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Dystonia Patients' Use of Mindfulness to Address Pain

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This is to certify that the doctoral dissertation by

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Walden University
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Abstract

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MA, Walden University, 2017

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Dissertation Submitted in Partial Fulfillment

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Abstract

This qualitative, phenomenological study was conducted to explore the lived experiences of 10 women who used mindfulness to alleviate their chronic pain associated with cervical dystonia (CD). Individuals who suffer from CD face challenges related to symptom management and the psychological effects from experiencing chronic pain. Since treatments for CD are limited and pharmacological options to treat chronic pain, like opioids, can lead to addictions, individuals with CD may seek non-pharmacological treatment options. Women, 18-60 years of age were interviewed using a semi-structured interview process. Bandura's self-regulation theory provided a framework for this study. Results from this study found that chronic pain associated with CD can contribute to a loss of a sense of control that can also be associated with depression. Mindfulness techniques helped participants to increase their functionality and allowed them to feel hopeful. Participants varied in their descriptions and definitions of mindfulness practices. The participants demonstrated self-efficacy by conveying confidence in their mindfulness practices with which they met the challenges they were experiencing. A limitation of this study includes comorbid pain from other diagnosed conditions other than CD. Future participant recruitment would benefit from elimination of participants with comorbid pain conditions. Study results have the potential to influence positive social change and awareness of how individuals understand and experience mindfulness practices as it relates to pain within the context of CD. Future research can build upon the present study by including a mixed gender sample and by utilizing a mixed method approach with a larger sample size.

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Dedication

This study is dedicated to all the individuals who participated in this study and all those other individuals who are suffering from CD or a chronic illness. Thank, you for sharing your story and being vulnerable and brave in the moment. Remember that you are strong and are true warriors.

Acknowledgments

I would like to acknowledge Dr. Esralew for being patient and keeping me laughing, and focused. Thank you Dr. Glidewell for the insight that you have provided. I would like to also thank my family and my friends who all have encouraged me and have been by my side since day one on this journey.

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Chapter 1: Introduction to the Study

Introduction

Dystonia is the third most common movement disorder after Parkinson's disease and essential tremors (Smit et al., 2016). It affects 164 million people worldwide (Steeves, 2012). Cervical dystonia (CD) is a form of dystonia which causes involuntary movements that affect the shoulder and neck muscles and may lead to an abnormal movement of the head and jerking of the neck, causing tremendous pain (Zetterberg et al., 2015). The worldwide prevalence rate of CD is 4.98 per 100,000 people (Zetterberg et al., 2015). Pain is the main nonmotor symptom, and it may be incapacitating for individuals who suffer from CD (Avenli et al., 2018). CD causes involuntary muscle contractions and abnormal postures of the head and neck which may cause pain (Albanese et al., 2013; Czekoova et al., 2017;). Chronic pain is difficult to manage as it affects performance of daily activities and is associated with significant mental health issues such as depression (Zoons et al., 2017).

The aim of this research study was to explore the lived experience of women who used mindfulness to help with chronic pain associated with dystonia. The prevalence of cervical dystonia in women is greater than in men; therefore, this study aimed to understand the lived experiences of the majority of the population of those diagnosed with cervical dystonia (Söderlund, & Nyholm, 2020). The study has the possibility to promote social change. I discuss women who engage in mindfulness interventions such as mindful breathing, yoga, and meditation to treat their chronic pain associated with CD. Treatment in this study may involve collaborations between patients and providers and knowing the effectiveness of nonpharmacological interventions can be critical for pain management.

This study can help mental health professionals treat CD using a nonpharmacological method by addressing the value study participants place on mindfulness practices to address pain associated with CD. This study may inform patients suffering from CD about other available treatment methods. In addition, results can allow mental health providers to understand lived experiences and implement mindfulness as a treatment therapy. This study involves lived experience of using mindfulness prior to and after a CD diagnosis. Insights gained from this study include context rich descriptions of which mindfulness techniques from the perspectives of participants were most beneficial. This information may prove to be useful in terms of gaining insights regarding specific mindfulness modalities to use in treatment planning.

This chapter includes the problem statement, purpose, and research questions, followed by the conceptual framework, nature of the study, definitions of terms, assumptions, scope, delimitations, and limitations, and significance of the study.

Background

Research on CD is limited, including research regarding the relationship between CD and mindfulness-based interventions in terms of managing symptoms. There has been extensive research regarding chronic pain or mindfulness interventions with other diseases such as PD and other neurological disorders. Graham et al., (2017) conducted a study on the use of Acceptance and Commitment therapy (ACT) in improving outcomes in functional movement disorders. Dystonia, tremors, and gait disturbances are a part of a subset of functional neurological disorders that involve disturbances in motor symptoms (Graham et al., 2017). ACT focuses on finding ways to enact meaningful activity, developing openness to difficulty thoughts and feelings, and offers the ability to change by attempting to change beliefs about the illness, self or the future, and to control distress (Graham et al., 2017). Chronic pain is often associated with functional neurological disorders. ACT teaches mindfulness meditation and psychological flexibility. According to Trompetter et al. (2017) psychological flexibility is the ability to perform value-based behavior when experiencing unwanted thoughts, experiences related to pain, like pain catastrophizing, and pain-related fear. Trompetter et al. (2019) found that ACT helped to reduce pain in two out of three participants. Motivators for change included positive changes in pain intrusion and emotional health. Similarly, Zangi and Haugli (2017) and Hilton et al. (2016) explored mindfulness and acceptance-based group interventions. Improvement in coping with pain and emotional distress, along with an awareness of personal needs were identified in both studies. Hilton et al. (2016) also found that more research is needed on mindfulness to determine the efficacy of its use in treating chronic pain and outcomes on pain-related interference, pain tolerance, analgesic, and related issues to opioid cravings.

Depression and psychological disorders are often comorbid with movement disorders. Zoons et al. (2017) examined depression in individuals who suffer from CD and showed a higher likelihood of depression among patients with and without tremors and jerking motions as opposed to patients without these symptoms. Nineteen percent of participants met criteria for depression. Ceylan et al. (2019) identified that depression and anxiety levels were higher in patients who used Botox as a treatment for CD. Additionally, CD patients showed a decrease in activities and quality of life due to depression, self-esteem issues, anxiety, mood disorders, and social phobias. Individuals with disabilities often struggle with a poorer health-related quality of life and receive fewer preventative health services like counseling and exercise services (Zetterberg et al., 2015). Zetterberg et al. (2015) explored self-efficiency and physical activity with individuals who suffered from CD and went to neurology clinics. Individuals with CD experience disturbed sleep, limited ability to walk, psychosocial inconvenience, and limited upper limb activity have a negative impact on physical activity. According to Zetterberg et al. (2015) individuals with CD often fear falling when participating in physical activity. This often inhibits CD patients from participating in social activities and adds to a low HRQoL and psychological disorders (Smit et al., 2016; Zetterberg et al., 2015). Smit et al. (2016) systematically explored the frequency of psychiatric disorders and factors that influence health-related quality of life (HR-QOL) among individuals with CD and explored depression and anxiety among 50 CD patients and 50 healthy individuals. There were notably higher frequencies of psychiatric disorders (64% vs. 28%, $p = 0.001$), higher depression (32% vs. 14%) and anxiety disorders (42% vs. 8%). Psychiatric disease is a crucial predictor of HR-QoL in CD individuals. Treatment of psychiatric conditions can help individuals who suffer from CD to have a good quality of life.

Bernstein et al. (2016) identified a major gap in the literature involving behavior interventions in dystonia management. There was limited support for relaxation and exercise procedures as approaches to reduce symptoms associated with cervical dystonia. Further research is needed involving holistic practices such as exercise and relaxation techniques. Avenali et al., (2018) further concluded that there is a need for better understanding of painful symptoms associated with dystonia to develop appropriate and effective therapeutic interventions. Due to the opioid epidemic, researchers have also identified that new techniques need to be researched to help to reduce opioid use and to develop new effective ways in alleviated chronic pain (Shipton et al., 2018).

Sandhu et al. (2016) said individuals with dystonia in a 3-day group residential program were unsure what to expect with this Botox clinic and discovered the advantages of seeing other individuals who had the same disease. Mindfulness was one of the coping strategies.

In this study, I address the gap in literature related to holistic practices by exploring use of mindfulness to manage chronic pain symptoms for individuals with CD. There is a need for future research regarding mindfulness effects of physical activity, emotional wellbeing, and quality of life.

Problem Statement

Chronic pain is an issue for many individuals with dystonia (Ceylan et al., 2019). Individuals with CD often experience chronic pain and have limited treatment options other than pharmacological approaches such as opioids and Botox (Knight et al., 2017). Individuals who pursue pharmacological treatment are at risk for opioid abuse, overuse, and addiction (Mahajan et al., 2018). Moreover, pharmacological treatment of chronic pain is being reevaluated due to insufficient empirical evidence involving its effectiveness and association with significant side effects and mental changes (Knight et al., 2017; Vowles et al., 2015).

Mindfulness is a mental practice in which one pays attention to the present moment with a nonjudgmental perspective to deal with what is happening (Zangi & Haugli, 2017). Mindfulness based interventions (MBIs) involve the individual's ability to observe and accept experiences in the present moment as they develop stable nonreactive states of mind which can improve physical functioning, psychological factors, and overall, wellbeing (Zangi & Haugli, 2017). There are several psychotherapeutic practices that incorporate mindfulness, including cognitive behavioral therapy (CBT) and acceptance commitment therapy (ACT), which have been shown to be beneficial in terms of treatment of chronic pain (Trompette et al., 2019). It is unclear whether CBT is successful in terms of management of anxious thoughts and mood into the context of muscle tension, which could cause better outcomes (Bernstein et al., 2016). Bernstein et al. (2016) identified that there is limited evidence regarding behavioral interventions, such as, exercise, relaxation practice, awareness training, solution-focused guided imagery, etc. Cervical dystonia has had limited research; therefore, the gap in the literature lies in the understanding of the effectiveness of mindfulness as a holistic approach for pain management among CD patents.

Purpose

The purpose of this phenomenological study was to gain better insight into experiences of individuals who report chronic pain associated with CD who used mindfulness-based interventions as part of their pain management strategies. I explored participants' perceptions of the value of mindfulness interventions in order to address their pain associated with dystonia via meditation, mindful breathing, and yoga. This will lead to a greater understanding of the value that participants place on mindfulness practices to address pain associated with dystonia.

Research Questions

RQ1: What is the lived experience of people who use mindfulness to help with chronic pain associated with dystonia?

RQ2: What is the lived experience involving pain within the context of dystonia for people with CD?

Theoretical Framework

Albert Bandura's self-regulation theory (SRT) was used as the theoretical framework for this phenomenological study. SRT involves individual behaviors, thoughts, and feelings via three different components: Self-monitoring, self-evaluation of one's behavior, and reaction to one's self-evaluation, or affective self-reactions. These explain the process by which individuals achieve management of their thoughts, feelings, and behaviors in the service of reaching their own set goals (Ozhiganova, 2018). SRT provides a foundation to understand the effectiveness of mindfulness techniques into the context of chronic pain coping strategies.

According to SRT, individuals choose to align their thoughts, behaviors, and feelings to move towards self-identified goals (Ozhiganova, 2018). Mindfulness practices have been linked to self-regulation and used to address pain and heightened emotions (Zeidan & Vago, 2017). Mindfulness practices viewed through SRT may help to better understand the value of using this nonpharmacological approach to address pain associated with CD. Bandura's SRT will be described in more detail as it relates to this study in Chapter 2.

Nature of the Study

This qualitative study involved using a phenomenological approach to explore participants' lived experience involving mindfulness practices as part of their strategies for dealing with CD and associated chronic pain. Qualitative methods involve gaining a better understanding of phenomena which are not well understood (Bliss, 2016). I recruited and interviewed 10 females between the ages of 18 and 60 who used psychotherapy-linked mindfulness practices as part of their chronic pain management within the context of CD.

Participants were recruited from Facebooks groups that focused on CD. Walden IRB approved flyers were posted in the approved private Facebook CD groups with contact email and phone number information to set up interviews for the assessment (see Appendix D). This allowed me to examine any patterns or trends that emerged during review of the data. Participant recruitment was stopped once saturation was reached.

Interviews were used to collect data for the study. The pre interview survey (see Appendix A) were given to each participant. A semi-structured interview process was used for all participants in this study (see Appendix B). Interviews were recorded and transcribed and then coded for themes. I conducted semi-structured interviews via Zoom. I submitted the research proposal to the Walden University Institutional Review Board (IRB) to make sure the research was following ethical guidelines.

Definitions

The following key terms are used throughout the research:

Acceptance Commitment Therapy (ACT): A type of behavioral therapy that involves coping strategies while being guided by core values and becoming the person one wants to become. ACT has been shown to be effective in terms of treating chronic pain (Harris, 2019).

Botulinum toxin Neurotoxin (BoNT): A neurotoxin from the bacterium Clostridium botulinum used to numb muscles and stop spasms and twisting (Han et al., 2016).

Cervical Dystonia (CD): A disease that causes involuntary movements and pain (Forbes et al., 2017).

Chronic Non-Cancer Pain (CNCP): Consistent pain in people who do not have cancer or CD.

Cognitive Behavioral Therapy (CBT): A form of mindfulness therapy to help to change thought processes (Simpson et al., 2017).

Deep Brain Stimulation (DBS): A surgical procedure that involves shooting impulses to the brain to help to stop muscles from involuntarily contracting (Sperry et al., 2017).

Hermeneutic Circle: Hermeneutics alludes to how an individual understands the data. It is not a technique but is a description of how one processes the information (Peoples, 2021).

Mindfulness Based Practices/Interventions (MBPs/MBIs): Interventions which involve mindful breathing, yoga, and meditation. Mindfulness training can help to alleviate stress and reduce pain (Greeson et al., 2019).

Nonpharmaceutical interventions: Treatments that do not involve using prescription medications.

Parkinson's Disease (PD): A persistent neurological disease that is genetic and affects the motor functioning and leads to similar issues involving chronic pain compared to CD (McLean et al., 2017).

Phenomenology: Is both a philosophy and a qualitative research design. It is a way of thinking or strategy for request in view of the reason that reality comprises of items and occasions as they are seen or understood in human consciousness and not of anything free of human cognizance (Smith, 2008).

Self-regulation Theory (SRT): The self-regulation theory is characterized as the capacity for individuals to control their way of behaving, thoughts, and feelings (Ozhiganova, 2018).

Assumptions

There were several assumptions that needed to be considered for this study. I assumed participants accurately, honestly, and openly conveyed their experiences involving mindfulness and pain involved with CD. Another assumption was that mindfulness was being used to address pain and other symptoms of dystonia. These assumptions are crucial to this study as accurate data is necessary to achieve validity.

Scope and Delimitations

I focused on women between the ages of 18 and 60 who were diagnosed with CD and used mindfulness methods prior to the study to understand why they chose these treatment methods and how they were applied to their disease and symptoms. Older participants were able to choose what treatments to engage in, whereas it was harder to diagnose children with CD. Prevalence of diagnosis for females with CD is .80 per 100,000 people (Kongsaengdao et al., 2018). Other comorbidities may be present in women who are over 60 due to physical aging. The possibility of comorbidity due to aging may interfere with the validity of data that were collected. Therefore, women over the age of 60 were not considered for this study. The aim of the study was to not generalize across the population but lead to transferability in a broader context across CD populations that will allow for future studies to be conducted.

Limitations

I have personal knowledge of CD and was aware of possible biases during recruitment, interviews, and review of data. Precautions were put into place to address biases, which could have affected any phase of this study. One method of addressing bias was to keep an audit trail through which participants' narratives were recorded verbatim. I journaled personal reflections regarding all aspects of the study and used member-checking, which helped in terms of bracketing personal reactions to distinguish my experiences from experiences of participants. Future research will need to be conducted as this study was phenomenological in design and cannot be generalized across all populations. This study was designed to provide insight into lived experiences of women with CD who used mindfulness-based practices to help manage their symptoms and not meant to be generalized. Future research involving quantitative or mixed methods approach could allow for more generalized information.

Significance

Due to the limited amount of research on CD, it is important to better understand the lived experiences of individuals with this disease. It was also important to gain insights involving their efforts to address psychological aspects of CD using mindfulness-based practices. Results of this study may provide information that can inform future empirical research involving quantitative and mixed methods approaches. Presently there is no cure for CD, and this study will advance knowledge in the field. I addressed the gap in literature by gaining insights involving lived experiences with CD and how individuals with CD used mindfulness techniques to manage chronic pain. This study can add information about managing chronic pain associated with CD. This was an important first step to better understand a phenomenon which may, with future empirical studies, have greater generalizability and assist physicians and healthcare providers to understand psychological aspects of chronic pain associated with CD patients. Due to limited treatment availability for individuals with dystonia, a more thorough examination can help to inform future research regarding mindfulness with this disease. Social change implications of this study include a greater understanding of how patients understand and experience mindfulness practices as they relate to CD.

Summary

Chronic pain is an issue for many individuals with dystonia and managing chronic pain has become problematic (Mahajan et al., 2018). Alternatives to treating chronic pain involve nonpharmacological approaches such as mindfulness practices. This project provided insight into individuals' lived experiences involving chronic pain associated with dystonia and the value of mindfulness practices when coping with their chronic pain. Results from this study have the potential to increase understanding of the phenomenon of pain within the context of CD. The topic was chosen to address CD and find out why women choose to cope with their CD with nonpharmacological methods. Study results led to a greater understanding of how nonpharmacological options were helpful to the study participants while they were coping with CD. Results may also be influential for developing future interventions that could assist with alleviating pain and symptoms of CD. Chapter 2 includes a review of current relevant research, as well as the gap in literature related to pain management of CD and mindfulness-based practices, which this capstone project is designed to address.

Chapter 2: Literature Review

Introduction

Although mindfulness practices have been applied to management of chronic pain that accompanies related conditions, there is limited research about use of mindfulness in addressing chronic pain in CD. The purpose of this study is to explore experiences of CD patients who use mindfulness techniques to manage their chronic pain. According to Zetterberg et al. (2015), the worldwide prevalence rate of CD is 4.98 per 100,000 people. According to Avenali et al. (2018), 75% of individuals have reported that they suffer from pain because of their CD. Sandhu et al. (2016) said reliance on dystonia prescription treatments do not help, and many individuals have suffered from side effects; however, mindfulness practices have helped with long term management of pain. According to Greeson and Chin (2019), mindfulness promotes wellness and mind and body health regardless of disease.

This chapter includes a review of the body of literature that is relevant to chronic pain associated with CD as well as other conditions associated with chronic pain like Parkinson's disease. The review contains a description of pharmacological and medical treatments that help with pain caused by dystonia and Parkinson's disease, such as Botox and medication. This review also includes literature on nonmedical and nonpharmacological treatments such as CBT and ACT, as well as combined approaches which include psychotherapy and mindfulness as treatments for this disorder. This literature review includes an overview of research that examines mindfulness as a pain treatment and MBIs for improving physical functioning and pain management as a potential treatment for those struggling with pain within the context of CD.

Literature Search Strategy

The following databases were used during development of this literature review: EBSCOHost, Google Scholar, PsycExtra, PsycInfo, Psych Articles, and Medline. A list of key articles was found using these search engines through the Walden University Library. Key search terms were *mindfulness*, *yoga*, *alternative medicine*, *chronic pain*, *meditation*, *dystonia*, *chronic pain and dystonia*, *deep brain stimulation and dystonia*, *chronic pain and opioids*, *opioids*, *Botox treatment for CD*, *botulinum*, *depression and dystonia*, *dystonia and Parkinson's disease*, *neck pain*, *pharmacological approaches*, *psychological aspects of dystonia*, and *pain*. This search resulted in 124 articles published between 2018 and 2022 that were used for this literature review.

Theoretical Framework

This phenomenological study utilized Albert Bandura's Self-regulation theory (SRT) as a lens through which to understand participants responses. The SRT involves individual behaviors, thoughts, and feelings using in terms of self-monitoring, self-evaluation of one's behavior, and reaction to one's self-evaluation, or affective self-reactions. According to Bandura (1991), self-regulation is a complex phenomenon which involves cognitive processes, self-monitoring, self-appraisal, affective self-reaction, and evaluative judgement to control environmental behaviors. It is connected to regulation of attention, thoughts, moods, impulses, stress, and emotions (Ozhiganova, 2018). SRT was used to provide insights involving conscious personal management processes that relate to mindfulness behaviors. This theory promotes the concept that self-regulation skills are procured from underlying processes. Individuals interpret and interact with their environment, influencing their emotions, thoughts, and actions throughout everyday circumstances (Bandura, 1991).

Individual thoughts, behaviors, and environments can influence how the person functions. Self-regulation is a psychological function that is developed with self-directed change as a result of learning and interacting within one’s environment (Bandura, 1986). Bandura’s SRT was chosen because of its function to frame lived experiences of individuals living with CD managing their pain. This approach helped me frame thoughts, behaviors, and environments to address living with chronic pain and managing symptoms through mindfulness techniques.

According to Benight et al. (2017), when individuals self-regulate, they pause to reflect upon their motivations and consider if their actions advance their goals. Individuals who are self-regulated, more thoughtful, more planful, and less impulsive or driven by emotions. According to Bandura (1997), individual thoughts can influence how people may be feeling and behaving. Self-efficacy and environmental conditions such as social support can determine one’s reactions to achieving goals (Benight et al., 2017). Benight et al. (2017) said self-regulation may help perceptions of pain as self-regulation is a human adaption and mind over matter. If an individual practices self-regulation, including mindfulness, they can feel pain start to diminish and feel better. Self-regulation decreases automated responses (Barnes et al., 215; Muraven & Baumeister, 2000).

According to Benight (2017), the key to self-regulation is self-evaluation, as it creates positive and negative self-efficacy insights. Ozhiganova (2018) said self-regulation involves controlling thoughts, behavior, and affect which is automated or deliberate. Gagnon et al. (2016) examined the impact of self-regulation on burnout and psychological wellbeing and found self-regulation involves individual feelings, actions, and thoughts to achieve goals and at the same time master their environment.

Benight et al. (2017) said self-evaluation helps individuals develop positive or negative self-perceptions, and self-monitoring involves examination of an individual's own performances. Self-observation has two crucial functions during the self-regulation process: self-achievable goals and evaluating one's own processes toward achieving them. To achieve goals, individuals need to focus on their own thought patterns and actions that can cause behavior changes to occur (Benight et al., 2017). Self-evaluation is a process that involves changing behaviors or goals to achieve an ultimate goal (Bandura, 1991).

To understand the current project, it was necessary to also understand literature involving chronic pain and CD. According to Tuner et al. (2020), social, psychological, and biological factors should be accounted for in order to create holistic treatments that are effective for chronic pain management. Mindfulness of CD helps individuals focus on and pay less attention to sensations and emotional pain they may be experiencing. Harrison et al. (2017) said nonpharmacological approaches such as mindfulness have been used to address pain that occurs with a variety of medical conditions. The SRT was chosen for this study to gain a better understanding of lived experiences of individuals with CD.

According to Bandura (1991), reciprocal determinism involves one's environment as well as cognitive, physical, and emotional experience's ability to cope with situations. For example, reciprocal determinism is when an individual experience an illness they need to process it first and then set a goal for pain management. According to Bandura (1991), individuals can have an influence over their actions, behaviors, and achievements. Fuente et al. (2018) noted that self-regulation involves an individual engaging in a specific behavior to achieve a set goal. Fuente et al. (2018) conducted a quantitative study with a sample of 38 students who were randomly assigned either to the experimental group or a control group. In Fuente et al.'s (2018) study, individuals experienced fewer addictive behaviors and displayed higher achievement, academic, and social adaptation. The researchers found that mindfulness training helped to enhance coping strategies and an understanding of their emotions. Mindfulness training was thought to contribute to better coping skills that help to add to improvement for strategic regulation. This supports Bandura's view on self-regulation and wellbeing theory of mindfulness.

According to Nes et al. (2009), chronic pain causes physical and psychological problems and challenges and can decrease an individual's QOL. Chronic pain and idiopathic pain interfere with emotional, psychological, and cognitive domains. The capacity to self-control differs, and self-administrative quality seems, by all accounts, to be a restricted asset that can be exhausted. The numerous difficulties of constant pain conditions could, in this manner, change self-administrative quality, prompting self-administrative deficiencies (Nes et al., 2009). According to Nes et al. (2009), chronic pain is a very hard condition to live with as it alters feelings, thoughts, and behaviors. Self-regulation requires gaining control over one's behavior, thoughts, cognition, and emotions and achieves acceptance of self (Solberg et al., 2009). The current research proposes a relationship among pain self-administrative limit, self-administrative requests, chief capacities, and self-administrative weakness, recommending that leader capacities and self-administrative shortfalls are in fact part of the etiology and support of chronic pain conditions. This study used self-regulation theory (SRT) to explore how mindfulness helped individuals to feel better and have a better QOL.

Literature Related to Key Concepts

Dystonia

Dystonia has several symptoms that are similar to other movement disorders, like Parkinson's disease. PD is known as the second most typical neurodegenerative disorders that affect a lot of elderly individuals. PD is a movement disorder where the non-motor symptoms largely affect the QOL (Advocat et al., 2016). PD has been known to use non-pharmacological and mindfulness-based approaches to help with the pain and symptoms of the disease. PD and CD have similar functions that, at times, PD can be connected with CD and vice versa. According to Sung et al. (2017), pain is a typical and debilitating non-motor indication of Idiopathic PD however its basic pathophysiological components are not surely known. Chronic pain occurs in 19% of adults and it affects 85% of individuals who are suffer from the early to moderate PD (Mattos et al., 2019).

Regardless of this high pervasiveness, pain is multifactorial, and the components are mind boggling (Mattos et al., 2019). Because PD and CD of their similarities, the body of research from PD can also be used to understand the impacts of therapies on chronic pain.

According to Singh and Singh (2016), CD, also called spasmodic torticollis, is a neurological disorder affecting the head and neck muscles causing them to involuntarily contract and posture to become distorted (Dool et al., 2016) and is one of the most common forms of focal dystonia (Mills et al., 2016). Research suggest that CD is a neurological disorder that causes uncontrollable spasms in which the body starts to twist and pull in different directions that cause extreme pain and changes in physical appearance (Zoons et al., 2017). According to Comella, (2018) approximately 4.2 per 100,000 suffer from CD with 164 per million diagnosed with cervical or focal dystonia (Van demark et al., 2018). According to Kongsaengdao et al. (2018) and Poliziani et al. (2016), the worldwide rate of CD is 0.80 per 100,000 per year and mostly seen in females in the fourth and fifth decades of their lives. The disease can affect an individual at any age. It can also develop in one part of the body and then move on to another part of the body at any time which can affect the person's functioning and QOL.

Kongsaengdao et al. (2018) estimated the rate of adult-onset dystonia was 5.7 per 100,000 and in Thailand 13.6 per 1000.000 individuals were diagnosed with the disease. According to Berman et al. (2019), the most prevalent form of dystonia is focal adult-onset dystonia which essentially affects one body part such as the cervical, laryngeal, larynx, neck, limb, and upper cranial, upper face. Dystonia is grouped by focal type:

multifocal, segmental, hemi, and generalized dystonia (Ortiz et al., 2018). According to the research of Ortiz et al. (2018) the earlier the onset of dystonia the more likely it may be hereditary acquired or generalized. Ortiz et al. (2018) suggest that if the dystonia is acquired as an adult, it will be more likely to be a focal or idiopathic form of dystonia.

According to Dool et al. (2016), within the last ten years there has been an increase in the recognition that non-motor and motor symptoms are connected in dystonia. While there are many physiological and neurological diseases that are comorbid with chronic pain, there is a paucity of research looking at CD and chronic pain. According to Camargo, Cattai, and Teive (2015), approximately 60% of individuals reported different sensations such as numbness, ache, tingling and some degree of pain associated with CD. This section will discuss the physical and psychological impacts of CD, including chronic pain associated with CD. According to Zoons et al. (2017), finding new ways to alleviate stress in chronic pain will help individuals have a more positive outcome on life as well as their disease outcomes.

According to Shukla et al. (2016; Werle et al. (2014), CD is a complex disorder which affects physical, cognitive, emotional, and psychological domains and may impact self-image. Although there has been extensive literature on the use of mind-body regarding physical disorders, there is limited research on the use of mind-body approaches in the treatment of CD (Olmo et al., 2018). The next section examines the body of work on the physical aspects of CD.

Physical Aspects of Dystonia

CD mainly affects one region of the body which is the shoulder and the neck and is known to be very painful (Singh & Singh, 2016). CD makes it harder for an individual to hold the neck and the head in one position, so the individual may experience problems with their coordination (Andrzejewski et al., 2018). Kongsaengdao et al. (2018) and others (Esposito et al., 2017; Merola et al., 2019) have found that patients with CD experience involuntary twisting and abnormal posture, horizontal tilting, and severe neck discomfort leading to complications with walking and spinal scoliosis.

According to Comella (2017), dystonia consists of two axes for diagnostic considerations. Axis 1 includes the clinical characteristics of dystonia and if the dystonia was early onset or developed later in life. Primary dystonia occurs without other neurological factors such as seizures and secondary dystonia can develop due to environmental factors that are from disturbance in the brain, and isolated is with or without tremors but has a neurological component. In Axis 1, the term changes from essential to auxiliary to the isolated dystonia which is one element of dystonia and in combination with other movement disorders, for example, Parkinson's disease. Axis 2 accounts for the acquired dystonia, idiopathic, or inherited dystonia. Axis 2 is connected with abnormal structures that can be progressive or can be brought on suddenly. This framework is used for clinical diagnosis and as a guide to help with future research and exploration of dystonia.

According to Andrzejewski et al. (2018), CD is associated with problems with balance and may impact vertical perception including the perception of what is straight ahead and centered is skewed, as noted by Desrochers et al. (2019). CD can also cause individuals to have neck and head pain as well as disturbance with sleep, problems with walking and a limited motion of upper limb activities and other psychosocial factors that can impact an individual's social and daily life and employment status (Zetterberg, Urell, & Anens, 2015). Because CD causes uncontrollable spasms, it is associated with extreme pain (Zoons et al., 2017). Jackson et al. (2019) stated that addressing physical functioning as a pain management outcome is critical in improving productivity and QOL among chronic pain individuals.

Parkinson's Disease

According to Kwok et al. (2017), PD attacks roughly 10 million individuals worldwide and is the second most normal constant neurodegenerative ailment. PD is characterized by four cardinal motor symptoms, specifically, inflexibility, postural shakiness., bradykinesia, and resting tremor. Ayromlou et al. (2020) explored the impact on QOL in Parkinson's Disease (PD) with the use of mindfulness. The study consisted of 40 patients ages 56-80 who were diagnosed with PD and for one year have been taking dopaminergic medication. Participants were placed in an experimental and control group. The experiment included an 8-week Mindfulness-based stress reduction (MBSR) training, preparing each for 2 hours with a 15-minute break between the first and second hour. MBSR was first conceptualized by Jon Kabat-Zinn as a complementary intervention for individuals in a hospital setting to serve as an alternative approach for physicians treating chronic pain or multiple chronic conditions (McLean et al., 2017). The results of the study conducted by Ayromlou et al. (2020) concluded that mindfulness training, improved the QOL in PD patients. Advocat et al. (2016) conducted a similar qualitative mixed method study using control and experimental groups with participants of similar ages and concluded that mindfulness has the possibility to help individuals to control the difficulties that are connected to the neurological disorder as Parkinson's disease. According to Kwok et al. (2017), the side effects of pharmacological methods nonpharmacological methods such as Complementary and Alternative Management (CAM) approaches have also helped to relieve, pain, and reduced anxiety and depression in PD patients. The positive effects of CAM, and mindfulness methods are the easiest for the PD patients to understand and they are more apt to follow the routine.

CD is an underestimated manifestation that can develop at the end of Parkinson's Disease (PD) (Kida et al., 2018). Kida et al. (2018), in a private neurological hospital in Japan from the years of 1983-2008, examined 22 deceased individuals who suffered from sporadic PD and pneumonia. CD was seen in 40.9% of the elderly patients. Pneumonia was noted in later stages of CD. The conclusion of the study was that CD was seen in the later stages of PD which suggest that dysphagia and pneumonia may have been the cause of death. The end result is that if CD can be treated then the QOL and PD survival may be longer. The understanding of how to manage symptoms is often difficult as the self-efficacy in the management of cognitive abilities is low in PD patients (Toglia et al., 2020). Toglia et al. (2020) examined the cognitive self-efficacy (CSE) using The Cognitive Self-Efficacy Questionnaire (CSEQ) to understand how participants deal with symptoms. The study results showed that participants who suffer with PD have a lower CSE in comparison to individuals without the disease. The low CSE can be connected with a bigger medication dosage and can cause depression to occur. Cognitive self-adequacy (CSE) is the confidence in one's own ability to adapt to psychologically challenging exercises and to utilize psychological skills adequately in different circumstances. It adds to self-regulation, objective setting, inspiration, and utilization of self-administration methodologies. People who suffer with lower CSE may avoid errands that require mental exertion, discouragement, may become dependent, social confinement, joblessness, and diminished personal satisfaction.

Pain as a Disease

According to Raffaeli et al. (2017), pain is a significant medical problem around the world. However intense pain may be viewed as an indication of disease or injury, interminable and intermittent problem is a particular medical care issue, an illness in its own right. The understanding of pain is a huge undertaking as it is one of the biggest mysteries in the entire existence of medicine. As expressed by John J Bonica, the establishing father of pain medicine, in 1953, torment "in its late stages, when it gets obstinate, it not, at this point fills a valuable need and afterward becomes, through its psychological and physical impacts, a ruinous force". According to Milla et al. (2016), pain, is defined as an uncomfortable emotional feeling that could be caused by tissue destruction over a long period of time. Wojcikowski (2020) stated that chronic pain is caused by neuroplastic changes in the orders of three neurons which are connected with the pain transmission pathways. Skolnick (2018) noted there are approximately 125 million Americans who suffer from chronic or acute pain.

In conditions associated with chronic pain, the unconventional idea of pain is uncovered in its intricacy, especially in light of the twofold estimation of the phenomenon. Chronic pain is the most common cause of disability and reduction in QOL, and is higher than those of heart disease, diabetes, and cancer (Sir et al., 2019). Pain is naturally a defensive device, yet it can likewise lose its versatile capacity and turns into a pathologic problem that can impact QOL (Raffaeli et al., 2017). Chronic pain endures longer than the typical course of an intense physical issue or ailment, lasts longer than three months, and reoccur intermittently (Majeed et al, 2018; Raffaeli et al., 2017; Sir et al., 2019). The underlying foundations of the origination of pain as a disease was crafted by the pioneers of torment medicine, the clinical branch built up in the USA during the 60s with the point of making a particular control for the investigation and the administration of pain (Raffaeli et al., 2017). Today, it is recognized that there is a fundamental contrast between pain as a side effect and chronic pain.

Chronic Pain as a Key Symptom of Dystonia

Around 70% of CD patients experience pain (Avenali et al., 2018) and 80% of physician visits consist of pain associated symptoms (Hernandez et al., 2020). In Olmo et al.'s (2018) study, 75% of the CD individual stated that pain was the predominant cause of their disability. Between 8 and 45% of individuals report suffering with chronic pain but only 10 to 15% will go see a doctor for the pain (Hernandez et al., 2020; Mills et al. 2016). According to Ahmed et al. (2019), chronic non-cancer pain accounts for 20-50% of physician's visits.

According to Zoons et al. (2017), the constant involuntary movements from CD cause discomfort and pain impairing the lives of individuals with CD. Jackson et al. (2109), addressing physical functioning as a pain management outcome, stated that improving productivity and QOL among individuals who experience chronic pain is critical to their overall wellbeing. Research suggests that chronic pain is linked to depression, anxiety, sleep disturbances, and neuroticism (Hernandez et al., 2020). According to McNaughton et al. (2019), individuals who suffer from chronic pain will be exposed to excessive pain that can be disabling.

Tinazzi et al. (2019) suggests that CD pain may be caused by abnormal central process of nociceptive stimuli. Conditioned pain modulation may be the cause of the CD pain. Sudan et al. (2019) estimated that approximately 70%-80% of individuals with CD have neck discomfort and 60% may have recurrent or persistent neck pain. According to Sudan et al. (2019), the constant involuntary movements of the head and neck may cause the neck muscles to become weak and alter posture. According to Becker et al. (2017), there has been a lot of evidence that taking medications is ineffective and unhealthy when treating chronic pain. According to Volkow et al. (2016), long term use of prescription opioids from chronic pain treatment can lead to addiction and misuse and can alter the mesocorticolimbic dopamine system.

The most common treatment for CD has been pain medication. Research has suggested that the use of medications may eventually lead to substance abuse. The most common and disabling non-motor symptom for patients with CD is pain and is reported in 75% of patients (Avenali et al., 2018). Mahajan et al. (2018) noted that individuals who suffer from dystonia experience severe discomfort and often start to take medications to alleviate the pain. Mahajan et al. (2018) conducted a study with 208 CD patients; 10% met SCID criteria for substance abuse (SA). The therapies used were benzodiazepines, botulinum toxin, muscle relaxers, anticholinergics, baclofen, opiates, non-benzo hypnotic, and dopaminergic medication. In the study, 100% of the CD patients showed a past dependence on alcohol or SA including cannabis, cocaine, and other substances with 47.4 % with SA had been prescribed benzodiazepines and 32.2 % without SA (Mahajan et al., 2018). Aveneli et al. (2018) noted that oral medications like benzodiazepines, baclofen and anticholinergic drugs show general improvement in early stages of CD, but not specifically for pain. Long term use of medications such as opioids can worsen the symptoms and can become addicting (Mahajan et al., 2018).

Coping with chronic pain can be difficult and pursuing other approaches to pain management can help to manage the chronic pain issue (Lestoquoy et al., 2017). Not all individuals will have pain alleviated by the same therapies as their bodies and pain levels may tolerate pain differently. The literature has mixed reviews about the efficiency of complimentary therapies in addressing chronic pain (Wojcikowski, 2020). According to Becker et al. (2017), research studies have shown that NPM’s such as CBT, mindfulness-based stress reduction, yoga, physical therapy, and chiropractic treatment can be effective. Research has demonstrated various integral treatments may be viable in alleviating chronic pain or potentially the requirement for analgesics, which may offer a decreased unfriendly influence on the body. These treatments incorporate curcumin, capsaicin, nutrient D, omega-3 unsaturated fats, lipoic corrosive, needle therapy, yoga, contemplation, and care reflection (Wojcikowski, 2020). Reaction rates to treatment are probably going to differ among individuals and therapy treatments. There were a number of treatments used in Wojcikowski's (2020) research study including vitamin D, curcumin, lipoic acid, capsaicin, meditation, yoga, omega 3 fatty acids as well as mindfulness meditation. Wojcikowski found that 30% pain reduction for approximately half of the patients in the study used a combination of treatments. Because changes can occur during the treatment of chronic pain, the researcher recommended that treatment should be tailored based on an individual's ability to manage their pain as opposed to a one size fits all approach.

I found that chronic pain was connected to an interference in one's sense of self, predictability with experiences of pain, a lack of control, and individuals felt that other people did not believe or understand the pain that they were experiencing. Thus, psychological components of chronic pain are just as important to understand as the physical aspects of pain as part of holistic individualized treatment. An individual who suffers with chronic pain may feel upset and out of sorts as the body is not healing or functioning as it was before the pain (Appel, 2020). There are psychological implications that can be associated with experiencing chronic pain. The next section explores the literature related to the psychological aspects that can be experienced by individuals who experience dystonia.

Psychological Aspects of Dystonia

Having a chronic illness can affect cognitive, affective, and behavioral processes involved in the ongoing management of the illness (Abdallah & Geha, 2017). According to Abdallah and Geha (2017), chronic pain causes 20%-30% of adults to have stress and associated psychiatric disorders. Dystonia can impact multiple domains of functioning including physically affecting the body, influencing one's psyche, and interfering with interpersonal relationships (Morgan, Eccles, & Greasley, 2019). Non-motor symptoms including diminished cognition, mood alteration, pain, and sleep disturbances, account for 48% of the variation of the individuals QOL (Sandhu et al., 2016).

CD has been linked to depression among those individuals who experience uncontrollable movement to the head and neck (Hentschel et al., 2016). According to Bernstein et al. (2016), individuals with CD may develop a negative self-perception, withdraw from social events, develop health problems, and have a poor QOL. Individuals with CD have a 91.4% chance of developing and meeting the criteria for psychiatric disorders in comparison to 35% of the general population (Bernstein et al., 2016).

Non-motor symptoms of dystonia impact sleep, emotions, cognitive functioning, and mood (Bernstein et al., 2016). Additional non-motor symptoms associated with CD includes autoimmune diseases. Hentschel et al. (2016) conducted a cardiovascular autonomic screening on 85 CD patients and tested its link to depression. Their study revealed that 21% had heart rate variability (HRV) impairments, 14% orthostatic hypertension, and 30% of CD patients showed depression symptoms. Cardiovascular autonomic unevenness in patients with CD is firmly connected with depression. Decreased vagal regulation speaks to a potential cardiovascular danger issue, which is autonomous of motor seriousness, Botox treatment, and different properties of the dystonia patient.

Psychological stress can alter the individual's behavioral performance and affective reactions, which can affect self-pain management and QOL (Abdallah & Geha, 2017). Zoon et al. (2017) said learning a new routine can be extremely stressful at times and may cause psychological and physiological problems. Dystonia is associated with stress in that the affected individual can show signs of extreme shaking, self-consciousness, depression, and anxiety (Zoons et al., 2017) as well as sleep disturbances and grief at the changes in their lives (Jiang et al., 2019).

Bernstein et al. (2016) noted that dystonic individuals under stress may experience uncontrollable shaking and muscle tension. Individuals report that fighting these symptoms is often frustrating and exhausting (Semerdjieve & Milanov, 2018; Zoons et al., 2017). According to Bernstein et al. (2016), individuals who live with adult-onset dystonia may withdraw socially, have a negative self-concept, poor health, and low quality of life.

Perozzo et al. (2016) found that individuals with CD often exhibit signs of heightened anxiety and moodiness. The lack of social support coupled with self-deprecation, maladaptive coping strategies, and the interference with daily activities brought on by the disability, often leads to depression in dystonia patients (Sandhu et al., 2016). Given the severity of symptoms and their effects on patients' lives, understanding the best treatment options become paramount in order to ensure the best QOL. Patient education is necessary so that the individuals when experiencing chronic pain understand the choices, risks, benefits, and alternative treatments available to them.

Pharmacological Treatment of Pain

An estimated 56% of adults in the United States have reported experiences of chronic pain within the past three years (Lestoquoy et al., 2017). Pharmacological treatments for pain include anti-inflammatories, pain relievers, opioids, and nonsteroidal medications which have shown to provide moderate to mild relief to individuals who suffer from pain symptoms (Lestoquoy et al., 2017). Chronic pain has become more prevalent and those who suffer from it are more likely to experience psychological dependence due to the pain symptoms (Priddy et al., 2018). Previously, the treatment of CD consisted of oral medications such as baclofen, levodopa, clonazepam, and tizanidine (Kongsaengdao et al., 2018). Today as noted by Han et al. (2016), two options exist for chronic pain associated with CD: Opioids and Botox (onabotulinumtoxinA) injections. This section will explore these options as they relate to CD and their efficacy in treating CD.

Opioids

Opioids can be effective in the treatment of pain management with chronic pain (Carpenter, 2019), but it may lead to health concerns or misuse (Hale, 2016). Opioid use has become a concern of many researchers as over 50% of Americans do not have a valid prescription for use with chronic pain (Shipton et al., 2018). A review of opioid use by Shipton et al. (2018) found approximately 40% of the chronic opioid individuals in the United States already have an opioid problem. According to Hale (2016), approximately 33 million individuals, or 0.7% of the adult population abuse prescription medications. Opioid long-term use can cause sleep apnea, driving impairment, endocrine problems, myocardial infarction, fractures, overdose, and sexual dysfunction (Shipton et al., 2018). According to Shipton et al. (2018), opioids have cost an estimated $78 billion a year in the United States alone not counting the decrease in QOL, problems in family relationships, social dysfunction, and psychological problems. There has been an increase in the use of morphine, oxycodone, and hydrocodone prescriptions from 2% to 9% of physician's visits (Ahmed et al., 2019).

Individuals who experience severe chronic pain are more likely to utilize opioids and risk the dangerous effects of addiction (Knight et al., 2017). There is an estimated 25% of individuals who experience chronic pain individuals to be susceptible to opioid abuse as the prescription becomes ineffective (Vowless et al., 2015). Misuse and abuse of opioids has led to addiction, overdose, dependence, drug related suicide, traffic accidents, shared drug paraphernalia leading to the spread of infectious disease or death (Hale, 2016).

Knight et al., (2017) found a heightened concern among United States physicians, individuals, media, and the policy makers about the community and health risks associated with opioids. Opioids are generally being prescribed to alleviate pain in individuals who are suffering from chronic pain (Carpenter, 2019). According to Priddy et al. (2018), in 2015, there were over 33,000 opioid deaths. According to Knight et al. (2017), in the last 25 years opioid used has led to a higher increase in the treatment for Chronic Non-Cancer Pain (CNCP) and has led to opioid misuse.

There has been a national concern about the increase with prescription use and misuse of opioid analgesics and has drawn the attention of the political, scientific, and media province (Dowell et al., 2016; Newkirk, 2016; The White House, 2016). According to the American Medical Association (AMA, 2016) opioid prescriptions have increased globally creating an epidemic of overdose. The AMA has called for reform among governmental regulatory bodies, medical communities, and in the large public domain. In Knight et al.'s (2017) qualitative study, the unfavorable outcomes connected to the use of opioids demonstrated a need to have other treatments for chronic pain.

The Centers for Disease Control and Prevention (2018) states that the opioid pandemic in the United States is a major public health concern as over 130 people are overdosing daily. Recent work by Ahmed et al. (2019) found approximately 28.6 million Americans 12 years and older used illicit drugs in 2016, and 3.3 million have admitted that they abuse prescription pain medications. Opioid deaths started increasing in the United States in the 1980s (Ballantyne, 2017) with over 33,000 unintentional deaths due to opioid misuse in 2015 alone (Priddy et al., 2018) and opioid abuse has increased 10-14 times over in the last 20 years (Shipton et al., 2018). Many physicians are not prescribing opioids due to the increased risk of individuals misuse of the prescription (Castaneda et al., 2018). Shipton et al. (2018) found that the life expectancy in the United States has been decreased due to the opioid problem associated with opioids. Because of this, alternative treatments have become important for those in the chronic pain community.

Botox Injections

CD can be improved with the use of Botox (Tinazzi et al., 2019). Botox injections are available in different forms such as BONT-A (onabotulinumtoxinA, abobotulinumtoxinA, and incobotulinumtoxinA) and BONT-B (rimabotulinumtoxin-B)

(Contarino et al., 2016). Botulinum toxin (BoNT) is a neurotoxin from the bacterium Clostridium botulinum which is used to numb the muscles (Han et al., 2016). According to Contarino et al. (2016), Botox treatments are the most accepted form of therapy in the treatment of CD. Among individuals who receive Botox injections, 70 to 85% have improvements with this form of treatment (Camargo et al., 2015; Contarino et al., 2016). Camargo et al. (2015) noted that when individuals go to their appointment for the Botox injections, they should inform the doctor of what muscles are causing them pain from spasming. Botox is injected to paralyze the tremors and correct the head and neck positioning (Kongsaengdao, 2018). The Botox injections can only be administered every three months and the duration of effectiveness can vary. CD symptoms are similar among most individuals, but the results vary between individuals with this treatment. The physician uses an ultrasound machine to hear when the muscles are twisting and then they will inject those muscles (Marion et al., 2016).

According to Mario et al. (2016), Botox offers a viable option for CD patients for treating their pain. Botox is currently considered the treatment of choice for CD (Camargo et al., 2015). The study conducted by Mario et al. (2016) estimated that 20% of CD patients stop receiving Botox injections as the shots did not improve the symptoms of dystonia. They also found that another reason individuals who experience CD stop getting Botox injections is in part due to the proximity of available doctors who are able to perform these treatments. They also found that Botox injections may cause the individual to experience dysphagia and trouble swallowing with bilateral injects to the sternocleidomastoid. Planning the application and dose of Botox according to the level of pain and location of pain in specified muscles is a key factor for treatment (Camargo et al., 2015). When an individual has poor Botox results, they may develop depression due to the way they thought it would alleviate the symptoms. According to Leplow et al. (2017) depression and anxiety is reported to be prevalent in 40-60% of the CD population. Social phobia, avoidance behaviors, anxiety and depression are frequently observed in individuals with CD (Leplow et al., 2017). Long term use of Botox in the treatment of disease specific health-related quality of life (HRQol) has been shown to be beneficial, improving physical functioning, role limitations due to health, and bodily pain (Kongsaengdao et al., 2018). Emotional functioning and well-being also improved with Botox treatments (Leplow et al., 2017).

Botox studies have shown an increase in mental and emotional problems such as anxiety, social phobia, avoidance behavior, and depression among individuals with CD (Leplow et al., 2017). Social phobia was increased by 10 times in individuals with CD (Leplow et al., 2017). Within the dystonia population, 71% of the patients experience QOL issues related to personality and neuropsychiatric disorders (Leplow et al., 2017). Botox injections are tailored differently for all individuals (Marion et al., 2016). Although there is an overall positive benefit of Botox injections for dystonia, the effects will vary for each individual (Leplow et al., 2017).

Nonpharmacological Approaches

Evidence has suggested that the reliance solely on pharmacotherapy is ineffective in the treatment of chronic pain (Becker et al., 2017). According to Turner et al. (2020), literature has emerged in the last few years about the social, psychological, and biological factors that are causing the pain symptoms as well as the interventions that may be utilized to alleviate pain. There are many different nonpharmacological resources that can be used to treat pain (Harrison et al., 2017; Sir et. al., 2019). Nonpharmacological approaches to the pain of dystonia are more beneficial for the QOL and well-being of individuals who suffer from dystonia (Becker, et al., 2017). Mindfulness-based interventions (MBI), CBT, yoga, and hypnosis can lessen pain perception and help to increase function and mobility (Becker et al., 2017; Elkins et al., 2012; Hughes et al., 2017; Kabat-Zinn et al., 1985; Majeed & Sudak, 2017). Deep brain stimulation (DBS) surgery can also help with the twisting and pulling of the neck muscles, alleviating the cause of pain in those who experience CD. Many studies have shown the effectiveness of non-pharmacological modalities which can improve the results of chronic pain. This section will focus on DBS, CBT, and ACT, as they are the most common ones.

DBS

DBS is a surgical option when Botox is no longer effective in managing CD symptoms. DBS is a neurological surgical procedure that implants a pacemaker unit that distributes high electrical impulses to the brain area where the device is located. DBS implantation has shown 35%-80% improvement with dystonia (Sperry et al., 2017). The U.S. Food and Drug Administration (FDA) has currently approved DBS for dystonia as it falls under the humanitarian device exemption (HDE) (Sperry et al., 2017). The HDE means that it was approved by the FDA without having information on how effective the device may be. DBS has been implanted into 125,00 individuals since 1995 (Medtronic

Inc., 2016). One issue with DBS implantation is that the device may not work for all CD individuals.

Kroneberg et al. (2017) reported reduced symptoms of CD with use of DBS. Kroneberg et al. (2017) found that DBS procedures are also being conducted with individuals who suffer from Parkinson’s disease and more recently randomized controlled and open-label studies have also reported a reduction of motor symptoms associated with CD. Kroneberg et al. said DBS is still being studied and the mechanism by which DBS is effective is still unclear. The current literature shows minimal cases have been reported regarding the outcome of DBS surgery used for the treatment of dystonic tremors (Sobstyl et al., 2019). DBS surgery is reversable and can be adjusted as needed to alleviate the CD symptoms (Lizarraga et al., 2019). Lizarraga et al. (2019) noted that DBS for dystonia also has negative ramifications such as the cost of the surgery. According to Lizarraga et al. (2019), the batteries have to be frequently replaced and the hardware parts may malfunction. The highest rate of DBS battery replacements and lead failures is among dystonia patients. DBS can malfunction and cause abnormal neck and head positions that cause tremors, twisting the neck and damaging the software and give more problems for the patient (Lizarraga et al., 2019). DBS surgery was recommended if all other available dystonia therapies fail to help alleviate the symptoms (Wang et al., 2020).

Psychotherapeutic Approaches

There is evidence that Cognitive Behavior Therapy (CBT) and Acceptance Commitment Therapy (ACT) are among the psychotherapeutic approaches which can be used in order to target chronic pain (Gilpin et al., 2017). ACT can help individuals identify goals and values that are crucial when managing their thoughts and emotions related to acceptance and awareness (Gilpin et al., 2017). According to McNaughton et al. (2019), psychological methods have shown to be favorable in addressing chronic pain. Although CBT has been popular for decades, ACT and mindfulness methods are becoming more predominate and are known to be helpful in the treatment of chronic pain (Soer et al., 2015). The ultimate goal of psychotherapeutic approaches is used to change the way an individual perceives and responds to their pain. CBT and ACT help an individual change their thought process and to have a more positive view of how to cope with the chronic pain (Simpson et al., 2017). When an individual that suffers from pain feels less tension and stress it may help to alleviate the chronic pain.

CBT

CBT can address the psychological aspects of dystonia and has been utilized to improve the individuals the quality of life of individuals who experience chronic pain, chronic fatigue syndrome, and diabetes (Sandhu et al., 2016). According to Sandhu et al. (2016), CBT and mindfulness helps with mood disturbance in connection to medical problems and anxiety through awareness and has been an effective treatment for the non-physical and physical conditions associated with chronic pain. Studies involving the efficacy of CBT have shown positive outcomes for the treatment of chronic pain

(Cederberg et al., 2016). Individuals who utilize CBT techniques can beneficially change the focus of their experience and behaviors. (Gilpin et al., 2017).

According to The World Health Organization (WHO) chronic pain is viewed as a challenge for health care (Cederberg et al., 2016). CBT is used to alleviate maladaptive cognition, intense pain and unhealthy patterns of behaviors such as psychological aspects or acceptance and pain self-efficacy (McNaughton et al., 2019). According to McNaughton et al. (2019), psychological methods have shown to be favorable in addressing maladaptive cognition, intense pain, and unhealthy patterns of behaviors such as psychological aspects or acceptance and pain self-efficacy. According to Van Demark et al. (2018), CBT can help to address the CD individual's depression or anxiety that often result from chronic pain.

Kobayashi et al. (2019) explored the tolerability and efficacy of CBT regarding individuals' dystonia symptoms and their mental health. The study consisted of 15 individuals that had no prior history of mental illness and who had focal dystonia. The individuals in the study had scored 14 or higher on the Beck Inventory II which indicates mild to moderate depression (Kobayashi et al., 2019). The study consisted of eight sessions of CBT. Focal dystonia improved as well as the disability, pain, anxiety, depression, and QOL and this included the relation with the environment (Kobayashi et al., 2019). According to Kobayashi et al. (2019), the CBT-FD was effective as a holistic recovery approach of all the study individuals. Additionally, Miro et al., (2018) examined the impact of CBT on chronic pain management and found that CBT showed improvement in the individual's ability to accept the chronic pain condition. The development of coping skills is effective in conjunction with CBT (Heapy et al., 2018). CBT programs that include mindfulness meditation to treat chronic pain management has shown a reduction in anxiety, depression and in pain, an increase in acceptance and mindfulness in connection to psychological problems with the exception in depression which can change with the level of mindfulness (Andersen & Vaegter, 2016).

ACT

ACT is a third-generation modification of CBT and is used to promote lifestyle changes n in combination with the process of self-regulatory skills and psychological flexibility (Hayes, 2016; Hooper & Larsson, 2015; Rogers et al., 2017). According to Gilpin et al. (2017), ACT utilizes mindfulness practices by exposing the irrational thoughts people used to avoid the experience of pain, unpleasant emotions, thoughts, and sensations. ACT teaches the individual that the negative thoughts can be used to understand the pain and to change their perception of the event (Zangi & Haugli, 2017). According to Simpson et al. (2017), ACT is used to address the pain in order to achieve the goal and core values.

ACT is supported by the American Psychological Associations Division of Clinical Psychology for having a powerful effect on chronic pain (Society of Clinical Psychology, 2015). ACT is utilized all over the world by physicians in the treatment of chronic pain (Holmes et al., 2019). ACT has been shown to have a higher effect with depression and anxiety rather than mindfulness based cognitive therapy and mindfulness-based stress reduction (Veehof et al., 2016).

According to Hayes et al. (2016), ACT increases psychological flexibility to change the barriers and allow for responsibility of one's well-being to be developed. According to Hayes (Hayes et al., 2006; Hayes 2016), acceptance is one's readiness to believe their sensations, thoughts, and feelings although the hard thoughts may be difficult and not to suppress, avoid, or not try to change them is crucial. According to Simpson et al., (2017) ACT is a behavioral based intervention which is psychological method to help to manage chronic pain by reducing symptoms and to gain a better QOL. ACT allows people to learn how to address tough feelings and thoughts and can change their belief of future control of the illness (Graham et al., 2017). Simpson et al. (2017) explored a systematic review of random control trials of ACT as a therapy for non-cancer chronic pain evaluated adults regarding the effectiveness of ACT. Self-efficacy and physical activity may help to alleviate chronic pain (Simpson et al., 2017). The results of the study concluded that ACT was beneficial therapeutic intervention for managing chronic pain (Simpson et al., 2017).

According to McCracken et al. (2016), therapy changes in ACT have shown an increase of mindfulness, psychological flexibility, committed and acceptance actions. The study was conducted using 86 chronic pain adults and showed that patients had showed a reduction of physical functioning, pain acceptance, social functioning, depression, and pain. According to McCracken et al., (2015) if individuals are accepting and aware of their pain without, they may expand reflection and self-focus and achieve and align values, goals, and enhance their QOL. According to Miro et al. (2018), ACT is a similar therapy as CBT that’s aim is to focus on patients learning to change the connection to their thoughts whereas CBT teaches people to change their thought content.

Bendelin et al. (2020) said ACT builds on established CBT methods and ACT focus on the outcome of different aspects of psychological flexibility with chronic pain. ACT uses six core principles to advance an individual’s psychological flexibility values, committed action, contact of present moment, diffusion, observation of self, and acceptance. Qualitative studies of ACT for chronic pain have shown that it is crucial to set goals can be the key point in changing behavior (Bendelin et al., 2020). The focal point of ACT is engagement, awareness, and openness to improve an individual’s symptoms as well as their QOL (Graham et al., 2016; Graham et al., 2017).

Exercising

Nonpharmacological approaches, such as exercise, can have a greater impact on QOL (Becker et al., 2017). However, the accompanying muscle soreness and joint pain often lead patients to avoid exercise. People who suffer from dystonia may experience involuntary movements of the head and neck, and often resort to sensory tricks to control these movements (Sandhu et al., 2016).

According to McCambridge (2019), physical activity and exercising are healthy and can reduce the risk of comorbid heart disease and the individual will have a better QOL. McCambridge et al. (2019) found that exercise can give a positive perception with health and the progression of the disease for individuals who suffer from neurological disorders. Physical activity should consist of 150 minutes of activity daily (McCambridge et al., 2019). Physical activity and exercise are becoming more popular with individuals who suffer from neurological disorders and many individuals feel that with PA helps to improve their health and the improves progression of the disease. Greenberg et al. (2019) said participants improved their emotional and physical functions. Physical activity is important for the chronic pain population as deconditioned bodies and a sedentary life can cause pain to activate and cause a negative impact on the disability and condition (Greenberg et al., 2019). Individuals experiencing chronic pain can increase physical and emotional functions by increasing activities and learning mindfulness techniques to combat the pain and aim to take part in physical activity (Greenberg et al., 2019). According to Contarino et al. (2016), future studies should be conducted to focus on physical therapies in the treatment of chronic pain. The unmet needs with regards to the management and treatment of CD should be explored (Contarino et al., 2016).

Saadat et al. (2019) explored a double blind, randomized controlled research study. The study consisted of 53 participants who suffered from chronic non-specific neck pain. The study was made up of two groups both had 12 supervised intervention sessions 3x's weekly and the combined group was required to perform sensorimotor. The results of the study revealed that the combined exercise class showed more enhancement than the traditional group although both groups saw muscle increase. The researchers felt that traditional and exercise training is more apt to help individuals to help with balance, walking pace, endurance, joint position improvement. Physical exercise should be also considered as a method in the treatment for chronic neck pain (Southerst et al., 2016). Exercise can ease chronic pain by improving muscle tone, quality, and adaptability. Exercise may cause endorphins, which helps the chronic pain feel less heightened.

Different physical activities are easier for certain individuals who suffer from chronic pain to do than others. Physical exercise is not important as it once was and has decreased in age groups (Grasdalsmoen et al., 2020).

Mindfulness

Mindfulness practices refer to coping strategies and techniques that are used to promote wellness and mind and body health, regardless of the state of the disease (Greeson & Chin, 2019). Mindfulness is rooted from Buddhist tradition and is connected to self-regulated attention and focuses on acceptance and curiosity and openness (Bawa et al., n.d.). Mindfulness may improve the mental experience of pain by decreasing thoughts, reasoning, and reactivity. Increasing a feeling of acknowledgment for pain sensations may improve pain adaptability (Sir et al., 2019). Mindfulness techniques can help individuals to have a focal point that concentrates on mind and body in a non-judgmental moment. A daily routine of mindfulness (such as yoga, deep breathing, meditation, physical exercise, and listening to calming sounds) can help to alleviate chronic pain as well as the negative perception of pain. A study conducted on the hypnotic sounds of the impact of hypnotic and music treatment recommendation for alleviation of pain by Johnson et al. (2017) found that the music and hypnotic suggestion were very beneficial. The researchers had 12 participants ranging from 36-79 years of age who were a part of a 2-week intervention where participants listened to hypnotic suggestions in combination with music. The participants felt that the level of pain, depression, anxiety decreased with each of the sessions.

When an individual who suffers from chronic pain has positive thoughts the pain will decrease (Beks et al., 2018). Chinese traditional Health-Qigong exercises (CTHQ), such as Tai-chi, help with posture and stretching, mindfulness, breathing methods, and are helpful with QOL benefits (Zou et al., 2017). Another example, according to Zou et al., (2017) is Baduanjin which is a stretching technique that consists of 8 movements and can help with the whole body, mind, regulation of breathing, pain, and can be done at work or at home. A study conducted by Kwok et al. (2017) on the effects of yoga on the spiritual, HRQoL, psychological, physiological, and QOL of PD patients found that participants experienced improved awareness of PD symptoms, flexibility, pain, sleep, relaxed bodies, calmness, loss of anxiety, and improved their moods. Cramer et al. (2017) concluded that yoga did help for a short period of time but did improve range of neck and cervical movement. Similarly, Dunleavy et al. (2015) examined the efficacy of yoga and Pilates group intervention exercises with chronic neck pain. The results of the Pilates study showed a substantial change from the baseline pain ratings and from week 12 compared to week 6 which was a 95% difference, but no change was noticed in the yoga or control group. There are many different styles and forms of yoga and Pilates. Allende et al. (2017) and Sutar et al. (2016) point out that there needs to be more research on effectiveness of different types of yoga for different types of chronic pain conditions. The authors noted that there are no studies conducted in comparing different methods of yoga interventions for chronic pain.

Mindfulness Skills Training (MST) is a therapy that helps the individual to develop skills for meta cognition and connect with their body sensations, emotions, and increases their awareness of moment to moment (Jackson et al., 2019). Mindfulness can be viewed as a cognitive exercise and is seen as a non-judgmental way to bring attention and awareness to the present moment (Jackson et al., 2019; Zangi & Haugli, 2017). Mindfulness originated in ancient Buddhist philosophy and included yoga, meditation practice, and moment to moment views (Zangi & Haugli, 2017). Mindfulness is linked to Buddhism within the Western medical and psychological cultures. Buddhist monks hypothesized that mindfulness practice meditation can help to change the individuals experience of pain (Zeidan & Vago, 2017). Mindfulness is also known as a western philosophical and psychological school of thought (Zeidan & Vago, 2017) and has become a psychological treatment globally (Murphy, 2016).

Bawa et al., (n.d.) conducted a systematic review and meta-analysis which included randomized controlled trials of mindfulness-based therapy for chronic pain. The study participants ranged from 47-52 years of age although 2 studies had older participants ages 75 years. Chronic pain conditions that were included in the study was rheumatoid arthritis (two studies), failed back surgery syndrome (one study), chronic musculoskeletal pain (two studies), mixed aetiologia (three studies), and fibromyalgia (three studies). The focus of the systematic was to discover if mindfulness-based therapy helps individuals who suffer from chronic pain. Out of the 2463 identified titles, 11 studies (12 articles) were used in the study. Included in the study eight were conducted in the United States, one in Hong Kong, one in the UK, and one in Germany. The study review found that mindfulness was effective in the treatment of chronic pain.

According to Murphy (2016), there are many positive benefits to practicing mindfulness. Mindfulness helps combat anxiety, depression, stress, and mental health disorders (Murphy, 2016) as well as reduce pain and psychological stressors in chronic pain individuals (Westenberg et al., 2018). According to Zangi and Haugli (2017), acceptance-based interventions and mindfulness (MBIs) has become extremely popular in the past two decades. Mindfulness is rooted from ancient Buddhist philosophy as yoga and meditation practices (Zangi and Haugli (2017). Many individuals are turning to mindfulness as there are no side effects (Sir, et al., 2019). Mindfulness practice achieves clarity without a preconceived thought (Majeed et al., 2018). Individuals who practice mindfulness need to understand what their needs, motivation and aspirations are as this will be their manifested perception of reality (Zeidan & Vago, 2017). Physicians and researchers have recognized that pain relief may not be as crucial as improving physical functioning as a way to reduce the cost of health care and to improve QOL in pain patients (Jackson et al., 2019). According to Jackson et al. (2019), mindfulness-based intervention (MBI) showed great promise for individuals with chronic pain, but no systematic review has yet addressed MST effects on physical functioning.

When in a state of mindfulness, feelings, complex thoughts, and emotions are perceived in a nonjudgmental manner and will not have any influence on behavior (Beks et al., 2017). According to Waldron et al. (2018), mindfulness methods should be included with chronic pain management programs which will benefit an individual’s pain level. Mindfulness techniques have become popular in the treatment methods with health conditions (Zangi & Haugli, 2017). Mindfulness methods activate both states of systemic training, awareness, and internal and external experiences (Zangi & Haugli, 2017). Some studies have shown that pain is alleviated with the use of mindfulness techniques (Hendrickson et al., 2016). Tinazzi et al. (2019) noted that this causes pain in the shoulder and neck muscles of 75% of patients.

Being mindful makes us feel an awareness of clarity and calmness as it is an emotional state of mind. The sense of clarity allows us to make proper choices with having full awareness and allow for things to be seen as they really are (Sandhu et al., 2016). According to Becker et al. (2017), the more attention a dystonia individual gives to the pain the more it causes the tremors and the jerks to occur. Dystonia causes an individual to feel self-conscious and heightens the involuntary movements. The brain can cause an individual who suffers from dystonia to expect the involuntary movements and can play a crucial part in how an individual emotionally feels. Mindfulness can help the individual who suffers with dystonia to live in the present moment and not to focus on the predicted behaviors (Beks et al., 2018). Mindfulness helps people to focus their attention which can positively impact any given feeling or experience (Beks et al., 2018). Jackson et al. (2019) felt that future research should be further explored on the MST effects and physical functioning should be studied. Further research is needed to explore how dystonia patients utilize these techniques to improve their QOL.

Summary

This chapter includes a review of relevant literature on the SRT, chronic pain, CD, pain within the context of CD, and pharmacological and nonpharmacological treatments for pain and CD. There are many physiological and neurological diseases that are comorbid with chronic pain, and one disease that has limited research is cervical dystonia. Individuals who experience chronic pain involving CD can often struggle with overall symptoms of both chronic pain and dystonia, which can in turn affect their QOL and mental health. Research has shown that pharmacological treatments come with limited effectiveness and the possibility of addiction.

Literature has supported the need for exploring alternatives to pharmacological treatments, including effectiveness of mindfulness practices for alleviating pain among individuals who experience CD (Greeson & Chin, 2019; Sandhu et al., 2016). Many chronic pain diseases can be exacerbated by stressors, and mindfulness may be used to combat behaviors and biological actions which add to stress (Greeson & Chin, 2019). Stress can exacerbate spasms and CD symptoms, increasing pain (Sandhu et al., 2016). Mindfulness is becoming more prevalent as a pain management strategy. Mindfulness techniques are being used to successfully treat chronic pain, but there is limited research on the effects of mindfulness interventions in terms of decreasing psychological and physiological symptoms related to chronic pain (Harrison et al., 2017). Literature has indicated the value of nonpharmacological approaches used in treatment of pain accompanying other movement disorders such as Parkinson's Disease. Exploration of the connection between mindfulness and chronic pain management among individuals who have CD can not only address this gap in literature, but also help others who struggle with chronic pain as well. Chapter 3 includes methods used in this study to examine lived experiences of individuals who suffer from CD and endorsed the use of mindfulness practices

Chapter 3: Research Methodology

Introduction

The purpose of this phenomenological study was to better understand the lived experience of people who report chronic pain related to CD who used mindfulness-based meditation for pain management. I investigated CD individuals' views of mindfulness techniques that were used to address their pain. Mindfulness assists with alleviation of chronic pain, yet there is a lack of information involving individuals with CD.

This investigation was conducted using phenomenological methods. I used a phenomenological study as it was a method that explained lived experiences of the participants using a psychology approach. A phenomenological approach centers around research questions, for example, what it resembles to encounter a specific circumstance. The subjective meaning methods will be utilized to study the information on lived experiences of chronic pain. This part of the exploration study includes how, why it was chosen, the researcher's job, just as the moral perspectives. This chapter discussed the aim of the research, research design, recruitment, data collection and methods, ethical, limitations, and conclusion of research study.

The research questions for this study are:

RQ1: What is the lived experience of people who use mindfulness to help with chronic pain associated with dystonia?

RQ2: What is the lived experience involving pain within the context of dystonia for people with CD?

Research and Design Rationale

A phenomenological qualitative methodology was used for this study to increase comprehension of lived experiences of people with CD who use MBIs as a component of their pain management.

Qualitative Approach

Qualitative research involves getting information and data through open-ended questions and conversational correspondence. This technique involves exploring what individuals think and why they feel like they do (Creswell & Creswell, 2018). This method is used when the researcher wants to know about individuals' lived experiences regarding a phenomenon. Qualitative research methods were best to use in this study as there was a major gap in literature regarding the use and experience of mindfulness for CD. The study allowed for me to understand lived experiences of CD participants.

Qualitative research involves understanding lived experiences of individuals regarding a phenomenon and trying to gain knowledge and the meaning that the experience brings to the individual (Creswell & Creswell, 2018).

Phenomenological Methodology

The phenomenological method involves comprehending and deciphering implications of everyday encounters (Vagle, 2018). Research on CD is limited in understanding what it is like to live with this disease. This study aimed to understand the lived experiences of women with CD and their use of mindfulness; therefore, a phenomenological approach is appropriate for this study.

Because use of nonpharmacological methods has become a popular topic in much of the research in the last decade and may involve subjective experiences, the qualitative phenomenological design helped in terms of understanding how mindfulness helps change the participant’s lived experiences.

Role of the Researcher

It is the role of the researcher to understand personal biases, experiences, and perspectives in any study. For the purposes of this study, my role was as an observer. I have personal knowledge of movement disorders and chronic pain associated with the disease. Phenomenological research involves understanding lived experiences (Creswell & Creswell, 2018). It is important to be aware of personal biases to have a rigorous and valid qualitative study (Creswell & Creswell, 2018). I kept detailed notes of personal feelings during interviews to allow for transparency during the data collection process. Detailed notes included reflections on participants’ feelings to ensure there were no biases.

Methodology

Sampling Selection and Recruitment

I recruited 10 participants. All participants were females between the ages of 18 and 60 who were diagnosed with CD and used mindfulness practices to manage their chronic pain. I used a convenience sampling technique. Convenience sampling is when participants are chosen based on their availability and convenience (Creswell & Creswell, 2018). Participants were recruited from Facebook groups that were focused on CD.

Flyers were posted in Facebook groups with contact email and phone number information to set up interviews for assessment (see Appendix D). Participants were provided with a consent form (see Appendix A) and a preinterview survey to participate in this study (see Appendix B).

I recruited until saturation was reached. Saturation is when the data shows no new information or themes (Rudestam & Newton, 2015; Saunders et al., 2017). It was crucial to reach saturation so that every avenue was exhausted, and the results will be accurate. Morse (2015) said immersion is “available in all subjective examination' and as recently noted, it is generally considered as the 'highest quality level” for deciding sample size in subjective exploration, with little differentiation between various sorts of qualitative examination. It is important that the study’s findings show an in depth understanding of the life experiences, and connections to the features of this phenomenon.

Data Collection Method

Interview

Semi structured interview was used to ensure uniformity across interviews. Semi structured interviews are where the researcher has open ended questions the researcher reads out word for word and then the answers recorded and analyzed for themes (Smith, 2008). All the participants were asked the same questions in the same way.

The researcher developed open ended questions for the participants to answer in their own words (Appendix C). The semi-structured interview was the best approach for this study as it allowed for the researcher to hear about the lived experience and had reliability and control of the research study data (Creswell & Creswell, 2018). The questions were consistent and gave the participants a free response forum.

A structured interview was not used for this study as it does not permit novel topics to be raised during the interview because of what the interviewee says and does not allow for further inquiry across the interviews (Smith, 2008). In an unstructured interview, the researcher doesn't follow any structured questions; it depends solely on the course of the discussion and can cause the individuals to stray from the desired topic and not discuss their lived experiences (Creswell & Creswell, 2018). Thus, the interview method for this study was semi-structured as the set of questions guided the research and the individual could not deviate from the conversation, but it did allow for the researcher to ask for elaboration on the topic being explored.

The meetings were recorded using Zoom. After each interview the recorded meeting was transcribed using MAXQDA software. The researcher did a preliminary review of the transcripts to ensure accuracy in accord with recorded interviews. The transcripts were sent to the participants for an accuracy check. Participants checked for accuracy to best practice to ensure the accuracy of the lived experiences of the participants. Once its returned, it was put into the software to begin coding. Researcher reviewed the data and identified themes and meanings manually as well as compared the results from coded software. A Hermeneutic circle theoretical framework was utilized to understand and interpret the process about each participant’s experience (Peoples, 2021).

Data Analysis

In vivo coding was used in this study as the researcher created their own codes. In vivo coding is also known as verbatim, emic, indigenous, inductive, and natural coding (Charmaz, 2014; Corbin & Strauss, 2015). The root meaning of Vivo is “in that which we live” as the code is a word that is “short phrase located in the qualitative analysis by the individuals themselves” (Strauss, 1987, p. 33). The Vivo coding method is for beginning researchers and is valuable as it is by the voice of the participants (Saldana, 2016). Vivo coding allowed for the researcher to use the verbatim language of the study participants.

In the last step of the process the researcher input the data into the MAXQDA software and explored what patterns emerged and then coded and printed out all the data analysis. The researcher journaled reflections regarding all pieces of the assessment, which helped in sorting out individual reactions to perceive the understanding from the experience of the individuals. The data was prepared and hand coded and given labels. (Creswell & Creswell, 2018). All the codes were compiled and any that are redundant, they were be deleted. Codes were grouped into themes which became the focus of the qualitative results (Creswell, 2016, pp. 169-170).

Issues of Trustworthiness

In research trustworthiness is crucial in the qualitative research design (Ravitch & Carl, 2016). Having research that is valid is the goal of this study. The criteria are dependability, confirmability, credibility, transferability, and dependability (Guba, 1981). The validity refers to the rigor and quality in a study (Ravitch & Carl, 2016). Credibility includes the researcher obtaining thick depictions from the members that incorporate the phenomenon, however the specific situation and culture also (Ravitch & Carl, 2016). Tending to credibility requires the researcher to require some time with the member during the interview and to check in with the participant a while later. Offering the outline of the interview to the participant and utilizing member checking will permit me to hear the participants feedback and guarantee that the participant's words are conveyed properly and accurately. A potential downside may be that the participant may not be eager to take an interest or accessible at this progression.

Transferability can end up being a troublesome assignment as it isn't same as generalizability, as known in quantitative research studies. Or maybe, transferability is accomplished with the being transparent, straightforward, and open about the exploration in the research. It is not the plan that these research findings will be generalized to different populations or settings.

Dependability can be cultivated by the scientist recording the cycle, from the plans to data collection to examination. Ravitch, & Carl (2016) focused on the scientist utilize a log to keep itemized records of exercises, measures, impacts, arising subjects, classes, and examination notes. I journaled and recorded thoughts and dates on the research as well as all the steps taken. This allowed for individuals to comprehend this research and empowered them to repeat this research study on the off chance that they ought to decide to do as such. The last basis is confirmability.

Confirmability depends on the reason that exploration is rarely completely objective (Ravitch & Carl, 2016). Nonetheless, there are approaches to address this issue. Reflexivity was utilized, as I unveiled my biases and fundamental encounters that are mine. Guaranteeing confirmability will be a progressing cycle of keeping itemized records and continually monitoring and being aware of any personal biases at all phases of the exploration in the research. It is through these four methods that this research kept up the elevated expectations. Dependability can be a consistent impact, just as morals, which are depicted in the next section.

Ethical Considerations

This project was approved by Walden University's IRB. The researcher guaranteed that the exploration has a scientific logical reason, is suitable, the dangers to participants are minimum, and the advantages exceed the dangers. Prior to the beginning of the interview the participants were asked if they had any questions. The participants were asked if they are experiencing any pain or discomfort. The interviewer explained to the participants that they can stop the interview at any time for any reason and opt out of the research. Since the essential objective of any IRB is to protect human participants, this project sought IRB approval before data collection begins. The researcher kept all the private information on the computer with a lock out access key and all the paper data were kept in a lock file or safe. The privacy of the participants was crucial and was fully protected by using numbers rather than their initials. Informed consent was given as well as explained to the CD participants to be signed. The research information was not shared with anyone other than the doctoral chairs and the IRB and URR. Due to the COVID-19 pandemic safety precautions were followed but no face-to-face interview was warranted. Recommendations per Center for Disease Control (CDC) and local health departments were always practiced.

Summary

This chapter explains what methodology and steps were taken to conduct the study, ensure the integrity of this study and protect the privacy and confidentiality of all the participants' data and information. The chapter also explains the coding and the steps that were utilized for data analysis. The next chapter reviewed the results of the research related to pain management in CD and mindfulness practices.

Chapter 4: Results

Introduction

The purpose of this phenomenological study was to examine lived experiences of women who suffer from CD and experience chronic pain and endorse using mindfulness practices. Research questions were used to understand and identify the problem and purpose for this study:

RQ1: What is the lived experience of people who use mindfulness to help with chronic pain associated with dystonia?

RQ2: What is the lived experience involving pain within the context of dystonia for people with CD?

Chapter 4 includes descriptions of experiences of 10 women with CD based on findings from semi-structured interviews. This chapter includes a description of the study setting, sample demographics, data collection, and data analysis techniques. In this chapter, I also address issues of trustworthiness, credibility, transferability, dependability, and confirmability. This chapter concludes with study results and a summary.

Setting

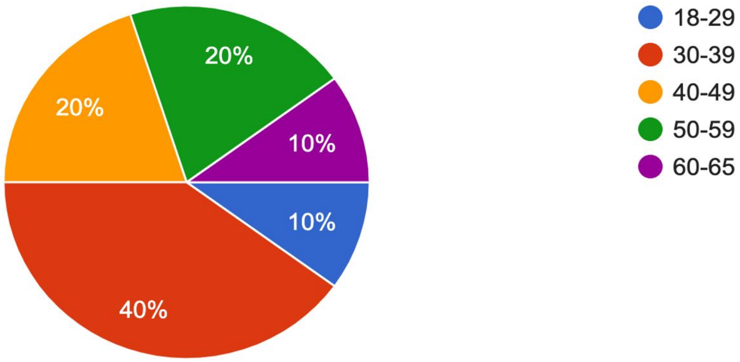
Interviews were conducted via Zoom and scheduled in advance with participants based on days and times that were convenient to them and myself. Participants were located worldwide; I was located in New Jersey. Scheduling interviews was challenging for some participants due to differences in time zones. On some occasions, schedules were changed, and interviews were rescheduled to accommodate participants' changing schedules. Zoom interviews took place in a quiet office room in my home using a password-protected wi-fi network. Privacy and consent to participate in the study were confirmed prior to recording each interview.

Demographics

Of the 10 female study participants diagnosed with CD, seven participants had been diagnosed for 6 or more years, and the other participants were diagnosed for less than 3 years. Participants were between 18 and 60, with most participants between 30 and 59. Eight participants were White/Caucasian, one participant was Asian or Asian American, and one other participant preferred not to indicate a racial or ethnic background.

Table 1

Participant Age Ranges



Data Collection

The study was started after final approval was given by the Walden University IRB (approval #03-23-21-0669360). I did not encounter any problems with recruiting individuals for the study, so no request for change in procedures was needed. All interviews were recorded with participants' permission and lasted between 35 and 60 minutes. Participants were told to ask if they needed any clarification or questions repeated. Also, participants were informed if a break was needed to communicate those needs to me. Some participants answered questions quickly, and other participants provided detailed answers. I asked participants to elaborate further if answers needed more explanation. At the end of each interview, participants were asked if there was anything they may want to add or further explain. Primary interview questions were consistent for each interview. On a few occasions, participants provided lengthy and detailed answers, which provided opportunities for additional elaboration of responses.

Data saturation was achieved after conducting 28 question semi-structured interviews (see Appendix C) with 10 female CD participants, so there was no need for further exploration with other participants. If new information was given, then I would have needed to continue analyzing data and interviewing until saturation was achieved. As no new information was discovered during data collection, it was evident that saturation was attained. Data were formulated and coded and research collection then ceased.

Following each interview, participants were asked if they felt any other questions should have been asked to provide richer descriptions of their experiences. At the end of each interview, participants were told that transcripts of interviews would be sent to them for review, and if they needed to add something, to put it at the bottom of a Word document without changing what was already typed, and then they would be called to discuss changes. No participants changed or added to transcripts.

Data Analysis

Data analysis was completed using the MAXQDA software and in-vivo coding. MAXQDA is a software designed for qualitative data analysis in recognition of German sociologist, Max Weber, gaining the name of MAXQDA. In vivo coding, also known as verbatim coding, natural coding, and inductive coding, is when researchers create their own codes (Charmaz 2014; Corbin & Strauss, 2015). I used a phenomenological approach with in vivo coding to address emergent themes from context rich descriptions provided by participants. The phenomenological approach allows for examination of lived experiences of research participants (Peoples, 2021). I examined all participant statements to find what was relevant. I read thoroughly through each participant's interview transcripts. Second, each important statement was reread, and I wrote notes involving relevance of participant responses to interview questions. Repetitive statements, as well as any overlapping statements, were also noted. Codes were then structured and developed using associated themes. Themes were used as the basis for descriptions of experiences.

Each interview was transcribed and read thoroughly; no analysis of any statements was made. During my second transcript reading, I generated short descriptions of interviews by highlighting main points, and these were structured and summarized. This allowed me to get a sense of each participant individually and put aside any biased ideas or thoughts. Interviews were then coded. Codes were developed by using phrases or words participants used in response to interview questions.

As a researcher with lived experience that is relevant to the topic, I used a hermeneutic circle approach for this study. The hermeneutic phenomenology is a constructivist approach. This approach helped in terms of constructing meanings of lived experiences of 10 participants. Participants' interpretations of their lived experiences were formulated for interpretation. The hermeneutic phenomenological approach was the best choice for this study because it allowed me to distill meanings of participants' experiences while accounting for my own relevant lived experience. The reflective journaling process allowed me to evaluate descriptions of my experiences and thoughts during all interviews. This allowed me to reflect on each interview before proceeding to the following interview.

I reflected on each interview, which allowed me time to explore what impact participants' responses had on themselves and me. As part of the interviewing process, I asked participants to provide feedback on any additional information or questions which should have been provided. P3 said:

> I think that the type of mindfulness or type of techniques vary widely and I think that could have an impact on if somebody just does the breathing or if somebody just does the stretches or do you know I mean or if you are just looking at it from physical mobility versus the ability to keep waking up every day and go to work or go doing what your purpose is at this point and time because there is very different directions that you could go with that.

P5 said, "I think you should add or talk about the breaths as it is really key in the mindfulness and that is kind of like the guide where we are at in our bodies. Like what state we are in and how calm we are so may the breaths question." P9 said, "I don't know what the family thinks about the diagnosis. I don't know if that relevant or not. It's really about the patient."

Evidence of Trustworthiness

Credibility

Credibility was confirmed during the interview process by utilizing semi-structured, open-ended questions which the participants had the opportunity to review and emend during the member check-in phase of the study. This form of interviewing permitted the participants to give detailed information on their feelings and thoughts regarding the questions and to incorporate the phenomenon (Ravitch & Carl, 2016). This method of interviewing permitted me to ask further clarifying questions to gain a full understanding of the CD participants' individual experiences. In accordance with the plan for credibility outlined in Chapter 3, all interviews were conducted via Zoom and audio recorded.

A transcript of the research participants' interviews was given to the participants for member checking to ensure words were accurately and properly transcribed. The research participants were free to provide corrections or further explanations to their interview question responses through member checking. After all the themes for the participants were developed, a collation of common themes for each participant's answers transpired, validating the data. However, the development of common themes achieved enough data and provided a detailed description of the phenomenon of the experiences of individuals with CD and saturation was achieved.

Transferability

Qualitative research is not meant to be generalizable; it is bound contextually with the development of descriptive, context-relevant statements (Ravitch & Carl, 2016). Transferability in this study was identified throughout each response in that the participants described the phenomenon of mindfulness. The experiences from the perspective of women with CD in managing symptoms related to chronic pain and other symptoms of the disease were all contextually similar. This study can be transferable to other chronic pain populations as it allows the audience of the research to identify with the lived experiences of individual’s who suffer with CD and chronic pain. Details from the individual interviews were included, providing context rich descriptions that could be compared to other contexts based on relevant information to help with transferability. (Ravitch & Carl, 2016).

Dependability

Ravitch & Carl (2016) stated that there are several ways to increase dependability of a study, among them are journaling, maintaining a log of itemized records of examination of notes, and arising subjects. Dependability was undertaken by using reflective journaling and note taking during the data analysis part to ensure the consistency of the interview quality. I used reflective journaling in my thought process to decide how to code and theme the data to make sure it was unbiased. To provide an in-depth, realistic description of the phenomenon of individuals with CD hearing all their stories from suffering from CD further establishes dependability. Inside phenomenological research, to foster a precise portrayal for the phenomenon being examined, the analyst should acquire point by point depiction from the participants (Moustakas, 1994).

Confirmability

Confirmability was established through reflexive journaling to show the findings and interpretations and to demonstrate how the interpretations and conclusions have been reached. Journaling was a method used by the researcher to help to alleviate any perspective biases as the researcher has first-hand knowledge of CD. Reflexive journaling began during the data collection phase to assure no biases were mapped on to the interpretations from the researcher (Ravitch & Carl, 2016). Following each interview, I reflected on that interview, including my responses to the participant interview, the participant's responses, and the environment in which the interview took place. By this process, I, as the researcher, provide a rationale for my interpretations, impressions, and thoughts throughout the data collection and analysis processes.

Results

The research questions for this project explore what the lived experiences of people with CD are and whether mindfulness helps them with this condition. For the first research questions there were two major themes that emerge: Loss of control and psychological impact of CD, especially anxiety and depression. For the second research question there were also two themes: mindfulness increasing functionality and mindfulness and hopefulness.

RQ1

Theme 1: Loss of Sense of Control

The first theme was participants describing how they struggled with a loss of independence because of the pain and symptoms from CD. One of the biggest issues with CD is the loss of physical control over their bodies from the constant involuntary movements and discomfort and pain due to the disease. Loss of control contributes to the participants' feeling of loss of independence and basic life functioning.

P1 said:

> Literally the pulling, the turning, the twisting part of it you know my head turns to the right and back so just that pulling and loss of control is very challenging and makes it challenging to walk, it makes it challenging to think because you are using these muscles in a way that you're constantly fighting against yourself in order to move and to move forward or to think properly.

Struggling with acceptance of the disease appeared to be a prominent concept among all participants upon initial diagnosis, which contributed to many participants' feelings in their loss of sense of control. Participants expressed the emotional and social aspects of the disease as very difficult in the beginning.

Camargo et al. (2015) said approximately 60% of CD individuals reported experiencing many different feelings such as tingling, pain, and aches connected to CD. P5 said,

> It was very hard for the first year and I started to like and then I met a friend online who had cervical dystonia and that was key, and it was very important to me in like getting some hope and just like getting understood by someone else and she was very proactive dealing with it like I was. So, and we were the same age

> so, yeah it was very intense I would focus solely on getting better and working with plans and gradually I just became used to taking care of that lifestyle and myself like that and I started to kind of open myself back up to the world.

P4 said, “upon diagnosis, it was quite frustrating. Just the lack of research in the variety of diagnosis was really frustrating because I couldn’t relate to any of the current at that time the research that was out there.” P10 said, “I am currently struggling with acceptance.” All participants shared similar experiences when expressing their thoughts and feelings about techniques.

Theme 2: Experience of Stress and Depression

This theme reflects the psychological impact of living with CD. CD has been known to have psychological impact due to the emotional trauma of the body, the overall loss of control and the decline in functionality. According to Zoons et al. (2017), CD causes individuals to experience uncontrollable movements, and this is associated with extreme pain. Adding to the loss of sense of control is the experience of depression.

Abdallah Geha (2017) said that a chronic illness can involve affective, behavioral, and cognitive processes to affect the management of the disease. P2 said:

> I was in a pretty deep depression when I was first diagnosed with CD. I have a little pity party and you know kind of go back to that remembering that time that was stressful and what life was before, but I really don’t go there often. I think that in time there has been a lot more acceptance and a lot more of forgiveness and I think a lot more of willingness on my part to do everything that I can to make myself have a good life. In the beginning I was so depressed.

P1 said:

> It's hard but it is not life ending but there are days when the symptoms get really bad. I don't have bad days anymore, but I have bad moments and during those bad moments it makes it challenging to want to present yourself to the world. When I feel like that, I have the control over my body although I know I still have dystonia and I feel it in my body, and I can function then I am ok with it as it is a part of who I am.

P8 said, "I didn't want to be here anymore and what was happening is that it kept getting worse."

P4 said, "I started listing digestive stress, emotional stress, mental stress"

Perozzo et al. (2016) said individuals with CD can show signs of heightened moodiness and anxiety. P10 said:

> I have become very socially anxious, and I try to avoid like going out and I like to go out and I love meeting new people but since this has gotten worse, and it has been like three years now and almost four years and I have no social life at all and this is the most challenging thing like social life.

RQ2

Research question two explored the lived experience of people who use mindfulness to help with CD. Two themes emerged from the data, mindfulness increasing functionality and hopefulness.

Theme 3: Mindfulness Increasing Functionality

This theme involves how mindfulness techniques help to increase functionality around pain. Participants found that mindfulness allowed them to have a coping mechanism that helped to expand their functionality and live a better quality of life. There are three ways in which respondents reported how mindfulness increased their functionality. The first one was physical, second one was psychological, and the third one was general relaxation. Mindfulness is a mental practice in which one pays attention to the present moment with a non-judgmental perspective to deal with what is happening (Zangi & Haugli, 2017). MBI focuses on the individual's ability to observe and accept experiences in the present moment as they develop stable non-reactive states of mind, which can improve physical functioning, psychological factors, and overall well-being (Zangi & Haugli, 2017).

In reference to mindfulness as it relates to pain, P6 said:

> It is so valuable to me to alleviate any of the symptoms but at the same time, I am aware that it doesn't take away all the pain, but it lessens it and I think that is the easiest and the best way of explaining it as it lessens the pain.

P8 said, "I reduced my pain from probably by 80% just by putting all of these symptoms into place." P10 said, "I really start doing the deep breathing and doing like the walking and going to the gym it completely helps. Like but I do not become A symptomatic but I deep inside I feel like 70-80% times better."

According to Greeson and Chin (2019), mindfulness promotes wellness and mind and body health regardless of the disease. Harrison et al. (2017) noted that non-pharmacological approaches, such as mindfulness, have been used to address pain within various medical conditions. The participants all noted how they found mindfulness as an important part of their learning to live with CD.

For some participants, the use of one mindfulness technique was the most useful; however, others employed several techniques to reduce pain. P7 said:

> I definitely know a difference in it though getting yourself on to a schedule of focusing on your breathing in doing some exercises for your neck and your whole body and then incorporating that time you can, for me meditation is most useful in the laying down position where my head is most supported or reclined in a chair rather than seated up in the upward position because of the support that it gives my neck.

Participants also indicated that mindfulness helped to relax their muscles to increase functionality. Participants described how mindfulness techniques are integral to their daily functioning. Participants indicated that relaxation of their muscles helps to alleviate some of the symptoms of CD and their pain. P1 said, “I do a series of neck exercises, yoga, meditation, mindfulness, stillness and knowing when to allow my body to relax that kind of stuff. I am trained in Reiki and Breathwork.” P2 said, “I use the meditation as it is my big foundation of what I am building when I want to be calm, relaxed and I want to be less tense.” P10 said, “So, I feel like deep breathing helps me in my lower chest in this area like when this area gets relaxed the whole body and my cervical dystonia gets like better and my whole body feels way relaxed.”

Having a range of motion was important to several participants as it helped them with gross motor movement and daily functioning. P3 said:

> The PT and yoga give me more range of motion which should loosen up the surrounding muscles which aren't necessarily dystonic but are stuck because of the dystonic muscles. Then I have all the mental stuff to get over the pain and the loss of all kinds of things due to dystonia, you know you lose a lot when you get this.

Participant #1 said:

> The point of mindfulness techniques is to get the muscle to relax and then to tone that muscle and then to restrengthen the muscle. So, the key is you can't exercise muscles that are in complete spasms as your body is so twisted that you can't move and do what you need to do, and it may make it worse. So, the beginning of my exercise is about learning to relax those muscles so that is what incorporates a lot of mindfulness and then developing exercises like turning the head that creates a range of motion.

In addition to helping increase physical functionality, mindfulness practices helped with psychological distress which was impairing quality of life. It provided relaxation and created a good mindset. P4 said:

> I usually start off with a positive attitude as I always wake up with a grateful heart knowing that I have been in this place, and I have come a long way and the ability to have that safe place to do it. So, I practice gratitude and positive affirmations and ensuring that my body understands that it is strong, healthy, and well. It is a big part of my life.

Mindfulness practice was shown to increase functionality by reducing experienced symptoms of anxiety. P7 said:

> My anxiety is less and when it does come up it gives me a tool to use. Like I said, if I am in a place where I feel like or I am starting to get stress, pain, or have a bad day coming on as I am somewhere I can't sit or support my neck those practices come into play and it definitely helps until I can remove myself from the situation and sit down or lay down or whatever I may need or what my body needs at that time.

P4 said:

> I also have been able to use the mindfulness to identify emotions, and that has been a big thing too. I have been able to improve that mind-body connection and have been able to sit with the emotions long enough to work through them.
>
> Mindfulness techniques have been beneficial in reducing the experienced anxiety through the reflection of the experience or situation. P2 said mindfulness was a reflective practice:
>
>> I do an hour-long meditation, and I think that over the last year that I really dedicated myself to that practice and so my ability to manage the pain is far greater and I feel that it also carries me thought so I feel that my experience in meditation that I really don't even have an awareness of discomfort but I struggled with a long time trying to carry that through my every day. Over the last year, that is something that I really found that as long as I stay committed to that practice in the morning and give myself

> that time, then I am able to carry it with me even when I get those heaps they are not always as intense, or they are just not bothering me that much, and I am able to focus on other things and not have my mind constantly going from this is horrible and awful and I am in so much pain.

One of the keyways that mindfulness helped people with CD is through relaxation, whether that is to physically or emotionally relax. Relaxation is particularly important to people with CD as it helps to relax the mind and muscles for better functionality. Beks et al. (2018) said individuals who suffer from chronic pain will decrease the pain through positive thought process. P9 said, “So, I feel like deep breathing help me in my lower chest in this area like when this area gets relaxed the whole body and my cervical dystonia gets like better and my whole body feels way relaxed.” The mindfulness practice of learning to be in the moment helped several participants to learn to relax, accept their emotions thoughts, and react in a more positive way of self-awareness. P6 said:

> They help me to be more at the moment and so I am not worrying quite so much about the future or about the pain, and they really help me to respond to my pain rather than react in a negative way. I am very conscious of responding to and not only my pain but my every day-to-day life.

P5 said: “They just really help me take some distance from the way that my body is feeling, my sensations and what is going on around me and become calmer in general.” Working with a psychotherapist to learn mindfulness relaxation techniques has been beneficial for P4, who said,

> So, I work with a dynamic psychotherapist now and we always have these kinds of talk with that you have a great study on how your body functions, and you have a great awareness of what's going to be your triggers. So, I mean that I have never had a negative experience as I chose to use these experiences as lessons to grow from, and so my body and mind are able to work cohesively and in alignment, and that is when I am striving at my best at my optimal function right then and there.

P1 said:

> I feel that my mind is very stable, and I do not freak out all the time like I have dystonia because I feel like I come back to center and that is what mindfulness does it brings you back to center and allows you to accept what it is that you are going through. So, to be aware of that it helps tremendously because it helps to accept what I am dealing with what I am going through.

P2 said:

> "I would say, oh gosh lots of advice to think that my first piece of advice would be that you know yourself better than anyone else and trust what your body is saying to you. Also, be open to the other things that can be small and thinking outside of the box. I do not think that it is just main stream medicine that is the cure all and that is we can have access to more alternative methods and pathways I think that it opens up the door on how we can deal with it as we are not treating the symptoms of the dystonia but we are really getting to the root of what and where do I hold tension and when do I have more symptoms of CD.

Theme 4: Hopefulness

The theme of hopefulness emerged when participants discussed how the experiences of CD changed their outlook on life. Many of the participants identified that they felt better after they were able to accept their disease and found the mindfulness practices, among other alternative and holistic practices helped to ease the experience of pain. 9 out of the 10 participants felt that mindfulness gave them hope in alleviating the pain associated with CD as well as a positive outlook that the disease could be controlled and was not all in their minds as they were once told by doctors. CD taught the participants that they were stronger than they thought they ever could be.

P1 said:

> [Mindfulness] has made me really focus on me and it has made me focus on my wellbeing and made me really focus on my own selfcare and I think when we take care of ourselves it is so much easier to want to take care of somebody else. So, it has kept my life very simple or keeps my life very simple.

Many participants stated that utilizing mindfulness has made them feel more hopeful about their future living with CD. Murphy (2016) said many positive benefits are seen in practicing mindfulness: P2 said,

> It was a blessing in disguise. I never asked for this to happen and in a lot of ways it did force me to grow and to recognize that a lot of inner anguish and it pushed me to use my experience to help others and that is what I do, I teach my experience to help others. So I think that in some ways it has been a gift, not one that I would have asked for but it really has given me an amazing amount of

> strength as I think I have realized ways I have always had but it really had been brought out when I can to that place well there is nothing that I can do about it so I might as well focus on the good."

P2 said:

> Well, I think it has helped me to manage this journey with these symptoms for sure. It has given me the ability to kind of know apparently that the sense of control well I almost feel like control is not the right word but there is something that I can do about it. Maybe I can't stop the pain from hurting and maybe I can't stop it from being what it is but I feel like there is a sense of being able to in tune with myself enough that I don't have to let it get worse umm and I think it has given me a lot of and it has given my voice for sure in being able to speak up for myself and you know to say no when I need to say no and to say yes when I need to say yes and to ask for help when I need to ask for help.

P1 said, "It's about using that sense of empowerment in order to heal, and I think that is good part of mindfulness." P5 said, "it helped me to force my way into mindfulness and so I am grateful for it."

Table 2

Participant Therapies

	Neck Exercises	Yoga	Meditation	Reiki	Deep Breathing	Mindfulness
P 1	X	X	X	X	X	X
P 2		X	X		X	X

P 3	X	X		X	X
P 4	X		X	X	
P 5	X	X			X
P 6	X	X		X	X
P 7	X	X		X	X
P 8	X	X		X	X
P 9	X	X		X	X
P10				X	X

Table 3

Themes

	Loss of Sense of Control	Experience of Stress & Depression	Mindfulness Increases Functionality	Hopefulness
P 1	X	X	X	X
P 2		X	X	X
P 3			X	
P 4	X	X	X	
P 5	X			X
P 6			X	
P 7			X	
P 8		X	X	X
P 9	X			
P10	X	X	X	

Summary

I explored lived experiences of 10 participants who were diagnosed with CD. The four themes that were identified were mindfulness, loss of sense of control, the experience of stress and depression, mindfulness increasing functionality (physical and psychological), and hopefulness. Participants shared many different emotions involving how they felt about suffering from CD. Many participants felt their CD was tolerable when using mindfulness techniques. They discussed other forms of mindfulness that they used to alleviate the pain of CD.

All participants were impacted in different ways in terms of coping with their CD. Participants used mindfulness coping during daily life activities. Women research participants felt that mindfulness techniques increased their QOL and were the best approaches to address CD pain. In Chapter 5, I interpret the study findings, and address limitations and recommendations as well as restrictions and social change implications.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The aim of this research study was to examine lived experiences of individuals living with CD who use mindfulness practices. Individuals who suffer from chronic pain and related conditions use mindfulness, but there is limited research on mindfulness techniques involving addressing chronic pain or other symptoms associated with CD. Addressing physical functioning is crucial in terms of improvement of QOL among pain management and chronic pain (Jackson et al., 2017). A qualitative phenomenological approach was used to gain knowledge of lived experiences of CD participants. The sample consisted of 10 females who were interviewed using one-to-one semi-structured interviews. All participants revealed they were impacted by CD both physically and psychologically. Some participants expressed that their condition influenced whether they wanted to socialize in public or leave their homes. These participants indicated a self-consciousness regarding their movement disorder with an accompanying fear of people's comments and ways that strangers looked at them. Participants shared their mindfulness practices and strategies such as meditation, deep breathing, yoga, four square breathing, and exercises that help with their pain or other CD symptoms. P1 said, "mindfulness, deep breathing, the yoga, the healthy eating all these things allowed me to regain control of my body." Finding a new normal for their daily routines is crucial to how they feel about themselves and their daily activities.

Interpretations of Findings

Many participants conveyed they tried many different methods to alleviate the pain and symptoms of CD and found that mindfulness methods work. Findings in this study did confirm that CD participants were able to use and greatly benefitted from mindfulness practices. Managing this neurological disorder is not an easy task as the neck, head, and shoulders are twisted and pulled involuntarily, and posture becomes distorted (Singh & Singh, 2016). CD is unpredictable due to involuntary spasms that are brought on any time without any warning. Although the disease is highly unpredictable, stress adds to physical discomfort of individuals diagnosed with CD due to increases in tremors and spasms. Mindfulness helps in managing these highly uncomfortable symptoms of CD. It increases functionality in participants in that it helps them feel better, and they were able to quiet their minds, which helped with emotional and social wellbeing. As treatment of CD is still controversial, this research showed that individuals who use mindfulness practices for the disease had a much better QOL. Mindfulness is used to treat chronic pain, but research is limited involving the effects of mindfulness in terms of decreasing physiological and psychological symptoms in relation to chronic pain. Finding new methods to alleviate chronic pain and stress may help individuals experience a positive QOL (Zoons et al., 2017).

Findings from this study aligned with relevant literature which showed that mindfulness practices are used for physical and psychological disorders. Harrison et al. (2017) said nonpharmacological and mindfulness practices have been used for pain that are associated with many medical illnesses. Based on findings of this study, it appears that the use of mindfulness practices may be valuable for individuals with CD. In addition to pain, participants indicated that mindfulness was helpful in terms of addressing the unpredictability of symptom onset. This is a unique finding of this study and an important consideration for CD sufferers for whom unpredictability of symptoms can represent major physical and psychological challenges.

A psychological challenge that participants acknowledged was the effect their CD symptoms had on their social life. Individuals with barriers in terms of positive social interactions often develop symptoms of depression and anxiety. Emotional aspects of CD have impacted participants' social life and family and friends. Many symptoms of CD are dismissed by physicians, as blood tests and imaging are often inconclusive. Social embarrassment as a result of CD as well as abnormal body positions can cause individuals to feel self-conscious and may cause them to isolate. When going out in public, stress causes symptoms such as spasms and head jerking to occur. Many individuals feel that CD impacts their social life and causes them to experience self-consciousness about their appearance. Many individuals with CD experience feelings of judgment from others, which may be due to lack of awareness about the disease.

As previously discussed, many participants felt their CD symptoms affected their ability to maintain positive social interactions. Several participants described exponential increases in anxiety and development of depression and fear, which caused them to isolate and become introverted. According to Murphy (2016), mindfulness helps with depression, reduction of pain, anxiety, and stress. P10 said, "it causes you to feel self-conscious about the spasms, resulting in isolation." P8 said, "dealing with the pain and isolation because of non-believers is difficult.” Some participants developed stress and depression due to ways people treated them when they were in public. Another stressor was that many doctors did not understand their symptoms that they were describing, and this caused them to shut down and feel sad and defeated. CD is an extremely complex disease and affects cognitive, emotional, physical, and psychological behavior, which can impact individual self-image (Shukla et al., 2016; Werle et al., 2014).

Mindfulness is a hopeful approach to address chronic stress. Hentschel et al. (2016) said CD is linked to depression in individuals with uncontrollable movement disorders. The study also showed that participants used mindfulness to cope with life, work, and daily activities. Participants expressed they employed a range of mindfulness practices such as tapping, four-point breathing, Reiki, Acupuncture, Tai Chi, EMDR, and music to manage mental and psychological effects as well as pain of CD.

Some participants described daily stressors. They reported experiencing extreme fatigue and exhaustion; as a result, they had to limit activities and rest during the day in between everyday activities. Some participants were unable to work or had to cut back from full time to part time, which they associated with anxiety, depression, and stress. These emotional stressors related to their need to curtail activities which were triggered by CD symptoms of spasms and pain. Many participants lacked energy and were unable to make plans with friends and family as they were unsure of how they would feel. This causes frustration as CD symptoms can cause individuals to miss out on weddings, baptism, birthday parties, picnics, or family get togethers. Abdallah & Geha (2017) said psychological stress can change individual behavior, performance, and affective reactions, which can affect QOL as well as pain management. Mindfulness helps in terms of seizing opportunities for participants to reduce symptoms of CD. Mindfulness can help to improve cognitive performance and overall health and wellbeing. Mindfulness assists to increase functionality and can give individuals a better QOL. Mindfulness has many benefits as it guides the mind and body to feel less stress and can give an individual a better frame of mind which allows them to feel more positive and stronger.

Many CD participants stated it was difficult to find a doctor to understand symptoms and pain they were experiencing. The CD diagnosis was difficult to achieve due to the lack of knowledge of the disease. Some participants were told the symptoms and pain they were experiencing was on in their head and they needed to take medication for the pain and to seek help from a psychiatrist or psychologist. Differential diagnoses were given as movement disorders can mimic one another. For example, CD at times may be misdiagnosed as Parkinson's disease. Kida et al., (2018) stated that CD can develop at the end of Parkinson's disease. A lack of CD knowledge caused a few participants to not seek help when experiencing the symptoms of CD. The participants stated that they did not feel comfortable or did not trust the physician as they were made to feel that their feelings did not matter, or they were not real. For example, a few participants decided to research their symptoms and tried mindfulness techniques that they found to be a life changer. The difficulty in engaging medical personnel led to delays in getting diagnosis and treatment and may have undermined the participants' confidence in their own self-assessment of their challenges.

The participants had so many different ways of thinking about mindfulness. The participants knew that yoga, meditation, breathing were all forms of mindfulness but did not know that you can use mindfulness in all aspects of your life. For example, you can use mindfulness when you are walking, cleaning, washing your hands, dishes, sitting in the sun or simply sitting in a quiet space and relaxing. This established Bandura, (1997) SRT which describes individuals' ability to control how they are behaving, thinking, and feeling. Bandura's SRT describes an individual's thoughts, behaviors, and feelings with utilizing three different elements, self-evaluation of one's behavior, self-monitoring, and affective self-reactions. Mindfulness helps individuals to reflect on cognitive processes, self-appraisal, affective self-reaction, evaluation of judgement to manage environmental behaviors (Bandura, 1991). Mindfulness can help to achieve the ability to control their life. Mindfulness methods help to develop self-awareness and gives the individual to the ability to self-focus on their needs and can increase self-transcendence. Future research should consider furthering the literature on mindfulness in relationship to CD with using the framework of Bandura's SRT.

Zangi and Haugli (2017) said mindfulness is a mental method in where an individual pays attention in a non-judgmental way to deal with what is going on. When individuals constantly experience fear, loss of control or anxiety due to chronic illness it causes them to have to quickly adapt to changes they never have experienced before. Changes in QOL due to chronic illness change an individual's perspective from what they once felt and saw as normal to an uncontrollable life with many unforeseen or understood events. The findings from this study have provided valuable understanding and rich descriptions of the lived experiences of individuals with CD and their use of mindfulness to control and manage their symptoms and pain. My findings did not reveal CD participants having a greater dependence on medications to help with the symptoms associated with CD.

Limitations of the Study

There were limitations of this research study. All the CD participants have been diagnosed with CD but only 9 out of 10 are experiencing pain. I was extremely careful that my own bias did not factor into this research as I used semi-structured interview questions and transcribed the interview data verbatim and never used any of my own words. I conducted the interviews via ZOOM and wonder if some of the participants answers were shortened due to their severity of pain that they may have been experiencing. Future research may be considered for a face to face in person interview or use of subjective units of distress to identify the levels of the participants pain on the day of the interview.

The focus of this research was to recruit CD individuals from Facebook to understand the lived experiences of their CD and the utilization of mindfulness. A few of the participants did state that they had other illness such as sciatic arthritis, Parkinson’s, hypermobility syndrome, Cranial Continuum, and migraines. In the understanding with the context of lived the experiences of pain associated with CD it is unclear that severity of pain can solely be associated with CD pain as a few of the participants had comorbid illnesses that are also associated with pain symptoms (i.e., hypermobility syndrome, Parkinson’s, and migraines).

Recommendations

The research study presented information on the lived experiences of CD as well as how these participants manage this chronic illness by utilizing mindfulness methods. According to Beks et al., (2018) individuals who suffer from chronic pain, will decrease the pain if they have positive thoughts. There are various ways to build upon this study with future research utilizing male participants, increasing the sample size and mixed methods approach including face-to-face (as compared to Zoom) interviews. According to Mahajan et al., (2018) chronic pain continues to be an issue for those with CD as well as complicating the management of dystonia. Sandhu et al., (2016) stated that relying on medication for dystonia does not help individuals who experience side effects; mindfulness practice has shown great long-term management associated with pain. Findings from this study also indicate that mindfulness practices help to manage symptoms of pain as several participants have used mindfulness for 10 plus years. Participants expressed their frustrations with treatment options therefore another recommendation would be to educate the doctors on what CD is and explain what options are available to the patients to help with the management of CD and pain.

Social change can occur when more individuals understand CD and the lived experience of individuals who suffer from CD. Bumping up the level of awareness of this disorder might help individuals in social situations and might help the medical community diagnose and treat CD in a timelier way.

According to the participants in this study, mindfulness practices can help improve the symptoms of CD by alleviating pain, helping restore a sense of control over their uncontrollable body movements and the condition and aiding functionality. Utilizing mindfulness practices such as deep breathing, meditation, yoga can help to reduce depression, anxiety, stress, pain, and can increase an individual’s quality of life. Participants reported that mindfulness practices have changed their lives for the better. Many of the CD participants felt that mindfulness has helped them to feel more present in the moment and to experience more good days than bad. Utilizing mindfulness techniques such as walking, meditation, yoga, and deep breathing has made a few of the CD participants feel better about their life and gave them a more positive outlook of their everyday tasks. Zoons et al. (2017) said finding different ways to help with stress in chronic pain helps individuals to have a positive view on life as well as their disease. The research participants stated that since they started practicing mindfulness that they have significantly noticed that they think less about the CD and how it affects their lives and more about accomplishing daily activities. Many of the participants stated that their anxiety, depression, pain, and stress decreased, and they are much happier and live a better QOL. Mindfulness has given many of the participants hope that they once had lost. Although mindfulness is not a cure it is the answer to many of the problems that CD individuals have experienced.

Implications

The study findings have important implications for those suffering from pain within the context of CD and for those working with individuals with who experience pain in relationship to their CD. Mindfulness practices can be valuable for individuals with CD who are actively coping with pain caused by CD. The participants endorsed that mindfulness practices increased their functionality and helped them to be more hopeful about managing pain, this study contributes qualitative data to the field of psychology that demonstrated the value of mindfulness for pain, functionality and sense of control associated with CD as a chronic illness. More research is warranted on mindfulness regarding how it helps with CD and pain. Replications and extension of this research study may help doctors, patients, psychologist, and psychiatrist who are seeking non-pharmacological approaches to pain managements. Researchers can expand on this study through mixed methods or quantitative research to aim towards generalizing a wider population. Mindfulness can be implemented into healthcare practices as a new form of therapy for their patients who are suffering from CD or any other chronic illnesses.

Furthermore, the implications of this study suggest that physicians and psychologist need to gain more knowledge of CD and how mindfulness can help to contribute to patients' QOL. This study helps to give clarity to the lived experience of CD individuals and to the benefits of mindfulness practices. More knowledge of CD and the approaches that help to alleviate pain associated with the disease will help individuals to experience a better QOL. Knowing the options that are available to them will help individuals to pick the right course of action for their care. Having a say in your health care is going to be beneficial for the doctors as well as the patients as it will help them to decide what works best for them and to alleviate the pain and symptoms associated with their disease. As shown from this study SRT as a framework was valuable in identifying the individual's feelings, behaviors, and thoughts in managing their own treatment for CD both pharmacologically and non-pharmacologically.

Individuals with CD would benefit from more psychoeducation on mindfulness practice as a non-pharmacological means of addressing symptoms of their condition. Psychologists working with individuals with CD might want to consider introducing mindfulness practices into their work with clients. As a profession, psychologists need to be more cognizant of the value of mindfulness practices within the services we offer to our clients and help them understand the non-pharmacological approaches that may be beneficial for their situation. More knowledge about non-pharmacological approaches will help individuals who might otherwise not understand what choices for coping with pain in CD are available to them.

Conclusion

The aim of this phenomenological study was driven by my curiosity to find out if people were utilizing mindfulness practices as a non-pharmacological/non-medical approach to address the symptoms of Cervical Dystonia. It was also conducted by someone who has first-hand knowledge of how this disease can change one’s life and how medications can cause more complications due to affects they may have on the disease or the body. Many of the research participants stated that mindfulness was beneficial as no prescription is needed and mindfulness can be done at any time or anywhere. Greeson & Chin, (2019) stated that mindfulness is used as a coping strategy to promote wellness of the mind and body, health, and no matter the state of the disease.

Individuals in this study possessed limited understanding regarding the usefulness of mindfulness. Due to the limited understanding of mindfulness individuals in this study were uncertain as to how useful mindfulness can be in coping with CD.

P2 said:

> "I actually began practicing mindfulness before I was diagnosed with dystonia and before the tremor began. I have been practicing for my own mental health and then it really became kind of my mission once I was diagnosed and decided that I didn't want to be miserable anymore and I needed to find something as I am so sensitive to medication".

Gender played an important role in use of mindfulness. 9-10 female participants stated that they only utilized mindfulness practices after their CD diagnosis and never thought about the possible benefits of mindfulness prior to the disease.

Interviewing these participants has shown me that no matter what may occur in life, how you look at things is what will help you to survive this life's journey. It was evident that all the literature has shown that mindfulness is a great resource to utilize no matter what stage the disease may be in. Mindfulness is a powerful tool that can be used at any place and time and needs no prescription. Being able to utilize mindfulness can help individuals to become more focused on positive views and behaviors. Mindfulness is not a cure for individuals who suffer from CD but is a new method that can help alleviate symptoms and pain of the disease. This disease not only hurts individuals mentally and physically but also may cause problems with family, relationships, and friendships.

Mindfulness is a nonpharmacological method that can be practiced in any form that is comfortable for the individual and for as long or short as they can withstand. Many of the CD participants expressed that they wanted to give up and felt heartbroken and hopeless. Many of the participants felt that they had a loss of control in their lives which lead to high levels of depression and anxiety. Many participants researched alternative treatments and found mindfulness methods worked best for them physically and psychologically. Not only did their flexibility increase but their emotions were lifted and the ability to function psychologically became easier.

I learned from this research that mindfulness has benefits. Mindfulness helps the body in terms of flexibility, which can be beneficial when the neck and shoulders start to develop uncontrollable spasms. Mindfulness methods are being used to treat pain, but there is limited literature on mind and body interventions in terms of treatment of CD.

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Appendix A: Pre-Interview Survey

Cervical Dystonia Research Study

Please complete the following questions to the best of your ability. This information will only be used for descriptive purpose and your answered will not be designated to you personally but will help to describe the participant group as a whole. Your answers will help the researcher during the interview process.

1. **Have you been diagnosed with Cervical Dystonia?**

○ Yes
○ No

2. **What is your current age group?**

○ 18-29
○ 30-39
○ 40-49
○ 50-59
○ 60-65

3. **Do you use mindfulness techniques to alleviate chronic pain for CD?**

○ Yes
○ No

4. **What is your household income?**

○ Under 15,000
○ Between 15,00 and 30,000
○ Between 30,00 and 50,000
○ Between 50,000 and 75,000
○ Between 75,00 and 100,000
○ Over 100,000

5. **What is your race or ethnic background?**

○ White or Caucasian
○ Black or African American
○ Asian or Asian American
○ Native American or Alaska Indian
○ Native Hawaiian or other Pacific Islander
○ Hispanic or Latino
○ Another Race
○ Prefer Not to Say

6. **Are you currently employed?**

- Yes
- No
- Other

7. **What is your relationship status?**

- Married
- Single
- Divorced
- Domestic Partnership
- Widow
- Prefer Not to Say

8. **What kind of mindfulness techniques do you currently use?**

- Yoga
- Meditation
- Stretching
- Deep Breathing
- Weights
- Exercising (Cardio)
- Walking
- Other

9. **How often do you experience chronic pain associated with CD?**

- Always
- Sometimes
- Never
- Usually
- Rarely

10. **How long have you been diagnosed with CD?**

- Less than one year
- 1-3 years
- 4-6 years
- 6-9 years
- 10+ years

Appendix B: Interview Questions

9IQ1 What has been your experience of Cervical Dystonia?

IQ2 What are the most challenging aspects of this for you?

IQ3 What aspect of your CD pain do you experience that is most challenging?

IQ4 What is it like living with CD?

IQ5 How long have you had the diagnosis of CD?

IQ6 Do you experience pain relevant to any other condition?

IQ7 Where do you feel the most pain?

IQ8 How did you begin using non-medical techniques?

IQ9 What was it like for you when you were first diagnosed with CD?

IQ10 How have your symptoms changed from when you were first diagnosed to the present?

IQ11 What is it like for you as the years have gone by dealing with your symptoms?

IQ12 What are the main treatments that you have tried for managing pain associated with CD?

IQ13 How long was the treatment you used effective with pain management?

IQ14 Do you have any concerns about your pain management?

IQ15 As you experience the pain with CD what techniques do you feel helps the most?

IQ16 If you could practice one technique to alleviate the pain of CD what method would you choose and why?

IQ17 If you could give someone who was diagnosed with CD any advice on how to alleviate their pain what would it be?

IQ18 (You endorsed that you use mindfulness techniques) What mindfulness techniques do you use?

IQ19 Before your diagnosis of CD did you utilize mindfulness practices? If so which ones?

IQ20 How have you benefited from these mindfulness practices?

IQ21 After your CD diagnosis did it become harder to practice mindfulness techniques that you were using, or did you have to find other techniques that worked better for you?

IQ22 What is your experiences of CD with using psychotherapy that includes mindfulness (yoga, deep breathing, and meditation) strategies for pain reduction?

IQ23 Can you describe how you use mindfulness practices? Which ones do you use? What technique do you find to be the most valuable? How or Why?

IQ24 Are there any techniques that you previously described that you use specifically to address your type of pain?

IQ25 How has your mindfulness therapies been more effective than other therapies you have used?

IQ26 What value if any does mindfulness practices for addressing your pain associated with the symptoms of the CD?

IQ27 Have mindfulness practices been helpful to you in addressing symptoms other pain associated with CD?

IQ28 Describe any connection that you see between your mindfulness-based practice and your experience of CD?

Additional questions will be asked based on participants responses.

Appendix C: Recruitment Flyer

Do you have Cervical Dystonia? Do you use non-medical techniques to alleviate your pain symptoms?

A new study invites women participants to describe their lived experiences with CD pain and your use of mindfulness.

There is a new study called *"A Qualitative Study of Mindfulness Practice related to Cervical Dystonia"* that could help care providers like doctors and counselors better understand and help their patients. For this study, you are invited to describe your lived experiences using mindfulness treatments.

This interview is part of the doctoral study for a Ph.D. student at Walden University. Please provide days and times that you are available for a prescreen interview along with a contact phone number.

About the study:

- One 30-60-minute interview
- To protect your privacy, no names will be collected

Volunteers must meet these requirements:

- 18-60 years of age
- History of using mindfulness therapy
- Currently using mindfulness practices such as yoga, meditation, exercise, and deep breathing to alleviate pain