

**EXPLORING PARTICIPANTS' EXPERIENCES OF AN 8-WEEK MINDFULNESS-
BASED STRESS REDUCTION (MBSR) PROGRAM IN THE CONTEXT OF
ADAPTING TO LIVING WITH CHRONIC PAIN**

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ABSTRACT

At least one in five Canadians lives with chronic pain, and the prevalence rate is rising. Chronic pain can be a result of injury, disease, surgery, and in some cases, the cause remains unknown. Due to the complexity and variability in the etiology and presentation of chronic pain, it can often be a challenge to implement an appropriate and effective treatment plan. Often, the effects of chronic pain are so debilitating that relief is only available temporarily with pain medication. However, there is the concern and possibility of addiction, health issues, and even increased risk of death with some medicinal interventions.

Living with chronic pain can have widespread ramifications, affecting more than just the physical body. This includes psychological, emotional, interpersonal, and vocational challenges. In essence, all aspects of one's quality of life can be affected by chronic pain. As chronic pain often persists over many years or even the lifetime, it is important to better understand how one might adapt to living with chronic pain. Mindfulness-Based Stress Reduction (MBSR) is a structured 8-week program that is commonly used as an intervention for people living with chronic pain, as several research studies have shown promising effects on pain outcomes and quality of life.

Using hermeneutic phenomenology, the purpose of this study is to learn about the lived experiences of participating in an 8-week MBSR program from those living with chronic pain. Particularly, it explores how, if at all, an MBSR program may play a role in the participants' adaptation to living with chronic pain. In depth semi-structured interviews were conducted with 3 participants at the end of the MBSR program. They were then analyzed, interpreted and checked by the researcher. The interpretative analysis involved the researcher explicitly detailing

their own positioning in order to inform the interpretations and allow for a well-informed continued interpretation and understanding from readers.

Overall, participants described several key aspects which may shed light into the benefits that MBSR can have in regards to adaptation to chronic pain as delineated by the following categories: physical pain and pain management, self-perception and identity, relationship dynamics, and emotional equilibrium. Lastly, broader themes included: being heard and understood, letting go and being here, the healing perspective, and moving from surviving to living. The results of this study speaks to the experience of living with chronic pain, and how an MBSR program offers the tools to help facilitate the adaptation process to living with chronic pain, thereby improving quality of life.

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DEDICATION

To all those living with chronic pain, this was inspired by you and written for you.

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CHAPTER 1: INTRODUCTION

Preface

“It made no sense to me that with all the modern miracles in medicine there was no way to relieve my pain. What I did not realize then was how complex chronic pain is. I did not know how many areas of my life and my family’s lives the pain invaded” (IOM, 2011, p.11).

Chronic pain is unquestionably a complex and intrusive condition that can alter one’s life entirely. Many people living with chronic pain are subjected to several treatments and interventions with the ultimate hope of pain relief. Despite the modern miracles in medicine, chronic pain persists for many. In addition to trying to discover drugs or interventions that might eliminate pain, it is important for researchers to try and understand how one might adapt to, or experience their pain, in a way that ultimately reduces suffering.

Pain Defined

The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage ... Pain is always subjective ... It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore an emotional experience” (IASP, 1994, p. 210).

Pain can be divided into two categories: acute pain and chronic pain. The Institute of Medicine (IOM, 2011) offers that acute pain often has a specific cause, such as injury or disease, with a sudden onset and a hopeful prognosis of a quick recovery. For example, a trauma leading to a broken bone, or the postoperative time after a surgical procedure, can often be the source of acute pain. Therefore, acute pain is an outcome of an event which causes tissue damage, and as a result, is often described as a symptom (EFIC, 2001). Interestingly, acute pain is explained as an

adaptive response, as it serves as a signal to the brain that there is tissue damage, warning the individual of harm and the need for help (EFIC, 2001). Although acute pain can be successfully treated with sound patient outcome, it is nevertheless important to recognize the possibility of the developed from acute pain into chronic pain.

In contrast, chronic pain is variably defined as pain that lasts longer than 3 to 6 months, but definitely exceeding what the “normal healing” period should be (IOM, 2011, p.33). In other words, the pain perseveres past the adaptive and usefulness stage of the signal and even after the tissue damage has been treated and has healed (EFIC, 2001). Therefore, it has been argued that chronic pain may not be the direct outcome of an initial injury or disease like acute pain, but rather due to a specific pathology and derived secondary changes that occur to the nervous system (IOM, 2011, p.3).

To summarize, the key distinguishing factors between acute and chronic pain are the length of time from pain onset to recovery, the pathology involved, the level of deterioration, and the biological usefulness of the pain (Jackson, 2000). Chronic pain is now recognized as a disease in and of itself.

Prevalence of Chronic Pain in Canada

An analysis using data from seven cross-sectional cycles in the National Population Health Survey (>25 years of age) and the Canadian Community Health Survey (>20 years of age) graphed the prevalence of chronic pain in the Canadian population from 1994 to 2008, and reported prevalence estimates of 15.1% to 18.9% over time (Reitsma, Tranmer, Buchanan, & Vandenberg, 2011). With the exception of one cycle (1994/1995 to 1996/1997), there has

been a progressive increase over time, with a significant increase from a rate of 15.1% in 1996/97 to 18.5% in 2007/08 (Reitsma et al., 2011).

Furthermore, the survey data found that there were higher pain estimates among women than men in each time cycle, with estimates ranging from 13.6% to 16.2% in men and 16.5% to 21.5% in women. There was also a significant difference in the prevalence of pain between age groups, with prevalence rates increasing with age. Particularly, the highest rate of chronic pain was 31% among those aged 65 years and older (Reitsma et al., 2011).

Another survey study assessed the prevalence of Canadians living with chronic pain, and found that from a random sample of 2012 Canadian adults, 29% of respondents reported experiencing chronic pain (Moulin, Clark, Speechley, & Morley-Forster, 2002). This study also found a higher prevalence of chronic pain among women (31%) compared to men (27%), and among those 55 years and older (39%).

A more recent study sought to capture chronic pain in Canada by using a strict screening process. The inclusion criteria consisted of the IASP definition of pain lasting 6 months or longer, suffering several times a week or more, and with a specific score on a pain severity rating (Schopflocher, Taenzer, & Jovey, 2011). This study found the prevalence of chronic pain to be 18.9% among adults aged 18 years or older in Canada.

Although there is variability in the reported prevalence rates of chronic pain, it appears that it affects at least 1 in 5 Canadians, with rates increasing among the aging population (Millar, 1996; Moulin et al., 2002; Schopflocher et al., 2011).

We can expect the prevalence of chronic pain to increase because (IOM, 2011):

1. There is an increase in the aging population, which means there will be more people living with painful medical conditions and diseases.
2. There is a rising prevalence of obesity which is linked to painful conditions like diabetic peripheral neuropathy, and orthopedic problems resulting in surgery.
3. Although medical advancements are improving, and more lives are being saved from traumatic injuries, there are increased levels of chronic pain in relation to survival.
4. There is a concern of post-surgical pain trending away from acute pain towards chronic pain.
5. Education and awareness about chronic pain and its' treatment are rising, which may cause more people living with pain to come forward and seek treatment.

Needless to say, chronic pain is a highly prevalent and serious problem among our population and healthcare system today. Furthermore, the anticipation of a steady rise in prevalence, particularly with our aging population, undoubtedly deems chronic pain as a major public health issue.

Etiology of Chronic Pain

There are several causes of chronic pain, and in many cases, the reasons are unknown. Although this poses a challenge for the understanding and etiology of chronic pain, the general causes of chronic pain can be categorized (IOM, 2011).

First, age is a common factor, as “wear and tear” can cause arthritis among an older population, which is a common source of chronic pain. Secondly, genetics can play a role, as certain predispositions may increase the chances of chronic pain caused by migraines, for example. Commonly, chronic pain can also be a relentless element of chronic disease, such as cancer, heart disease, endometriosis, and diabetes. Furthermore, surgery can result in

postoperative chronic pain, as a result of nerve damage. Lastly, injury and trauma are predominant causes of chronic pain, particularly for low back pain (IOM, 2011). Some types of pain, such as neuropathic pain, can either be a cause of disease such as diabetes or injury such as spinal cord damage (IOM, 2011). However, conditions such as fibromyalgia, irritable bowel syndrome, and chronic headaches are among the types of chronic pain that are not as easily explained or understood.

Overall, chronic pain is most often associated with other chronic diseases and terminal illnesses, or persistent pain after illness or injury (Lynch, 2011). It is now understood that chronic pain involves a neural response to disease or tissue injury, and these responses can “trigger long-lasting changes in peripheral nerves, spinal cord and brain such that the system becomes sensitized and capable of spontaneous activity or of responding to non-noxious stimuli, which results in pain. In this case, pain persists beyond the point where normal healing takes place and is often associated with abnormal sensory findings” (Lynch, 2011, p. 78).

Mindfulness

Mindfulness is rooted in the teachings of the Buddha, and has been described as “the heart” of Buddhist meditation (Thera, 1962). In its’ origin from the ancient Indian language of Pali, the word ‘Buddha’ means ‘to awaken’ or ‘to understand’ (Huxter, 2007). Through the teachings of the Dharma, the Buddha taught ways to understand or awaken to the truth (Huxter, 2007). One of the most fundamental Buddhist practices can be described by the Pali term ‘sati’, which was first translated into the English term of mindfulness in 1921 (Davids & Stede, 1921/2001). Although the exact definition has varied across authors, ‘sati’ signifies attention, awareness, and remembering (Siegel, Germer, & Olendzki, 2009), which are all integral to Buddhist practice.

However, mindfulness is not solely a Buddhist way of being, as the Buddha had the insight to teach in a way that would be applicable to other cultures (Huxter, 2007). The Buddha taught practices such as mindfulness in such a way that it could be realized without an authority but rather on one's own.

Although the term mindfulness was coined centuries ago, the most common, or well-recognized Western definition is that of John Kabat-Zinn (1994) as he defines mindfulness as “paying attention in a particular way, on purpose, in the present moment, and nonjudgmentally” (p. 4). However, mindfulness can be described and variably understood in different contexts and as such, many definitions have unfolded, including that of Bishop et al. (2004) who operationalizes mindfulness as, “self-regulation of attention so that it is maintained on immediate experience, thereby allowing for increased recognition of mental events in the present moment” in addition to “adopting a particular orientation toward one's experience that is characterized by curiosity, openness, and acceptance” (p.232). A definition more specific to *therapeutic mindfulness* has been described and adopted by the Institute of Meditation and Psychotherapy, which they define as “awareness, of present experience, with acceptance” (Germer, Siegel, & Fulton, 2005). Additionally, the term mindfulness is often used synonymously with acceptance in clinical psychology (Germer, Siegel, & Olendzki, 2009) and in education it has been explained as “a cognitive process that implies openness, curiosity, and awareness of more than one perspective” (Langer, 1989).

Commonly, and at the root of all definitions, is that the intention of practicing mindfulness can be understood as “actively working with states of mind in order to abide peacefully in the midst of whatever happens” (Siegel, Germer, & Olendzki, 2009, p. 18).

At the core of mindfulness is the view that human suffering, both of self and others, may be alleviated “through meditative practices that calm and clarify the mind, open the heart, and refine attention and action” (Kabat-Zinn, 2003). Meditation is a component of mindfulness practice and can take place in several forms, including concentration, lovingkindness, and mindfulness meditation (Siegel, Germer, & Olendzki, 2009). While concentration meditation has a central focus such as the breath to bring calmness, and lovingkindness meditation sets an intention to be loving and kind and to experience a moment as it is, mindfulness meditation seeks to explore change and gain insight into one’s condition (Siegel, Germer, & Olendzki, 2009). Overall, Shapiro (1980) defines meditation as “a family of techniques which have in common a conscious attempt to focus attention in a non-analytical way, and an attempt not to dwell on discursive, ruminating thought” (p.14).

As Kabat-Zinn’s definition of mindfulness is the most common Western definition, and this thesis is structured around his mindfulness program, it is important to consider other aspects of Kabat Zinn’s teachings surrounding mindfulness. Importantly, he believes that mindfulness is not a notion or a concept or something to ponder. Rather, it is a way of being, and can be understood as an attitude. Particularly, as the words “mind” and “heart” are often used to mean the same thing in the context of Asian language, the term heartfulness can also mean mindfulness (Kabat-Zinn, 2013). Furthermore, Kabat-Zinn (2013) describes the endless value of awareness as he explains awareness as “a kind of knowing that is simply bigger than thought and gives us many more options for how we might choose to be in relationship to whatever arises in our minds and hearts, our bodies and our lives” (2013, p. xxxv). Essentially, it is our relations that Kabat-Zinn believes to be at the core of mindfulness, including how we are in relationship to our

own minds, bodies, thoughts and emotions. Mindfulness fosters integrity, kindness, and wisdom, and is meant to be a way of living and being.

Kabat-Zinn compares mindfulness to any other skill, in that it can be developed through practice (2013). However, it is imperative that a person must carry a certain attitude in order to practice mindfulness, which includes the following: non-judging, patience, beginner's mind, trust, non-striving, acceptance, and letting go. Moreover, it is important that these attitudes are cultivated by commitment, self-discipline, and with intention (Kabat-Zinn, 2013). With these attitudes, the cultivation of mindfulness can begin through practices such as meditation, yoga, body scans, walking, eating, and breathing. Lastly, practicing mindfulness does not need to be limited to these activities, for mindfulness can be cultivated with all tasks of daily living, including washing the dishes and cleaning the house to taking the bus and walking the dog, so long as moment-to-moment attention is brought to these tasks (Kabat-Zinn, 2013).

CHAPTER 2: REVIEW OF THE LITERATURE

Living with Chronic Illness or Disability

Facing chronic illness and disability (CID) is a life-changing event. It often involves a lifelong process of adapting to significant physical, psychological, social, and environmental changes (Bishop, 2005). Not surprisingly, the adaptation process to living with CID is both intricate and subjective (Bishop, 2005). However, several factors impact those living with CID, including the following: functional limitations, interference with the ability to perform daily activities and life roles, uncertain prognosis, prolonged course of medical treatment and rehabilitation interventions, psychosocial stress associated with the trauma or disease process, impact on family and friends, and sustained financial losses (Livneh & Antonak, 2005).

Psychosocial Adaptation. Psychosocial adaptation can be understood as the process of responding to changes that occur as a result of living with a disability or chronic illness, and in particular with the functional, psychological, and social changes (Bishop, 2005). Many concepts interact and affect the process of psychosocial adaptation including stress, crisis, loss and grief, body image, self-concept, stigma, uncertainty and unpredictability, and quality of life (Livneh & Antonak, 2005). Taken together, Livneh and Antonak (2005) define psychosocial adaptation as, “the process in which a person with a disability moves from a state of disablement to a state of enablement and is characterized by the transformation from negative to positive well-being”.

Psychosocial adaptation is an important part of rehabilitation for those living with all types of chronic illness or disease, including chronic pain. Undoubtedly, the psychosocial implications of chronic pain are in large part due to the long duration of the disease. It is not uncommon for patients to report living with chronic pain for more than 10 (Moulin, Clark,

Speechley, & Morley-Forster, 2002) or even 20 years (Breivik, Collet, Ventafridda, Coehn, & Gallacher, 2006).

The following section provides an overview of the various psychosocial consequences experienced by those living with chronic pain, including the mental health, social, vocational, and medical challenges.

Mental Health Implications. There is a large body of research describing the comorbidity of mental and physical health problems (Dersh, Polatin, & Gatchel, 2002), and the intersection of the two is most pronounced among pain disorders (Gatchel, 2004). Although it is well-documented that physical pain and mental health disorders often co-occur, the directionality of the relationship between physical pain and mental health disorders is variable. Research has shown that as anxiety or depression heightens, physical symptoms worsen, and that those with more physical symptoms have an increased risk of developing an anxiety or depressive disorder (Kroenke, Spitzer, & Williams, 1994).

Noticeably, research from the World Health Organization demonstrated a significant increase in mental health disorders among a heterogeneous chronic pain population. They found that anxiety and depressive disorders were four times greater among those with reported pain of greater than six months (Gurege, Simon, & Von Korff, 2001). A study conducted by Choinière et al. (2010) found that more than half of Canadian pain clinic patients have severe levels of depression.

Furthermore, sleep challenges affect the majority of chronic pain patients, and as such, it is not surprising that those living with chronic pain have sufficient sleep problems to be diagnosed with insomnia (Tang et al., 2013). It has been reported that more than 50% of chronic

pain patients are also diagnosed with insomnia (Smith, Perlis, & Smith, 2000), a sleep disorder which is connected to both impaired daytime functioning and increased mood disturbance (Morin, 2004).

Most significantly, research has unveiled that the risk of suicide is double among those living with chronic pain as compared to those without pain (Tang & Crane, 2006). Although several factors are important for assessing risk of suicide, a review by Fishbain (1999) discovered that pain-severity and depression appear to contribute the most to the increase in suicidal tendencies among patients with chronic pain.

Overall, the link between chronic pain and mental health problems is very well documented and needs to be taken into account for the assessment and treatment for those living with chronic pain.

Social Ramifications. Chronic pain can influence several aspects of social living, including everyday functioning, social interactions, sense of self-worth and belonging (Banozic, 2011).

For instance, the Canadian STOP-PAIN project is a two part project that sought to explore the human and economic burden of chronic pain among those on waitlists for Multidisciplinary Pain Treatment Facilities (MPTF) (Choiniere et al., 2010). The results showed that more than half of the patients stated that their pain greatly interfered ($\geq 7/10$) with different aspects of everyday life including walking, recreational and social activities, and enjoyment of life, and half of the patients reported that pain interfered in their relations with others. Additionally, research has shown that chronic pain most commonly affects working outside the home, driving, exercise, and sexual relations (Breivik et al., 2006).

In order to better understand the social consequences of living with chronic pain, one phenomenological study (Thomas, 2000), inspired by the ability to “give a voice to the voiceless” explored the deeper meaning of what it is like to live with chronic pain. Participants were adult community members living with chronic pain. Participants described how they do not have the luxury of thoughtless movement as they perceived that pain results from movement. Their perception of their bodies had been deeply altered in that they now experienced their bodies to be unpredictable and damaged. Interestingly, participants spoke of living with something that was invisible to others because their bodies appeared healthy to onlookers. All participants generally explained how they keep their chronic pain condition a secret from others as they believe other people have judgemental views of those living with chronic pain. Particularly, participants spoke of how they believe that others are often skeptical and disinterested, rather than supportive, of their chronic pain. As a result, isolation from others, lack of support, and the inability to be authentic with others, were common themes among participants. Interestingly, the meaning of life was also discussed and questioned by participants. Thoughts of why they were living with pain, and how long their pain might persist, were among the topics of existential discussion among the participants.

A phenomenological study by Osborn and Smith (2006) sought to explore the personal experiences of chronic benign low back pain in relation to participants’ bodies and sense of self. In order to yield an in-depth understanding, the six participants included in the study were asked to speak as freely and widely as possible about how their pain has affected their feelings, attitudes or beliefs about themselves. Through interpretative phenomenological analysis, the authors unveiled one prominent theme of ‘living with a body separate from the self’. Interestingly, this theme was paradoxical in the sense that participants did not consider their

body to be as prominent to the self in the absence of pain, yet when any body part was in pain, participants described their body part and pain as detached from their preferred self-concept and categorized as ‘not me’. Osborn and Smith (2006) made the interpretation that “the participants’ self-concept and their painful bodies was defined more by alienation and exclusion rather than integration, accommodation or acceptance”.

Importantly, the invisibility of chronic pain is highlighted; not having physical signs suggestive of illness or disability has been described as a factor contributing to the stigmatization of chronic pain (Jackson, 2005). Stigmatization is a significant social issue among those living with chronic pain and several factors contribute to this process including the inappropriate pain behaviour, the pain sufferer’s existential situation, and the absence of a physical sign, which all serve to delegitimize the chronic pain experience (Jackson, 2005).

Overall, it is clear that chronic pain affects day to day living, including the ability to carry out daily tasks and to foster and maintain healthy relationships. Osborn & Smith (2006) and Thomas (2000) yielded rich descriptions of the experience of living with chronic pain, particularly how chronic pain affects the view of self, and the belief of the views’ of others. Lastly, stigmatization is a common experience that is primarily believed to be a result of chronic pain not being viewed as a legitimate condition.

Vocational Consequences. Many patients with chronic pain cannot work, leading to financial insecurity (IOM, 2011). For perspective, Statistics Canada (2001) reported that the leading cause of disability among working-age adults is uncontrolled pain. Lynch (2011) reported that “sixty per cent of people with chronic pain eventually lose their job, incur loss of income or will have a reduction in responsibilities as a result of their pain”. Also, although some people continue to

work, they often have higher rates of absenteeism. It is expected that those continuing to work will, on average, lose 28.5 days of work annually due to their chronic pain (Lynch, 2011).

Furthermore, there are several challenges associated with returning to work for pain patients, and one qualitative study explored the perceived barriers to return to work as described by unemployed patients with chronic musculoskeletal pain (Patel, Greaslet, & Watson, 2007). After interviewing 38 unemployed pain patients, the authors' thematic analysis revealed the following themes as barriers to return to work: pain related issues, physical and financial uncertainty, interactions with benefit providers, perception of employers, and personal limitations. It is important to consider these barriers for successful transition back to work as the challenges are often not noticeable to others yet they continue to affect the person living with pain. Generally, the consequences of job loss are plentiful, including changes in the family structure, stress level, and sense of self or identity (IOM, 2011).

Medical Challenges. There are several medical challenges in the form of assessment, treatment, and understanding the etiology or development of chronic pain (IOM, 2011). Vitally, the medical environment plays a salient role in the lives of those living with chronic pain. For instance, research has shown the importance of validation from clinicians among those with chronic pain, as one study reported that 47% of people with chronic pain switched doctors because they believed their doctor didn't take their pain seriously enough and they felt as though their doctor did not listen (Roper-Starch Worldwide, 1999). The IOM (2011) suggests that some of the patient-level barriers to improved pain care are influenced by the questions that might impact clinician perception, including 'Is this patient drug seeking?', 'Is this patient really in pain?', and 'Is this patient just trying to get disability payments?'.

One phenomenological study (Werner & Malterud, 2003) sought to explore the nature of the “work” done by female patients in order to be believed, understood, and taken seriously when consulting the doctor. Ten female patients with chronic muscular pain were interviewed and asked questions about whether their experiences had been positive or negative, how they had prepared, their activities during the consultation, and any challenges related to living with chronic pain. The analysis revealed that all participants appeared to try out various strategies including assertiveness, appearance, and trying to do what was “just right” in order to meet their physicians’ expectations. The participants also described stories of their struggle for self-esteem and dignity as women and as patients.

Another important challenge is that opioids are often considered and offered for the treatment of chronic pain. For the guidance of safe and effective use of opioids, the Canadian Guideline for Safe and Effective Use of Opioids for Chronic Non-Cancer Pain were created (National Opioid Use Guideline Group, 2010). The guidelines serve as a tool to attend to the potential consequences that often accompany opioid use including increases in abuse, serious injury, or death by overdose (Kuehn, 2007). The rate of prescribed opioids in Canada increased by 50% between 2000 and 2004 in Canada (International Narcotics Control Board, 2006). This rise raises several concerns, including the heightened alarm for potential overdose, as a study by Dhalla (2009) found that over half of their study population who died by overdose, were prescribed opioids within four weeks prior to their death. Guideline contributors acknowledge the effectiveness of opioids but know the risks and that other treatments should be considered as medication alone is often not adequate.

In summary, chronic pain is a multifaceted issue, with not only physical challenges, but psychological and social consequences as well. Therefore, it is nevertheless important to try and

address all of the components related to the process of psychosocial adaptation to chronic pain. There are a handful of models in the literature that seek to address the process of psychosocial adaptation to chronic illness or disease, including that of Moos & Tsu (1977), Cohen & Lazarus (1979), and Corr (1992). The following section will speak to one of the more recent models of psychosocial adaptation, the Integrated Task-Based Model (Samson, Siam, & Lavigne, 2007), which is distinguished by the addition of the vocational task to the adaptation process.

Psychosocial Adaptation: The Integrated Task-Based Model

The Integrated Task-Based Model (Samson & Hiam, 2008) is based upon five main assumptions regarding adaptation to chronic illness. First, the model takes into account the individuality of living with a chronic illness and takes the stance that adaptation is a highly individual process. It also acknowledges that individuals are not affected in a uniform way and therefore relies on subjective perceptions. In line with Moos & Tsu (1977), the Integrated Model also assumes that individuals have an innate drive to achieve and maintain social and psychological homeostasis in order to regain a sense of normalcy and life satisfaction. Furthermore, it is based on the assumption that individuals must reconstruct certain aspects of life that were affected by the onset of the chronic illness, and in agreement with Corr (1992), this model helps individuals to make choices about which tasks to carry out and when, thereby helping to restore a sense of control. Lastly, the process is believed to end in either a positive or negative outcome. The framework of the model incorporates five components including the following: 1) personal history and social context, 2) cognitive appraisal, 3) adaptive tasks, 4) coping skills, and 5) the outcome, which can either be positive or negative.

The model accounts for one's personal history and social context at the time of diagnosis and takes all facets of life history into consideration including ethnicity, socioeconomic status,

and social supports. Secondly, the model is interested in one's conceptualization, or cognitive appraisal, of their diagnosis. This is because perception is believed to be variable across individuals and it is one's perception that drives any experience. The five adaptive tasks (physical, psychological, social, spiritual, and vocational) of the model are meant to be operational tasks that can help rebuild certain areas of life that were affected by a chronic diagnosis. Lastly, the model suggests either a positive or a negative outcome, delineated by whether or not psychosocial equilibrium and normalcy was regained or if there was psychosocial deterioration or decline.

Overall, the Integrated Task-Based Model can be understood as a holistic theoretical framework for the psychosocial adaptation to chronic illness. It considers an all-encompassing approach to adaptation including the medical implications and the emotional and psychosocial aspects of illness and the influence that these components have in relation to adaptation.

Due to the complex, multi-dimensional nature of chronic pain, researchers and clinicians have been working endlessly over time to try and find an effective treatment solution for those living with chronic pain. With more research and scientific evidence being produced, there has been a shift within the culture of the scientific community, with more openness to exploring the implications of psychological and social components rather than just the biological facet of chronic pain. The following section describes the research that has created the movement from the historical biomedical model to the integrated biopsychosocial approach for the understanding and treatment of chronic pain.

Treatment of Chronic Pain: Historical and Current Approaches

Traditionally, the linear biomedical model of chronic pain (Barber, 1959; Melzack, 2001) was used to describe and understand the pain experience. It concentrated on the neurophysiological aspects, in isolation of the person and their experiences, emotions, or sociocultural context (Bendelow, 2013). This model has been defined as one of the responsible agents for physicians doubting their patients' pain severity, which in turn has led to the marginalization of those living with chronic pain. This is presumably due to the described "oversimplification" of the model (Bendelow, 2013). The biomedical model has been re-evaluated due to its limited consideration of factors contributing to chronic pain, and advances in research and theories have led to the development of the biopsychosocial model of chronic pain, which includes the interacting biological, psychological, and social factors (Gatchel, 2007). The biopsychosocial model offers a "comprehensive perspective that encompasses all the aspects of the pain experience" (Gatchel, 2011) and is now considered the most useful conceptual approach for the explanation and treatment of chronic pain (Gatchel, 2007). Not only does this model account for the variability in intensity and duration of pain, or differences in treatment outcomes, but it also offers an explanation for the social and cognitive ramifications of chronic pain (IOM, 2011, p. 2).

The IOM (2011) states that "pain often produces psychological and cognitive effects including anxiety, depression, and that interdisciplinary, biopsychosocial approaches are the most promising for treating patients with persistent pain". In fact, one of the recommendations from the IOM is to increase support, both federally and privately, for interdisciplinary research in pain.

A review by Ostelo et al (2005) demonstrates the instrumental shift in the use of non-pharmacological treatments including psychological interventions and behavioural treatments such as cognitive behavioural therapy (CBT), biofeedback, progressive relaxation training, and physical exercise with operant-conditioning approaches. Though their review revealed that cognitive and relaxation approaches are effective vehicles for pain relief, the authors conclude that further research is warranted to better understand what types of patients benefit from what types of behavioural treatments.

Research strongly suggests that CBT is the gold standard for the treatment of chronic pain with studies finding reductions in pain, emotional distress, disability, and medication use (Hoffman, Papas, Chatkoff, & Kerns, 2007; McCracken & Turk, 2002). Even within cognitive approaches, there has been a shift towards the use of Acceptance and Commitment Therapy (ACT), with up to eleven studies demonstrating its efficacy of its use among chronic pain populations (Vowles & Thomson, 2011). One recent study explored the long-term efficacy of ACT and found significant improvements in emotional and physical functioning for up to a 3 year follow-up period, with associated improvements in acceptance of pain and values-based action (Vowles, McCracken, & O'Brien, 2011).

In addition to ACT, other mindfulness-based approaches are increasingly being incorporated into the treatment of chronic pain. For example, Ussher et al. (2014) compared the effects of a 10 minute mindfulness-based body scan to a control condition among a chronic pain population. The intervention was delivered once in the clinic and once in the participants' "normal environment" within a 24 hour period. The results found that participants who received the body scan intervention in the clinic, reported significantly reduced ratings for pain related

distress and for pain interfering with social relations compared to the control group ($p = 0.005$; $p = 0.036$).

Overall, there has been a shift in the understanding, assessment, and treatment of pain, and current researchers believe that there is a “need to adopt integrative models of health care that take into account the relationship, not only between the mind and body, but among mind, body, and society” (Bendelow, 2013, p. 458). One promising approach which incorporates the value of the relationship between mind and body is that of mindfulness. The next sections will focus on providing a definition of mindfulness, a description of Mindfulness-Based Stress Reduction (MBSR), the use of MBSR in medical contexts, and MBSR for the treatment of chronic pain.

Mindfulness Based Stress Reduction (MBSR)

Mindfulness-Based Stress Reduction (MBSR) dates back to 1979, when John Kabat-Zinn launched the Centre for Mindfulness at the University of Massachusetts’s Medical school. The implementation of an MBSR program for chronic pain patients raised heightened awareness of the application of mindfulness in a clinical setting (Kabat-Zinn, 1982).

MBSR is a group-based intervention which seeks to foster attention and awareness to the present moment, including all forms of comfort or discomfort, all thoughts and emotions, through the application of mindfulness exercises (Kabat-Zinn, 2013). Through self-regulation, MBSR aims to promote both awareness of the present moment and adaptive ways to managing stress. Kabat-Zinn (2003) describes that the original vision of MBSR was that it was to serve as a model and training vehicle for the relief of suffering. Kabat-Zinn set the intention to effectively train medical patients in mindfulness meditation for the purpose of applying it to the stress, pain,

and illness that they were experiencing. It was originally meant for physician referrals, particularly for those patients with an array of diagnoses, who were not responding to traditional medical treatments, or for those patients whom physicians felt would receive complementary treatment from MBSR. The latter intention of MBSR as a model has surely unfolded as MBSR has been adapted to many other contexts, including hospitals, schools, and within community settings. Importantly, MBSR remains as a program for those primarily living with stress, emotional or physical pain, and disease or illness.

MBSR is an 8- to 10- week group course with up to 30 participants who meet weekly for 2-2.5 hours. During the weekly sessions, participants receive instruction and practice in mindfulness meditation skills, and participate in group discussions related to stress, coping, and the homework exercises. Typically around the sixth week, there is a full day intensive mindfulness session. Mindfulness is nurtured through meditation exercises, including seated meditation, body scans, gentle movements and hatha yoga, and focusing on the breath. Participants are encouraged to practice mindfulness in other ordinary activities like walking and eating. Participants are encouraged to practice homework exercise roughly 45 minutes a day for 6 days a week, which includes listening to audiotapes and practicing mindfulness by focusing attention on the target of observation (i.e. breathing, walking) and being aware of the moment-to-moment. Importantly, participants are reminded to notice any thoughts, feelings, or emotions that arise, and to observe them without judgement, and to bring attention back to the breath once they have noticed that the mind has wandered (Baer, 2003).

MBSR in the Context of Medicine

MBSR has proven to be clinically relevant in various contexts and among different populations. One meta-analysis (Grossman, Niemann, Schmidt, & Walach, 2004) included

research studies that explored the efficacy of MBSR group interventions on measurable physical or mental health outcomes using validated scales and either controlled or observational designs. The analysis included 20 studies and explored mindfulness among medical patients with the following diagnoses: fibromyalgia, mixed cancer diagnoses, coronary artery diseases, depression, chronic pain, anxiety, obesity and binge eating disorder, and other psychiatric disorders. The results showed large effect sizes of $d=0.5$ ($p<.0001$) across studies. Overall, the analysis demonstrated the effectiveness of mindfulness-based interventions for a variety of chronic disorders, in terms of coping with distress and disability.

One mixed-methods study investigated the possible effects of an MBSR course on women with breast cancer who had completed treatment (Dobkin, 2008). The study used focus groups comprised of 13 participants to try and gain some insight into the processes underlying the often reported benefits of an MBSR program. Analysis captured significant statements and common themes throughout, including themes of acceptance, taking responsibility of what they could change, and a spirit of openness and connectedness. Participants described acceptance as an understanding that things are not necessarily how one wishes them to be, taking responsibility of what they could change, and acknowledging changes they could make to feel better while knowing their own limitations. Lastly, participants described their newfound mind-set of openness and awareness to their way of living, and emphasized the value of participating in a group, as it fostered a sense of connectedness.

Furthermore, a purely qualitative study by Mackenzie et al. (2007) interviewed 9 cancer survivors after completing an 8-week MBSR course and applied a grounded theory methodology. The authors found common themes of opening to change, self-control, shared experience, personal growth, and spirituality. Their analysis described that participants appeared

to see life from another perspective, and were able to confront their illness with a more adaptive attitude; that participants developed a sense of self-control, particularly through meditation practice which facilitated change in emotional control; that participants placed strong value on the group cohesiveness and supportive environment as they felt it was empowering; participants cultivated their own personal growth and inner experience and noticed changes in their relationship to their cancer and self; and lastly, participants spoke of an interest in spiritual growth despite the secular nature of MBSR, which the authors suggest might be due to the unthreatening nature in which spirituality is presented in the program.

Overall, there is a widespread application of MBSR in the context of medicine, and these studies are simply offered as examples as the literature is extensive. Importantly, a few of the studies offered here are qualitative approaches used to gain a deeper understanding of the experience of participating in an MBSR course.

MBSR and Chronic Pain (Quantitative Studies)

Studies specifically investigating the effectiveness of MBSR for the treatment of chronic pain began with Kabat-Zinn (1982) himself, as his original study showed that the majority of patients reported more than a 33% reduction in pain after participating in an MBSR course. A review by Baer (2003) found a total of 4 studies that examined the effects of MBSR on patients with chronic pain, including Kabat-Zinn's original study (1982), and two of his other projects (Kabat-Zinn, 1985; Kabat-Zinn, 1987). These early studies found significant, long-lasting changes in pain intensity, medical and psychological symptoms, coping abilities, and restraint in activity due to pain among patients with various chronic pain conditions. The fourth study investigated the effects of MBSR in combination with medical treatment among a heterogeneous chronic pain sample and found significant changes in self-reported measures of pain, pain

beliefs, and psychological symptoms (Randolph, Caldera, Tacone, & Greak, 1999). Baer (2003) concludes that findings for chronic pain patients generally showed statistically significant improvements in ratings of pain, other medical symptoms, and general psychological symptoms. Furthermore, follow-up evaluations revealed that many of the changes found were maintained.

Since Baer's review, there have been a handful of studies that have explored the effects of MBSR among different groups of patients with pain conditions. Research studies among fibromyalgia patients have found improvements in pain, anxiety, depression, coping, and sleep quality after completing an MBSR program (Kaplan, Goldenberg, & Galvin-Nadeau, 1993; Sephton et al. 2007; Weissbecker et al. 2002; Grossan, 2007). An investigation into the effects of MBSR among those living with rheumatoid arthritis did not find a change in disease activity following the program (Pradhan, 2007), although it could have been valuable to look at pain level as an outcome measure in this study. Interestingly, research of older adults with chronic low back pain found significant improvements in pain acceptance after the MBSR course, but no difference in pain intensity (Morone, Greco, & Weiner, 2008). Lastly, a trial exploring the effects of MBSR as compared to massage therapy or standard medical care among those with chronic musculoskeletal pain did not find a difference in pain intensity, but those who participated in the MBSR program had improved psychological well-being at follow-up (Plews-Ogan, 2005).

Due to the variability in findings between different groups of pain conditions, one study compared MBSR treatment effects among subgroups of patients with different chronic pain conditions who participated in a MSBR program (Rosenzweig et al., 2010). The health-related quality of life outcomes and psychological distress outcomes differed considerably among the various specific chronic pain conditions. Particularly, patients with chronic back/neck pain and

other forms of musculoskeletal pain had the largest improvements in pain severity and functional limitations due to pain, whereas those with fibromyalgia and headaches/migraines showed the least improvements.

MBSR and Chronic Pain (Qualitative Studies)

Although there have been several randomized-controlled trials investigating the possible effects of mindfulness-based interventions for those living with chronic conditions, there have been much fewer qualitative, or in-depth inquiries, into the phenomena. The few studies that have sought to explore the intersection of MBSR and chronic conditions by qualitative measures, have mainly been among cancer populations, including breast cancer patients (Dobkin 2008; Hoffman, 2012; Weitz, 2012), and patients with varying types of cancer (Mackenzie, 2007).

One study by Morone (2008) explored the effects of an 8-week MBSR program among older adults (>65 years) with chronic low back pain through grounded theory analysis of participant daily diaries. The analysis yielded the following six themes: experiencing pain reduction from mindfulness meditation, improvement in attention skills, improved sleep resulting from meditation, achieving well-being, barriers to meditation, and processes of meditation. Interestingly, participants described their change in pain as being a result of their recently developed awareness of pain leading to change in behaviour, better coping with pain, distraction and elimination from pain. Improved sleep was noticed and detailed as better quality of sleep and getting back to sleep more readily. Notably, participants spoke of sleepiness and time as barriers to mediation. Overall, participants provided narratives detailing many beneficial changes in the way they cope with their pain and improvements in sleep, along with challenges such as finding time and familiarity with meditation and focus (Morone, 2008).

A phenomenological study (Hawtin & Sullivan, 2011) explored the experiences of an MBSR program among 5 individuals with rheumatic disease, a chronic pain condition. Using focus groups and interpretative phenomenological analysis, this study found 2 common themes: responding to pain and psychological wellbeing. Participants spoke of their change in responsiveness to pain, as their awareness now allowed them to engage in the experience rather than avoid it, or to focus their attention elsewhere. Furthermore, participants described a sense of acceptance with their pain, and a greater appreciation for life despite their pain.

Overtime, there has been ample research which has sought to explore the clinical efficacy of MBSR on physical and psychological outcomes. Although the empirical evidence is variable among populations, there is evidence to suggest the efficacy, value, and importance of MBSR in the context of chronic pain populations. Furthermore, the qualitative investigations to date have produced detailed accounts from participant perspectives which provides rich information about participant experiences, and the potential positive effects of MBSR programs.

Problem Statement

There are several high quality, quantitative research studies that support the usefulness and efficacy of MBSR among chronic pain populations. However, there have been few studies which have sought to explore the experience of participating in an MBSR program from the perspective of those living with chronic pain. Given the complex and subjective nature of chronic pain, it is important to take a deeper exploration into the lived experience of those living with chronic pain after participating in an MBSR program. The lived experiences and insights from those who continuously live with chronic pain might allow for a richer understanding of what it is like to live with chronic pain and what it is like to participate in an MBSR program, using their own words, language, and examples. In-depth interviews might allow participants the

time and space to share their thoughts and feelings which may enhance the overall understanding of the MBSR experience in the context of adapting to living with chronic pain. The heightened understanding will contribute to the knowledge that researchers and clinicians need to improve the care of those living with chronic pain and might inform other people living with chronic pain about MBSR.

Therefore, the purpose of this present study is to explore participants' experiences of an 8-week Mindfulness-Based Stress Reduction (MBSR) program. Detailed accounts of participant experiences may shed light into what it is like to live with chronic pain and how an MBSR program might facilitate the process of psychosocial adaptation. Furthermore, this study seeks to demonstrate the potential value of MBSR from the perspective of those living with chronic pain.

Research Questions:

1. What is the experience of participating in an MBSR program for individuals living with chronic pain?
2. What changes, if any, do people experience in the way they adapt to their chronic pain in wake of participating in an 8 week MBSR program?
3. What aspects of an MBSR program do participants perceive as the most useful, and why, in relation to their experience of chronic pain?

CHAPTER 3: METHODOLOGY

Epistemology: Hermeneutic Phenomenology

A hermeneutic phenomenological framework guided the exploration of the research questions associated with this study. Phenomenological research seeks to describe a common meaning associated with a lived experience among several individuals (Creswell, 2007). It tries to uncover an overall essence of an experience based on all individual experiences with a phenomenon (Creswell, 2007). The term essence denotes the essential meanings of a phenomenon (van Manen, 1990), and the goal is to develop a description of the essence of the experience for all of the individuals (Creswell, 2007). Moustakas (1994) details that the description consists of “what” they experienced and “how” they experienced it. Phenomenological methods are adapted and modified depending on the phenomenon, research question, and role of the researcher, and as such, there is not one absolute or correct method for conducting a phenomenological study (Hein & Austin, 2001).

For the purpose of this research study, I selected the phenomenological method in order to better understand the lived experience of participating in an MBSR program in the context of living with chronic pain. As phenomenology seeks to express the meaning of a lived experience, it appeared to be the most suitable method for addressing my research questions. However, I needed to reconcile my ontological and epistemological underpinnings by reflecting on what I believe to be the nature of reality and what I believe counts as knowledge. I also needed to consider how, if at all, I fit into the research process as the research investigator. These reflections led me to my fit with the ontological and epistemological underpinnings with that of Martin Heidegger.

The focus of hermeneutic phenomenology, as depicted by the work of philosopher Martin Heidegger, is to better understand existence, which he interpreted as our experience of being in the world, and that we come to know our world through our participation in it (Hein & Austin, 2001). Heidegger's work emphasizes the value of one's being in relation to the world and holds the ontological assumption that meaning is essential to reality (Polkinghorne, 1988). From an epistemological standpoint, Heidegger's (1927/1962) approach to phenomenology is an interpretative understanding of existence in the world, placing high importance on history and language for shaping our understanding of phenomena. In other words, we do not come to know the world through understanding, but we come to know the way we are (Polkinghorne, 1983). Therefore, phenomena are "interpreted" and are believed to be textual (Hein & Austin, 2001), meaning that an experience can be explored through written or verbal communication and can be interpreted to find meaning (Kvale, 1996). Hermeneutics seeks to understand texts (Gadamer, 1975), and views human experience as having a semantic and textual structure (Packer, 1985).

The results are descriptive texts, which "aims to create a rich, deep account of a particular phenomenon, an uncovering rather than an accurate analysis of participants' descriptions" (Hein & Austin, p. 9). In other words, the results are a well thought out interpretation which seeks to understand an experience, rather than claiming to be a definitive answer to the research question. Although this approach seeks to avoid prior theoretical assumptions (Packer, 1985), it is understood that researchers cannot bracket their implicit assumptions and perspectives, and therefore need to make them explicit (Hein & Austin, 2001). In fact, Heidegger suggests that the researcher's background and experience is even essential to the research process (Lavery, 2003). Overall, van Manen (1990) describes hermeneutic phenomenology as having an orientation

toward lived experiences (phenomenology) and interpretation of the “texts” of life (hermeneutics).

My Positioning as a Researcher

I am a 25 year old Master’s thesis student in the Counselling stream at the University of Ottawa. Alongside my graduate studies, I have been working as a research assistant at The Ottawa Hospital Research Institute in the Departments of Anesthesiology and Psychosocial Oncology. The research programs that I have been involved with have primarily used quantitative methodologies for exploring their research questions. I have also worked with Dr. Howard Nathan on his research project which seeks to determine the potential effects of an interdisciplinary program, including MBSR, for those living with painful diabetic neuropathy. My involvement included screening patients for study inclusion criteria, consent and recruitment, and data collection in the pain clinic. While working on this project and interacting with the patients, I quickly learned that each and every patient had a different background, experience, and story to share. I found myself being curious about their lived experiences and how they would describe their journey in the MBSR program.

I then participated in the same MBSR program being offered to those in Dr. Nathan’s project and to those involved in my thesis project on two separate occasions. The first time was in the winter of 2014, where I was invited to participate as a student to learn and to observe. The second time, I assisted a client with the hatha yoga poses incorporated into the program. Both of these experiences heightened my own awareness about not only my own being and the world around me, but the ways in which chronic pain appears to impact those living with it daily. Though I do not live with chronic pain, I have a keen academic and research interest in

mindfulness, particularly since participating in the MBSR program. I believe that MBSR can foster something new and restorative within those who are open to it. I saw and heard the emotions, challenges, and growth of those in the MBSR program as they shared their vulnerabilities during the 8-week program. I wanted to learn more and I wanted to give people an opportunity to share their in-depth experiences as I believed that they had important journeys to share. Altogether, these experiences ultimately lead me to my Master's thesis project.

I completed my clinical training through the Pembroke Regional Hospital, where I provided counselling at a generic mental health outpatient center. My approach to counselling is client-centered, with strong leanings towards narrative, cognitive, and mindfulness-based approaches. I worked with clients diagnosed with various mood and personality disorders, and several of my clients also presented with chronic pain. With most of these clients, I incorporated some form of mindfulness in our work together, namely guided breathing meditations and seated body scans. I am planning to pursue mindfulness instructor training in the near future.

In addition to my participation in the MBSR program, I have been practicing mindfulness with Buddhist Priest Innen Ray Parchelo and his Red Maple Sangha. Although I most often participate in the secular programs he offers, I have attended Buddhist practice as well. Although I am Catholic, I am always interested in learning more about Buddhism and I keep an open and curious mind when I am welcomed to their practices. I attend several retreats offered by Innen Parchelo, where we practice mindfulness in the form of contemplations, walking and seated meditations, earth and sky movements, chanting, and various exercises involving the mandala and readings to facilitate discussion and meditation.

For me, mindfulness is truly a practice and like anything else, some moments I struggle with my own journey. However, I continue to appreciate the growth I have experienced in my overall attitude, and remind myself of the positive changes in the way I feel, think, and act, when I apply even the most basic mindfulness principles in my life. I am a firm believer in the power of the breath to re-focus and re-center the body and mind when other approaches seem to fall short. I continue to live gratefully for each and every breath that I take.

Methods

Participant Recruitment

Ethics approval was obtained from The University of Ottawa Research & Integrity Board (File #08-14-31). I thoroughly explained the study to each participant, reviewed the consent form, and answered any questions before obtaining their consent. I recruited 3 individuals living with chronic pain who completed an 8-week MBSR program offered for community members living with pain or other physical or mental health conditions. The facilitators of the MBSR program first introduced the concept of the study to all group members during the third week of the 8-week program. Upon briefly explaining the basic principles of the study, the facilitators asked the group collectively if they felt comfortable having the study further explained by myself, a Masters student from the University of Ottawa, at the beginning of the following session. There were no objections from the group to this proposition. Therefore, I attended the beginning of the fourth session and was personally introduced to the group by the facilitators. I explained that I was a Masters student from the University of Ottawa and that this project would fulfill the thesis requirement for my degree. I described the purpose of my study and the relevance and potential implications of conducting this qualitative project. I detailed the

eligibility requirements and what participation in the study would involve. The group was not asked for their interest in participation during this meeting, but were informed that a formal recruitment script, that was reviewed and approved by the facilitators, would be emailed on my behalf by the facilitators (see Appendix A). The recruitment script detailed that anyone interested in learning more about the study could contact either the researcher or thesis supervisor directly. Lastly, members of the group were given the opportunity to ask any questions or make any comments. This initial point of contact and in-person introduction was valuable for creating rapport and allowing the group members to learn about the project, to ask questions, and to obtain a sense of comfort that email contact might not otherwise have provided.

Sampling and Eligibility Criteria

For phenomenological methodologies, it has been suggested that conducting interviews for 5-25 individuals who have experienced the phenomenon is sufficient (Polkinghorne, 1989). However, my original sample size goal was to recruit 4 participants. As hermeneutics seeks to explore in-depth accounts of lived experiences, this sample size was consensually agreed upon by the research team as a sufficient number to obtain a thorough account of participant experiences in order to explore the research questions being asked. However, there was a limited response rate with my first attempt at recruitment, and as such, the initial selection criteria was amended in order to reach the most fulfilling sample size possible.

As prospective participants responded to the recruitment invitation with interest, I first screened them for eligibility via the telephone (see Appendix B). The final sample size reached was 3 participants who demonstrated interest in participating and who met the following inclusion criteria: (1) at least 18 years of age, (2) English speaking, (3) living with chronic pain

(>6 months), and (4) must have completed at least 6 of 8 sessions of the 8-week MBSR program offered by the Mindfulness Health Professionals in [REDACTED]. Individuals who had previously completed an 8-week MBSR program were not considered for the study. I recruited the first 3 interested participants and therefore did not select based on any additional criteria.

The Participants

In order to honour the anonymity of the participants in this study, I assigned each participant with a random pseudonym. Participants' demographic information including chronic pain diagnosis and years living with chronic pain is presented in the following table:

Table 1 – Participant Demographics

<u>Participants</u>	<u>Gender</u>	<u>Age</u>	<u>Profession</u>	<u>Chronic Pain Diagnosis</u>	<u>Years Living with Chronic Pain</u>
Mark	Male	64	Retired	Neuropathy, chronic post-operative pain (neck surgery, heart surgery)	10 Years
Mary	Female	65	Retired	Chronic migraine, MSK pain, Fibromyalgia, Complex Regional Pain Syndrome	30 Years
Stephanie	Female	24	Records Clerk (Sick leave)	Endometriosis	5 Years

Mindfulness-Based Stress Reduction (MBSR) Program

Participants were enrolled in, and completed, the 8-week Mindfulness-Based Stress Reduction Program offered by the Mindful Health Professionals. Although the program is offered to community members, it is more specifically aimed for those living with chronic pain and it is therefore promoted as a pain management program.

The program was taught by a Clinical Psychologist (Ph.D, C. Psych) and a Pain Specialist (M.D) who were both trained by Jon Kabat-Zinn and Saki Santorelli and the program is therefore structured and based on the MBSR program conceptualized and created by John Kabat-Zinn (1982). Participants were asked to attend a 2.5 hour session weekly for 8 consecutive weeks, and one full-day of mindfulness at week six of the program. The program is presented in a group format and includes educational pieces about stress and pain management and the mind-body connection, group discussions, and mindful activities including gentle hatha yoga, body scans, seated and guided meditations, and walking. The program also includes weekly homework which varies from week to week but includes materials to facilitate body scans and meditation at home. Included in Appendix C is further information and detail about the 8-week MBSR program.

Informed Consent and Demographic Questionnaire

After the completion of the MBSR program and upon meeting inclusion criteria, I scheduled the study meeting with the prospective participants. I met with participants in a quiet place where they felt comfortable meeting with me. The meeting process was consistent across participants in that I first explained the study in great detail and allowed each participant to read the Consent Form (see Appendix D) and ask any questions before signing 2 identical copies (one

for them to keep and one for my Research Ethics Board records). I then asked each participant to complete a brief Demographic Questionnaire (see Appendix E). The purpose of this questionnaire was to retrieve basic demographic information including age and gender, and importantly, to gain some historical context for each participant. Information gathered for historical context included their pain diagnosis(es), the number of years they've been living with pain, and their experience, if any, with mindfulness prior to the 8-week MBSR program. Although this information was relevant for presenting a sound description of the participants included in the study, these details are more thoroughly captured and relevant in the analysis and results sections. An understanding and appreciation for individual historical contexts is an inherently valued aspect of hermeneutics, and as such, the information gathered from this questionnaire provided important context for each participant and their own backgrounds.

The Interview

After providing informed consent and completing the demographic questionnaire, I explained to each participant that the interview would be audio-recorded and would take roughly one hour. The interviews were fifty-five minutes, one hour and six minutes, and one hour and sixteen minutes in length and were each audio-recorded. The interview questions were created in such a way to capture their lived experiences both before and in wake of participating in the MBSR program. For instance, participants were asked to reflect back on life prior to their participation in the program before describing their experience with the MBSR program and life since. The interview was arranged in this way as a pre- and post-interviews were not possible due to time limitations for this research study. I adhered to the interview guide (See Appendix F) during each interview and at times, would ask, “what does that mean for you?” or “may you explain what you mean by that?” I specifically used these prompts in order to further understand

each individual lived experience by the meaning that they assign to their experiences and the meaning behind some of the language used by participants. This helped to uncover and better understand the meaning of the participants' experiences, ultimately allowing for an understanding of their individual realities (van Manen, 1990). Participants were offered the opportunity to take a break during the interview, and although they expressed their appreciation for the offer, they all kindly continued to share their experiences.

Field Notes

Upon ethical approval from the University of Ottawa, I attended the beginning of the fourth session of the MBSR program to introduce myself to the group. At this time, I began taking field notes. I wrote about the environment, what I saw and felt from those in the group, and my own perceptions and attitudes. I continued to write field notes throughout the course of my research, including during the screening and recruitment process, before and after each interview, and during the analysis and writing process. The field notes served as a channel for me to voice my experiences and interpretations and I often made reference to my notes in order to help me interpret the data all while maintaining a secure sense of my own influences during data analysis. The field notes also helped jog my memory about certain details that I had previously noticed that were important to remember during the interview and analysis stages. I set the intention to focus on the language used by the participants and to incorporate this into my field notes as much as possible. I tried to maintain a sense of curiosity and imagination while reading and trying to understand the language of the texts and I often took field notes about the use of common and diverse language used by participants. This was an important step as working with language is believed to develop an understanding of the meaning and the essence of the text, contributing to the phenomenological approach (van Manen, 1990).

Member Checks

Once I completed what I believed to be my most polished interpretations of each participants' interview in the form of my categorical results, I reminded each participant that I was going to be sending them my interpretations for their review and feedback (See Appendix G). I emailed them each a password protected word document of the results and asked that they read through the document and provide any comments or changes that they would like to see using tracked changes (see Appendix H for detailed instructions sent to participants). I emailed the participants their individual categorical results which are identical to the results section of this thesis. Each participant responded to me within two weeks of receiving their interpretations and other than one grammatical change, there were no other changes requested by the participants. In fact, they each responded with positive comments and reassured me that my written interpretations captured their experiences the way that they had hoped for.

Data Analysis

Categories

The journey and application of using phenomenological methodology is one that is felt and experienced by the researcher, without being bound by strict procedural steps (Smythe, et al 2008). Phenomenological research truly relies on the researcher being aware and willing to let go of stringent, systematic ways of doing research, and instead, trusting in the process and new opportunities (Smythe et al., 2008). Although there is no step-by-step method or analysis with hermeneutic phenomenology (van Manen, 1990), the analysis naturally developed as I continuously reflected upon my philosophical assumptions and research questions, which

ultimately let me to be inspired by the following research elements as detailed by van Manen (1997):

1. Turning to the phenomenon, which seriously interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualize it.
3. Reflecting on the essential themes, which characterize the phenomenon.
4. Describing the phenomenon through the art of writing and rewriting.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon.
6. Balancing the research context by considering parts and whole.

The first two activities are at the forefront of the hermeneutic approach to this study and were an intrinsic part of the research process. I first listened to the interviews and reflected on what I heard. I took notes during this process and then I carefully transcribed each interview. I did this within the two weeks following each meeting while the interviews were still fresh in my mind. Next, I attended to the entire texts (holistic approach) and I read and re-read the texts in order to gain an overall sense of the texts. I continued to make reference to my field notes and reflected upon my research questions in order to ensure that I understood the source of my interpretations all while maintaining a strong pedagogical relation towards the experience of MBSR. I also considered the parts and the whole of the research context through the application of the hermeneutic circle (Heidegger, 1927/1962). The hermeneutic circle places value on the reciprocal movement from pieces of the text to the whole of the text, and visa-versa, for the purpose of a continuous and iterative process for understanding and interpreting the phenomenon (Heidegger, 1927/1962). Overall, this analytical approach seeks to “transform lived experiences into a textual expression of its essence” (van Manen, 1997, p.36).

During this process I began to notice preliminary patterns in content and deeper meaning. As I continued to re-read the texts, I began to employ the selective or highlighting approach to identify significant statements, or participant statements regarding the topic of interest from the text (Creswell, 2007) and I continued this process in an iterative fashion. As I began to feel resonant meaning among the significant statements based on the language used (Gadamer, 1975), I temporarily assigned an interpreted meaning to each statement. I then went back to the whole text and repeated this step several times until I felt, as the researcher and interpreter, that the meanings of the statements were true to the language used and overall experience of the participants. Next, these significant statements were placed into clusters, or categories, based on content that supported these themes, and patterns of meaning (Creswell, 2007). Moustakas (1994) details that the phenomenological description consists of “what” participants experienced and “how” they experienced it. The categories that were created during this analysis naturally emerged as the “what” component of the experience. Particularly, the categories appeared as groupings of what participant experiences were like before and after the MBSR program and the results are presented in a fashion that showcases this developmental process of analysis. Although the categories appeared to be a platform for showing what changes may have occurred for participants, the vehicles for potential change, or how things changed, arose as well. The “how” component of these categories were described in the categorical findings of the results section.

Themes

Although the categories appeared to capture several important common patterns of meaning including the “what” and “how” of the experience, I felt as though there were untouched meanings that were missing. This led me to believe that there were larger, more

conceptual, over-arching themes that were somewhere to be found in the data. When I began to feel and experience this during analysis, I simply wrote out several key words and phrases that I was noticing within the texts. For me, these transcending patterns felt like supports for the overall experience. Interestingly, themes can be understood as the structures of an experience (van Manen, 1997). The following elements of hermeneutic phenomenological analysis (Lavery, 2008) were intrinsically cultivated during this analytic process: imagination (Smith, 1991), and attention to language and the writing process (Gadamer, 1975; van Manen, 1990,). Imagination involves attentiveness to the ways in which language is used, awareness of life as an interpretive experience, and curiosity in how humans make sense of their lives (Smith, 1991). Altogether, I placed particular attention on the language of the texts as they relate to the participants' accounts of their experiences (Gadamer, 1975; van Manen, 1990). My field notes and self-reflections as the researcher played an important role in this development. In this way, themes emerged and they developed in such a way that the "how" (van Manen, 1990) of the experience was captured. Similar to the creation of categories, the themes were formed by pulling significant statements from the texts and often, the themes included significant statements that transcended and overlapped categories. At this point in analysis, I felt as though the ambient experience was uncovered and that the "what" and "how" of the experience could be shared (Moustakas, 1994).

Trustworthiness

I adopted Lincoln and Guba's (1985) conception of credibility, transferability, dependability, and confirmability to nurture trustworthiness for my study. In order to ensure credibility, I employed and adhered to my research methodology that was inspired by the work of van Manen (1990) and remained consistent with my methodological and analytical approach throughout the course of the study. Although they caution the potential for becoming too

immersed in the culture, Lincoln & Guba (13) also suggest that the investigator develop and early familiarity with the culture of participants. Although I did not engage with the participants prior to their involvement in the study, I myself participated in the 8-week MBSR program 6 months before beginning this study. This allowed me to gain an understanding of the program and its' nuances all while providing me with the opportunity to experience it for myself. Further, member checks were also used to foster credibility, by providing participants with the opportunity to review and judge the accuracy of my interpretations, and to provide feedback and revisions if necessary. Creswell (2009) notes that rather than using transcripts, member checking is best done with "polished" (p. 191) interpreted pieces such as emergent themes from the data and analysis. Therefore, I sent what I believe my most polished interpretations to be to participants. Each participant reviewed their personalized interpretations and each responded with confirmation of the accuracy of my interpretations.

Transferability, as believed by Lincoln & Guba (1985), is left to the hands of the reader and their own interpretations of the research text. However, they advise that for readers to thoroughly assess the transferability to their own unique situations, the researcher must provide sufficient background context. First, the background and literature review sections of my thesis thoroughly details the concepts needed to gauge any amount of transferability, including chronic pain, psychosocial adaptation, mindfulness, and MBSR, including previous research conducted. Further, I developed my interview guide with the intention of drawing out a comprehensive history of each participant before moving forward to the experience of the MBSR program. Lastly, I included a demographic table to show the sex, age, and chronic pain diagnosis for each participant.

I detailed my methodology, from consent, recruitment, and field notes to the interview, analysis, and member checks to every step in-between. This provides a sense of dependability for my study and would allow the study to be similarly replicated if desired. I also wrote detailed notes of all decisions that I made during both data collection and analysis.

Lastly, to address the notion of confirmability, I outright detailed my own experiences and thoughts about chronic pain and mindfulness in the methods section of this thesis. I explained my positioning as the researcher and any underpinnings, beliefs, or biases that may have affected the objectivity of the results of this study.

CHAPTER 4: RESULTS

Categorical Descriptions

The categories that emerged from analysis include physical pain and pain management, self-perception and identity, relationship dynamics, and emotional equilibrium. The following four categories will be used to speak to each participants' individual lived experiences and will be differentiated by before and after the MBSR program. The categorical descriptions preceding the MBSR program form the historical context for each participant and what their lived experience was like prior to participating in the MBSR program. Importantly, the detail and information provided by each category following the MBSR program are presented, and should be interpreted as, potential changes that may or may not have occurred in wake of participation in the MBSR program. However, several changes as described by participants were attributed to the MBSR program and direct quotes will serve as a support for any of these self-perceived changes.

Physical Pain & Pain Management

The physical pain and sensations that arise and remain for those living with chronic pain can be felt, lived, and described in a variety of different ways. The effects that chronic pain can have on one's functionality and ability to carry out basic day to day tasks is often debilitating. Importantly, there are countless ways to try and reduce and alleviate pain, with some methods being more successful than others in terms of pain outcome and functionality. The purpose of this category is to try and relay how each participant physically felt and experienced their pain both before and after the MBSR program. The quotes included here are meant to speak to the rawness of sensations experienced by the physical body, and in essence, allow for the reader to

try and visualize and feel the pain as though they were experiencing it themselves, resembling but not being minimized by, the cliché popular culture phrase, “I feel your pain”. Similarly, as participants often spoke of their pain and ways in which they have tried to alleviate their pain in the same breath, this category will also describe the pain management techniques and methods used by each participant. After reading this category, the reader should have some sense of knowledge and understanding for how the pain might have felt, and continues to feel, for each participant along with the pain management techniques they employed both before and after the MBSR program.

Self-Perception & Identity

Participants described how they felt about themselves and how they viewed themselves in the context of living with chronic pain. They also spoke about how they believe others perceive them as a result of their pain. In some sense, this category touches on individual identities and the role that pain plays in shaping or perhaps misshaping one’s identity. Furthermore, participants spoke to the effect that pain had on what they find meaningful. The goal of this category is to provide a sense of how the participants viewed themselves and their sense of identity before and following the MBSR program. The descriptions preceding the MBSR program offers a narrative of how each participant perceived their own sense of self and identity in the context of living with chronic pain, and how their pain affected their own conceptualizations and self-perceptions. The descriptions of this category following the MBSR program sheds light into how, if at all, participants’ sense of self and purpose changed in wake of participating in the MBSR program.

Relationship Dynamics

Chronic pain affects not only the individual living with chronic pain but the surrounding people in their lives as well. The way in which chronic pain sneaks into the lives of others is an intricate process involving various psychological, social, and environmental factors. Therefore, this category seeks to demonstrate the relationship dynamics that each participant experienced in the context of living with chronic pain both before and after the MBSR program. Relationships described in this category include, but are not limited to, friends, family, and healthcare providers. Before the MBSR program, this category describes how relationships were perhaps affected due to chronic pain, and any challenges that were faced or perhaps lessons learned as a result. Following the MBSR program, this category speaks to any potential changes that occurred in relationship dynamics in light of participating in the program. Overall, the reader should get a sense of what relationships existed and the quality and dynamics of these relationships, prior to and following the MBSR program. The role that both chronic pain and mindfulness can play in relationships should be evident.

Emotional Equilibrium

In addition to the physical feelings that one experiences from chronic pain, there are also deep-seated emotional feelings tied to the experience of living with chronic pain. The participants spoke of several emotions that they experienced and the potential changes in affect from before and after the MBSR program. As emotions are a complicated human experience, the quotes used to reflect the emotional experience are often drawn from interviewer prompts regarding emotions in order to facilitate a more thorough understanding of the affective experience. Typically, emotions are tied to an experience or a thought, so the examples provided in this category are in context of particular events. The purpose of this category is to try and gain

an understanding of the emotional experience of chronic pain and the emotional feelings that the participants experienced throughout their continued years of living with pain and perhaps how mindfulness facilitated any emotional awakenings or changes among the participants. The category delineates the emotional experience before the MBSR program and any changes in their emotional experience that may have occurred for participants in wake of participating in the MBSR program.

Mark

Before the MBSR Program

Physical Pain and Pain Management

Mark has been living with chronic pain for the last decade. Although he had been living in pain for quite some time, he described his orthopedic neck surgery as the onset of his chronic pain. Before the surgery, Mark was experiencing loss of sensation down his arms but the post-operative pain and tightness that he experienced in his neck and arms remains today.

Additionally, Mark also lives with heart disease and has suffered two heart attacks and as a result has had multiple cardiac surgeries. Again, he lives with pain associated to his heart disease and post-operative scar tissue. Mark also has diabetes and suffers from painful diabetic neuropathy in his feet.

When asked to describe his pain before the MBSR program, Mark said with much automaticity: *For me, it was pain every day, in different degrees.* Although this appeared to be very factual, there was a brief pause after Mark relayed this statement during the interview, suggesting perhaps a contemplative moment about how pain each and every day was in fact his reality, almost in awe of his own lived experience. Mark believed that it was important to

continue to stay active in order to avoid further muscle tension and immobility, and that although the pain limited his activities, he chose to not let it stop him entirely: *It didn't stop me from doing things, it just hindered me from doing things.* Although Mark continued to do activities such as golf, cut the lawn, and chores around the house in order to remain active, he clarified that this was not always easy: *There are times when it would be overbearing and I would think about not going to do something.* It was clear that two things remained constant for Mark: being in physical pain every day and trying to combat the pain every day.

Mark explained that he has taken various prescribed medications but he spoke to his beliefs about medicinal interventions: *I really have been against taking medications unless I really have to ... you gotta keep moving and finding alternative ways to solving those problems rather than just popping a pill.* Mark also described his high tolerance for pain and how he tended to push through the pain: *There would be days where you know, I was really sore and my feet were killing me or whatever, and you know, it didn't stop me.* One of Mark's main pain management strategies was to be persistent and work through his pain, rather than letting the pain take over and stop him from doing things. He connects this way of being to his upbringing: *I guess it's the age group I grew up in too right, when you played sports and that, it was put an ice pack on it, put a heat pack on it, and go back out and play. So I've kind of done that most of my life.*

Interestingly, he felt as though he had previously been practicing some level of mindfulness: *I would just focus on something else and it would kind of go away.* One example that Mark gave was that when he would go for a walk when his feet were sore, he would begin to focus on the walk rather than his feet. Despite his keen persistence, Mark has also missed out on some experiences such as having to leave the theatre because the pain becomes too bad or

staying home rather than going out for dinner. He explained how he would rather not let the pain stop him from doing the things he enjoys but that there were times when the pain would simply become too much. Mark described how he has had to slow down and take his time doing activities that once came with such ease, and he qualified this change as a significant challenge for him.

At times, Mark's pain also affected his concentration and ability to remain present and connected in what he was doing: *Sometimes when I had a lot of pain, it was hard to concentrate on anything, you know, watching TV, things like that. I'm watching TV but I'm not really watching TV.* Due to the fact that he would have difficulty continuing to stay focused Mark would try and switch focus: *I'll get up and walk around just to change that feeling so that it's not focused on that and sometimes it helps.*

In order to try and alleviate his pain, Mark also detailed several remedies that he has tried over the years including hot showers, sitting in the jacuzzi, exercises, and dietary changes. He describes these techniques as natural interventions which provide short-term relief. He says that it can be frustrating when these techniques don't work and that he questions if he could be doing something differently in order to make the pain diminish. Mark also had to think ahead before committing to activities and had to always be cognizant of the ramifications of doing certain things: *I have to plan things more, if I know that I'm going to golf on a Saturday I know not to plan anything for Sunday or Monday because I'm not going to feel like doing much of anything because I'll be really sore.* Golf is like a double-edged sword for Mark as it is his favourite activity and one of the only sports he is able to continue to play, yet it brings him pain and limitations afterwards.

In summary, Mark has lived with pain every day for ten consecutive years. His pain is a result of disease and surgery and has significantly affected his ability to lead the same life he now reflects back upon. Due to his chronic pain, Mark is no longer able to play the same sports he once lived for or simply watch a television program comfortably. So much of his focus and attention is on planning his day to day activities around his pain. Prior to the MBSR program, Mark had researched and read several natural ways for reducing pain and only took medications as a last resort. Mark's pain was every day and only relieved temporarily by hot compresses, dietary changes and massage therapy. He would also have to schedule his life according to his pain and at times, would have to remove himself from activities that brought him joy. His pain impeded his physical functionality and he could only, at times, find very temporary, short-lived, pain relief, despite trying several interventions.

Self-Perception & Identity

Athletics and physical activity were an integral part of Mark's life and way of being. The joy and passion that exuded from him as he spoke of these pastimes was palpable. However, his discouragement for how he is no longer able to play most of the sports he once lived for was even more evident: *Well, the challenge for me is I've always been very sports all my life, I've played every sport there is and I've been very competitive at it, that's probably been one of my biggest challenges. I mean I used to play basketball, football, hockey, volleyball, basketball, you name it all. I play golf now, that's it.* Notably, Mark denotes much of this reduction in activity to more than just the physical limitations: *And it's just because I don't feel the same confidence that I had. So the challenge is really doing things that I used to be able to do.* It appears as though Mark now lacks the confidence he once had and does not have the same views of himself as a strong and capable athlete.

Mark shared that trying to manage his pain holds a large space in his life and his way of living. Always referring to himself as a diabetic, Mark provided the example of how a major part of his day to day living is observing his diabetes: *Monitoring what I'm doing to make sure the pain doesn't come back. I don't know if it's normal for most diabetics but for me, like I check my blood sugar probably 6-8 times a day.* Although Mark is unsure if his constant monitoring of his diabetes is a shared lived experience with others living with diabetes, he now explains how it is his normalcy.

Likewise, Mark associates much of his behaviour with being a diabetic and having Neuropathy, and uses language which signifies how this disease is a part of his identity: *You know just getting up and moving around, I think that's just part of being a diabetic and having Neuropathy. Getting up and moving around is more important than just sitting around all day.* It sounds as though Mark most often makes decisions from the perspective of someone living with chronic disease and pain. Moreover, he speaks to how a large part of his living is trying to manage his diabetic symptoms.

Mark explained how much of who he was and what he did was done in a way that ensured the wellbeing of others and not necessarily himself: *Trying to please everybody else is probably what I did for most of my life. Always trying to make sure that whatever I was doing was not necessarily good for me but it was my job, part of being a father, a husband, a good community member."*

Generally, Mark's sense of self had changed as a result of his pain. He no longer feels the same confidence in ability as he once did, particularly in relation to his athleticism. Mark appears to be defined by his pain and his diabetes and his life is consumed by managing his symptoms.

Lastly, he finds that much of what he does is based around his role as an employee, a father, and as a husband.

Relationship Dynamics

One of the first remarks that Mark made while describing his experience with chronic pain before being enrolled in the MBSR program was: *I can suffer and nobody knows it.* When asked to further explain what he meant by this, Mark said: *If I'm at home and I'm in pain, my wife never knows it.* In fact, Mark explained how he makes a deliberate effort to try and not let anyone notice that he is in pain: *I'm conscious of not showing pain to people only because I don't want them to feel sorry for me. Or have pity, you know.* Although Mark tries to keep his suffering from most people in his life, he particularly does so with his wife: *My wife you know, she's gone through a lot, based on what I've had to make her go through. She's not one that could take a lot of pain so I think in a lot of respects I've hid it for that reason, so she doesn't know.* By both Mark's introspective tone and melancholic body language while talking about this dynamic with his wife, it appeared as though remorse was being illustrated.

Mark's way of "pushing through his pain" transcends into his relationship with his wife and how he tries to live life with his wife despite his pain. However, he says that she has learned cues that tell her he is in pain which typically leads to this type of dialogue: *Even days when I didn't feel well when we were going to do things that she wanted to do I would say, "Yup no problem, yup, let's go". I may not feel well and she kind of over the years has recognized that she can tell that I'm not feeling well or not 100% and she'll say, "Are you sure you want to go?", and I mean, I'll still say yes and sometimes she'll say, "No, it's ok. We'll go another time."*

So much of Mark's social interaction is based on trying to hide his pain and suffering, and this became consistent in his descriptions of several of his relationships. In order to try and hide how he is feeling, Mark explains that it is not effortless: *I'm focused on trying to make sure that no one knows I'm uncomfortable*. He discusses the challenge of living with pain and how it not only affects him but others around him as well. Mark tries to constantly minimize the effect that his pain has on those close to him in fear of the potential and perceived ripple effect that his pain might have on others: *It's hard because I don't want to penalize my wife, my family, or my friends because of my illness or my problems*.

Mark says he often thinks, and is cognizant of, how his pain could affect other people and how they might treat him if they were fully aware of his state. He explained why he refrains from sharing his pain experience with people: *If people see you're in pain, they treat you differently. You know, some want to help you, some want to offer solutions to you, "Have you tried this, have you tried that?" and you know, I don't want to make them feel like it's not a good idea or something but ugh I think at the end of the day you know your own body and it's easier for you to decide whether that's good or bad but at the same time you don't necessarily want to make other people ... because the ones that love you, they want to help you. And that's their intent is to help you, but sometimes they're reminded you of you know, I have this pain and yes, you don't need to remind me of it, I know it. I think part of the reasons why I try not to show it because then that type of conversation never comes up*.

In summary, Mark tries to foster and maintain his relationships separate from his experience of living with pain. He regularly attempts to keep his chronic illnesses and pain in isolation from his relationships in order to avoid having others be penalized by his pain. However, he explains how those closest to him, particularly his wife, have learned, and can

recognize when he is in pain without having to have a conversation about it. Mark also prefers to keep his pain to himself to avoid having others try and offer their opinions or pity towards how he is feeling. Overall, Mark would rather hide his pain so that his loved ones are not affected and so he avoids having people feel sympathetic towards him.

Emotional Equilibrium

Mark described some of his experiences before taking the MBSR program with varied emotion and spoke to how he would feel when he experienced pain or challenges associated with his pain.

When he first started experiencing pain from his diabetes, Mark explained how he believed he was in denial: *There is no history of diabetes in my family and there's no history of heart disease. For whatever reason, I got both. With the diabetes, I think that in the beginning, I was in a lot of denial. That can't happen to me, you know, I am physically fit. I'm not overweight. I watch what I eat. How can this possibly be happening?* He explained how early on, he ignored his pain and continued to lead the same lifestyle. Mark said it wasn't until he started experiencing other symptoms, like vision problems, that he realized that “this was for real”.

Mark described a fluctuation in his emotions and thoughts in relation to his chronic pain, similar to the ups and downs of a roller coaster: *Sometimes I think about how I'm going to be stuck with this, and that's kind of been up and down in my thought process but sometimes when I'm feeling good I think, 'Ok, good. Life's ok', and then I realize I'm not watching what I'm doing and things start to slip and I go back into that.*

Mark also explained how he tried to continue to do things despite his pain because he did not want to be defeated by his pain: *It becomes a very negative thing when you stop doing things.*

He associated times when he could not do certain activities or had to say no to certain events with negativity and frustration. Mark often spoke about how he would continue to fight the pain in order to avoid any negative emotions from having to withdraw from things in which he finds joy, almost to suggest that he would rather experience the physical pain than emotional pain.

While sharing some of the ways in which he has tried to adapt to, or manage his pain, prior to the MBSR program, Mark said: *Sometimes when it doesn't work, it can be frustrating.* He said he doesn't necessarily get angry, but frustrated and then begins to question his pain relief techniques and if he should be doing something differently.

In the very beginning of his experience with chronic pain, Mark described being in denial, for he could not fathom the idea of being “stuck” with diabetes, heart disease, or chronic pain. Generally, Mark tried to avoid emotions that he knew to be associated with his pain, for they were all felt to be negative emotions. He often felt frustrated when he experienced pain and when his techniques to relieve his pain failed him. Although Mark never said it directly, it sounded as though he would rather try and combat the physical pain than any associated emotional pain.

After the MBSR Program

Physical Pain & Pain Management

Following the MBSR program, Mark describes a significant change in his relationship to his pain, in terms of how he feels physically, and how he now tries to manage his pain. While talking about the MBSR program Mark says: *It's definitely helped me reduce my pain. I notice that very much so. I don't have to take Lyrica anymore. I haven't taken any Tylenols in the last, well, six, seven weeks from that perspective.* Although Mark describes such a remarkable

improvement in his pain and his need for medication, his pain is still present: *My pain is pretty well constant. Like even now when we're sitting here, my level of pain is calm, it's not something that's annoying or distracting me but it's there. I can feel it.* Interestingly, prior to the MBSR program, Mark explained how his pain was a distraction and a huge frustration, whereas he now says that although the pain remains, he does not relate to it with similar annoyance or distraction.

Rather than seeking an almost desperate, temporary relief from the pain, Mark's goals in terms of pain relief have shifted to a more livable and sustainable approach: *You know, so whether it's doing things smarter better I don't know, using reading material anything I can, not a magic pill, you know I realize that there is no magic pill but if there are ways that I can reduce it and make it livable, then I think that's more the reality where I am now.* Mark says that now he doesn't analyze his pain as much as he once did, and is now more proactive about trying to ease his pain: *When my shoulder or neck will be bothering me I find now that as soon as I start to feel the pain I'll start to do exercises whereas before the pain would grow and I would try and deal with it later ... now I'll do some yoga exercises and I'll feel better.* Mark appears to be more aware of his pain and ways in which he himself can adapt to, or manage his pain, rather than using medications: *I would have just thought, 'oh hear it comes', I'd go get a couple of Tylenols and life would be good. And now, in some cases where you know, I've been sitting in a doctor's office or whatever and the chairs are uncomfortable or not meant for tall people, I'll just go into a state of mindfulness and sit there and focus on other things that are not causing me pain or discomfort so it's helped me to adapt to some of the things around me that I can't control. But I can control me. So that's what I try and do. I try to use that to help me stop the pain before it gets started.*

Remarkably, Mark says that he is now better able to do outdoor chores which he believes is a result of some of the activities taught in the MBSR program: *I've noticed that when I've cut the grass and worked in the garden and stuff like that I've had a lot less pain just because of the yoga, the mindfulness, and I just feel calmer doing it.*

While exploring new strategies that Mark now uses to try and adapt to his pain, he explained how although walking meditation was a challenge for him and did not work for him, that the seated or laying down meditations came easier to him and were more helpful. He explained how meditation did not come second nature to him, but was rather something to be practiced before noticing any beneficial changes. He also spoke to the value of meditation, whether it be for a brief or extended period of time: *And I find that now when I do it I can do a meditation for five minutes or half an hour and I get the benefit of it.*

Similarly, Mark now practices yoga as a way to manage his pain. He relates yoga to his athletic background and feels as though it is a good fit for him: *The yoga is definitely a good one for me. And I think that's because I've been so sports active all my life that I can recognize the value of that for my pain because a lot of what I have especially in the neck, is because of the surgery and everything tightens around that if I don't address that and help that to relax and stress that, then it continuously gets worse and worse and worse. And I've tried everything from chiropractor to physio to ART to massage therapy. And at the end of the day, just yoga type exercise and stretching does more for me than all of those other things.*

Mark believes that his pain will always be present but that some of the teachings from the MBSR program will allow him to be in a better state in relationship to his pain. He explains how he is able to do more things now because he does not experience as much debilitating pain: *When you're in pain all the time, you don't necessarily want to do those things right. It's kind of like,*

oh no this means you gotta stand in front of the stove for half an hour, 45 minutes, that's not gunna be fun right so I'm not going to enjoy it. Whereas now, it doesn't really bother me.

Overall, although Mark continues to live with pain, it is not of the same calibre. Furthermore, he does not feel it, or relate to it, the same way he did before the MBSR program. Mark's new pain management strategy appears to be focusing on his relationship towards his pain and how it can be an adaptive one, rather than a negative and maladaptive relationship. He is now able to notice his pain with more awareness which allows him to practice some mindful activities including yoga and meditation. His pain is no longer a source of dire frustration, but rather, serves as a signal to be proactive about doing some stretches or yoga, which he says is now a large part of his pain management strategy.

Self-Perception & Identity

When talking about his experiences before participating in the MBSR program, Mark appeared to be largely defined by his athleticism, competitive nature, pain and neuropathy. In discussing life following the MBSR program, Mark recognized a major shift in his competitive quality: *Even though I'm very competitive that's not such a big thing anymore. It's kind of like, no, if I'm enjoying myself and I'm having fun with good friends, hey, that's what it's all about right.* This reflects both a transformation in self and meaning in that competitiveness is no longer a prominent quality for Mark and that enjoyment is a more sought after goal and purpose than before.

With great insight, Mark articulated a significant change in perspective related to how he no longer dwells on what he cannot do but rather, ways in which he can promote self-gratification. Interestingly, the transformation involves being less focused and consumed on how

the pain impedes his life and more about how he can still manage to do things around the house to help his wife: *I've always been active all my life and when I'm not that way I think about things that I shouldn't be thinking about, including pain, or you know, other things that really I can't change. Whereas now, there are a lot of things, probably self-gratifying that I'm making my wife's a little bit easier.*

Mark touched on the value of time for doing things that bring him more fulfillment and joy: *I've always liked to cook and do things like that so it's kind of enjoying because now it gives me the chance to experiment and do things that I've wanted to do but never really found the time to do, or thought I could find the time to do.*

There also appeared to be a notable heightened sense of self for Mark following the MBSR program. In particular, Mark appeared to experience perhaps a newfound sense of self-compassion and self-appreciation. He reflected upon how he had always put himself secondary to everyone else, but that he now sees the value in including himself in the picture: *I'm thinking more about myself, rather than trying to please everybody else. I mean it's part of what I probably did for most of my life. Always try to make sure that whatever I was doing was not necessarily good for me but was my job, part of being a father, a husband, a good community member, things like that. Whereas now, I think I kind of do more for what's good for me and what's hopefully good for everybody else at the same time too.* Mark went on to describe how he had never thought about himself before the MBSR program: *I'm a parent. I'm a husband. It was always just you know that's what you do because that's what the role says you do. Once I went through this mindfulness thing, it allowed me to realize that it doesn't necessarily have to be about whatever everybody else wants but maybe what I want and if it's good for me then it might be good for everybody.*

With depth, Mark explains how he is no longer really burdened by, or defined by his diabetes or heart disease. His language shifted from referring to himself as a “diabetic” to “having diabetes” while discussing his experiences following the MBSR program. He now feels more gratitude for being alive than disarray for having chronic pain: *I think now with the diabetes and heart conditions it makes me appreciate more of the fact that I’m still alive and I shouldn’t abuse the fact that I’m still alive ... I think that’s probably the one thing I’ve noticed about caring for myself more.*

Following the MBSR program, Mark experienced growth in self-awareness which is allowing him to have a more connected sense of self and what brings meaning to his life. He reflected about the new sense of importance for caring for himself, while continuing to be cognizant of others, rather than excluding his needs entirely. He now believes that experiencing joy and gratitude is purposeful in and of itself, rather than having to compete and achieve certain goals. Mark speaks to his gratification from cooking, self-care activities, and being more involved at home and helpful with his wife.

Relationship Dynamics

During the second phase of the interview, Mark expressed a change regarding his relationships and interactions in the context of living with chronic pain. He talked about his sense that people around him have noticed a change about him and that he reacts with them in a calmer way since the MBSR program: *I think my family has noticed it. In the sense that they haven’t said anything but I think they’ve noticed that I’m not reacting as quickly as I would typically. When I was in pain, I could tell myself sometimes that I would probably not bite off their head but say something in a tone that probably wasn’t very nice but it wasn’t you know causing a conflict but it was different, wasn’t the right tone. So I think it’s helped me that way. Although*

Mark says his family members have not explicitly commented on his change in behaviour and interactions with them, he says that he has noticed his changes and that he believes they have too.

Mark explained how his wife has always been able to tell when he is in pain and he says that since the MBSR program, he believes that she has seen an improvement: *And in some aspects of it, I think my wife has probably said this is a good thing for you because I think she sees a difference. Again, because I don't typically show that I am in pain. She knew somewhat but I think she knows now that the pain I have is very small compared to what I had before.* He also says how he now feels more comfortable with talking about his pain and sharing what he is going through: *I think part of this mindfulness has made me more open to talking.* Mark explained how he had never really shown emotions before but that the mindfulness program has allowed him to feel more comfortable with self-expression with others: *It might make it easier for me in the future if I am not feeling well that it's not a bad thing, not a weakness, but that my body is trying to tell me something and I need to address it. So ya, I think it will help me in the sense that it will not make me feel uncomfortable talking about it, and it's not a crime to be able to say, "I have a sore back, can we do this another time?"*

Similarly, Mark's relationship and interactions with his wife have shifted as he says he is more willing and agreeable when it comes time to helping her around the house as compared to before the MBSR program: *You know, if my wife would say, "Could you fix this or could you fix that?" I would kind of go, "Here we go, another job on the list of things to do". Now I just say, "Ok, I'll get to it and I'll let you know when it's done".* Even the way that Mark's voice changed from a harder to softer tone in sharing these responses dictates a change in attitude towards tasks that he once found burdensome.

Overall, not only does Mark feel as though he communicates in a softer, less reactionary way to his family, he also describes a change in insight and how he now tries to recognize how someone else is feeling, particularly his wife: *And you know, there are times when my wife may have had a bad day at work and she comes home and I probably have a better understanding of why she needs to talk to me about the day she's had.* Interestingly, this speaks to the newfound value that Mark places on communication and honesty about one's feelings and experiences. In summary, Mark is more open to sharing his experiences with others, and this openness and transparency has had positive effects on his relationships.

Emotional Equilibrium

When asked about his general experience with the MBSR program, some of Mark's first comments were related to how he felt emotionally. Specifically he gave examples of how he now feels more composed and more tolerant: *I think it has helped me to be calmer. I'm not as reactionary. I'm finding that I'm probably a little more calm and a little more understanding. Before this, I mean, if I'd go to a shopping mall and I have to stand in a line for ten minutes, I'm cursing, I'm going 'come on let's go, let's go!' Now, I'm kind of like, 'OK', and I think about something else and when it's my turn to go to the cash register, I go through.*

Similarly, Mark says he also notices that his stress level is not as high as it once was. He details being able to step back from a situation and feel it through and reflect with less tension or pressure: *Even when I do things at home, when I have chores to do, I'm not stressing about it. I kind of think, 'OK, I need to do this. How do I want to do it? When do I want to do it?' Stuff like that.* Reduced stress appears to be a significant change for Mark as he detailed his stress before and after the MBSR program a second time during the interview: *It [the MBSR program] helped me to be a lot calmer inside. I don't feel so stressed inside. Things used to eat away at me forever*

until I resolved it or something had to be done to get it done. Now, I can bring it in and let it go. It doesn't necessarily have to be there eating away at me 24 hours a day until I find a resolution to it or whatever. I just bring it I, look at it, and go 'ya, I'll deal with it another time'.

Much of what Mark described feeling he related to his thought processes. He explained how he does not visit negative thoughts as frequently as before the MSBR program: *It's [the MBSR program] helped me to not have the negative thought process. Like, 'oh jeeze if I go there, I'm going to be sore after an hour and I won't want to do this'. That doesn't even come into my mind anymore."*

Importantly, Mark has experienced a shift of focus; rather than trying to focus on things he can't or shouldn't do, he now thinks about things that he wishes to do, and he relates this to a change in mentality: *From a mental perspective, not having that pain is allowing me to think about the things I want to do, you know, travel, among other things.*

Overall, Mark describes feeling a change from negativity to positivity in both his thought processes and his emotions: *[The MBSR program] has taught me to be positive and there are ways to resolve the pain rather than giving in.* He says he is better able to "notice things and let them go". In summary, Mark no longer describes being in denial of his pain and his experiences, but rather has started to acknowledge them. Instead of feeling frustration towards his pain, he says he is less reactionary and more calm which is partly a result from choosing to view things from a positive lense as opposed to seeing things from a negative lense.

Mary

Before the MBSR Program

Physical Pain & Pain Management

Mary has experienced pain her entire life, beginning with migraines at the very young age of 13. Back then, she says, people didn't know too much about migraine headaches or how to treat them. She also said how she did not feel like she was "taken seriously", a likely result of her age at the time. Mary shared an early memory of her mother taking her to the doctor in order to try and help her migraines: *So my mother took me to a doctor, they gave me some pills, they might have been nothing for all the impact it had on me. I went back after I took the course of pills and he told me "if these pills haven't helped you, then you don't have a headache". And that was sufficient to lock myself, lock my mouth away every time I saw a doctor after that. I was so sort of shocked because I didn't believe that was true because they just kept getting worse. That's my first experience.*

For most of her adult life, Mary says she had severe headaches or migraines three times a week on average. She was put on and off various hormone replacement therapies over a span of several years and says that never really made much of a difference. Unfortunately, Mary's pain became worse and more widespread over time: *Gradually, what happened for whatever reason, is that my pain started, which used to be classic migraine position up there, it started walking down my back, vertebrae by vertebrae. I just gradually had a lot of back pain.* When her pain progressed to this point, she began seeing a pain management specialist. Additionally, Mary was seen by a neurologist for nearly 20 years, and describes herself as "his oldest living patient". Mary was referred to other physicians over the years and says she has been on "countless

combinations of medications” and he has several MRIs of her head and spine. Her pain eventually moved down her spine and into her hip and sciatic nerve.

When asked what living with pain meant to her, Mary said in a soft and shaky voice: *It means that I used to grin and bear it and get through the day and raise my children. Oh, and I worked too. So you know, there were only small periods of time where I actually relaxed. By relaxed I mean surrender to it, or something. So from the age of 13, it's always been a significant factor in my life.* Mary continued to speak to her pain, which is undoubtedly chronic, as she explained that for at least the last 20 years, she has experienced one element of pain every day. Mary described how she finds escape from her pain while she sleeps: *I've also discovered that if I sleep I can escape. So I actually take sleeping pills in order to sleep in order to get out of it. I wake up in the night, and there it is, there it is, I scramble out of bed in the morning and there it is.* Similarly, Mary says she reads a lot, not only for her love of reading but to “get out of it [the pain] for a little while”.

When asked what other ways she has tried to adapt to her chronic pain, Mary detailed several “Western medical ways” including acupuncture and intramuscular simulation. Furthermore, she had tried yoga at a young age and meditation in an unstructured format. Mary explained how she also enjoys exercising including Zumba classes as she says she feels better afterwards.

Before participating in the MBSR program, Mary was seen by several healthcare professionals including general practitioners, neurologists, and pain specialists. She has tried various medications, including hormone therapies. Overall, Mary has tried acupuncture, heat compresses, massage therapy, hypnosis, and various exercise programs. Although many of the medicinal interventions were ineffective, Mary described some relief from exercise and a feeling

of escape while sleeping or reading. Mary has experienced pain nearly every day for over 20 years and has tried countless traditional and non-traditional pain management interventions. Lastly, Mary shared that she was often just “pushing through and denying it”.

Self-Perception & Identity

It was with great passion and pain that Mary shared her sense of self throughout her life with chronic pain. She first and foremost spoke to the unconditional love and effort she always exuded in raising her children, though this came with many challenges due to the effects of her pain. During the interview, Mary asked herself the following rhetorical questions: *I still had my life to live and I mean, what do you do? What do you do with your children? What do you do with your job? What do you do with your husband? You're a tiny little piece of all of that when you've got young children.* It appeared as though Mary had to ask herself these questions in order to figure out the best possible ways of adapting to her life while living with chronic pain.

Before having to take early retirement due to her pain, Mary worked in international development and described “learning a zillion things every day” and found great meaning in her work. She said that through her work, she had always hoped she was making a difference. Mary described how leaving her work was the only thing that could be done because her pain became too much for what her job entailed: *But at the point when I left, it was the only thing to be done. It got to the point where I couldn't travel to the countries, to anywhere where I had business dealings with, they were often remote places that didn't have the kind of facilities.* For Mary, leaving work was a true hardship: *What it [the pain] really made me do was pay more attention to what all of this was telling me. Leaving work was a challenge, I loved my work.*

Due to the high demands of trying to manage her pain in combination with the busy lifestyle of trying to raise children, Mary felt little space for herself: *When you're a really busy person, and when you have kids and such, there's not that much space in your life for yourself anyhow.* She explained how living with pain becomes much of what you do in terms of trying to alleviate and escape from the pain: *A week doesn't go by where I don't have one or two appointments.* In retirement, Mary continues to lead a busy life: *But of course I'm retired and I read every night before I go to bed. I'm too busy to read during the day. Just because you're retired doesn't mean you're not busy ... and certainly with grandchildren you are!*

Overall, it appeared as though Mary's sense of self was often dictated by her pain, as so much of who she was and what she did was in relation to her migraines. Similarly, her identity included her work, raising her children, and trying to combat her pain in order to achieve her goals. Unfortunately, due to her pain, Mary had to leave her work, a place where she found undefinable meaning. Pain also appeared to affect her role as a parent. Although these changes caused her much sadness, she now reflects fondly back upon the very meaningful work she accomplished during her working years. Mary also describes her newfound joy of being a grandmother.

Relationship Dynamics

As detailed previously in other categories, Mary's love of her children is evidently a large part of her. During the interview, Mary became teary while she explained how her chronic pain transcends into the lives of those around her, including her children: *My kids take one look at me and they can see how I'm feeling.* After sharing this remark, Mary took a lengthy pause, suggesting a state of reflection. This comment regarding her children seemed to resonate with her, and rather than pursuing with further questions on this specific point, Mary was given space

to reflect, re-group, and take a break if needed. Mary provided reassurance that she was OK to proceed with the interview, and continued to describe how she believes her pain affects her husband: *It's been difficult with my husband who's a very intuitive kind of person who I can't really hide my pain from. He and I have had to adjust a lot of things, he's had to reduce a lot of the activities that he does because he doesn't want to do everything or many things without me. So, he's been a partner.* Mary qualified this comment by saying that she did not think that it would be this difficult to talk about her pain in this way. She explained how she feels upset that her husband has limited his activities so that she wouldn't be left out.

Although Mary shared the true partnership nature of her marriage, she also explained how she felt as though she had little time or energy for herself because she wanted to ensure the wellbeing of not only her children but her husband also: *I would feel like a wreck but I felt like I had to be OK for my husband, and it wore me down.* Despite her unrelenting pain, Mary explained how she had to fight her pain so that her husband wouldn't be impacted by her pain or limitations. She said how she had to be there for her husband and her children, essentially having to place her pain on the back burner in order to be a wife and a mother. However, this took its' toll on Mary and she says how living this way wore her down and became defeating.

Despite the brevity of conversation about her relationships prior to the MBSR program, it became notable that Mary acknowledged the role that her pain has played in her relationships with her family, particularly her husband and her children. She says that she knows her family is aware of her pain and that they know when she is not feeling well. Mary admits to the fact that her husband has minimized his activities because of her limitations, and that at times, she has had to desperately try and be OK for him in order to lessen the impact that her pain has on their relationship and his wellbeing.

Emotional Equilibrium

While sharing her lifelong experience with chronic migraines, Mary was visibly emotional at times throughout the interview. She often explained how she was surprised at her arising emotions and did not anticipate any difficulty with talking about her experiences. The emotions that Mary felt and displayed throughout the beginning of the interview sheds some light into the emotions that she often experienced in relation to her chronic pain and her own lived experiences. At times, it was difficult for Mary to describe her emotions as her past experiences with pain seem to be raw and sensitive for her.

As mentioned previously, one of the most difficult decisions that Mary had to make due to her chronic pain was to leave her work. She described how it was emotionally difficult for her because she loved her work and that it was a very sad time for her when she ultimately had to walk away from her meaningful work. Mary acknowledged the role that pain played in her early retirement and the emotional effect that this had on her: *Leaving work made me sad. It was a challenge to decide to leave. I loved my work.*

As Mary reflected about some of her challenges in living with chronic pain, she primarily explained the emotional and psychological hardships that she faced: *Just feeling icky, awful, struggling, every day.* When asked to elaborate on her every day, she said that she was basically “grim for most of the day”. Mary described being worn down by her pain and that she had “no shock absorbers left”: *It took everything to kind of keeping going. And being my type A personality I kept pushing beyond the point of healthy, if you could ever describe pain as being healthy. Psychologically, it was very difficult. Emotionally might be the better word.*

Furthermore, Mary recalled the application process to attend the MBSR program and remembered that she had written down several other reasons other than her pain for wanting to be registered for the program including anxiety: *I had written in the application that I wanted and needed help to relax about the future.* Mary explained her unease with the uncertainty and unpredictability of what the future holds for her, particularly in relationship to her pain.

Ultimately, Mary experienced several difficult emotions during the course of living with chronic pain. She detailed the emotional pain she experienced in addition to her physical pain and how sometimes, it took everything to keep going. Interestingly, her primary goal for the MBSR program was to learn to better manage her anxiety and uncertainty with the future, as her pain was even affecting a time that had yet to come.

After the MBSR Program

Physical Pain & Pain Management

Mary spoke of a newfound acceptance of her pain following the MBSR program. In order to try and externalize this feeling of acceptance, she explained how when she is in pain now, she will go lay down for the afternoon whereas she would never have done this in the past. Although Mary never described her pain as being less severe than before the MBSR program, she explained it in terms of suffering less: *I was all tearful at the beginning because I was talking about something painful and that involved suffering I guess ... I told myself to accept it and get through it and now it's different, perhaps the removal of some of the suffering ... I think I am sunnier about it. So maybe that means that I was suffering. I just feel much more hopeful as you can hear that I've told you about the various things that I had done before taking the course. I'm willing to try anything. I've always been hopeful. And I think one of the things that I've learned*

is that it's probably not going to go away. Yes it's good to try anything that comes along that seems like it might help you but it comes back to the acceptance. It's realizing that it's going to be there and so that I think, is acceptance.

Prior to the MBSR program, Mary said she would read or take sleeping medications to “escape her pain”. Since taking the MBSR program, Mary no longer tries to desperate push her pain away: *It's going to be there. It's fine to try new things. It's just this giving into it, it really is. Not giving into it and saying, “oh my if this is it how am I going to live my life?” but it's a different kind of giving in. It's not fighting it as much, not pushing it away.*

Mary explained how this change from wanting to escape her pain to no longer fighting it or pushing it away as a significant shift for how she manages her pain and that she continues to use medication when needed: *I don't like to take the pain medication, or strong pain medications, when I'm out living my life, so I tend to only take the migraine medication when I'm at home at night.*

Furthermore, Mary spoke to how she now plans to manage in her pain in relation to others: *I have this kind of goal that I will not try and be so tough when I'm in a situation where I'm around other people and I'm feeling really awful. To just excuse myself and go home or something like that instead of staying and thinking that people know about the pain. Maybe only in that I am more accepting of the situation now.*

Following the MBSR program, Mary says she has continued to exercise and practice yoga in order to manage her pain. She is planning on participating in the half day meditation sessions that the MBSR program leaders run once a month, and she has continued doing some of the homework exercises that she did not complete during the course of the program.

In summary, Mary continues to experience pain, but rather than trying to push it away, she says she is turning more towards acceptance of her situation. She says that this has helped her to live with her pain in a way that removes some of her suffering, which has had great impact on her life and her pain.

Self-Perception & Identity

During the first session of the MBSR program, participants were given the opportunity to review their original application to the MBSR program, and Mary described being “shocked” as she reviewed her reasons for wanting to take the program: *I was shocked to discover and even though I was theoretically attending this course for pain management purposes what I had written on the piece of paper was pretty much everything except that ... and I framed it all in my husband. Everything I had written was not about myself, it was about um somebody else or some kind of a situation ... so one of my first experiences was to realize how much I was not focusing on myself even though I was going to these countless appointments.*” While discussing her experience with the MBSR program, Mary explained how one of her first experiences was to realize how little she focused on herself and her own experiences. She described how the “magic” of the program: *It focused me right in on myself. A structured period every week that just really made me focus in and of course I immediately observed what a hideously busy mind I have and how difficult it is to shut it down.* This appeared to be one of Mary’s most notable self-reflections, an experience that she described as being new to her.

Mary explained how she learned about herself from the experiences shared by others during the program: *When I heard this young woman who was afraid of going out, who could not go out and live her life, and she talked to briefly about the agony of trying to go force herself to get somewhere and when she went somewhere she’d have to leave and she kept beating herself*

up about it. That's it. A lot of people were talking about how they didn't respect themselves so I became very pleased that part didn't apply to me. Though one could argue that since I don't spend much of my life focusing on myself that could be an argument to the contrary. But believe it or not, I don't beat myself up. That's something I'm extremely lucky for.

Mary also says that since the MBSR program, she has realized that her pain will likely always be a part of her: *And I think one of the things that I've learned is that it's [the pain] probably not going to go away. It comes back to the acceptance. It's realizing that it's going to be there.* Furthermore, Mary described an experience during the MBSR program that reflected an unexpected moment with new meaning for her: *The other meaningful moment I had was when all of a sudden I found myself looking back over that short period of space when I was trying to meditate in the seated position listening to [the facilitator's] voice, there was like this golden light shining down on me. I had this image. And to me that's quite magical. I'm not a person, what's the word, a spiritual person, particularly. So I wouldn't see that experience in that term. They just encouraged me to keep going and trying and that even I could get the occasional moment of escape or bliss or whatever it is.*

Lastly, Mary attributes her work towards acceptance as an important stepping stone to trying new things in her life, perhaps things that she once was unsure of attempting due to her pain: *The pain is going to be there. It's fine to try new things. It's just this giving into it. It really is. Not giving into it and saying, "oh my, if this is it, how am I going to live my life?" but it's a different kind of giving in. It's not fighting it as much, not pushing it away."*

Overall, it seems as though Mary has started to re-discover herself through the MBSR program and it continues to be a process for her. Particularly, she seemed to have experienced some elements of self-compassion and loving kindness in the context of her chronic pain. She

admits that she is more aware of herself, and in some senses, is no longer lost in her pain. It appeared as though Mary had forgotten about herself and the mindfulness program has allowed her to reach new levels of heightened awareness, bringing her to be more grounded and rooted in herself. She had the self-described joy of experiencing a blissful moment during a meditative practice, which was particularly meaningful for her. Mary is no longer afraid to try new things and step outside her comfort zone a little more than before, which is proving to provide her with new meaningful experiences.

Relationship Dynamics

There are times throughout the MBSR program where the program leaders discuss interpersonal relationships, and Mary found this to be extremely relevant and helpful for her. She detailed how she now has insight into the stress that her husband feels at times in his own life, and how the MBSR program would likely be of benefit to him: *They only touched on interpersonal relationships for a very brief part of the course but I found it quite helpful, in dealing with my husband in particular. He's not good at dealing with stress and it became more and more difficult to deal with. And I just feel like I got a little bit of a primer to help him diffuse his stress. After the second class I said to him, "you should be taking this class". And he is going to be taking it now as a result.*

When asked if she has noticed any changes in how she relates to others since the MBSR program, Mary acknowledges her uncertainty about this for now, but says she plans to be more open in time: *Good question. Maybe not yet. But in my mind I have this kind of goal that I will not try to be so tough when I'm in a situation where I'm around other people and I'm feeling really awful. To just excuse myself and go home or something like that instead of staying and thinking that people know about the pain. Maybe only in that I am more accepting of the*

situation now. That's a bit of a different spin of what I just said. So more accepting, so likely to be more open. However, Mary admits that she continues to be cognizant of how her pain affects those around her: *I know how boring it can be for people. In a chronic situation, where somebody is suffering, and the people that you're with, that you're with a lot, your loved ones, etc. it can really bring them down.* However, she also says how maybe she shouldn't act or think this way: *So I'm just talking myself out of talking about [the pain] with others, maybe I shouldn't do that.* It appears as though she is contemplating shifting her approach and perhaps in time this will change for Mary.

Altogether, Mary says that the MBSR program has provided her with tools to diffuse some of her stress, particularly with her husband. She says that she believes the program would benefit her husband as well and as a result, he is set to take the program in the near future. Mary was honest in her response to how her relationships have changed, if at all, since the MBSR program. She admits that although she has not noticed any major changes as of yet, she believes that there may be room to grow and change in good time. Specifically, Mary says that she might try and be more open to those around her by letting them know when she is in pain and unable to do something, rather than pushing through and assuming that people are aware and understanding of her situation. She admits that this would be a big step because she often feels as though she is bringing those down around her because of her pain. However, she is beginning to shift her thinking in a direction that might allow her to be more open with those around her.

Emotional Equilibrium

It seems as though Mary's outlook has shifted from pessimistic and hopeless to optimistic and hopeful. This change in outlook has played a role in how she feels emotionally in relationship to her pain. Mary attributes much of her change in emotion to acceptance of her pain

and the newfound sense of hope she now has: *I think am sunnier about it. So maybe that means that I was suffering. I just feel more hopeful as you can hear that I've told you about the various things that I had done before taking the course.* Throughout the interview, Mary discussed her ambivalence about what it means to suffer and if she was in fact suffering throughout many of her years living with pain. Her recent feelings of hope and positivity makes her believe that she was in fact suffering, and Mary continues to be introspective about this change.

Although Mary describes some of the emotional struggles she has had to overcome in living with her pain, she says the MBSR program has shown her that her emotional challenges were manageable in comparison to others: *I would much rather have the physical pain than some of these very extreme emotional issues or pains that people were dealing with.* Hearing the stories of others not only made Mary look at her emotional challenges with less hardship, but her physical pain as well.

For Mary, acceptance of her pain and her experiences has played a role in how she feels. Although she is unsure if it was the MBSR program or timing in her life that has facilitated this change for her, she describes acceptance as a positive experience for how she lives and feels: *It's this whole acceptance thing. It's such a warm fuzzy ball of everything else that it wasn't like working with the psychologist one on one. Or maybe I was just ready for it finally.*

Lastly, Mary now feels as though she has the tools and techniques to manage her situation, whether it be the pain or emotions that arise as a result. Prior to the MBSR program Mary would question how to manage a situation with “what do you do?” Now, she believes that she is better equipped to combat the pain and experiences that come with pain, allowing her to feel more prepared and not as emotionally overwhelmed: *Some people go for pain and some go for anxiety. And you get so much more in terms of tools to help you live and deal with your*

situation which could be applied to things that have nothing to do with pain or anxiety or whatever. It's really quite over-arching and I think that's a point I wanted to make because that's been my experience.

In summary, Mary describes being calmer and more accepting towards her pain experience. She feels more hopeful towards her pain and in her ability to manage it as she feels she now has the tools to work with. Rather than feeling unprepared and overwhelmed, Mary says she is sunnier about her situation and feels like she can now live and deal with her situation. Although Mary continues to reflect on her emotional experience and any changes she may be feeling, she is beginning to feel an alleviation from suffering.

Stephanie

Before the MBSR Program

Physical Pain & Pain Management

Stephanie recalled her long history of pain, beginning at the age of twelve with progressively worse pain and symptoms over the past 10 years. At 19, Stephanie underwent surgery to treat her endometriosis. Although the surgery alleviated some of her pain for a couple of months, the pain became worse and she began experiencing pain every day. Next, she had another surgery including an appendectomy, and said how there were no more options left: *They basically tried everything and now I'm just considered like a chronic pain patient I guess.*

For a very long time, Stephanie was in so much pain that she remained physically frozen: *I was debilitated and couldn't really get out of my bed at all. I was always in the tub which was the only way I could really get relief was through the heat, so I was alone a lot.* Due to the fact that pain relief was essentially obsolete in this way, Stephanie described feeling hopeless,

exhausted, and frustrated by her debilitating pain that she lived with every single day. There would be times when her pain would be so inconsolable that her and her mother knew that the only potential solution was to go to the hospital Emergency Department: *We always thought there was something else wrong so we were constantly going into Emerge at like 9:00 at night ... because the only thing that would work for me when I was around 15 was Tramadol or Naproxen at pretty high doses and then when I was 18 I was taking like Morphine ... and that would make me feel better for a couple of months because I would have that little break from the pain and I could just sleep and not have pain all the time.*

It was with much emotion that Stephanie explained how she was looked down upon by doctors and treated like a “drug seeker” and as a result would be sent home without any medical help: *They were really judgemental and were afraid to give me something because they weren't sure if it was something I was just seeking. So that was tough because there was nowhere to turn. And I know it wasn't a solution but I didn't have a solution, and they [the doctors] kept telling me “well it's not the solution”. Would they rather just me go home and still be in pain? So they wouldn't give me that but then they'd want to send me home and be on my own to deal with it so it was hard because it felt like nobody was trying to help get through that really tough point where I just needed to sleep basically or just have a little bit of relief and I just never really had any relief.*

Despite the frequency and severity of her pain, there was no resolution: *It was just trying to figure out what was wrong and trying to find a solution all the time and there was nothing to offer me anymore because I had tried everything.* When asked what other ways she had tried to alleviate her pain, or other strategies, Stephanie offered several examples: *I have tried the homeopathic way of changing my whole diet and everything. I went to a therapist,*

physiotherapy, every kind of natural thing that I could to because I had already tried everything medically ... it was hard to keep trying these things when I didn't see any improvement.

Unfortunately for Stephanie, these were not effective interventions, but they lead her to move forward: *They haven't really helped. I think they helped me accept that nothing is going to help medically because I had to just move on but that took a long time to accept that and move on from that whole idea.*

One of the most helpful and thoughtful remedies was a gift from her uncle: *When I was admitted the last time my uncle got us a hot tub for a month and that really, really helped and he ended up buying it for us so now we have it and that's helped a lot because when I'm in pain and I need to be in the bath, I was in the bath a lot, for like 6 hours a day, maybe some days it was all day.*

Finally, Stephanie explained that it felt like she had tried everything, with little respite, which lead her to the MBSR program: *Not a lot of things were very helpful, I tried like everything. Which is why I ended up going to mindfulness because I was in the pain clinic and they had tried everything too and they recommended that I go to the course.*

Self-Perception & Identity

Stephanie specifically spoke to how she felt in relation to her life and way of being for many years prior to participating in the MBSR program: *Before the program it was pretty constant just "this", I don't know, I wasn't really living my life I was pretty much debilitated for a long time.* For Stephanie, "this" meant being in pain, alone, and constantly trying to survive the pain. Her pain affected her sense of her appearance as well: *I think also just gaining weight and all the other things that come with it ... it was overwhelming.* She described her frustration with

weight gain because of her sheer physical inability to exercise, despite having the desire and motivation to be physically active.

A major challenge that Stephanie faced in relation to not only her pain management but her sense of self as well, was the way she was treated by healthcare providers. Stephanie described the way she was perceived by doctors: *Going into the hospital and being treated like a drug addict ... it was fighting with doctors and I was so emotional already and in so much pain and didn't think like I needed to tell them why I needed it, you know?* Stephanie felt as though she had to justify herself to those who should understand her the most. However, she explained how she often needed her mom to help speak for her, almost to suggest how self-defeated she had become with her pain and the medical system: *My mom was always with me but I wasn't able to talk for myself because I would just get too emotional or angry because they were really judgemental and were afraid to give me something because they weren't sure if I was just seeking.*

While exploring what challenges she faced in living with chronic pain, Stephanie expressed her difficulty with being committal to her friends and family and inability to pursue her educational or work-related goals: *I think not being able to work was hard or to go to school or commit to anything, whether it be a job or just a night out with friends or whatever. I could never really just commit until the day of or the afternoon of because I never really knew how I would be feeling. Even now, I'm still like that. It's hard because everybody's planning their life out at this age it seems and everyone is graduating from university and I've never been, you know, so that was really hard. But other things I think, with just dating too. I broke up with my boyfriend a week before my first surgery and just trying to get back into all that.* Undoubtedly, Stephanie was challenged by the fact that she was unable to achieve the goals she had once upon

a time set for herself, nor in the same timeline as her friends and peers. After high school, Stephanie wanted to go to college or university, but was unable to because of her pain.

There was so much uncertainty and unpredictability for Stephanie, which affected her ability to have future-oriented goals or aspirations: *I wasn't sure what my future was going to be anyways and it was hard to accept that too. That was like another thing I was really struggling with – everybody seemed to be moving on and I was just stuck. Like, I literally felt like I didn't exist for 3, 4 years. I was at home every night just watching everyone's lives continue and nothing was happening for me.* Due to the constant, debilitating, and immobilizing pain that Stephanie appeared to be defined by, she felt stagnant in her life, including physically, socially, and academically. Her entire self and way of being was at a standstill, like a stalled car watching others pass by at different speeds. Although this perspective was defeating at times, it was with great strength and courage that Stephanie was able to pull out positives from her situation: *A lot was happening medically and pain and stuff and that was more valuable than anything I could have learned in school or like partying or whatever. I think I have a bit of a better understanding of life and people's feelings and what other people are going through.*

Despite Stephanie's courageous persistence, it was a constant battle with herself to feel like she had any self-worth: *When I was able to actually have people over and get some relief while visiting with my family or friends, I got to be feeling like a person again so that really helped.*

In essence, Stephanie described feeling minimized by her pain. She felt as though she was unable to live her life the way she had planned due to the debilitating effects of her pain, to the point of feeling as though she didn't exist. Her sense of self was impacted by the way she was poorly treated and disrespected by the medical system. To battle the physical pain that she

endured and then to be treated like a drug seeker was unbearable for Stephanie, and surely affected her confidence, sense of hope, and courage to fight for herself, her health, and her wellbeing.

Relationship Dynamics

One of the most significant challenges that Stephanie said she faced in living with chronic pain was feeling misunderstood by others. She said how this also lead to some loss of relationships: *With friends and family not understanding because they can't see it, so to them it's not there – why can't you do this? Or go out? Or drink? And I'm young so a lot of my friends were never very understanding and lost a lot of people because of it just trying to explain to them something I didn't even understand or my parents didn't even understand or the doctors didn't even understand. To try and explain that to my friends, they thought I was just making it up. Just as an excuse to get out of things basically, so that was hard.* Those close to Stephanie even struggled with how to interact with her: *Family as well ... it was hard because they didn't want to acknowledge it but by them not acknowledging it, they didn't want to bring it up but that's what my life was consumed by at that time so it was hard for them to figure out how to be around me for a long time so that was hard too.*

There always seemed to be a lot of thought and navigation about how, if at all, to talk about her pain experience. Stephanie said how others often thought to themselves, *“Should I ask how she's doing?”* and how she would question if someone chose not to ask her how she is doing: *And when they asked me I would be annoyed. So I guess I would just rather be alone then actually go through all of that I think. So that was tough too. To find somebody to relate to was hard.*

Due to the nature of her disease being a solely female illness, Stephanie explained that it took her father a while to understand what she was experiencing. Again, because her symptoms were not always obvious to others, she said her father would try and push her to do things: *That was always the cause of it and when it was constant chronic pain it was like, “common you have to work you have to try and do something”*. It was difficult for Stephanie to hear this when she herself wanted to be able to work and do something, or anything, for that matter, but was in too much pain. She had to try and work through the fact that she was unable to do the things that she wanted to be doing or should be doing, and had to justify herself to others on top of that: *Eventually he came around and obviously was really understanding when it was clear that it wasn’t me just making it up but even that was hard to be constantly trying to defend myself. And be the one who was suffering all the time.*

All in all, Stephanie’s relationships were affected by her chronic pain in large part due to the fact that those around her were unsure of how to act around her – should they ask her how she is doing? Should they avoid bringing up her pain like the black plague? In the same vein, Stephanie never knew if she wanted people to ask her about her pain or to simply treat her as though she was not living with pain, in essence to try and normalize her life. Stephanie felt as though nobody understood what she was going through and she felt like she was continuously trying to defend herself and why she is feeling a certain way.

Emotional Equilibrium

At the beginning of the interview, Stephanie made an impactful comment when she said that for the longest time she “wasn’t really living her life”. She explained that she was “definitely depressed because she was debilitated”. As chronic pain affected more than just her physically, Stephanie felt overwhelmed by the overarching effects on her life: *Just being alone, and in pain,*

and not sleeping, the whole thing. It was overwhelming. The stillness in her voice and her physical withdrawal while describing feeling alone and overwhelmed resembled her emotional isolation.

The “constant battle” that Stephanie faced most times she went to the hospital was very hard on her because she was in dire pain and thought that doctors would at least be understanding of her experience but instead, she was often treated like a drug seeker and sent home without any help. Stephanie said that she was already emotional and in so much pain that she didn’t think she needed to explain to physicians why she needed some form of pain relief. As physician after physician told her that pain medication was not the solution, Stephanie began to feel hopeless: *At that point, I was like I can’t do this anymore and was basically like suicidal and it was hard to be alone and away from everyone without a little break. So they wouldn’t give me that [pain medication] but then they’d want to send me home and be on my own to deal with it so it was hard because it felt like nobody was trying to help get through that really tough point where I just needed sleep basically or just have a little bit of relief and I just never really had any relief.* All while Stephanie was trying to seek help from those who she felt she could trust, she felt rejected and let down. Stephanie began to experience hopelessness and helplessness like never before all while feeling the physical pain manifest. It surely appears as though the relationship dynamics with her healthcare providers have caused Stephanie further emotional distress and challenges.

Stephanie further described her loneliness and how it caused her to feel emotionally down: *When I’m in pain, I need to be in the bath, I was in the bath a lot, for like 6 hours a day maybe, some days it was all day. So lonely like alone and just depressing really.* It appears as though trying to manage her pain became a negative and difficult cycle for Stephanie

emotionally; she would want to be with others but because her pain was too bad she had to try and manage her pain the only way that brought some relief, which was by being in the bath. This pain strategy kept her from being around the support of others or living her life the way that would bring her joy, so she felt alone and depressed.

Altogether, Stephanie experienced several emotional hardships during her many young years of living with endometriosis. First, being treated like a drug seeker rather than a young woman in pain made her feel rejected and certainly took a toll on her emotionally. Additionally, having to try and treat her pain by hot baths for hours on end, limited her social interactions which caused her to be alone and feel alone, physically and emotionally. These emotional challenges were felt throughout the course of the interview.

After the MBSR Program

Physical Pain & Pain Management

For perspective, leading right up to the minutes before the MBSR program, Stephanie was still fighting her pain within the medical system: *I've tried everything to try and alleviate it and it hasn't really helped so even the day mindfulness started I came right from the hospital because I was in a lot of pain and I went in for some relief and didn't get any.* Following the MBSR program, Stephanie continues to experience pain. However, rather than trying to do anything and everything to get rid of her pain, she has changed her view on pain: *I am in pain but I can't change that.*

The MBSR program, particularly the meditation, has allowed Stephanie to be “OK in her own body”. She explained the shift that she has experienced since pursuing mindfulness: *I feel like I was trying to escape myself for so long. With drugs or watching TV. I didn't want to think*

about what was going on with me. I was trying to just forget about it and that wasn't helping anything so once I was meditating I realized, "OK this is what's going on with me, and that's OK". Then I felt empowered with that and I can do something about it, it will just be in a different way. Just to be with it and to be OK with it and to realize that it's just life.

When Stephanie was asked to speak to her adaptation to chronic pain since the MBSR program she said: *I think I'm OK with [the pain] now. I feel like I can handle [the pain] better.* She explained that by expressing herself and being open and honest has allowed her to better manage her pain. By being more transparent with others, she is being more transparent with herself and how she is feeling physically and can therefore adapt her activities accordingly. Prior to the MBSR program, Stephanie had been searching long and hard for a solution to her pain. Since the program, Stephanie explains how she has stopped searching and has found harmony in this: *[The MBSR program] brought me out of this hole that I was in and thinking about the negatives and constantly trying to find a solution and when they were talking about just being with yourself and accepting what you're going through I felt so much better because I was kind of peaceful in my own body for a change, it was really nice.*

Furthermore, Stephanie has since stopped taking medication: *I think it's a combination of things like stopping medication and trying to just be with the pain and be OK with it rather than trying to numb it. The medication never really helped with the pain it just sedated me basically. But that wasn't helping anything, it was causing more issues like all the side effects from it. So when I started mindfulness I decided that I was just going to do that and take the least amount of medication as I could so that helped too. I think it was a combination of both of those things that made everything more clear and feeling more present in everything that I'm doing which is nice.*

Isolation from others and social events was how Stephanie coped and managed her pain for several years. However, this has changed for her. Since the MBSR program, Stephanie no longer segregates herself from the world around her: *I'm OK with doing more ... I am forcing myself to go anyways and see how I feel because I'm going to have the pain whether I'm at home or out with friends and it's better to go out with it and live with it because at home I just think about it and that just takes over. So it's been helpful to live with it and to let myself live and not let it control what I'm doing or how I go about my day and just do things for me and not have pain influence all of that. That's pretty much what has changed, realizing I'm still going to be me but I'm going to be me in a little bit of pain and less activity but I can just modify what we're going to do.*

The yoga lessons and movements that are incorporated into the MBSR program had a lasting impact on Stephanie and her pain: *I loved the yoga. It's really helped relax my whole body and stretch out my muscles so I'm definitely going to continue to do that hopefully. Find somewhere where I can do it on a weekly basis because that was really awesome. One of the highlights of my experience for sure.* Stephanie felt more meditative during movements like yoga and walking as opposed to seated meditations and continues to incorporate it into her lifestyle now as she experienced some benefits: *When we were moving around I found now I can just let things go and that was really nice too. And I thought the walking was nice too. I do that with my dog now.*

Overall, Stephanie has experienced a significant shift in how she views her pain which has changed the way she tries to manage her pain. Before the MBSR program, she saw her pain as something she wanted to desperately escape, or better yet, get rid of entirely. She would isolate herself at home because the pain was too debilitating. When the pain got to the point

where it would be too much to bare, Stephanie would have to go to the hospital. Now, Stephanie says she knows she cannot change the fact that she has pain. Instead, she says she feels like she can be OK and at peace with her body now. Rather than trying to fix her pain, she says she acknowledges its' presence and the role that it plays in her life. She now tries to engage in social activities and modifies her commitments based on how she is feeling as opposed to isolation. Stephanie also continues to practice yoga and meditation to help with her pain management.

Self-Perception & Identity

One of the first comments that Stephanie made even before being asked about the MBSR program was: *At the end of the [MBSR program] it was totally different. I just left there feeling more like myself and it was pretty amazing.* Stephanie voiced this as a major shift for her sense of self as she felt as though she was not living her life or existing for many years before the program.

So much of who Stephanie felt she was for many years was affected by the significant role that the medical system played in her life. For her to be perceived as a drug seeker by healthcare providers, left her feeling hopeless, minimized, and defeated. Stephanie felt lost in the upheaval of emotion inflicted upon her by the medical system. However, she details how this has changed for her in part due to the MBSR program: *I think it was more finding myself again and being OK just having more confidence I think really helped me get through all of this kind of moving on from the medical side of things. I just sort of centered me again and realized ok, I am OK ... I feel like I exist again which is kind of really nice. It's kind of like self-worth.*

For Stephanie, it was not simply a shift in her identity, but more largely, that she now feels as though she exists again: *It's just feeling like I was so blurry for so long, like not even*

here. But since I've taken mindfulness I feel like important again or I do have something to say and it can help somebody, I don't know.

Furthermore, Stephanie experienced self-reflection, and has looked back upon her lived experiences and views her pain as perhaps a stepping stone or building block for who she has become: *Maybe my experiences are what I was meant to go through all this time. I think it's going to help me going forward, moving forward, who I am supposed to be. It just made me feel, I don't know how to explain it, it's so hard, just alive again.*

From a sense of blurriness to awareness, Stephanie says she now feels more aware which has allowed her to direct her focus in more positive directions: *I realized I was focusing on everything that was wrong instead of focusing on everything that's right or good. So when I started to do that I started to realize that there are good things and that I could be the person I was 3 or 4 or 5 years ago. I think I'm just more content more and more everyday and more aware of what I'm going through.*

Rather than defining herself by what she hasn't done yet or what she should be doing, Stephanie now thinks about herself and her world in more of a present than future tense: *I think that was really powerful to just be able to say "take it one step at a time, one day at a time and one experience at a time and just go from there" instead of just, I was always thinking too far in advance – OK, what am I going to do for school? What am I going to do for work? I'm not able to, just going off on all of that stuff ... what am I going to do when I'm 24 and haven't gone to school, it was just so overwhelming ... So I think just to be here and be OK with what I'm doing right now is much better than worrying about the future when I can't control it anyways so that was really helpful I think.*

Finally, one of the most profound changes that Stephanie spoke to was her newfound acknowledgement that she is here for a reason, and is no longer passively living: *It helped me to be more confident in who I am too. I feel like myself or I don't know, just OK with who I am. That really made me feel like a person again. I am here and I am here for a reason so to just acknowledge that was really powerful for me.* Importantly, this appears to be Stephanie's way of experiencing self-compassion and loving kindness.

Thus, Stephanie has felt an internal shift in how she perceives herself and how her pain is not who she is. Stephanie recognizes the role that pain has played in her life but is now able to externalize the pain as something outside of who she is and how she views the world around her. Stephanie has developed a sense of courage and persistence which she plans to utilize in a way to move forward with her life and her goals. She says she has acknowledged that she cannot necessarily control her pain but that she can control how she chooses to view her experiences. Stephanie has experienced a change from feeling non-existent to feeling and recognizing that she is here for a reason, and perhaps that reason is to empower women in similar situations, a course of action that would be filled with meaning and undeniable relevance to healthcare today.

Relationship Dynamics

For the longest time Stephanie felt uncomfortable in many of her social interactions, whether it be with family or friends, for her pain became an unspoken topic. Stephanie said that people were unsure if they should bring it up with her, and she did not always feel comfortable talking about her pain. Now, her relationships are based upon honesty and transparency: *I can express myself better. If I can't make it to something, I'm honest about it ... And I'm just honest about what I've gone through in general if people ask me. Even in the summer, friends that I used to have before all this happened, I used to dance around the subject. This just made me feel*

like I can tell my story and either people are going to understand or they're not going to. And people who understand I want around, and people who don't, I don't really want around.

Along the same vein, Stephanie says she is more open to talking to people, and this open communication has taught her about others' experiences: *I've had a lot of friends who have been through medical issues, and I've been able to talk to people since I've been feeling better and realizing that everybody has their little things and everybody can customize their life to what they're going through and whether it be stress, pain, kids, divorce, or whatever it is, it's not necessarily medical but just being able to relate to other people and realize I'm not the only one to deal with this reality and that's OK.*

Despite the turmoil that Stephanie experienced with the medical system, she described how she would interact differently if in a similar situation again: *I wish there was a situation that I could go back or go with someone who was going through it to be the calm voice just to explain why this is happening and why people are going to emerge and why they react like that and it's because they've been up for weeks and weeks in pain.*

Lastly, her day to day interactions have become calmer as a result of some of the breathing techniques learned during the course of the program: *The breathing has really helped. Even with my sisters or my mom if I feel like I'm going to blow up, I just breathe. And then I can kind of re-center myself and speak a bit more politely about things or clearly.*

In summary, Stephanie has become more open to talking to others about what she is going through. She says that some people are either going to understand, or they won't. Stephanie says that moving forward, she plans to surround herself with those who will take the time to try and understand where she is coming from and to be considerate of her decisions. Furthermore,

Stephanie says that she is now better able to see the experiences of others and how people on either side of her may be going through hardship. This has allowed her to be more empathic towards those around her. Lastly, Stephanie explains how she is less reactionary and more calm in her interactions with her family, and she attributes this to “just breathing”.

Emotional Equilibrium

For so long, Stephanie tried to fight her pain and the lack of improvement made her feel hopeless and she says that she was certainly depressed for quite some time. Now, she says “I am still in pain but can’t change that”. Since she is no longer trying to fight her pain, Stephanie feels a recent sense of calmness: *So it just kind of mellowed me out a bit I guess*. To further elaborate on this newfound calmness, Stephanie explained it in terms of acceptance and what that means to her: *People, I think, underestimate what it is to meditate and to be alone with your thoughts, and to acknowledge them and let them go. That’s harder than anything else but it’s so helpful to kind of accept that things are what they are and you can’t control them. But to just be with them is OK*.

The adjective overwhelmed was consistently used by Stephanie as she described her experiences before being introduced to mindfulness. This feeling of being overwhelmed has since left her every day way of being, and rather, she emotes a type of peace since the MBSR program: *I felt so much better because I was kind of peaceful and in my own body for a change, it was really nice*. Similarly, Stephanie says she does not feel as much stress in regards to her relationships and interactions. She no longer worries about letting others down because she is more in tune with herself and what she is feeling, which was less pronounced in the past. She says she no longer feels responsible for others: *And to also know that I’m not in the wrong and to*

not feel guilty for everything because I can't control people's decisions or reactions to everything.

Motivated and inspired were two words that were practically unheard of in Stephanie's vocabulary, until she received inspiration from those in the MBSR program: *There was one lady in the class who always spoke so elegantly and I always thought that was so inspiring that even though she was in so much pain she would always find the positive in it and still do stuff for herself and that was really, it gave me a lot of, I don't know how to say that, just energy. It gave me something to relate to and when I would think I can't do this, well, she could do it. So I need to try.*

It appears as though Stephanie looks back upon her experiences with strong emotion, but from a different, healthier perspective: *My [endometriosis] made me feel like the biggest loser and made me feel so gross. And that something was wrong with me. Something WAS wrong with me and it wasn't my fault. I wish I could talk to young girls and be able to tell them that if this is happening to you, this is what you need to do and it's OK. You're not crazy and pain is real.*

Interestingly, Stephanie continues to have heavy emotion towards endometriosis, but more so how it continues to affect others: *It just breaks my heart that people are going through this ... I wish I could prevent that from happening to somebody else.*

Evidently, Stephanie now describes herself as mellow, peaceful, and motivated. This is a major transition from the hopelessness she once described. The major factor that has helped her get to this point was changing her mindset from "something is wrong with me" to "something is wrong with me and it isn't my fault". For so long, Stephanie took responsibility for her pain and this affected so much of how she felt day to day. Now, Stephanie feels empowered from the

program and from learning that others have gone and are going through similar experiences, which validated that pain is real. This validation has given her confirmation of her physical and emotional experiences and is now the source of her motivation to make positive change in the world of pain and endometriosis.

THEMES

The previously detailed categories spoke to what changes, if any, occurred for the participants in wake of participating in the MBSR program. Each category is bounded by certain parameters and definitions and are comprised of significant statements that are based on meaning. The following themes are meant to speak to broader findings that are not limited to specific categories, but rather, encompass or even transcend all of the categories. The themes incorporate meaning, both from the language used by the participants, and as understood and reflected back upon by the researcher. Although there is a large interpretative element in the themes, direct quotes are used to support the themes and as such, they are anchored to the data. The themes are intended to demonstrate how any changes experienced by participants is a part of a process which involves shifts in how one relates to the world, to others, and to their pain, and a change in perspective.

Being Heard & Understood

Statements such as “people don’t understand” and “I don’t want to be a burden” were shared remarks across the three participants. Not only did the participants explain how they often kept their feelings and experiences to themselves rather than sharing with people, they also explained how discussing their pain experience with those in the MBSR group was a very valuable and meaningful experience.

Mark provided the distinction between sharing with people who might not necessarily understand compared to those who are living a similar experience. While describing how he used to avoid conversation about his pain he said: *Uh, if people see you’re in pain, they treat you differently. You know some want to help you, some want to offer solutions to you know, have you*

tried this, have you tried that? And ugh you know, I don't want to make them feel like it's not a good idea or something but ugh I think at the end of the day you know your own body and it's easier for you to decide whether that's good or bad but at the same time you don't necessarily want to make other people.. because the ones that love you, they want to help you. And that's their intent is to help you, but sometimes they're reminded you of you know, I have this pain and yes, you don't need to remind me of it, I know it. I think part of the reasons why I try not to show it because then that type of conversation never comes up. Mark also admitted that not talking was difficult and that mindfulness has helped with this: *Not being able to talk was tough for me. Because I think part of this whole mindfulness has made me more open to talking.* He also detailed how being in a group of people living with similar lives was reassuring: *After the second day where we got to know each other more and we got to hear their experiences and why they were here and things like that, it kind of helped calm you in a sense, ok, I'm not the odd person out here. These people are all here for the same reason, some more so than others. But at the end of the day, we're all looking for the same thing.* For Mark, being with people that can relate is vital: *I think when you have a group like that, who are people experiencing the same problem as you, it's easier to talk to those people because they can relate. Sometimes it's hard to talk to someone who doesn't understand pain. Or to talk to the doctor because the doctor hears it all day long and can shut it out, unless you're crawling and crying and dying on the floor, right, so sometimes, I think being in a group session like this and in a session that allows you to be focused on that one thing.* Importantly, Mark believes that this experience will help him be more open to sharing in the future: *I think it will help me in the sense that it will not make me feel uncomfortable talking about it, and it's not a crime to be able to say that I have a sore back, can we do this another time?*

Similarly, Mary reflected about the connectedness she felt in the group: *Friends, not like long term friends, but a couple that I would actually like to continue to know, but just the comradery of being in the group, I found that to be really good. I found that almost everybody ... they really needed to talk ... and suddenly there was like this really direct kind of contact and when you had a shared experienced, whether it was an emotional experience or pain or whatever it is and just instant connections which I thought were really neat.*

For Stephanie, she experienced a major change in feeling heard and understood. Prior to the MBSR program Stephanie said, “I’m young so a lot of my friends were never very understanding and lost a lot of people because of it just trying to explain to them something I didn’t even understand or my parents didn’t even understand or the doctors didn’t even understand. To try and explain that to my friends, they thought I was just making it up”. Interestingly, feeling understood did not necessarily require conversation with those in the MBSR program, as non-verbal cues signified a sense of relatedness for Stephanie: *I met a lady there who at first she was in so much pain I thought she had back pain and I could see her doing a lot of the things that I do when I’m at my worst and was really relating to her but we had never spoken. It wasn’t until she sat next to me and we got to talking that I realized she has the same doctor as me and has the same disease that I do and it was really interesting to hear and to relate to somebody who is going through it. Although Stephanie said it took her a while to feel comfortable talking to those in the MBSR program, doing so made her feel more confident and less alone in her experiences: It took me a long time to be able to feel comfortable enough to speak up or I don’t know, to express myself. But by them expressing themselves gave me a lot of confidence to do it myself and made me realize that there are things that may be different but it was really inspiring to hear that they were putting it into their own lives and that it was helping*

them. And that everybody shared the same kinds of things and that it wasn't just me having a hard time. Feeling understood was also a valuable experience for Stephanie: People go through things, and this was just my thing. So it was really nice to feel like other people understand that and to connect with everybody in the group on that level, and what people would say, I could relate to every single person. And that was really interesting as well, it didn't matter if it was stress related or pain related, or in between, it was all the same feelings so that was really interesting.

Overall, being heard and understood was a novel experience for Mark, Mary, and Stephanie. It proved to be a powerful experience for them because it not only validated their own pain experience, but it showed them that they are not alone. Rather than being dismissed because people assume their pain is not real or that they are a “drug seeker”, the participants felt a sense of comradery with the MBSR group and knew that those around them understood because they too, have lived with chronic pain.

Letting Go and Being Here (laying down the fight)

“From countless appointments to nearly every Western medical way” was how Mary explained the way she managed her pain for so long. With a melancholic tone, Mary said that she found it hard to accept how much impact the pain was having on her and her life. She described herself as Type A and suggested that she is a fighter with perseverance and determination, unwilling to let the pain win, so to speak. While narrating how she tried to manage her pain in the past, Mary said, “I was just pushing through and denying it”. She continued to say, “I guess I tried to work at accepting it”. Although she uttered that statement, Mary did not appear too convincing of what she had said, not even to herself. The difference in vigour from when she talked about “fighting the pain” to “accepting the pain” was evident. This became more

transparent as she began to share her experiences of acceptance since the MBSR program, and it appeared as though Mary began to sense her own transference with the word acceptance and what it means to her. When Mary was asked how, if at all, she has changed in the way she lives with her chronic pain since the MBSR program, she immediately said, “in my mind, I go back to the same thing about acceptance”. This was a notable change as acceptance sounded like something she perhaps thought about trying in the past, but that fighting, persevering, and pushing away were her main tactics. Now, Mary speaks to acceptance as her newfound practice: *[Acceptance] is the major finding ... I just had to sit there and focus on it and think about it and you know, reflect on it.* The phonetics and ease at which Mary said “acceptance” was apparent, and the fact that there was a change in how she uttered the word was brought to her attention during the interview, and Mary re-assured this perception: *That’s very perceptive of you to say that. Umm ... I guess maybe I didn’t really know what accepting really entailed. I mean it was more mental. It had a very strong emotional and psychological impact on virtually everybody I could see in the class. I have a brain that thinks and analyzes all the time. So I told myself to accept it and get through it and now it’s different, perhaps the removal of some of the suffering and I hadn’t quite thought of it in those terms.* When asked what acceptance means to her, Mary said, “It’s more like laying down the fight a little bit”.

From battling with the healthcare system, physicians, educators, and peers about her chronic pain, Stephanie’s journey with pain was a challenging one with a lot of fighting through the pain and trying to justify her pain to those around her, which caused her a lot of angst and emotional distress. Although she sought out all medical options, Stephanie says she’s come to “accept that nothing is going to help medically ... I had to just move on but that took a long time to accept that and move on from that whole idea”. Stephanie said how she was always trying to

find a cure for her pain and to fix how she was feeling. When she began sharing her experiences with the MBSR program she said: *I think it really helped me get through all of this kind of moving on from the medical side of things. It just sort of centered me again and realized, okay, I am OK. I am in pain but can't change that.* To acknowledge that she is in pain and can't necessarily change that, sounded like a hint of acceptance for Stephanie. The word hint speaks to the surprise of acceptance that Stephanie experienced during the MBSR program: *Umm, the meditation surprised me, like how hard it was. People, I think, underestimate what it is to meditate and to be alone with your thoughts, and to acknowledge them and let them go. That's harder than anything else but it's so helpful to kind of accept that things are what they are and you can't control them. But to just be with them is OK and to be in your own body is OK. I feel like I was trying to escape myself for so long. With drugs or watching TV. I wasn't, I didn't want to think about what was going on with me. I was trying to just forget about it and that wasn't helping anything to once I was meditating I realized, "OK, this is what's going on with me, and that's OK", then I felt empowered with that and I can do something about it, it will just be in a different way. Just to be with it and to be OK with it and to realize that it's just life.* Stephanie recognized that this was a huge change for her and she explained what she believes facilitated this change: *I think it's a combination of things like stopping medication and trying to just be with the pain and be OK with it rather than trying to numb it ... I think it was a combination of both of those things that made everything more clear and feeling more present in everything that I'm doing which is nice ... just to be grateful for what I'm going through right now and to just enjoy this moment because it's never gunna happen again and I think that was really powerful just to be able to say "take it one step and a time, one day at a time, and one experience at a time and just go from there".*

Letting go, for Mark, was resembled in a moment he had during the half day of silence during the 6th week of the MBSR program: *[The half day] allowed me to forget about everything else that's going on around me for that period of time. When I went home that day it was like I can remember being a kid you know, sitting in the field, watching the wind blow and the sky and nothing else bothered me. Just you know, I guess in a nice place. It was just like that.* This childhood reflection reminded Mark of a time and a place that is absent of fighting pain. He also says that he is not as reactionary as before and that the MBSR program has helped him to be calmer about his pain and his day to day life and attribute this to his now open-mind: *My mind is more free to explore things and to hear things. Physically, I don't think I'm thinking about things.*

For so long, each of the participants described how they were always desperately trying to continue to search for a solution to get rid of their pain. They used statements such as “fight the pain” and “find a solution” while explaining how they once tried to combat their pain. Now, they have all experienced a shift towards a more adaptive response to their pain, including acknowledging that their pain is present and they can't change that. Some participants described this change as a movement towards acceptance. In essence, they have revised how they relate to their pain, and now viewing it as something that will at times be there has allowed them to move forward with their lives, rather than hanging on to the idea that they can get rid of their pain. The constant drive to trying to find a permanent solution to their pain was physically, emotionally, and psychologically consuming, whereas now, acceptance of the situation has allowed them to begin to let go of this expectation. The tools such as finding and noticing the breath and walking meditation have helped to facilitate relaxation and openness which appears to be an important piece to letting go and laying down the fight.

The Healing Perspective

Although perspective is entirely an individualistic experience, with each set of eyes noticing and feeling something different, the common thread was that each participant experienced a new and changing perspective, one that seemed to have a healing effect in some capacity.

Mary's first insight from the MBSR program, which happened very soon into the program, was that she had never really focused on herself: *So one of my first experiences was to realize how much I was not focusing on myself even though I was going to these countless appointments.* In fact, Mary admitted that she originally signed up for the MBSR program in order to learn how to manage stress in her family and not necessarily for her own pain, stresses, or anxieties. Mary was in so much awe that she described the experience of honing in on herself as magical: *It was the magic of [the MBSR program]. It focused me right in on myself. A structured period every week that just really made me focus in and of course I immediately observed what a hideously busy mind I have and how difficult it is to shut it down.* Similarly, Mark says how he has learned the importance of focusing on himself: *[The MBSR program] has helped me to focus more on myself and not the pain and other things.* He also described being more conscious of himself and how that might help the bigger picture: *And I think that's part of what the whole mindfulness program was that it might sound selfish to say this, but I'm thinking more about myself. Rather than trying to please everybody else ... which is what I probably did for most of my life ... Whereas now, I think I've kind of got to do more for what's good for me and what's hopefully good for everybody else at the same time too.*

Mark also spoke to the mind body connection that he experienced in the MBSR program and how he has learned to enjoy things more: *Yah and I think the whole mindfulness thing is that*

it encompassed both the body and the mind and a lot of aspects of day to day life and it puts it in perspective ... that I could die tomorrow and somebody would be in my job tomorrow. So in this case, it just allowed me to enjoy things more. He also noticed how his thoughts have shifted from negative to positive, particularly in the context of his pain: *It's helped me to not have the negative thought processes. Like, "oh jeeze, if I go there, I'm going to be sore after an hour and I won't want to do this". That doesn't even come into my mind anymore. If anything, it's like, "OK. If the pain starts to come in, maybe you know, I'll just start to meditate for a little while, or I'll do a couple of yoga exercises or something ... I think that's probably the biggest thing, it's turned me from being negative about things".* Stephanie also addressed a major shift in how she views the world around her and she attributes this to the teachings of the MBSR program: *I think it was mostly all the explanations, examples, and diagrams. I related to that so much and I realized I was focusing on everything that was wrong instead of focusing on everything that's right or good.* Reflecting back, Stephanie describes her constant battle of trying to find a solution to her pain as "being in a hole". She has since been able to "climb out of the hole", and it is not necessarily because she has found a cure for her pain, but because she has learned to accept herself which has brought her newfound peace: *I am here and I am here for a reason. So to just acknowledge that was really powerful for me. It brought me out of this hole that I was in and thinking about the negatives and constantly trying to find a solution and when they were talking about just being with yourself and accepting what you're going through I felt so much better because I was kind of peaceful and in my own body for a change, it was really nice.*

Interestingly, Mark, Mary, and Stephanie all talked about the perspective they achieved from others in the MBSR program. For Mark, being in a group with others experiencing pain, allowed him to feel less isolated: *After the second day where we got to know each other more*

and we got to hear their experiences and why they were here and things like that, it kind of helps calm you in a sense, “OK, I’m not the odd person out here”. Mark also observed how his pain was in comparison to others and acknowledged that despite his pain, he is still functioning: *There were some of us who had some very chronic, very severe pain. One being in a wheelchair and obviously his pain was taking him to that level. And there were those of us, like myself, who had a lot of pain but we are pretty well functioning on a day to day basis. You know, hindered somewhat but we were still functioning.* The way that the participants spoke of their awareness of their own pain in relationship to those around them, was not so much in a way to minimize their own experiences, but to acknowledge their abilities with gratitude. Mary explained how she began to view herself in relation to others: *Another thing that I observed right away was listening to people’s introductions for why they were there at the course on the first night ... I would much rather have physical pain than some of these very extreme emotional issues or pain that people were dealing with ... also hearing people describing their different levels of pain I was trying to calibrate how I feel within that range, and I began to feel grateful right away that I didn’t have the pain that some of those people spoke about ... I think that put it in perspective of the other people in pain that were there. So I think I’m thinking to myself that’s not right. But in my mind, I’m thinking this isn’t as bad as it could be and that’s sort of important. Because as you’re struggling through something and you don’t think it could end for a long time, because that’s the meaning of chronic, you could feel discouraged and everything, then I realized it could be so much worse. So one change was just a different attitude.*

Stephanie also found herself gaining perspective from another woman in the program, who provided Stephanie with motivation: *Just being able to relate to other people and realize I’m not the only one to deal with this reality and that’s OK. There was one lady in the class who*

always spoke so elegantly and I always thought that was so inspiring that even though she was in so much pain she would always find the positive in it and still do stuff for herself and it gave me a lot of, I don't know how to say that, just energy. It gave me something to relate to and when I would think how I can't do this, well, she could do it. So I need to try. Furthermore, Stephanie also experienced a change in how she plans to use her experience with pain. Rather than reacting to it in a destructive way, she says she plans to use it in a productive way: I think that' one of the most important things that I've learned, to not be ashamed. I was so ashamed of it for so long and it was holding me back and all this stuff. It's not my fault. It's this. I didn't bring it upon myself. For so long I thought it was something I was doing do it's nice to be OK with myself and not be OK with this and I can use this in a productive way and not in a self-destructive way.

Whether it was the development of a new perspective, a change in attitude, or a refreshing point of view, each participant described an eye-opening experience that has proven to be healing in some fashion. Most commonly, they heard and saw the lived experiences of others in the MBSR program which provided them with a sense of commonality, but also a feeling of how “things could be worse”. While not minimizing their own experiences, the pain of others allowed them to step back and acknowledge what others are also going through, and this served as a source of motivation for some participants. Lastly, Mark, Mary, and Stephanie each explained a change in attitude, from dwelling on all of the negatives in their lives to seeing and allowing the space for positivity and gratitude for what they do have. The ability to set aside the pain and welcome in new joys despite their chronic pain is a remarkable act, and one that is allowing the participants to feel a sense of much needed healing.

Moving from Surviving to Living

Surviving can be defined as “to endure or live through” (“survive”, 2015). This definition appears to capture the way that the participants once described life for themselves. Before MBSR, life appeared to be more about enduring pain and trying to meet basic needs in order to get through their challenges associated with their pain. It sounded as though they were very often trying to survive and push through their pain, almost to suggest that fighting their pain was their way of being, rather than living a life filled with anything other than just pain, like joys or pleasures. For example, Mary explained how she used to “grin and bear it and get through the day to raise her children.” The language she used is in parallel to the definition of survival. However, each of the participants spoke to how they now feel a shift towards living their life rather than just living through their pain. This meaning of surviving to living was different for each participant, and it varied from less suffering and more hope to philosophical changes of how they want to live their life in a more meaningful way.

For instance, Mark began to think about his life with more depth and substance. As Mark moved his way through the following statement, his voice progressively became calmer, softer, and more reflective: *For me, after going through this session now is, it's my thought process it not so much focused on life and being alive, but life and what I want to do with it.* Despite the brevity of this statement and subtle change in phrasing, this comment is both powerful and impactful. He explained how he now thinks about how to make his life more purposeful and meaningful. It sounds as though Mark is opening more avenues to channel his life as best as possible, with more life flowing into his world than ever before. He explained how his pain held him back from living for so long that it is not going to stop him from doing the things that he wants to do now in his life: *If I want to do something, I'm not going to be restricted, I'm going to*

do it. Yes, I might have some minor restrictions to it but it's not going to stop me from doing it. So that's kind of where I think I am with the present.

Stephanie relayed a similar experience with her own self-discovery: *And then at the end of [the MBSR program], I just left there feeling more like myself and it was pretty amazing. But ya, before that it was ... I don't know, I wasn't really living my life, I was pretty much debilitated for a long time. While Stephanie spoke of how she was essentially always in survival mode, she sounded sombre and her eyes would disconnect to another place, perhaps reflecting about the past. Upon reflection, Stephanie also said, "I feel like I exist again which is kind of really nice". As existence can be variably defined, Stephanie was asked what she meant by existence, and for her, existence encompasses being heard, having purpose, and being present, which ultimately has now allowed her to feel alive: I think cuz I felt for so long that I wasn't present, in any kind of situation, with family or at home, I just didn't feel like I was being heard, or I just didn't feel like my opinion was valid because I hadn't really done anything or that people acknowledge anyways in society today. But ya, no, once I did the mindfulness I started to realize that ok I don't need to, I think I was putting more pressure on myself than anything else and over thinking things and I don't know putting all of that on me when people weren't putting that on me, I was doing that to myself. I was the one holding myself back from being there. I wasn't valuing my own opinion. I don't really know how to explain it. It's just feeling like I was so blurry for so long, like not even here. In my mind, maybe it was the drugs I was taking, or just everything combined, just overwhelmed. But since I've taken mindfulness I feel like important again or I do have something to say and it can't help somebody, I don't know. Maybe my experiences are what I was meant to go through all this time. I think it's going to help me going forward moving forward who I am supposed to me. It just made me feel, I don't know how to explain it, it's so hard, just alive again.*

Although the terms suffering and surviving are inherently different words with varied meanings, Mary described her experience with pain and mindfulness in terms of the “removal of suffering”. When asked what she meant by the removal of suffering, Mary explained how during the beginning of the interview, as she spoke about her way of life and trying to live through her pain, she was tearful and emotionally upset, and that meant she was suffering. Mary pointed out that while she described her experiences since the MBSR program, she did not become tearful and that was a sign to her that she was no longer talking about suffering or enduring, but something different. Although Mary did not use words like “exist again” or “feel more alive”, it seemed as though she is in the process of reflection and discovery about what the removal of suffering does mean to her and in terms of her life: *So maybe that means that I was suffering. I just feel more, umm, hopeful.*

In summary, Mark, Mary, and Stephanie each spoke to an experience that can be understood as a change from surviving to living. Although this was shown in a slightly different fashion for each participant, the most significant change from enduring their pain in order to survive towards living a life external to their pain, was evident across the participants.

CHAPTER 5: DISCUSSION

The purpose of this study was to explore participants' experiences of an 8-week MBSR program in the context of adapting to living with chronic pain. The research questions included: (1) What is the experience of participating in an MBSR program for individuals living with chronic pain? (2) What changes, if any, do people experience in the way they adapt to their chronic pain in wake of participating in an MBSR program? (3) What aspects of an MBSR program do participants perceive as the most useful, and why, in relation to their experience of chronic pain? As the answers to these questions are interconnected, the following discussion section will seek to address them as coherently as possible based on scholarly theory, mindfulness and chronic pain literature, and my interpretations as a researcher. Implications for the treatment of chronic pain in relation to both healthcare providers and patients will be discussed, along with strengths and limitations of the study, and possible future directions.

Through conducting the interviews, taking field notes, transcribing the interviews, reading and re-reading the transcripts, several significant statements surfaced. As the meaning and content of each significant statement was dissected, they were grouped into categories based on common meanings and interpretations. The interview guide was created in such a way that the participants' experiences could be delineated as best as possible by before and after the MBSR program. In order to establish context for each individual participant, the first set of questions asked participants to reflect and think back about their experience with chronic pain and means of adaptation prior to participation in the MBSR program. The latter half of the interview guide asked questions pertaining to their experience of the MBSR program, and any self-perceived changes with adaptation in wake of participating in the program, along with what they felt was the most useful in facilitating this change. Therefore, the categorical findings were described in

detail for each participant before and after the MBSR program. The categories described after the MBSR program also speak to what participants felt attributed to the changes they may have experienced. Finally, broader themes emerged during the iterative process of re-reading and interpreting the transcripts, with constant reflections of my own positioning as the researcher. My own experiences played an important role in the analysis of the themes in the sense that I felt as though there was something more within the data. These themes encompass and transcend the categorical findings and speak to the commonalities and differences across the participants. The themes emerged as an over-arching structure for the results. Overall, the answers to the research questions arose throughout the interviews and in-depth analysis and are answered throughout the categories and themes.

Perhaps the most meaningful moment shared during this research study was when Stephanie said that for a handful of years she didn't feel like she even existed in this world. She explained how she felt as though she was just standing still, without any sense of presence or purpose in this life. The stillness of her experience was felt as she relayed this during the interview. However, she went on to say with strong, palpable emotion, that she now "feels alive again". This lived experience is extremely powerful for it appears to fulfill, or even exceed, the ultimate goal of psychosocial adaptation, which has been characterized by the transformation from negative to positive well-being (Livneh & Antonak, 2005). Similarly, Mark says that now, his focus is not so much on living his life, but what he wants to do with it, and Mary says that she has felt the removal of suffering from her life. These self-reflections and lived experiences are momentous for so much of their lives had been compromised and dictated by their chronic pain. This is deeply noted in the results outlined prior to the MBSR program which provided their individual contexts. Most notably, Stephanie, Mark, and Mary all appeared to experience some

form of healing. Though these comments are largely meaningful, how is it that these participants were able to reach such desired outcomes following an 8-week MBSR program?

The vulnerability and willingness from the participants to share their emotional experiences with their chronic pain, nurtured the important findings of this study which sheds light into how it might be possible for those with chronic pain to find healing. Each participant experienced a shift or a change in perspective, which ultimately led to improved psychosocial adaptation, to reach a stage of well-being. An alteration in perspective has been suggested to be a vital component to restoration and healing as Kabat-Zinn (2013, pp.217) so vividly says, “healing is a transformation of view rather than a cure”.

Interestingly, Mark reflected upon the fact that he is no longer seeking a magic pill, for he says that he has now accepted that it merely does not exist. However, while talking about the MBSR program, Mark said, “these people are all here for the same reason, some more than others. But at the end of the day, we’re all looking for the same thing”. When asked what Mark meant by “the same thing”, he replied with, “at the end of the day, we’re not all looking for the magic pill, but we’re all thinking how this could be something that could help any one of us”. I can’t help but wonder if healing was what Mark was alluding to, and if some form of healing was what ultimately began to happen for each participant throughout the MBSR program. The categories which surfaced speak to specific factors that are important for adaptation and how the experience of the MBSR program may have helped to foster positive changes in these domains. The main, over-arching theme found in this study was a shift in cognitive appraisal, and this is reconciled/substantiated throughout the themes in the results section. Overall, it appears as though the participants experienced several positive shifts physically, emotionally, interpersonally, and internally. Importantly, a shift in cognitive appraisal seems to have been the

major factor in facilitating these shifts. These findings are in line with previous research which suggests that the cognitive appraisal is the driving factor for psychosocial adaptation in that it helps one to achieve certain tasks imperative for a new state of psycho-social equilibrium (Moos & Tsu, Cohen & Lazarus, Corr, Samson & Siam).

Although the goal of psychosocial adaptation is to enter a state of improved well-being, it is nevertheless a process of responding to changes that occur as a result of living with a disability or chronic illness, particularly within the functional, psychological, and social changes (Bishop, 2005). Particularly, the categorical findings are encouraging in this regard, as participants described their perceived changes to their physical response, sense of identity, relationship dynamics, and emotional equilibrium. These changes appear to involve several of the tasks detailed by the Integrated Task-Based Model which suggests the importance of physical, psychological, social, spiritual, and vocational tasks in the process of psychosocial adaptation (Samson & Siam, 2008).

Categories

Physical Pain & Pain Management

Although the participants described times of temporary relief from some of the interventions they tried in the past, the result was always only short-lived and then distress would persist. Following the MBSR program, participants detailed how although they continue to experience pain, it does not feel as incapacitating as before. It appears as though their relationship towards their pain has shifted to a healthier, more adaptive space. This appears to be in line with the findings of Dobkin's (2008) study which found that for cancer patients, acceptance meant understanding that things are not necessarily how one wishes them to be, and

taking responsibility for what one can change to feel better all while being aware of self-limitations. This category is similar to the experience of those with chronic lower back pain who found significant improvements in pain acceptance after the MBSR course, but no difference in pain intensity (Morone, Greco, & Weiner, 2008).

Furthermore, all participants were pleased to say that they are either no longer taking pain medication, or have reduced the amount that they take. They described how mindful activities such as meditation, yoga, and breathing have become ways in which they manage their pain and how they are skilled means for maintaining a balanced and healthy lifestyle. It appears to be more of a long-term adaptation process than an acute, reactionary attempt to address pain. The physical pain does not seem to be as distressing as each participant touched on their movement towards acceptance during the interview, which is one of the seven attitudinal factors of mindfulness in MBSR which means to see and experience things as they are in the present (Kabat-Zinn, 2013). Each of the participants spoke of their original denial and anger towards their pain, which Kabat-Zinn (2013) says is part of the process before one reaches acceptance. The physical task of the Integrated Task-Based Model speaks to the value of minimizing distress and dealing with pain (Samson & Siam, 2008). The development of an accepting attitude in combination with less reactionary pain strategies such as yoga and meditation appear to adhere fairly well to the physical task which is an integral task particularly in the context of chronic pain.

Self-Perception & Identity

Reflecting back before the MBSR program, all participants spoke of their pain as a part of who they are, and how they view themselves. It appeared as though pain was a consuming

factor in their lives and was a defining aspect of their being. They all explained how their pain was so interwoven in every facet of their day to day life that it essentially defined who they were.

Following the MBSR program, there appeared to be a shift in the self-perceptions and identities of the participants. Although pain continues to be a part of their lives, it does not seem to be such a consuming part of their lives, almost to suggest that they now separate their pain from their identity, which in turn has changed the way they view themselves.

The MBSR program allowed each participant an allocated time period where they could self-reflect and meditate which helped to facilitate self-awareness. This is in line with the “psychological” task (Samson & Siam, 2008) which involves developing a positive self-image and sense of autonomy. This task appeared to develop among each of the participants in different ways, and at different times throughout the MBSR program. Hawtin & Sullivan (2011) also found that participants with painful rheumatoid arthritis developed an awareness which allowed them to engage in the experience of pain rather than avoid it or to focus their attention elsewhere. This awareness of not being entirely defined or controlled by pain is an important discovery which is validated when Kabat-Zinn (2013) says that “your pain is not you” and that one’s life and being is bigger than the pain.

Although the participants did not explicitly describe some of their experiences as spiritual, they spoke to a new sense of hope and meaning. Previous research has shown that following an MBSR program, those living with chronic illness often gain an interest in spiritual growth despite the secular nature of MBSR (Mackenzie et al. 2007). The “spiritual” task encompasses the tasks of finding meaning and developing a sense of hope (Samson & Siam, 2008). Whether it was the new joy from simply being alive or the motivation to help others with

chronic pain, each participant shared how they have developed new meaning, purpose, and hope in their lives.

The vocational consequences of chronic pain continue to persist as a significant problem (IOM, 2011; Lynch, 2011). Although two of the participants were retired, they described their ability to take on tasks such as rehabilitation activities and volunteer work. Mark spoke of not only how he is more active in the community, but he also feels as though he looks at his community and volunteer work from a healthier perspective. Although Stephanie is unable to work at this time due to her condition, she plans to pursue her plans to help young girls with endometriosis. Although the results did not show reintegration into work, the fact that the participants became more involved in the community and have set vocational goals is promising for the vocational task which includes reintegration into either the work environment, rehabilitation, or volunteer work (Samson & Siam, 2008). It appears as though the participants developed tools to be less apprehensive, and more motivated and confident to pursue these types of vocational goals. Perhaps the MBSR experience might help individuals with chronic pain navigate the barriers associated with return to work including physical uncertainty, perception of employers, and personal limitations (Patel, Greaslet, & Watson, 2007).

Overall, the categorical finding of “self-perception and identity” seems to have captured some of the integral tasks associated with the Integrated Model, including the psychological, spiritual, and vocational tasks. Each participant detailed several accounts of changes that they have experienced in terms of their sense of self, autonomy, meaning, hope, and involvement in the community.

Relationship Dynamics

Each participant provided examples of how some of their relationships were impacted by their chronic pain experience. Particularly, they described some of the challenges in terms of being understood by those around them, not wanting to be a burden, and being in too much pain to engage in social activities. Their chronic pain appeared to be a barrier to maintaining supportive relationships and healthy social lives. The “social” task of the Integrated Model embraces seeking social support and establishing meaningful relationships. First and foremost, the MBSR program is structured in a group format with those living with similar hardships, although not always a homogenous group. Importantly, each participant voiced their gratitude for this format as they each felt heard and understood by those in the group and were able to form strong relationships with those in the program. For example, Mark said, “I think when you have a group like that, who are people experiencing the same problem as you, it’s easier to talk to those people because they can relate”. Previous research has also found that MBSR participants living with cancer valued the group format as it fostered a sense of connectedness (Dobkin, 2008) and created a supportive environment and feelings of empowerment (Mackenzie et al. 2007).

Furthermore, participants felt a certain level of connectedness with the group facilitators which they felt validated their experiences even more. Interestingly, the participants also each said how they are noticing a change in their relationships since the MBSR program. Particularly, how they now foster those relationships that are reciprocal in understanding, and how they place high value and effort in communication. These important shifts in relationships, as described by the participants, is a largely valuable transformation. Kabat-Zinn (2013) says that in order to enter each moment mindfully and to heal relationships, one must be in touch with feelings,

accept them, and even share them in ways that are not defensive. All of these qualities appeared to have developed in some capacity for the participants and have been noticeable in their relationships.

Importantly, the MBSR program promotes the “social” task (Samson & Siam, 2008) by being conducted in a group format, inclusive of small group discussions which often fosters new relationships. This allowed the participants to feel understood by those around them as they could relate to one another, and this sense of comradery proved to be a valuable asset. Furthermore, the participants described feeling more open in their relationships and more willing to share their experience with pain. It also instilled the importance of reciprocal relationships and that communication and openness are qualities which strengthen meaningful relationships.

Emotional Equilibrium

Lastly, as the experience of chronic pain is more than just a physical experience, it is not surprising that emotions are a visceral part of the journey. Participants shared how their emotions were often heavily influenced by their chronic pain. Evidently, emotions are an important aspect of psychosocial adaptation. The “psychological” task of the Integrated Model speaks to re-establishing emotional balance. Kabat-Zinn (2013) says that similar to chronic pain, one can be mindful of emotional pain and can utilize energy to grow and heal. Importantly, the participants explained how they noticed a positive change in their emotions, including feeling calmer, brighter, and more alive. These findings provide complimentary, in-depth data to support several reviews that suggest the efficacy of MBSR on psychological and emotional outcomes (Hawtin & Sullivan, 2011; Plews-Ogan, 2005). The participants shared how they no longer feel the overwhelming negative and painful emotions towards themselves, their pain, or their experiences. Overall, some of the teachings and experiences of the MBSR program seem to have

helped to re-establish emotional balance among the participants, particularly the teachings of lovingkindness and self-compassion (Kabat-Zinn, 2013).

In summary, the categorical findings suggest that the participants experienced some form of growth in areas that are important for not only the psychosocial adaptation to their chronic pain, but for feeling alive and present in who they are. The Integrated Model soundly demonstrates a comprehensive conceptualization of the adaptation process, as it not only takes into account the specific context of each individual, but it addresses tasks in all realms of life that can contribute to the adaptation process. Interestingly, the participants in this study spoke to each of the tasks in some capacity, suggesting large value of the MBSR program to the adaptation of chronic pain. The MBSR program appears to positively address and influence each of the tasks involved in psychosocial adaptation including the physical, psychological, social, spiritual, and vocational tasks.

Themes

As analysis proceeded and the language of the text was pulled apart, it became evident that several common themes were interwoven throughout the interviews, transcripts, field notes, and categorical results. The phenomenological analysis touched on what aspects of the MBSR program were the most useful in facilitating positive psychosocial adaption to chronic pain. This included being heard and understood by those in the program, letting go, and the development of a new and healing perspective, ultimately creating a transformation from surviving to living, which was the final theme. The common denominator across the categories and themes is that of a shift in perspective, or cognitive appraisal. Interestingly, it is believed that one's cognitive appraisal is the integral factor which dictates the process of psychosocial adaptation (Cohen and Lazarus, 1984). Particularly, individuals assign meaning to their illness at the time of diagnosis,

which is known as the primary appraisal, and then proceed to assess their coping resources and tools, known as the secondary appraisal (Cohen and Lazarus, 1984). The secondary appraisal is what shapes one's perceptions of the tasks involved in psychosocial adaptation (Moos & Tsu, 1997) and drives the achievement of the tasks (Samson, 2008). It makes sense then, that the overarching themes involved shifts in conceptualizations and perceptions, as it is the appraisals that facilitate the accomplishment of the tasks involved in adaptation, including the physical, psychological, social, spiritual, and vocational tasks (Samson, 2008). It appears as though the participants were able to begin to achieve some of the important tasks involved in the process of adaptation, ultimately leading to a more positive well-being as detailed in the final theme of "from surviving to living". These findings are consistent with research that suggests that a person's belief about their pain and experiences affects how well one adjusts to or copes with pain (Balderson et al 2004). Even more so, Turk & Theodore (2011) suggest that beliefs and expectations are better predictors of pain than physical pathology. For an MBSR program to potentially help transform one's beliefs and appraisals about their pain could be instrumental for facilitating the adaptation to living with chronic pain.

Being Heard & Understood

Each participant detailed the undeniable importance of being understood by others. Stephanie explained how people tend to not understand or even believe that she is experiencing pain because it is not visible to others. The absence of physical signs suggestive of illness has been described as a factor contributing to the stigmatization of chronic pain (Jackson, 2005). However, the MBSR program fostered a feeling of being understood among the participants, and Mary voiced this well when she said the instant connection between people, despite the differences in their pain experience, was invaluable. Not only did participants feel connected to

those in the MBSR program, but they also described how they are now more open to sharing with others and are more readily able to understand the experiences of others. Importantly, the findings of this study might even extend to what Kabat-Zinn (2013) refers to as emotional intelligence, which means, “the capacity for being in wise relationship to your thoughts and feelings of others who might see things very differently from the way you do” (pp.488).

Letting Go and Being Here (laying down the fight)

Throughout the MBSR program, as the participants began paying attention to their inner experiences, each one of them appeared to realize that there are particular thoughts or feelings that their mind seems to hold on to, predominantly in relation to their pain. It was no surprise then, that letting go is a fundamental attitude to the practice of mindfulness and should be nurtured (Kabat-Zinn, 2013). The participants described how pain crept into so many areas of their lives, and how their pain felt relentless because it appeared to be so persistent in their thoughts, feelings, and everyday life. The awareness of the intrusive nature of their pain allowed the participants to recognize that their mind was holding onto their pain and in this process, they were able to begin the practice of letting go. For instance, Stephanie said how she now holds the attitude that she “is in pain but can’t change that” and for her, this has meant letting go of her attempts to try and find a cure for her disease and her pain, which was such a large part of her life previously. This was a similar experience for Mary as she explained how the MBSR program first and foremost allowed her to notice how busy her mind was and how she had been grasping onto certain thoughts and sensations. This finding is an important one as the cultivation of the attitude of letting go is an integral ingredient for the journey of healing (Kabat-Zinn, 2013).

The Healing Perspective

Ultimately, one of the most encompassing findings was the healing perspective. The participants spoke about seeing things from a different point of view, including newly developed angles of positivity, self-control, meaning, and gratitude. Each participant realized that they had been focusing on all of the negatives rather than the positives in their lives. Research on optimism and pessimism suggests that how we see and think about our experience is a major factor for what puts us at increased risk of illness (Seligman, 2008). Participants also came to learn that although they may not be able to fully control their pain, there are different ways of thinking and behaving that can influence their health. Mark said how he is choosing not to let the pain take over his life, which demonstrates a sense of self-control and efficacy, which has been proven to be the best and most consistent predictors of positive health outcomes (Bandura, 1977; Lorig et al. 2001). Stephanie used to look at her pain as an unbearable burden, and despite years of hardship she now says she hopes to use her pain in a productive rather than a self-destructive way, by being an advocate for young women with endometriosis. Her ability to view her pain as manageable and meaningful perhaps suggests a new sense of coherence (Antonovsky, 1993), which is an adaptive way of seeing the world which improves the psychological impact of stress and illness. There is promising research to suggest that MBSR may improve sense of coherence among Fibromyalgia patients (Weissbecker, 2002). Lastly, each participant experienced gratitude which they felt was one of the most profound experiences of the MBSR program. They described feeling gratitude for not having worse pain than they do, for having the ability to make positive change in their lives, and for being alive. It is no wonder that gratitude is a vital quality of mind and heart that broadens and deepens the practice of mindfulness (Kabat-Zinn, 2013).

Moving from Surviving to Living

This final theme demonstrates an integral point that mindfulness seeks to foster, that is focusing on the beauty of life and the surrounding world, rather than passively existing. Mark says that since the MBSR program, his life is not so much focused on just being alive, but life and what he wants to do with it. Stephanie echoed similar comments and said how she hadn't been living her life because she felt she was not as present in any kind of situation. However, this has since changed for Stephanie as she now feels more present and aware of herself, her experiences, and the world around her. For Mary, she says that she has felt the "removal of suffering". She explained how before the MBSR program she was in a place of suffering, whereas now she can feel the minimization of her suffering. Interestingly, the term of awareness came up as participants spoke of their newfound approach to living life rather than just surviving. This makes sense as meaning is lost in unawareness and cultivated through awareness (Kabat-Zinn, pp.12).

Implications for the treatment of chronic pain

Despite the high prevalence rate and longstanding history of chronic pain, the assessment and treatment of chronic pain remains a challenge for healthcare providers (IOM, 2011). Throughout the last decade however, there has been a transformation from the strictly biomedical approach to a more interdisciplinary, biopsychosocial framework to assessing and treating chronic pain. An expert group of healthcare providers and public health professionals formed the Institute of Medicine (2011) to comprise an overall picture of the impact of chronic pain on individuals and society as a whole, and to better understand the challenges associated with pain and potential ways to improve the prevention, assessment, and treatment of chronic pain. This expert panel also recognizes the interaction of the biological, environmental, psychological, and

societal factors involved with the experience of pain and believes that there needs to be a transformation in how pain is viewed and understood by society, the healthcare system, and everyone involved.

The shift towards using the biopsychosocial model to understand and treat chronic pain (Gatchel et al. 2007) is a step in this direction. The findings of this study attest to the dynamic interplay of the biological, psychological, and social factors involved in the experience of chronic pain which supports the need to address all facets of life that are tremendously affected by pain. Furthermore, the experiences shared in this study speak to the reality that although pain can be controlled at times, it cannot always be eliminated (IOM, 2011) and that interventions or strategies to improve the adaptation to living with chronic pain are surely needed. The dynamic, over-arching MBSR program seems to be a viable option for facilitating positive and effective psychosocial adaptation to chronic pain and should be strongly considered and presented as an option for those living with chronic pain. Importantly, the MBSR program addresses the logistical challenges including the financial barriers, the high demand of pain specialists and resources for chronic pain patients, and the need to turn towards a community-based treatment approach.

Implications for Chronic Pain Patients

Chronic pain patients often experience several hopeful referrals with long wait-lists only to be referred to the next specialists or clinic with high expectations and rare positive outcomes. Often times the poor outcome is a result of the expectation that their pain will be cured or fully treated. Due to the discrepancy between the expectation of medicine and what is possible in reality, people often become frustrated and angry (Kabat-Zinn, 2013). The findings of this study shed light into the possibility that although the tools developed in an MBSR program do not

necessarily eliminate the pain, they may help people learn how to better live with their pain and minimize the effect that it has on various areas of life.

Although the MBSR program is a structured 8-week program with facilitators, the program and long-term effects are a result of self-management following the program. MBSR participants are taught several tools and techniques in the 8-week program with the hope that they will continue to practice mindfulness. Self-management is a vital step to relieving pain, particularly because it fosters the belief that people can control their own pain (Keefe et al. 2008) which improves pain outcomes (Keefe et al. 2000). Additionally, the MBSR program is a community-based intervention which is a sought-after environment for those who make frequent trips to the hospital setting. Particularly, the fact that the program includes those living with similar experiences can be validating for those living with chronic pain and it has shown to foster a sense of connectedness (Dobkin, 2008) and empowerment (Mackenzie et al. 2007), which hopefully helps to reduce the stigma that is far too often associated with chronic pain. Many people living with chronic pain do not want to rely on medicinal interventions for the rest of their life, or wish to at least minimize their use. The findings of this study suggest that perhaps the lessons learned and tools developed in an MBSR program may help to reduce the quantity of medications and interventions required by those with chronic pain. Overall, an 8-week MBSR program may help to facilitate improved adaptation to chronic pain. An improvement in adaptation may promote sustainable physical, emotional, and psychological changes, rather than short-term relief from just the physical pain.

Implications for Healthcare Providers

The movement towards an interdisciplinary approach to the assessment and treatment of chronic pain is underway (IOM, 2011) and there is a rise in the involvement of professionals

from the field of psychology. The MBSR program is a prime example of an alternative intervention which is led by trained mindfulness instructors who are most often in a mental health profession. Physicians should be made aware of interventions such as MBSR and should become educated on the usefulness and efficacy of such interventions. One of the major findings proposed by the IOM is to tailor pain care to each individual's experience with the recommendation for healthcare providers to promote patient self-management of pain. An intervention such as MBSR is certainly an option where patients would be given the opportunity to manage their pain and experiences autonomously. Once knowledgeable and on board with programs such as MBSR, an important implication for healthcare providers is to disseminate this knowledge as a resource offered in the primary care setting. When primary care providers are knowledgeable of other interventions and self-management pain strategies, unnecessary testing and referrals are avoided (IOM, 2011). Importantly, the rapport and trust between a clinician and patient is fundamental to good, positive outcomes (IOM, 2011) and the patient's biological, psychological, and emotional composition should be considered when suggesting treatment options such as MBSR.

Study Limitations

Phenomenological research seeks to describe a common meaning associated with a lived experience among several individuals (Creswell, 2007) and hermeneutics values the meaning of texts in this process (Gadamer, 1975). The results are a well thought out interpretation which seeks to understand an experience, rather than claiming to be a definitive answer to the research question. The initial interpretations arose as I, the researcher, situated myself based on my personal experiences and life history. My interpretations were continuously reflected back upon as I made thorough reference to my field notes and my own lived experiences. Although member

checks were completed and all participants provided validation of my interpretations, the results of the study can be interpreted and re-interpreted over time, and in different ways by each reader that comes across these texts. My explicit situatedness is meant to allow readers to consider how my own lived experiences may have shaped the interpretations presented in the results section. This interpretative process represents the goal of understanding an experience from various perspectives, rather than having the results be viewed in an identical fashion across readers.

While adhering to my methodology, I was able to uncover the lived experiences of the participants which allowed me to develop an in-depth interpretation of the meaning associated with chronic pain and the MBSR program. However, there are also several limitations in this study.

First, the sample size is small for a qualitative study and this was due to the fact that I only recruited participants from one cohort of the MBSR program, and participants were required to meet certain inclusion criteria. At the time of recruitment, I revised the criteria to be more inclusive which allowed me to recruit the three participants in this study.

Second, due to the tight timeline of the research plan, I was unable to conduct pre and post-test interviews. Conducting interviews prior to the MBSR program would have provided pure individual contexts without the experience of the program. However, I designed the interview guide in a way which could delineate between participant experiences prior to and following the MBSR program.

Lastly, as the findings of this study are based solely on the accounts and verbal telling of the participants, explicit changes experienced as a result of participation in the MBSR program cannot be confirmed.

Recommendations for Future Research

This study is based on participant accounts of their lived experiences which provided insightful details surrounding the potential value of an MBSR program for those living with chronic pain. Although this methodological approach provided participants with the invaluable opportunity to share their experiences, objective changes could not be reported. However, from the inception of MBSR, Kabat-Zinn (1982) has shown objective reductions in pain intensity, medical symptoms, and psychological symptoms. A more recent review supports that chronic pain patients generally show a clinically significant improvement in these symptoms as well (Baer, 2003). Interestingly, research has shown that there is variability in pain outcomes following an MBSR program among individuals with different pain conditions (Rosenzweig et al., 2010). A mixed-methodological study looking closer at why this might be would be a valuable direction for future research. As programs such as MBSR are proving to be an effective and valuable intervention for chronic pain populations, research should explore primary care providers' awareness, education, and attitudes towards such interventions, and if they are informing patients of these programs. Such research could take the form of an environmental scan in order to show who, if at all, are informing patients of these options, or even a qualitative exploration to better understand the barriers to the knowledge translation or execution of MBSR as an option for chronic pain patients.

Conclusions

The purpose of this study was to explore participants' experiences of an 8-week MBSR program in the context of adapting to living with chronic pain. Inspired by hermeneutic phenomenology, I conducted in-depth interviews with 3 individuals living with chronic pain and developed detailed descriptions of the lived experience of participating in an MBSR program. By

fully immersing myself in the data with the intention to understand the language and meaning of the texts, I organized significant statements into categories and broader themes which depicted the MBSR experience of the participants and their perception of the changes they experienced in their adaptation to living with chronic pain. Based on the participants' accounts of their chronic pain and MBSR journey, in combination with my interpretations, the findings suggest that an MBSR program is valuable for those living with chronic pain as it touches on several facets of life important for psychosocial adaptation and quality of life. Most importantly, the findings are indicative of the healing nature that an MBSR program can have on individuals living with unremitting, chronic pain. I am hopeful that this research speaks to the value of MBSR in the context of adapting to living with chronic pain and that researchers, clinicians, and those living with chronic pain are encouraged by the findings presented in this study.

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Appendix A: Recruitment Email

Dear Mindfulness Practitioners,

We are sending this email on behalf of Ms. Emily Hladkiewicz, the Master's student from the [REDACTED] who came to talk to our group about her research project. As you may recall, Emily is seeking four participants who live with chronic pain for her study looking at the experiences of participating in an MBSR program.

Those eligible to participate must (a) have chronic pain (greater than 6 months) and (b) be enrolled in and completed at least 6 of 8 sessions in our eight-week [REDACTED] Mindfulness-Based Stress Reduction (MBSR) program.

If interested, participants will be asked to partake in: (1) One meeting (approximately 20 minutes) to review informed consent and study procedures and to complete a brief demographic questionnaire. (2) One interview (approximately 60 minutes) regarding their experiences with chronic pain and the MBSR program. Part 1 and 2 can be done during the same meeting time. (3) Electronic communication in order to obtain participant feedback on the summaries of the interview data (reading document and writing feedback will take approximately 30 minutes and will occur just once at the end of the research project).

Participation in this study may give you the opportunity to genuinely reflect on your experiences. This research project will be important for helping others better understand the journey of those living with chronic pain and their experience with an MBSR program. Participants will be compensated \$50 for their participation and will be selected on a first-come first-serve basis.

Please know that your participation in this study is voluntary. If you choose not to participate, your decision will not affect your participation in the MBSR program now or any mindfulness programs you wish to join in the future.

If you are interested in participating, or if you have any questions, please contact Emily, the principal investigator, or her thesis supervisor, Dr. André Samson.

Ms. Emily Hladkiewicz
Master's Student

Dr. André Samson
Professor

Appendix B: Telephone Script (Screening Worksheet)

Participant Initials: _____

Screening ID: _____

Hello (*insert participant's name*),

How are you?

I would first like to thank you for following up with me and also for your interest in participating in my research project!

As you know, Drs. Kathy and Howard Nathan contacted you on my behalf as you indicated to them that you are currently living with chronic pain. Before we are able to move forward with the interview portion of this study, I just first need to ask you a few questions to make sure that you are eligible to participate. Is this OK with you?

Yes – move forward with screening questions below...

No – thank them for their time.

Ok great! First off...

- | | | |
|---|------------------------------|-----------------------------|
| 1. Are you 18 years of age or older? | Yes ☐ | No ☐ |
| 2. Are you fluent in English? | Yes ☐ | No ☐ |
| 3. Have you been experiencing chronic pain for at least 6 months? | Yes ☐ | No ☐ |
| 4. Have you ever participated in an 8 week MBSR program before? | Yes ☐ | No ☐ |
| 5. Have you participated in at least 6 of the 8 sessions of the MBSR program? | Yes ☐ | No ☐ |

Eligibility Criteria Met ‘Yes’ – move forward with explaining study details...

Eligibility Criteria Met ‘No’ – I’m sorry, it seems as though based on (*insert ineligible response*), you do not meet the criteria to take part in my study. I would like to thank you again for taking the time to follow up with me today and also for your interest in my study. Best of luck with your MBSR practice! Thank you so much for answering those questions for me. Based on your responses it looks as though you are eligible to take part in my study. We can now move ahead with scheduling a time to meet in person to go over the study’s written consent form, a brief demographic questionnaire, and our face-to-face interview. This meeting should take no longer than a couple of hours. Does this all still sound okay to you?

Yes – move forward with scheduling the meeting...

No – thank them for their time.

Ok that’s great, do you have any questions for me at this time? (*answer any questions as required*)

Now, when would be a good time for us to meet? (*record date/time of meeting*)

Great, now may I please confirm your email address and phone number in the event that scheduling changes need to occur?

Email: _____

Phone Number: _____

Perfect! So that is all for today, but please do not hesitate to contact me by telephone or by email should you have any questions for me before we meet or should you need to reschedule. Thank you again for your interest in my study and for taking the time with me today.

Appendix C - MBSR Program Details

The MBSR program is led by the [REDACTED]. The group leaders are [REDACTED] – who were both trained by John Kabat-Zinn and Saki Santarelli. It is an 8-week program with 2.5 hour weekly sessions and a day of mindfulness.

The group is offered to anyone, through physician, psychologist, and self-referrals. The course largely encompasses those living with chronic pain, although it is not limited to people with chronic pain conditions.

The group leaders conduct pre-training screening interviews which screen for exclusions such as: mental state not allowing participation in a group such as inability to concentrate sufficiently, thought disorder, severe PTSD where it may not be safe to do insight meditation, very severe depression or anxiety, dementia, language or comprehension barriers.

For more information please access the below link:

[REDACTED]

Appendix D - [REDACTED] Consent Form for Study Participation

Title of the study: Exploring participants' experiences of an 8-week Mindfulness-Based Stress Reduction Program (MBSR) in the context of adapting to living with chronic pain

Emily Hladkowicz
Master's Student

Professor André Samson
Thesis Supervisor

Invitation to Participate: I have been invited to participate in a research project conducted by Ms. Emily Hladkowicz under the supervision of Professor André Samson as part of her MA thesis at the [REDACTED].

Purpose of the Study: The purpose of the study is to explore the experience of participating in an MBSR program from those living with chronic pain.

Participation: My participation will consist of the following:

1. Eight-week MBSR program (study requirement is that you complete at least six of eight sessions).
2. One meeting which will include the following:
 - Review informed consent and study procedures (10 minutes)
 - A brief demographic questionnaire (10 minutes)
 - One interview (approximately 60 minutes) that will be audio-recorded
3. Electronic or written communication in order to obtain your feedback on my summaries of your interview data (reading and providing written feedback will take roughly 30 minutes).

Risks: My participation in this study entails no foreseeable risks. However, if I experience any discomfort, Ms. Hladkowicz has assured me that she will make every effort to minimize this discomfort. I may decide to withdraw from the study process at any time. I may call the 24-hour [REDACTED] Crisis Line at anytime if I require support at 613-722-6914.

Benefits: My participation in this study will provide me with an opportunity to share my own experience of living with chronic pain and my journey of participating in an MBSR program. My participation will add to the research on MBSR as an intervention for those living with chronic pain by providing a more detailed account of the experience. The results may allow others to better understand the experience of participating in an MBSR program which may have implications for future design of treatment interventions and may encourage others living with pain to participate in mindfulness.

Confidentiality and anonymity: I have received assurance from Ms. Hladkowicz that the information I share will remain confidential. I understand that the contents will be used only for the

Participant Initials: _____

Study ID: _____

purposes of this Master's project. My confidentiality will be protected by keeping all participant data and written communications private and storing all research materials in a locked cabinet.

Anonymity will be protected in the following manner: Pseudonyms will be used for all written reports and material quoted by participants in order to maintain confidentiality. Participant codes will also be used on other research documents. If any other potentially identifying information is shared by participants in the interview transcripts, the principal investigator will alter the content of this material so that no identifying information will be revealed in the study's written reports.

Conservation of data: I have been assured that during the research process, the audio- recordings of interviews and any written research materials (electronic and hardcopy) will be kept in a secure manner in a locked cabinet in Professor Samson's office ([REDACTED]) on a password protected computer. Data being sent to me by email will be password protected. If I choose to receive data by post mail, I understand the potential security risk. Upon completion of the project, electronic data will be stored on Professor Samson's password protected computer and hardcopy materials will be kept in his locked office. The data will be kept for five years following the end of the project. After five years, all research materials will be shredded and electronic data will be permanently erased.

Compensation: I will be compensated \$50 by email transfer upon completion of the data collection process. I may withdraw from the study at any time and still receive compensation.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions without suffering any negative consequences. If I choose to withdraw, all of my data gathered until the time of withdrawal will be destroyed.

Acceptance: I, _____, agree to participate in the above research study conducted by Ms. Emily Hladkowicz as part of her Master's thesis, at the [REDACTED] under the supervision of Professor André Samson.

If I have any questions about the study, I may contact Ms. Hladkowicz or Professor Samson.

If I have any questions regarding the ethical conduct of this study, I may contact the Office for Ethics in Research [REDACTED]

There are two copies of the consent form, one of which is mine to keep.

Participant's name	Signature:	Date
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Emily Hladkowicz

Researcher's name	Signature:	Date
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Dr. André Samson

Thesis Supervisor's name	Signature:	Date
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appAppendix F - Interview Guide

1. Reflecting back before you took the MBSR course, please describe your experience with chronic pain.
2. What challenges have you faced in living with your chronic pain?
3. Please describe in what ways, if any, you tried to adapt to living with your chronic pain prior to participating in the MBSR program.
4. Please describe how, if at all, these ways of adapting have worked for you in the past.
5. Please describe your experience with the MBSR program.
6. What changes, if any, have you experienced in terms of your adaptation to your chronic pain in wake of participating in the MBSR program?
7. How, if at all, have you changed in the way you live with your chronic pain since participating in the MBSR course?
8. Please describe any significant or notable experiences from the MBSR course.
9. Please describe what about the MBSR course you found to be most useful.

Prompts

I heard you say ...

1. May you please share an example of ... ?
2. May you please explain what you mean by ... ?
3. May you please describe this further ... ?
4. Can you share a particular experience of what you mean when you say ... ?
5. Please tell me more about the time when ...

Appendix G - Member Checking Instructions

You will receive a document via email that summarizes your interview responses. Please read through the summary document and add your feedback on these notes. This feedback is important to note any points of departure between my description of the interviews and what you intended by them. Please use the *highlight* function on Word to demonstrate which text you would like to comment on or revise and include revisions and/or comments by using the *comments* function. Please notify me if you prefer a paper copy of these documents and you will be given that option. Please return these documents by email ([REDACTED]) within two weeks of receiving them.

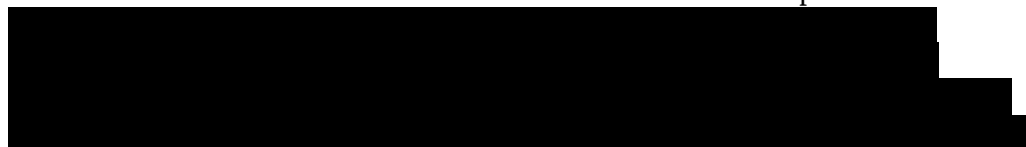
Please feel free to contact Emily Hladkowitz or Professor André Samson if you have any questions.

Thank you!

Emily Hladkowitz

Emily Hladkowitz
Master's Student

Professor André Samson
Thesis Supervisor



Appendix H - Member Checking Email/Mail Script

Dear *(insert name)*,

Thank you once again for your involvement in my research project. As discussed, I have attached for you a summary of my descriptions of the interview data. At this time, I would kindly ask that you review the document. If you would like to make revisions or would like to leave comments, please do so in the following way:

1. Please complete this exercise within 2 weeks of receiving this email.
2. Please use the “highlight” function to highlight over the text that you would like to revise or comment on.
3. Then use the “new comment function” by clicking on “Review” then “New Comment” and please type how you would like to see the text revised or leave a comment if applicable.
4. Once you are done:
 - If you received this by email, please email the document back to me at [REDACTED]
 - If you received this by post mail, please mail the document back to me at [REDACTED]
[REDACTED]
[REDACTED]
5. You also have the choice to not make any changes, revisions, or comments. However, please let me know of this choice by either phone or email within 2 weeks of receiving this email.

Please feel free to contact me, Emily Hladkowicz, or Professor André Samson if you have any questions.

Thank you!

Emily Hladkowicz

Emily Hladkowicz
Master’s Student

Professor André Samson
Thesis Supervisor

[REDACTED]