma from Doctors	Augoustinos et al., 2014; de C Williams, 2016; Jackson, 2005; Moseley & Butler, 2015; Monsivais, 2013; Newton et al., 2013; Phelan et al., 2015; Waugh et al., 2014; Zanini et al., 2016		X	X		X			X	X	X	X	X	X		X	X	X	12
Research Question 2-1	Stigma Other	Abdallah & Geha, 2017; Armentor, 2017; Hiller & Suominen, 2017; Monsivais, 2013;		X	X		X	X	X	X		X	X	X	X	X	X	X	X	14
	Opioids lead to addiction	Bruehl et al., 2015	X	X	X	X	X	X	X	X	X	X	X	X	X	X				14
	Doctors underestimating pain	Coleman, 2011; Groß, Blank, & Bayen, 2017; Katz & Rosenbloom, 2015; Larsen, 2016; Macciocchi & Eaton, 1995; Newton et al., 2013; Phelan et al., 2015; Roese & Olson, 1996; Wilbers, 2015; Waugh et al., 2014	X	X	X		X	X		X	X	X	X		X		X	X	X	13
	Complying with Medical advice reduces stigma	De C Williams, 2016; Moseley & Butler, 2015; Zanini et al., 2016					X			X	X	X		X	X	X				7
	Pain a separate disease	Siddall & Cousins, 2004	X	X	X		X										X			5
	Stigma Opioids	Breivik et al., 2006; Rajagopal, 2011															X	X	X	3
Research Question 2-2	Hiding Feelings of pain	Jackson, 2005; Monsivais, 2013; Slade et al., 2009; Sturgeon & Zautra, 2016; Waugh et al., 2014; Werner et al., 2004; Wilbers, 2015			X	X	X	X	X	X		X		X	X		X	X	X	12
	Stigma Social Identity	Jackson, 2005; Monsivais, 2013						X	X	X	X	X	X		X		X	X	X	10
	Stigma and cultural differences	Jackson, 2005; Major et al., 1998; Monsivais, 2013; Newton et al., 2013; Wong et al., 2015			X					X						X				3