

# Using Qualitative Methodologies to Explore the Lived Experience of Chronic Pain and Chronic Pain in the Workplace

by

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A thesis  
presented to the University of Waterloo  
in fulfillment of the  
thesis requirement for the degree of  
Doctor of Philosophy  
in  
Public Health and Health Systems

Waterloo, Ontario, Canada, 2021

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## **AUTHOR'S DECLARATION**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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## **Abstract**

Introduction: Chronic pain is a significant and challenging issue, impacting an increasingly large number of Canadians. The impacts from chronic pain are individually felt on a biological, psychological and sociological level and as a result proliferate one's life in entirety. The workplace being a key domain in one's life creates an additional layer of complexity in managing chronic pain conditions, both from the perspective of the worker with a chronic pain condition and the employer as well. This dissertation consists of three manuscripts, all using qualitative methodologies to explore issues of chronic pain in the work environment. Manuscript 1 - Contemporary Approaches to Phenomenology: This manuscript reviews two contemporary approaches to phenomenology in Jonathan Smith's Interpretative Phenomenological Analysis and Maxwell van Manen's contemporary approach to phenomenology and provides a comparison and critique of both of these approaches. Through detailing these approaches on a critical level should be feasible for novice researchers to adequately ascertain whether these particular applications on phenomenology are beneficial and applicable to their research. Manuscript 2 – Autoethnography of a Young Adult with Chronic Pain: This manuscript explores the author's personal experience in navigating their chronic pain condition as a young adult. From the narrative of these experiences, three major themes were discussed and analyzed through the existing literature in the field. These themes included: interactions of young adults with health care providers, impacts by and on caregivers in supporting a loved one with a chronic pain condition and the specific challenges of managing reduced capacity in the workplace environment. Manuscript 3 - An Interpretative Phenomenological Analysis of Chronic Pain in those who are Self-Employed or Teleworking: This final manuscript utilizes Interpretative Phenomenological Analysis (as discussed in Manuscript 1) to discuss the lived experience of four individuals who shifted to some form of self-employment or telework to help manage their chronic pain condition. Common themes emerged from the interviews completed, including: the strategies adopted to manage their chronic pain condition in their home-based work environment and the benefits and challenges that occurred with self-employment and telework and their chronic pain. Self-employment and telework were regularly found to be a necessary approach for managing their chronic pain given the increased self-efficacy and autonomy despite the number of challenges that they faced in this particular work environment. Conclusions: These three manuscripts work together in order to successfully apply a variety of qualitative methodologies to help increase the understanding of these nuanced conditions. The particular area of chronic pain among those who are

self-employed and teleworking is a valuable groundwork paper in the current workplace environment where more people are participating in various forms of self-employment or telework.

## **Acknowledgements**

I would like to thank my supervisors Dr. Phil Bigelow and Dr. Nancy Fenton for their ongoing support and encouragement throughout their process. I would also like to thank the entirety of my Examining Committee for their thoughtful review and feedback of this work.

I am incredibly appreciative of my parents (Brenda and Stephen) in supporting me to achieve this high level of education and to pursue this as a career. Thank you to all of my friends, both in academia and outside who have been along for the ride and helped me throughout this endeavor. I would particularly like to acknowledge Leia, Leah, Arsalan, Andrew, Brendan, Gibran, Zarah, Dom and Alice for their frequent chats and guidance. Thank you to my in-laws (Sholom, Rifka and my sister-in-law Yedida) for their regular excitement about these projects.

Finally, and most importantly, thank you to my wife Ayala and my son Sidney. They are the reason that I continued to forge ahead and wrap this up, and the inspiration behind all that I do. Their ongoing love and support was the most instrumental aspect in getting to this significant milestone.

## **Dedication**

This dissertation is dedicated to my wife Ayala and to my son Sidney whose constant support and inspiration made this work possible.

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# Chapter 1

## Introduction

### 1.1 Chronic Pain in Canada

Chronic pain in Canada is well documented and has its own set of background information and statistics that must be reviewed and discussed in order to identify the initial importance of studying this issue in academic research. More than 1.5 million Canadians, aged 12 to 44, reported having chronic pain in 2007 and 2008 (Ramage-Morin & Gilmour, 2010). This number accounts for 9% of men and 12% of women in the Canadian population (Ramage-Morin & Gilmour, 2010). Given these statistics are already over ten years old and the nature of chronic pain and chronic conditions in general, the current government report estimates that one in five Canadians now live with chronic pain (Campbell et al., 2019). The high percentages of Canadians who have chronic pain conditions indicate that this is a key issue for researchers in Canada to study.

The estimates for the health care costs of chronic pain on the Canadian health care system are more than six billion dollars per year (Lynch, 2011). Estimates originally expected costs related to chronic pain to rise to over \$10 billion dollars by the year 2025 (Lynch, Schopflocher, Taenzer, & Sinclair, 2009). More recently, the estimated combined direct and indirect costs of Chronic Pain in Canada are closer to \$60 billion per year (Campbell et al., 2019). The current and future estimates of the demands on the health care system for those with chronic pain in Canada indicate that these conditions are causing a significant drain on the finite resources that are available. Far more work needs to be done to understand how to get these costs under control and better manage chronic pain conditions in Canada, before they create an even greater burden on our health care system.

For patients with chronic pain, wait times for care in publicly funded pain clinics in Canada are greater than one year (Lynch, 2011). Large portions of Canadians do not even have access to these pain clinics (Lynch, 2011). This demonstrates that many Canadians are left without the necessary services and supports to help manage their chronic pain conditions. While there has been work recently completed by the Canadian Pain Coalition, there are currently gaps in the societal level statistics. More current work needs to be completed, especially to reflect the current circumstances with the global pandemic, further discussion about this has been included in Chapter 7 of this dissertation. Patients waiting to access pain clinics spent a median of \$17,544 per year in indirect expenditures including lost work time and private health care treatment options (Lynch, 2011). The

costs on the health care system are not the only issues facing Canadians today, those with chronic pain are struggling to get access to necessary services and are paying large amounts of money out of pocket to try to manage their pain while they wait for treatment (Lynch, 2011). While there are general implications to accessibility of care for those with chronic pain, these implications can be made that much more significant when factoring in elements of race, ethnicity, culture and socioeconomic status, which will be discussed in greater depth in Chapter 2 of this dissertation (Anastas et al., 2020; Shavers, Bakos & Sheppard, 2010). This is counter indicative of the primary tenets of the Canada Health Act, particularly that of comprehensiveness in that Canadians with chronic pain are lacking in insured services to treat their conditions. As a result of these significant issues, we must examine key issues within the realm of chronic pain, in this case workplace issues, and find ways to improve the lives of those with chronic pain in Canada.

## **1.2 Chronic Pain in the Workplace in Canada**

Chronic pain can have a devastating effect on the Canadian workforce. Approximately 60% of people with chronic pain will eventually lose their jobs and income, or will experience a reduction of responsibilities due to their chronic pain condition (Lynch, 2011). This loss of finances can be significant and can leave a number of Canadians below the poverty line and struggling to get by, while still incurring additional expenses to cover their pain condition that needs managing (Lynch, 2011). According to the Canadian Pain Strategy (2010), a government report developed following the International Pain Summit in 2010, there is an average number of 28.5 lost-work days per year due to chronic pain conditions for employees in Canadian workplaces and productivity costs related to job loss and sick days are estimated at \$37 billion dollars per year (Lynch, 2011). The impacts of chronic pain in the workplace are not isolated to the worker with chronic pain, there can be significant impacts on fellow workers, employers and on the day-to-day productivity of the workplace (Lynch, 2011; Soklaridis, Cassidy, van der Velde, Tompa, & Hogg-Johnson, 2012; Tveito, Shaw, Huang, Nicholas, & Wagner, 2010). The workplace in and of itself is a complex entity, with a number of elements working simultaneously to ensure productivity and success on a daily basis. When a worker with chronic pain is introduced into this system, it can create challenges for everyone, including: increased work-load on co-workers, and employer effort to create workplace modifications (Jakobsen & Lillefjell, 2014; Jakobsen & Svendsen, 2013). These challenges to the system can be seen in the financial costs listed above, but also the individual personal costs in stress and workload on the individuals surrounding the worker with chronic pain (Gignac, Sutton, & Badley, 2007).

The type of job in the workplace can be directly correlated with the type of chronic pain condition that develops. Workers who have a large amount of heavy manual labour are more likely to develop conditions with low back pain (Teasell & Merskey, 1997). In particular, three occupations are at highest risk for a compensable back injury: truck drivers, material handlers, and nursing aides (Teasell & Merskey, 1997). That being said, almost every type of work creates some level of risk for developing a chronic pain condition. While it is important to focus on the job types that create significant risks for injury leading to chronic pain, it is also valuable to look at those in other jobs as well, as they may still have chronic pain conditions and their experiences could be important to explore and understand. It is also important to note that chronic pain conditions may not be caused by a workplace injury and may either occur intrinsically or due to factors occurring outside of the workplace. These impacts on the workplace from pain conditions, regardless of their origins, will be discussed throughout the dissertation.

Beyond the aspect of job type, or the field of occupation, there is also a key facet to consider the nature of the workplace environment itself. The workplace environment can vary significantly based on a number of factors; for example whether the workplace is more rigid in their structures, or more flexible, if the job is a desk job versus factory work. This is the primary differentiation in which this thesis is focused. While there has been much research done, as will be seen in the literature review, on traditional work environments wherein one commutes to a workplace, interacts with co-workers and supervisors and completes their work in a standard work day, there is a paucity of research completed on non-traditional work environments and work situations, particularly those who are self-employed or teleworking. This differentiation will be expanded upon in the next chapter. The primary research question, as outlined below, helps to explore the relationship between those who have chronic pain and are self-employed or teleworking.

### **1.3 Research Question**

This thesis has an overarching research question at its core which asks: What are the lived experiences of those who have chronic pain and are teleworking or self-employed and what can we learn from these experiences using an Interpretative Phenomenological Analysis (IPA)? As has been discussed in more depth later in this research, IPA allows for a deeper analysis of a topic, in this case chronic pain in the self-employed and teleworking population, and goes beyond the lived experience of the issue to analyze what the experience itself means. The primary rationale for choosing this target population comes from an article by Gilman (2014), wherein she discusses the necessity for

funding for workplace accommodations and home-based work for those with disabilities. This discussion of the necessity of these accommodations, along with the paucity of research that exists on those who are self-employed and teleworking, helps to define this subpopulation that requires further research and exploration, particularly in describing and analyzing the interactions between work and their chronic pain conditions. The detailed rationale and justification behind using those who are teleworking or are self-employed, appears in the literature review chapter, along with a discussion of why phenomenology and Interpretative Phenomenological Analysis was used.

While this primary research question is at the core of the entire discussion of all of the works being completed for this thesis, there are a number of sub research questions that help to provide additional knowledge and context to help support and form a foundation for the primary research question. These sub research questions explore methodological and contextual issues that exist in the background, prior to exploring the primary research question.

The first sub research question is designed to explore the value of contemporary approaches to phenomenology for new researchers, particularly those who are exploring issues in the realm of chronic pain and chronic pain in the workplace. The first sub question is: What are the key benefits and challenges to using contemporary approaches to phenomenology for new researchers? With new researchers in mind, the exploration of this question reviews and critiques contemporary approaches to phenomenology to demonstrate their usefulness, limitations and challenges. This study of contemporary approaches should help to firmly situate IPA as an important and useful methodology to use to study issues of chronic pain, specifically in a workplace environment.

The second sub research question investigates my own context and background as a researcher experiencing chronic pain through using an autoethnographic approach. This sub research question asks: What are my experiences with chronic pain thus far, and how have they influenced my perception and viewpoints on chronic pain in the workplace and more generally chronic pain as a whole? This question is unique, as it allows me to delve into my own experiences, which can be valuable in their own right. Additionally, reflecting upon my own experiences helps to understand to how they relate to the overarching experience of managing a chronic pain condition and in doing so situating my viewpoints moving forward when discussing chronic pain in academic papers, particularly in my discussion of the primary research question.

## **1.4 Thesis Organization and Research Objectives**

Following the identification of the primary and sub research questions it would be prudent at this point to identify how the thesis has been organized to address the research questions through key objectives and aims. Following this introductory chapter, a detailed literature review discusses previous work that has been completed in the area of chronic pain and chronic pain in the workplace. This literature review narrows down and focusses on the research gaps that exist in the current literature. Following the literature review chapter, a methodologies chapter provides the necessary background information on all of the methodologies utilized in the thesis. After the methodologies have been discussed, the three main manuscripts of the thesis have been included in their entirety, a preamble to these manuscripts is included at the end of the methodologies chapter. The research questions identified here in this first chapter provides the backbone and structure that flow through the manuscripts. Following the manuscript chapters, a concluding chapter includes summaries of the results of each of the manuscripts, a discussion of how the manuscripts connect with each other and future directions and implications on research in the field of chronic pain in the workplace.

## **Chapter 2**

### **Literature Review**

#### **2.1 What is Chronic Pain?**

There are a multitude of conditions that can fall within the realm of chronic pain, varying based on the part of the body that is in pain and the nature of the pain itself. The discussion of chronic pain can be challenging based on the various specificities inherent in the different types of chronic pain conditions. In this dissertation, there is no distinction made based on the type and bodily location of the pain, but rather the focus is moreso on pain conditions that are considered to be chronic. For the purposes of this dissertation, the concept of chronic pain is defined based on the time elapsed from the initial onset of symptoms, in this case the shift from acute to chronic pain occurs primarily at the three-month point after the initial onset of pain (Gangapersad, Brouwer, Kurilsky, Willis, & Shaw, 2010). This point in time clearly delineates when pain evolves to a chronic state from acute and sub-acute forms of pain which each have separate and unique time periods.

Chronic pain itself is a complex and multifaceted issue and as such, it is important to develop a level of understanding about its more general impacts before delving into the specific nuances that occur within the workplace environment. For simplicity, the areas that have been focused upon in this literature review are the biological, psychological and sociological impacts of chronic pain.

#### **2.2 Biology**

The biological perspective on chronic pain in the workplace can be considered in a number of ways. In order to discuss chronic pain, one must first consider the heritable, lifestyle and environmental factors that may lead to the development of a chronic pain condition (Buckle, 1997; Burr, Pedersen, & Hansen, 2011; Fransen et al., 2002; Uhlig, Moe, & Kvien, 2014). After this initial understanding of how chronic pain manifests itself, one can start to develop an understanding as to how the biological aspects of chronic pain are treated and managed on a daily basis. The discipline of biology is an all-encompassing area that can cover a great deal of information on a particular health condition, as such it is important to also factor in one of its key sub disciplines throughout this discussion, the physiology of pain. Finally, it is important to consider the concept of disability when discussing chronic pain. All of these factors combine to form a complete understanding of the biological and physiological nature of chronic pain. This is a stepping-stone to comprehend how chronic pain



manifests itself in the workplace environment and to begin to understand some of the approaches that are being utilized to manage the biological impacts of these conditions.

The first biological factor being discussed is sex, which for the purposes of this discussion will encapsulate the sociological concept of gender. This factor influences the development and management of a chronic pain condition. The prevalence for the different chronic pain conditions can be divided among men and women. Rheumatoid arthritis and low-back pain tend to be more common among women (Uhlig et al., 2014). By comparison, upper extremity pain conditions are more common among men (Rustoen et al., 2004). An important question to consider when discussing sex differentiation for chronic pain conditions is whether or not the differences are a result of heritable factors, or if they may be related more to the physical exposures that may exist in the workplace (Buckle, 1997). This differentiation is significant when developing interventions in the workplace environment as different approaches might be utilized in each circumstance. Men and women also manage their pain conditions in different ways. Women tend to report pain more frequently than men, and also identify higher pain intensity levels (Rustoen et al., 2004). Long-term sickness absence is also more frequently seen in women as compared to men (Burr et al., 2011). These differences demonstrate that men and women experience pain differently and approach their chronic pain conditions in very different ways, as such it is important to consider these contrasting approaches not only when developing interventions for chronic pain, but also in exploring the issues of chronic pain in the workplace (Ahlstrom, Dellve, Hagberg & Ahlberg, 2017; Burr et al., 2011; Rustoen et al., 2004; Uhlig et al., 2014).

A second key biological influence on chronic pain is age. Those in the workplace who are older tend to be more susceptible to transition from acute pain to an ongoing chronic pain condition (Fransen et al., 2002). The physiological factors that can be attributed to this shift include diminished muscle strength and flexibility. Aspects of reduced capacity in the workplace, combined with the potential for disability create a situation whereby the older worker can cause a significant drain on the productivity in the workplace (Fransen et al., 2002). This identifies an area of focus in studying chronic pain in the workplace, in that extra attention must be paid to those who are older and may have increased injuries leading to chronic pain conditions in the workplace environment. While the focus of the literature on chronic pain conditions is often on older adults, due to their susceptibility to enduring chronic pain conditions, these conditions are not limited to older populations. Ramage-Morin and Gilmour (2010) identify a number of areas in which 12-44 year old individuals are impacted by their chronic pain conditions, including: activity limitations, requiring assistance, greater

use of health-care and demonstrating a lower overall sense of well-being. The nuances of this younger population are an important variable in two of the primary manuscripts in this dissertation.

Another significant physiological influence on chronic pain, particularly back pain, is a higher than normal body mass index, or BMI (Fransen et al., 2002). For chronic pain conditions including neck pain or low back pain, BMI is more of a predictive factor for women than men (Kaaria, Laaksonen, Rahkonen, Lahelma, & Leino-Arjas, 2012). These differentiations based on either sex, or nature of the chronic pain condition should be explored further in order to properly address how these conditions are to either be prevented or managed effectively once they occur.

While examining the issue of chronic pain in the workplace through a biological or physiological lens, it is important to also consider how the workplace itself, through personal factors can play a role in the development of a chronic pain condition. Personal factors in the workplace, including work position, lifting or stretching, often increase the risk for a long-term sickness absence (Burr et al., 2011). Additionally, there are a number of occupations that create a higher risk for sickness absence as a result of pain conditions. These occupations include: kindergarten teachers, healthcare workers, janitors and food preparation workers (Burr et al., 2011). The evidence for these personal factors causing sickness absence can be seen as more predictive as compared to some of the psychosocial influences. This is not said to diminish the importance of psychological or social factors on the development of chronic pain conditions, but rather it is to identify the continued importance of managing these exposures in the workplace environment. A fundamental challenge exists with the wide variety of possibilities of biological risk factors for chronic pain conditions. The issue that occurs through the development of so many potential causes of chronic pain, through heritability, lifestyle and physical exposure is that it becomes nearly impossible to directly identify the root cause of the pain and based on this information the best strategy to manage the condition (Buckle, 1997). In some cases, this could even lead to questions of the onus of responsibility, such that if chronic pain is not caused by a physical exposure in the workplace, is the employer responsible for accommodating their worker to manage their pain conditions. This concept of physical exposures and risks are not even taking into consideration psychological or sociological risk factors and causes. It is this reason that chronic pain in the workplace is such a difficult problem to address and manage.

## **2.3 Psychology**

Psychological factors have the ability to inhibit and challenge the repair and restoration of body tissue. This inhibition can lead to one's muscles becoming deconditioned, which creates

an environment where smaller mechanical loads may cause increased pain levels in someone who may be undergoing psychological issues compared to someone who is not (Kilbom et al., 1996). Psychological issues can also impact how one perceives pain. There is often a correlation between chronic pain and depression, which can lead to an increase in hormone levels or endorphins which influence one's sensitivity to various pain stimuli (Kilbom et al., 1996). It is in this section that the relationship between psychology and chronic pain are discussed in depth. This relationship is important to examine as psychology has significant influences on both the biology and sociology of one's chronic pain condition. The relationship between psychological issues and the physiological manifestation of chronic pain can be complex and nuanced. As such, it is important to separate this relationship into its distinct components including: the impact of psychological issues on the transition from acute to chronic pain, psychological issues impeding ongoing healing or management of chronic pain conditions and the ways in which chronic pain can develop or exacerbate any psychological issues.

Various forms of depression and somatization can at times be attributed to a pain condition transitioning from acute to chronic in nature (Pincus, Burton, Vogel, & Field, 2002). By comparison the evidence for fear avoidance beliefs and catastrophizing do not demonstrate nearly the same significance as depression and somatization (Pincus et al., 2002). It is important to consider depression and somatization when developing a secondary prevention intervention to help treat the psychological impacts of a pain condition. It should be equally important to consider the other logical factors that may exist and may not be measured effectively to demonstrate their significance.

Within the realm of chronic pain, a relationship exists between the pain condition itself and depression. In many ways, this relationship almost follows the proverbial chicken and the egg relationship, in that depression is related to the development of a chronic pain condition, but can also be caused by chronic pain. Chronic pain can cause a great deal of distress in one's life and can interrupt the normal processes of life, which can lead to the development of depression (Magni, Moreschi, Rigattiluchini, & Merskey, 1994). Spinal and hip pain conditions are often most responsible for depressive symptoms as compared to other pain conditions due to the increased likelihood of disability associated with these conditions (Magni et al., 1994). Similarly, anxiety disorders also frequently occur when one has a chronic pain condition. There is a strong association between chronic pain and the development of either panic disorders or post-traumatic stress disorders (McWilliams, Cox, & Enns, 2003). The development of these disorders is logical, as one might be

constantly fearful or anxious about the recurrence of pain. The co-morbidity of depression and anxiety can have significant impacts on one with a pain condition as seen in the development of more severe pain and greater interference on daily activities as a result of chronic pain (Bair, Wu, Damush, Sutherland, & Kroenke, 2008).

Psychological issues can also act as an impediment to an individual with chronic pain managing their condition and ideally rehabilitating it. An example of this is the term “disability syndrome”, where an individual with a pain condition develops a number of dysfunctional attitudes and beliefs as the pain persists (Robinson, Rondinelli, Scheer, & Weinstein, 1997). One with a disability syndrome will initially be highly motivated to rehabilitate their condition and return to their former life, although as the pain persists and becomes chronic the individual with chronic pain may become disillusioned with the rehabilitation process and become resistant to the various interventions suggested (Robinson et al., 1997). This is not to say that the individual who struggles the disability syndrome is at all to blame, after all it is only natural to feel some frustration and depression when one is not able to effectively manage and reduce their pain, but rather it is to indicate the rehabilitation process and fear of potential re-injury or exacerbation can cause a psychological burden that may impact those with chronic pain (Robinson et al., 1997). This psychological approach to chronic pain can lead to significant challenges for the workplace, family members, the health care system and the workers’ compensation system. It is in the best interest of all parties to have the injured worker return to the workplace and their normal routines as soon as possible. If the worker enters into this disability syndrome, it becomes increasingly likely that they will not be able to regain their complete level of functionality (Robinson et al., 1997). This adds significant time pressures when trying to manage a pain condition, as it is vital to restore the individual’s everyday function before the point when they may be too dissuaded to proceed (Robinson et al., 1997).

## **2.4 Sociology**

Prior to discussing the impacts of social relationships that an individual might have with chronic pain in the workplace, it would be prudent to discuss some of the overarching societal issues that are at play when exploring the area of chronic pain. Two primary social issues to be discussed in this section are race/culture/ethnicity and socioeconomic status. As is found in the literature and in society as a whole, these issues often intersect with one another, but will both be covered in their relation to chronic pain.

For the purposes of this literature review, race is being defined as a social construct, rather than a biological element. This social construct includes elements of physical characteristics as well as culture and self-identity (Shavers et al., 2010). Ethnicity, which will also be touched upon, are “cultural groupings defined by a common language, religion, nationality or heritage.” (Shavers et al., 2010) The discussion of chronic pain along the lines of race/culture/ethnicity consists of two primary elements. The first element is the influence of racial or cultural identity on the individual perception of pain and how this pain should be managed, whereas the second element is the external relationship with health care providers and the health care system as to how racially and culturally diverse populations are treated in managing their chronic pain condition (Morales & Yong, 2021; Shavers et al., 2010). While racial and ethnic minority individuals are no more likely to develop a pain condition, a number of studies have indicated that Black subjects report significantly more pain and suffering and are far more likely to catastrophize their pain. (Green, Baker, Smith, & Sato, 2003; Green, Ndao-Brumblay, Nagrant, Baker, & Rothman, 2004; Johnson et al., 2021; Meints, Wang, & Edwards, 2018; Morales & Yong, 2021). One’s internal understanding of their pain condition and the coping strategies that they adopt can vary significantly based on racial or cultural identities. Much of this can be based on the locus of control, such that Black populations are, at times, more likely to have behaviours exhibiting an external locus of control believing that there may be a higher power playing a role in their pain condition (Holt & Waterfield, 2018; Nahin, 2021). This can be compared with Asian populations that tend to have a more internal locus of control and using a mind-body strategy to find balance and cope with their pain condition (Meints et al., 2018; Nahin, 2021; Shavers et al., 2010). The cultural aspect can also play a role in how an individual with pain expresses what they are feeling, some cultures may have more open forms of communicating what an individual is feeling, compared to others that may see pain as something to be endured and not discussed with others (Encandela, 1993; Holt & Waterfield, 2018; Morales & Yong, 2021; Peacock & Patel, 2008).

In terms of the dimension of how physicians and health care providers may treat patients differently based on their racial or ethnic identity, there are a number of different and often subtle ways in which racial and ethnic disparities tend to occur (Encandela, 1993). Black patients in particular are found to have the greatest impacts on their health outcomes of other racial groups due to stigma and systemic challenges of discrimination (Ghoshal, Shapiro, Todd, & Schatman, 2020). Physicians are more likely to underestimate pain in Black patients, and also more likely to overestimate pain in patients who are not Black. (Ghoshal et al., 2020; Shavers et al., 2010). It has also been found that Black patients were far less likely to be screened for pain and receive diagnostic

imaging compared to white patients (Ghoshal et al., 2020). These disparities often lead to minority patient requests for pain relief to be seen as drug seeking behavior as compared to similar requests from non-minorities. Contraindicative to this point, racial/ethnic minority patients often have a greater fear of addiction or medication side-effects relative to White patients, and this is often likely due to an increase in non-adherence in prescribed pain medications or treatment plans (Haq et al., 2021; Shavers et al., 2010). Racial differences in prescribing opioids is an area of inconsistency in recent literature. Recent studies have indicated that Black pain patients, despite having greater pain, are prescribed lower doses of opioids to manage their pain and there may be a bias away from prescribing opioids for Black patients (Ghoshal et al., 2020; Haq et al., 2021; Morales & Yong, 2021). Conversely, another study demonstrated that physicians were more likely to prescribe higher doses or stronger types of opioids for Black populations as compared to White populations. These findings were based on the verbal expression of pain of Black patient populations relative to White patient populations (Burgess et al., 2008). Similarly, a separate study indicated that Black participants were more likely to be using prescription opioid medications, this difference was explained by potential race differences in opioid prescribing (Meints et al., 2018). While the differences in the literature may somewhat obscure the true nature of what is consistently occurring in pain prescribing on a racial/ethnic level, it is clear that there are at least some differentiations as to how pain patients are being treated based on their racial identity. Given the recency of the majority of the articles, it is increasingly likely that Black patients in particular are currently being under-prescribed pain medication and as a result have their conditions less effectively managed simply because of their racial or ethnic background.

The second of the primary issues related to chronic pain on a sociological level is that of socioeconomic status and its impact on chronic pain. It should be noted that one's socioeconomic status does not exist in a vacuum and is often interrelated with other biological, psychological and sociological dimensions of pain. This can be seen in the interrelationship between socioeconomic status and race/ethnicity that will be discussed shortly. It can be seen that lower socioeconomic status can lead to greater levels of impact of one's chronic pain condition, along with the inverse relationship of higher levels of chronic pain leading to a decrease in socioeconomic status (Booher, 2019). Those with lower reported socioeconomic status are more likely to identify having chronic pain conditions, as well as having increased pain severity, disability, impacts on caregivers and family members, decreased quality of life, along with unemployment (Booher, 2019; Fuentes, Hart-Johnson, & Green, 2007). The impact of chronic pain on unemployment creates a cyclical relationship with

socioeconomic status, that chronic pain can lower one's socioeconomic status and lead to levels of unemployment, which can in turn lead to challenges in treating one's pain condition, thus making it more challenging to improve one's socioeconomic status.

Socioeconomic effects were not only found on an individual level, but also on neighbourhood and racial levels as well. Studies found that those who lived in lower class or disadvantaged neighbourhoods tended to experience greater levels of stress, leading to higher musculoskeletal pain (Booher, 2019; Fuentes et al., 2007). The research on socioeconomic status is somewhat divided as to whether or not race/ethnicity is a contributing factor to one's pain condition, or if it is more based on the socioeconomic or neighbourhood element as to whether or not one's pain will be impacted (Bierman & Lee, 2018; Fuentes et al., 2007). Race is often found to be a contributing factor to lower neighbourhood socioeconomic status, but this begs the question as to whether or not it is the racial or ethnic background playing a direct role in a chronic pain condition, or whether the role of race or ethnicity is viewed through the socioeconomic disparities on racial or ethnic lines. The direct impacts of patient race, while accounting for socioeconomic status can be seen in a study exploring health care provider attitudes and pain ratings. This study accounted for socioeconomic status and found that in higher socioeconomic status groups, providers found greater pain interference in Black than White patients, compared to lower socioeconomic status groups where the pain interference was reversed (Anastas et al., 2020). Similarly, another study demonstrated that Black and Hispanic adults reported more pain than White adults and that pain conditions significantly ability to manage one's daily life in the lowest wealth quartile (Janevic, McLaughlin, Heapy, Thacker, & Piette, 2017). Additionally, providers were more likely to suggest opioids as a treatment approach for Black patients rather than White patients and for lower socioeconomic patients were more likely to recommend workplace accommodations for White patients (Anastas et al., 2020). This study begins to unpack the racial impacts of chronic pain not only on an internal level, through how one perceives and manages their pain, but also on an external level in how one is treated by others. Externally, one's socioeconomic status and race play a significant role in how they are treated with their chronic pain condition, which in the case of health care providers can impact how their chronic pain condition is managed

The impact of social relations on an individual with a chronic pain condition in the workplace can occur in two opposing manners. From a more helpful perspective for the worker with a chronic pain condition an increase in positive relationships can act as a protective measure against chronic pain

flare-ups. This can occur with either those in the workplace, with employers and co-workers, or those in their home life, including family and friends. By having positive relationships with these individuals, one is able to decrease their overall anxiety and potential overall depression, which in turn has an impact on one's chronic pain condition (Hutting, Heerkens, Engels, Staal, & Nijhuis-van der Sanden, 2014). The reverse can also be identified; whereby if one has negative interactions either in the workplace or at home this can lead to additional challenges in managing one's chronic pain condition and can facilitate additional psychological or physiological issues (Hutting et al., 2014; Jakobsen & Lillefjell, 2014).

The lack of support that one receives from their employer and/or co-workers is important for the overall management of a chronic pain condition (Franche et al., 2011; Fransen et al., 2002). If employers and/or co-workers are not understanding of the worker's chronic pain condition, or believe the condition to be fake or not as severe as the worker is mentioning, the employers and/or co-workers may treat them with animosity or hostility; this can lead to ongoing psychological issues for the worker (Hutting et al., 2014; Jakobsen & Lillefjell, 2014). The worker may feel persecuted as a result of their pain, which could lead to them feeling a need to work through their pain condition when they may actually be physically unable to do so to the extent they need to. This can lead to issues of both presenteeism, as well as absenteeism, both of which are issues in the realm of chronic pain in the workplace, and is discussed in more detail in the following section.

The positive components of mental support can be seen when the managers or coworkers identify that something may be amiss with the worker and either check in with them to see that they are alright, or give additional effort to help make certain that they are not overexerting themselves. Hutting et al. (2014) identify the positive feeling that one participant felt when they were checked in on by their supervisor when they came into work wearing a brace one day. This support can lead to positive psychological benefits for the worker over the course of a workday.

A primary issue that exists within the realm of social or physical support exists in the unwillingness of many with chronic pain conditions to ask for help when they require assistance. In the workplace, this could manifest itself by not wanting to burden others with their pain condition, or it could also be as a result of the belief that others will not be able to perform the job to nearly the same level, regardless of their diminished capacity because of the pain flare up (Hutting et al., 2014; Wynne-Jones et al., 2011).

The impacts of social support are not limited or restricted to the workplace environment. The relationships that one has with their spouse, family and friends can be a vital part of



managing a pain condition effectively (Jakobsen & Lillefjell, 2014). Many individuals with chronic pain identify that the communication they had with their significant others had diminished as a result of their chronic pain condition, that they had learned not to discuss it with others so as to not burden them (Jakobsen & Lillefjell, 2014). This can cause strain on one's relationship as there may be an expectation of support and help from loved ones, however the loved one may not realize the extent to which support was needed. This lack of social support at home can lead to couples divorcing as a result of a chronic pain condition (Jakobsen & Lillefjell, 2014). All of these issues that exist at home can exacerbate any problems that might be occurring at work, which creates a far more difficult challenge to overcome in addition to one's chronic pain condition. The discussion of social relations in the workplace is not restricted to the concept of support, or lack thereof. The previously discussed issues of support fall within the overall topic of job stressors. Research indicates that there is an entirely different area in the realm of social or environmental factors that is necessary to explore as well, which includes job strains and stressors (Gignac et al., 2007; Karasek, 1979). The job stressor can be defined as the more day-to-day social issues that occur within one's job, whereas the job strains are more long-term concerns that are impacting and influencing one with chronic pain in the workplace (Gignac et al., 2007; Karasek, 1979). These concerns can involve an overall fear of losing one's job as a result of their chronic pain condition; balancing multiple roles at work and at home while attempting to manage their chronic pain condition; and lacking in necessary control in either their workplace or condition on an ongoing basis (Gignac et al., 2007). These job strains are all based primarily on the workplace environment and the challenges that it provides, especially for those with a chronic pain condition. Many of these job stressors and job strains workers need to deal with on an everyday basis, however it is often the case that these issues are magnified when the person dealing with them has a chronic pain condition. It is important to not forget about these factors when thinking about chronic pain in the workplace, as they can have detrimental effects on the ongoing management of these conditions.

## **2.5 Chronic Pain as a Multidisciplinary Issue**

Now that the issue of chronic pain has been considered from each of the disciplines, it is important to consider chronic pain from a multidisciplinary perspective. That is to say not solely exploring chronic pain through each of the disciplines on their own, but rather looking at chronic pain as a complex and multifaceted condition that simultaneously includes challenges from multiple disciplines that can interact to create unique difficulties for individuals with chronic pain. As such, it is

important to examine chronic pain using a multidisciplinary perspective, keeping in mind all disciplines at once and considering them each as integral parts of a complete whole. To help consider chronic pain as a multidisciplinary issue, the biopsychosocial model was developed (Kuijer et al., 2006).

This model utilized by the International Classification of Functioning, Disability and Health (ICFDH) explores all facets of one's health both on a body functional level, as well as on a contextual level (Kuijer et al., 2006). One's body functions include the physiological and psychological functions, or the limitations that may exist within these functions (Kuijer et al., 2006). Contextual factors on the other hand explore the environmental factors in one's life, specifically their physical, social and attitudinal environment (Kuijer et al., 2006). These factors all help to create a detailed and in-depth structure for the various ways in which chronic pain can influence one's life, while considering aspects from each of the biological, psychological and sociological disciplines. The development of this model helps to provide a paradigmatic shift in how we consider chronic pain. Now, when looking at chronic pain, we are no longer limiting our perspective to what goes on at the site of pain, but rather we are starting to consider how this pain impacts and is impacted by our state of mind, as well as contextual factors that are outside of our body but can have just as significant of an impact.

The biopsychosocial model has some additional applications when it comes to chronic pain and work. Wynne Jones and Main (2011) created a flag framework to identify and categorize obstacles related to a chronic pain condition, particularly in the workplace environment. In this framework, red flags are biomedical factors, which focus on the physiological nature of the chronic pain condition (Lambeek, van Mechelen, Knol, Loisel, & Anema, 2010). Yellow flags are more psychological in nature and focus on one's beliefs and concerns about their pain condition (Lambeek et al., 2010). Blue flags focus on the relationships within the workplace, discussing elements of job satisfaction and demands (Wynne-Jones & Main, 2011). Black flags consist of systemic approaches in the workplace, exploring issues of sickness absence, workplace policies and financial issues (Wynne-Jones & Main, 2011). This flags framework takes the multidisciplinary approach to chronic pain to a new level of exploration, extending beyond the individual level interactions to the systemic and organizational level impacts of chronic pain. From this, it is clear that we are beginning to expand the scope of the impact of chronic pain in the workplace. It is no longer only important to consider the impact of chronic pain on the individual and perhaps a small group of people that the individual interacts with

on a daily basis, but rather in the workplace it is important to consider the ripple effects that may occur organizationally as a result. Chronic pain in the workplace is no longer limited to the worker, but also those they work with, their supervisors, and the overall productivity of the company. There are a number of additional moving pieces and factors to consider when thinking about chronic pain in the workplace, and these additional elements are aspects to keep in mind when researching this topic, which is why the flags framework presented above is so helpful, as it considers the other systemic factors. That being said, by focusing on the systemic and organizational factors of the chronic pain condition, it is possible to lose sight of the individual's lived experience with chronic pain and by focusing on the macro or organizational level perspective that one may be diminishing the impact that chronic pain may have on the micro level, or individual level. Both micro and macro levels are important and valuable to explore and there are a number of complexities to consider when it comes to the key issues of chronic pain in the workplace.

## **2.6 Key Issues in Chronic Pain in the Workplace**

The first of the key issues that exist in the realm of chronic pain in the workplace are that of presenteeism and absenteeism. For presenteeism, the worker is attempting to continue working through their pain condition so that it will not have any lasting impacts on either their co-workers or employers (Munir et al., 2007). This can create significant challenges for both the worker and the workplace long-term, as the worker might not be as productive due to the physical limitations that exist as a result of their condition (Agaliotis, Mackey, Jan, & Fransen, 2014; Patel et al., 2012). Due to the limitations caused by their chronic pain the worker may be causing additional physical damage to himself or herself due to overexertion, under the belief that they are trying to do what is best for the workplace in working through their pain, to not impact the overall productivity. This could lead to the worker needing additional time off work, which transitions into the problem of absenteeism. Absenteeism, is the issue of the worker requiring large amounts of time off of work to manage or heal their chronic pain condition (Agaliotis et al., 2014). This constant time off work can lead to, or exacerbate, problems that may exist with co-workers or management, as they regularly need to offset the lack of production from the injured worker (Hutting et al., 2014; Wynne-Jones et al., 2011; Wynne-Jones & Main, 2011).

There has been a fair bit of research completed on this issue of presenteeism with chronic pain. One of these work-based studies looked at psychological and demographic factors that might predict presenteeism versus absenteeism (Karoly, Ruehlman, & Okun, 2013). This study found trends that

those with lower pain severity, younger, Hispanic or Non-Hispanic white, married and having higher education would be more likely to continue working through their pain as opposed to taking time off work to manage it (Karoly et al., 2013). The particular differentiation noted by these authors is that those who identified as Hispanic, fairly consistently identified themselves as working, whereas African-Americans had an increased likelihood as identifying as work disabled as a result of their pain (Karoly et al., 2013). Compared to prior work in the field, these racial differences were a newer finding and something that was suggested by the authors as being necessary to explore moving forward. From the psychological perspective, those who remained at work reported more of an adaptive pattern, wherein the participants ignored their pain, were more persistent about achieving their tasks and were less fearful about their pain (Karoly et al., 2013). While this study offers a discussion on the differences of what may lead to presenteeism versus absenteeism, there is a disregard for some of the more negative aspects of presenteeism. The authors of the study laud those who stay at work as they are adapting to their pain and ignoring its impacts, but that may not be something truly helpful in the long run. Certainly not being fearful of one's pain and developing adaptive mechanisms to manage it is a positive thing, but for some people, this may lead to regression, or potentially masking one's pain at work and being debilitated at home later. This work on presenteeism is welcome, as it is looking at trends and patterns acquired from a larger population, however, it is not following up with those individuals and asking some of the key questions that could be playing a more significant factor as to why these trends are occurring, such as exploring the nature of the workplace environment, relationships within the workplace, and overall discussions on job stressors and job satisfaction.

Another study on presenteeism in the workplace explored issues of co-morbidity between mental disorders and pain conditions on the outcome of presenteeism. While this study did explore the more negative perspective on presenteeism in the realm of chronic pain at work, it did not find any benefit to focusing on both mental disorders and physical pain conditions, there was no correlation found between the two, in attempting to predict presenteeism (Bielecky et al., 2015). This study did have some use in exploring the issue of presenteeism through a multi-disciplinary perspective, however the results found from it were not really effective in demonstrating anything conclusively. It is here that qualitative approaches may have been helpful to dig deeper and to attempt to understand the co-morbidity between psychological and physiological disorders through the description and/or discussion of the experiences of those who had these conditions and were dealing with issues of presenteeism in the workplace.

A third, and final study exploring the issues of presenteeism in the workplace, explored the topic through the lens of nurse presenteeism due to low-back pain. Similar to the last study, this approach examined low-back pain through a multi-disciplinary perspective, wherein the researchers explored this phenomenon through: physiological factors, ergonomics, psychosocial factors, mental factors and work-related characteristics (d'Errico et al., 2013). This approach was of true benefit to this study, as it was able to better understand some of the reasons why presenteeism was taking place within this population. Primarily it seemed that the reasoning behind this increased level of presenteeism was primarily as a result of the nature of the job itself in caring for and helping patients, such that the nurses would push through their pain so as to not have a negative outcome on their patients (d'Errico et al., 2013). This concept was even stressed further through a negative attitude towards sickness absence, as there is a difficulty in finding suitable replacements and in the end of the day, the patients must come first (d'Errico et al., 2013). This research is valuable for understanding the concepts of presenteeism, that being said, providing the perspective on presenteeism from the nurses directly through qualitative methodologies would have benefitted this work.

In terms of absenteeism, there has also been research completed on the impacts of chronic pain on increased absenteeism from work. The first example of this sort of work, explored the incidence of absenteeism among professional public transport drivers with lower back pain (Kresal, Roblek, Jerman, & Mesko, 2015). The results of this study did find that those with lower back pain were at higher risk for absenteeism from the workplace, but also indicated that other factors such as low job control and excessive workload also played a factor in their absence from work (Kresal et al., 2015). This continues to demonstrate the argument that chronic pain in the workplace is a complex issue with many moving pieces. Certainly, the aspect of the chronic pain is a primary reason why absenteeism is occurring, but there are other factors involved as well, especially when considered in comparison to the presenteeism article on nurses with low-back pain (d'Errico et al., 2013). In either circumstance, the nature of the pain condition is very similar, but the work outcome is completely opposite. From this, it can be seen that relying solely on the type of pain as an indicator for presenteeism or absenteeism is faulty, and one must continue to consider chronic pain in the workplace as a complex set of circumstances with a number of constantly moving pieces that one must consider when examining it.

Workers with chronic pain conditions also often require modifications to the work that they were originally doing before the chronic pain condition occurred. These modifications use a number of

different approaches to help the worker with chronic pain, including: gradual return-to-work plans, pacing modifications, alterations in responsibilities, and/or ergonomic education and modifications (Bilski, 2008; Durand & Loisel, 2001; Jakobsen & Lillefjell, 2014; Jakobsen & Svendsen, 2013; Saunders, MacEachen, & Nedelec, 2015). Gradual return-to-work plans would consist of the worker, employer and potentially a representative from the workers' compensation system meeting to set up a system wherein the worker would gradually reintegrate themselves back into the workplace environment, starting with a reduction in their responsibilities or in the amount of time they spend at work (Durand & Loisel, 2001; Jakobsen & Lillefjell, 2014). This process allows the worker to ease back into work with a level of flexibility and accommodation from the employer, thus making certain that they are able to manage their condition in the workplace over time. The gradual return-to-work process could also be simplified to be a modification in the pace at which the worker does their job (Jakobsen & Lillefjell, 2014). While the worker with a chronic pain condition may be unable to perform their job tasks at the pace that they once were able to, it might be more reasonable to ask them to do their job tasks at a slower pace which might mitigate the possibility for re-injury or additional pain (Jakobsen & Lillefjell, 2014). Another option to manage a workers return-to-work would be to shift them internally to another role within the organization, one that does not require them to be performing actions which might exacerbate their chronic pain condition (Jakobsen & Svendsen, 2013). This can be particularly challenging to the workplace, as there may not be other roles available within the organization, or the worker may simply not be sufficiently trained to effectively work in those roles. It is here that the employer and workers' compensation system would likely work together to either find a suitable role for the worker, or attempt to find them adequate training for roles where they may not be already suitable (Jakobsen & Svendsen, 2013). The final area of modification in the workplace is that of ergonomics education or modifications. Ergonomics education would be used to inform workers about the postures that they use to accomplish their tasks at work, the frequency with which they complete their task, or specific rules for manual lifting or pushing/pulling heavy loads (Bilski, 2008). Another way that ergonomics can be used is to prevent chronic pain injuries and re-injuries by modifying the workplace environment, which would eliminate the risk of the worker performing a task that could lead to injury. Workplace modifications could include interventions such as modifying a seat to address sitting posture, or incorporating lifts or extension devices so that the worker does not need to stretch awkwardly to reach things while performing workplace tasks (Bilski, 2008). It is important to note that the majority of the research done in the area of accommodations is based on pain conditions originating from some form of

workplace injury and thus involving the workers compensation system. This identifies an interesting gap to explore moving forward in exploring the differences in approaches to workplace accommodation in workers whose pain originated due to a workplace exposure, as compared to workers whose pain originated elsewhere.

In discussing the first concept of workplace accommodations, there has been a research study completed in Canada that examines the impact of a variety of workplace accommodations on staying in the workplace and maintaining a level of productivity, despite having some form of arthritis. For the most part, various workplace accommodations were found to be helpful in improving work outcomes and limiting job disruptions and productivity losses (Gignac, Cao, & McAlpine, 2015). However, an interesting finding from this study was that many individuals with arthritis did not utilize work policies that were available to them, indicating that they did not actually need the accommodation. It was found that many of the participants who needed the helpful workplace policies but did not use them had overall poorer work outcomes (Gignac et al., 2015). This study demonstrates that accommodations in the workplace, such as flexible hours, short term leaves, modified work or special work equipment/ergonomic adjustments can be useful to workers to maintain a level of productivity and keep working despite their chronic pain condition (Gignac et al., 2015).

As mentioned above, ergonomics is a key intervention area when exploring the issue of chronic pain in the workplace. Ergonomics based interventions are often studied and evaluated in their effectiveness in managing chronic pain in the workplace. An ergonomics-training program can be an effective approach to reducing pain in the workplace, particularly low back pain. This approach to an intervention relies on instructing the worker in the proper ergonomic postures to use in their tasks at work. An evaluation of an ergonomics-training program was undertaken in a population of 124 nurses with low back pain. The nurses in this study were separated into a study group, which received the intervention once a week for a six-week period, and a control group, which received passive physiotherapy for the six-week period (Jaromi, Nemeth, Kranicz, Laczko, & Betlehem, 2012). Outcome measurements included pain intensity and body posture, which were determined through the Visual Analogue Scale and the Zebris biomechanical motion and analysis system respectively. Both the study and control group revealed reductions in pain intensity, however the study group demonstrated significantly better results over the control group at each of the follow up periods. The posture improvements were much more significant in the study group as compared to the control

group (Jaromi et al., 2012). The improvements on posture and back pain intensity can lead to ongoing ergonomic improvements in the workplace, which can have significant impacts on recurring pain episodes and reductions in productivity loss and absenteeism in the workplace. This study demonstrates the effectiveness of an ergonomics centric intervention on pain in the workplace. However as discussed above, ergonomics is a singular disciplinary approach to pain management, in this case only looking at the physiological aspect of pain. While this certainly has its uses in the ongoing management of pain in the workplace, it is not necessarily something that can be relied upon on its own and may be best suited as a part of a multidisciplinary perspective.

There are also a number of multidisciplinary approaches to chronic pain management in the workplace that examine the effectiveness of interventions designed to manage many facets of a chronic pain condition at the same time. A multidisciplinary approach to chronic low back pain can at times be seen as ideal to manage these conditions in the workplace, as the strengths of multiple techniques can be highlighted while offsetting some of the potential deficits and challenges in each approach that may exist. One such multidisciplinary approach to chronic low back pain in the workplace, is that of the Sherbrooke model (Loisel et al., 1994). This model organizes the involvement of different therapists and treatments over the course of a back-pain condition, allowing for an optimal collaboration between professionals, while making certain that overlap and potential conflicts between therapeutic approaches are minimized. The Sherbrooke model begins within four weeks of the initial injury, which allows for a screening of potential at-risk cases that may shift from an acute condition to a chronic one (Loisel et al., 1994). The first step of the model occurs on week six after the onset of the condition, wherein an occupational physician meets with the worker and an ergonomist goes to the workplace. This step is designed to solidify a diagnosis as well as determining the potential for a return-to-work on either full or modified duties. This approach, called participatory ergonomics, involves all of the impacted parties and associated professionals discussing the situation together to determine the best course of action to reintroduce the worker into the workplace, while minimizing any risk of future aggravation of their condition. The second step occurs if return to work has not occurred within seven weeks. At this point, the worker goes to a back school where they are instructed for one hour every day for four weeks on the ideal approaches to manage their pain condition appropriately (Loisel et al., 1994). If the worker is unable to return to work after twelve weeks, the condition is determined to be chronic, and the final step of the Sherbrooke model is implemented. In the third, and final step of this model, the worker undergoes functional rehabilitation therapy, which involves the worker undergoing strength conditioning along with cognitive



behavioural therapies to facilitate a return into the workplace (Loisel et al., 1994). This step concludes with a therapeutic return to work approach, whereby the worker alternates days of work and treatment, slowly easing themselves back into their formal position. Compared to the prior study which utilized a solely ergonomic focused intervention, this approach utilized a multi-disciplinary approach using a variety of approaches to address the many facets of chronic pain. As an intervention, this approach can certainly be seen as helpful in managing the entirety of a chronic pain condition, as opposed to the purely physiological aspect of pain.

A second approach to using an integrated, multidisciplinary approach to the management of a chronic back pain condition was developed based on the biopsychosocial model of pain and disability. This integrated approach to managing work disability due to chronic back pain incorporates aspects of biomedical factors, psychological factors, workplace factors, and healthcare and workers compensation system factors (Lambeek et al., 2010). A randomized controlled trial was completed to compare the effectiveness of this integrated care approach to the usual care on the return to work process of those who were sick listed as a result of chronic low back pain for twelve months. The integrated care approach was designed to primarily restore function in the workplace, rather than the common outcome of reducing pain. This approach was coordinated by an occupational physician, and included a participatory ergonomics intervention in the workplace, and a physical activity program that included elements of cognitive behavioural therapy (Lambeek et al., 2010). The primary outcome for this study was the number of days taken to return to work without a recurrence of their leave of absence. The median duration for sick leave in the integrated care group was 88 days after randomization, compared to the usual care group, which had a median sick leave of 208 days after randomization (Lambeek et al., 2010). This final intervention takes an even more involved approach to the management of pain in the workplace, including additional systemic factors as well. In terms of the multidisciplinary approaches to chronic pain in the workplace, this is likely the best representation as it addresses almost all of the facets of pain that impact the workplace.

While these modifications and workplace interventions are typically positive for the worker with a chronic pain condition, they do add a significant burden to the employer to try to manage. The employer has the onus put upon them to try to find a way to get the worker back into the workplace in a safe and productive manner, while at the same time not overly impacting the wellbeing of other workers, productivity and their yearly budget (Jakobsen & Lillefjell, 2014). These stressors can lead

to challenged relationships between the employer and the worker with the chronic pain condition, leading to an unpleasant workplace environment for all.

## **2.7 Chronic Pain in those who are Self-Employed or Teleworking**

While it is certainly useful to identify the general issues that exist within the realm of chronic pain in the workplace, it is also important to review research that has been completed in the specific topic area that is being discussed in the primary research question. The focus within this research question is not the general area of chronic pain in the workplace, but rather it is a specific subset of that population including those who are self-employed or teleworking. This population subset is incredibly underserved by the literature, with only some general information about the experiences of those who are disabled and are teleworking or self-employed. It is valuable to unpack and explore the experiences of these sub populations of the general chronic pain group, as they may have different experiences in managing their pain as compared to a standard and traditional work environment. This section of the literature review helps to define each of these populations, explore the research that has been done in the area and further solidify the gap that exists in the literature in which the primary research question addresses.

Those who are self-employed, or are teleworking are likely to have very different work experiences as compared to those who work in a traditional workplace environment. Both of these groups, have more job control and job autonomy as compared to those who go into a workplace, as they can determine where they work, the hours they work (to some degree), and how the work is completed. There may be external factors involved for standards, or check-ins, however this type of work arrangement allows for a greater amount of flexibility and control. This flexibility and control has been found to be of benefit to those who have disabilities, and is likely also helpful to those with chronic pain conditions (Prattas & Thompson, 2006).

Telework is very much a work accommodation that is on the rise (Moon, Linden, Bricout, & Baker, 2014). The concept of telework is defined as a means for people to work from home, rather than reporting daily to an office or workplace (Moon et al., 2014). Telework has been recognized as a positive and helpful workplace accommodation for people with disabilities, as individuals who may struggle with operating at full functionality in a traditional workplace environment, may be able to work efficiently and productively from their own homes (Moon et al., 2014). Telework is also helpful in that it can offset some of the issues that exist in role overload and work-family conflict, as it provides the worker with greater job control affording them additional time to balance work and

family demands (Duxbury & Halinski, 2014; Higgins, Duxbury, & Julien, 2014). This challenge of balancing roles can be exacerbated by the introduction of a disability, as it adds an additional element for the worker to balance (Linden & Milchus, 2014). The current circumstances of COVID-19 have added a new layer to the discussion of telework and its benefits on those with chronic pain. While the original work in this dissertation was completed pre-COVID-19, a study was recently released to explore the impacts of sedentary behavior on one's chronic pain condition while working from home as a result of the pandemic (Rodriguez-Nogueira et al., 2020). In this research, it was determined that the sedentary nature of working from home did have a negative impact on one's pain condition, but the freedom of working from home did allow the women in the study to participate in more exercise, which allowed them to work to reduce some of their pain symptoms (Rodriguez-Nogueira et al., 2020). These studies help to demonstrate the importance of exploring the relationship between telework and chronic pain. However, one common gap that was reviewed on teleworking is a lack of discussion on the impacts of this work accommodation on those with chronic pain conditions (Linden & Milchus, 2014).

Despite the potential for significant benefit in teleworking, or working from home, recent government publications have identified some disparities that exist within the population in their ability to work from home. Only 29% of all wage and salary workers had the ability to fully telework, with another 24% being able to sometimes work from home (Job Flexibilities and Work Schedules - 2017-2018 Data from the American Time Use Survey, 2019). Differences did not exist across genders as to who was more likely to work from home, or receive pay from their work (Job Flexibilities and Work Schedules - 2017-2018 Data from the American Time Use Survey, 2019). Black and Hispanic workers were far less likely to work at home (18 percent and 13 percent respectively), compared to White and Asian workers (26 percent and 32 percent respectively) (Job Flexibilities and Work Schedules - 2017-2018 Data from the American Time Use Survey, 2019). Additionally, workers with advanced education are more likely to be able to work from home, in that 47 percent of individuals with a bachelor's degree or higher were able to at least occasionally work from home compared to only 9 percent of workers with only a high school diploma, and 3 percent of those with less than a high school diploma (Job Flexibilities and Work Schedules - 2017-2018 Data from the American Time Use Survey, 2019). These American statistics demonstrate some of the recent and significant disparities that exist in the capacity to work from home. While teleworking may be of benefit to those with chronic pain, it is an option that is limited along class and racial boundaries. These disparities demonstrate that despite the knowledge and awareness that telework

may be an ideal environment for those with a chronic pain condition, it is not necessarily an option that is available to all. These systemic disparities along lines of race need to continue to be addressed so that options like telework are not limited to some based on their race or ethnicity.

Similar to the discussion on telework, the research being done on the self-employed population is just as limited. The initial work done in the field demonstrates the importance of discussing self-employment in terms of chronic pain, although it primarily explores these issues in the realm of general disability and not necessarily the specific issues of chronic pain. A study by Pagán (2009) examined self-employment and disability across Europe, using data from the European Household Community Panel. This initial study found some preliminary population trends that serve as important as a foundation for future research in the area, as it determined that people with disabilities were more likely to be self-employed as compared to those without disabilities (Pagán, 2009). Also, of note in this study is that it defines self-employment as a way to improve job flexibility, in terms of working hours or job environment, which greatly helps one with a disability manage their condition while still being able to work (Pagán, 2009). While this study is a valuable foundation piece, it is also only exploring the issue on a more general population level, as opposed to a more specific approach delving deeper into the issues regarding self-employment and disability, or even more specifically relevant issues of self-employment and chronic pain.

Other work completed in the area of self-employment, expands upon these benefits, but at the same time begins to unpack some of the deficits and challenges of self-employment. The prior research done in the realm of self-employment and workplace health discusses some of the benefits that exist from being self-employed, including: higher job satisfaction, increased workplace autonomy, and increased life satisfaction (Prottas & Thompson, 2006). However, for each of these benefits, comes an added challenge from the workplace, including: higher work demands, work-family conflict changes and increased stress (Prottas & Thompson, 2006; Schonfeld & Mazzola, 2015). These increased demands and stress were demonstrated even further in an exploration of self-employed farmers in Finland, where there was a finding of lower Quality of Life ratings and that even though there were increases in job control, the demands and stresses of the job still weighed significantly on the workers, while lacking in adequate resources to support themselves (Saarni, Saarni, & Saarni, 2008). Every positive here seems to be met with an equal negative, which would indicate that self-employment or working from home may be just as challenging as working in a traditional workplace

environment. That said, the added specificity of pain and disability is an important factor to take into consideration when looking at the benefits and challenges of self-employment.

Despite the fact that there has been some groundwork laid in research being completed on self-employment, there is still much work to be done to understand the benefits and challenges of self-employment on those with chronic pain. In an article by Gilman (2014) talking about the Washington Access Fund Telework Program, she briefly discusses the necessity for teleworking, or home-based self-employment initiatives for people with disabilities. Given the nature of chronic pain and its disabling nature for individuals with it, some of these concepts can be brought forward to be used as the impetus for this work. Individuals with disabilities often struggle in the traditional work force, being challenged by transportation to and from work, necessary accommodations at work and beliefs and attitudes of employers and co-workers towards their condition (Gilman, 2014). Self-employment and telework may be seen as a refuge for those who are unable, or do not wish to struggle with a traditional work environment, while allowing themselves the ability to achieve some level of economic independence by supporting themselves through meaningful employment.

Within these key issues in chronic pain in the workplace, both generally and specific to those who are teleworking or self-employed, some common threads appear within the literature. The approaches currently being used to examine chronic pain in the workplace are primarily looking at it through either an epidemiological lens, looking at the incidence or prevalence of certain aspects of chronic pain, or it is being explored through the evaluation of certain interventions being applied in the workplace. While these are certainly useful to research, there are still elements of chronic pain in the workplace that are under researched and underexplored. Specifically, it can be incredibly valuable to look at the complexity of chronic pain conditions through a more individual perspective, as opposed to taking a wider population-based approach. By digging deeper into the specific experiences, it should be possible to develop an even greater understanding of the intricacies of chronic pain and how they impact and are impacted by the workplace environment. The following sections demonstrate the types of research that have been completed to explore these issues at greater depth.

## **2.8 Qualitative Methods and Phenomenology to Explore Chronic Pain in the Workplace**

Given the background on chronic pain in the workplace and some of the challenges that occur as a result of these conditions, it would be prudent to discuss the ways in which researchers attempt to

unpack and understand these issues further. There has already been a great deal of quantitative research completed on various elements of chronic pain in the workplace, including the prevalence of these conditions, as well as evaluations of programs and devices to help with these conditions. As this research is completely qualitative in nature, a few examples of how qualitative research, specifically phenomenology, have been utilized in order to demonstrate the benefits of using these methodological approaches to understand other facets of chronic pain in the workplace is presented below.

The first study to be discussed uses phenomenology to explore the socio-cultural factors and experiences of chronic low back pain (Rodrigues-de-Souza et al., 2016). This study not only uses phenomenology as a research approach, but also identifies why phenomenology and qualitative approaches are particularly useful for looking at an issue like chronic low back pain. One of the major benefits that Rodrigues de Souza et al. (2016) mention about qualitative research is that it requires the researcher to become more involved in the data collection and analysis phases, requiring them to interact more with their study participants and develop a greater understanding of their condition. This study examined issues including: the meaning of pain, daily activities, social relations, family, strategies for controlling pain and factors that influence pain. After looking at these issues within pain, four themes emerged from the interview transcripts: ways of perceiving and expressing pain; socio-familial environment as a modulator of pain; religion as a modulator of pain and socio-economic and education status as a modulator of pain (Rodrigues-de-Souza et al., 2016). Modulators of pain are usually considered to be physiological in nature, but this article is focusing more on modulators of pain in the psychosocial domains. These themes became a number of key areas that were common among the lived experiences of many of the participants with chronic low back pain and therefore identified the primary areas that were necessary to describe the lived experience of the condition when looking specifically at socio-cultural aspects of it. One other study of note that explores an area of chronic pain using phenomenology as its method of choice is a study that explored the experiences of knee osteoarthritis using a descriptive methodological approach (Maly & Krupa, 2007). This study explored knee osteoarthritis among older adults and explored themes of self-worth, impacts on daily living, experiences with others and managing one's pain using the vanKaam method of phenomenological analysis (Maly & Krupa, 2007). As it is seen in both of these studies, phenomenology can be incredibly useful in exploring the experiences of different facets of chronic pain and its management.

In addition to its usefulness in exploring issues of chronic pain, phenomenology can be helpful to explore specific experiences of chronic pain in the work realm. One study (Saunders et al., 2015) that explores issues of chronic pain and work, using phenomenology as the methodology of choice to examine it, is a Canadian research study that explores issues of musculoskeletal injuries and the return-to-work process. This study is important to identify and discuss as it not only uses phenomenology to explore issues of chronic pain and pain related injuries, but also explores these issues in a work specific context. The researchers for this study identified that they were using phenomenology in order to understand the life-world of those with musculoskeletal conditions and wanted to specifically look at the meaning of work for those who were on long-term disability as a result of a musculoskeletal injury (Saunders et al., 2015). Phenomenology was of importance here as it allowed the researchers to understand the nature of being out of work for extended periods of time as a result of a musculoskeletal injury, as well as unpack the meanings of work itself for those who are unable to do so (Saunders et al., 2015). Through this phenomenological analysis, the authors were able to identify themes that guided their discussion which covered areas of system barriers, efforts to retain old jobs and find new ones, attempting to return to work and skills improvement. These themes help to bring the reader through the lived experience of an individual with a musculoskeletal injury and through the description of each of these areas, help them to better understand how the Return to Work process actually works in these circumstances. Another study on pain in the workplace, explores the area of pain coping, using a social phenomenology approach. This study explored how participants understood the terms coping and pain, as well as how they came to that understanding (Carroll, Rothe, & Ozegovic, 2013). Through social phenomenology, the researchers were able to identify that pain coping is a life-defining attitude and that coping was necessary in order to manage or reduce one's pain. It is through this study and the previous study, that it can be clearly seen that various forms of phenomenology can be useful in order to describe and discuss the experiences of chronic pain within the work realm.

## **2.9 Interpretative Phenomenological Analysis to Explore Chronic Pain**

While the aforementioned uses of phenomenology are key in describing the experiences of chronic pain and specifically chronic pain in the workplace, they are also lacking in a vital element that facilitates greater understanding and further discussion. Most of the approaches to phenomenology that were mentioned had the author end their work at the description and discussion of grouping the experiences into themes. This misses an important and useful aspect of interpretation and analysis,

something that Interpretative Phenomenological Analysis includes at its foundation. The nature of Interpretative Phenomenological Analysis is discussed at greater length in Chapters 3 and 4. For the time being, it would be prudent to discuss two studies that use Interpretative Phenomenological Analysis to explore areas of chronic pain. The first study used Interpretative Phenomenological Analysis to explore the concepts of justice and fairness across different socioeconomic groups of individuals with chronic pain. In using this approach, the researchers were able to define and attribute different meanings towards chronic pain and justice that each socioeconomic group had. Those in the highest socioeconomic grouping were searching for equality, but not necessarily from differences in socioeconomics, but rather from the built-in challenges of managing pain. This group stressed the importance of seeking support, living at their own pace, and finding a new level of normality (McParland, Eccleston, Osborn, & Hezseltine, 2011). The middle socioeconomic group identifies very much that they need help to live with their pain and must fight through the systems that are currently in place in order to get that help. This group of people see their experience with pain as an ongoing battle, one that is constantly being fought in order to manage their condition (McParland et al., 2011). The lowest socioeconomic group was also locked into the systems in order to acquire help with their pain management. The differentiation with this group was their right to receive help from the system, because they had a chronic pain issue that did not allow them to seek help on their own, they were more entitled to receiving help from the systems that were in place for that express purpose (McParland et al., 2011). These different socioeconomic groups were then analyzed against existing literature and theories to discuss why these trends occur and what this means in the greater scheme of things. It is through this final analysis that more conclusions were able to be drawn and the importance of justice-related issues for chronic pain individuals could be fully realized.

The second study that used Interpretative Phenomenological Analysis to explore issues of chronic pain, was one done by the creator of the methodology Jonathan Smith. Osborn and Smith (2008) explored issues of fearfulness in chronic pain and the ways in which hypnotic relaxation exercises might alleviate those fears. Ten participants were interviewed before and after their involvement in a hypnotic relaxation exercise, this study was not done to demonstrate effectiveness of the exercises, but rather to understand meanings of fearfulness in chronic pain and how it might be managed by a relaxation exercise. The two primary themes that emerged from these interviews included: “the fearfulness of pain” and “the containment of fear through a social connection” (Osborn & Smith, 2008). The theme of the fearfulness of pain discussed concepts of powerlessness, hopelessness and



being assaulted without being able to intervene (Osborn & Smith, 2008). The pain that was being faced was seen as an evil thing, and something that was threatening and could not be particularly managed. The second theme of the containment of fear through a social connection explored the ways in which the relaxation allowed the participants to face and address these fears and that it gave them confidence to fight their pain along with seeking out social supports to help manage their pain. The unpacking of these meanings of pain can be important to understand the nature of living with a chronic pain condition, but it is also useful to understand what can mitigate these concerns and how that effectively happens.

While the benefits to using Phenomenology and specifically Interpretative Phenomenological Analysis to explore the area of chronic pain should be clear at this point, there is still a paucity of research that has utilized these approaches in this field, particularly in the area of chronic pain in the workplace. To the researcher's knowledge, there has not been research completed that uses Interpretative Phenomenological Analysis to explore the specific population subset of those who have chronic pain and are teleworking and/or self-employed. Therefore, this research study has used Interpretative Phenomenological Analysis to discuss those who are teleworking and/or self-employed in order to fully understand the various aspects of chronic pain in their unique workplace environments. A detailed discussion of Interpretative Phenomenological Analysis and its benefits is contained in the next Chapters along with a discussion of its research application in the area of chronic pain and work.

## **Chapter 3**

### **Methodologies**

This chapter of the dissertation reviews the different methodologies that have been used to address the research questions and objectives (see sections 1.3 and 1.4). There were two methodologies that have primarily be used in this dissertation, which include Interpretative Phenomenological Analysis and Autoethnography. Interpretative Phenomenological Analysis was the methodology employed to address the primary research question exploring the issue of chronic pain in the self-employed and teleworking population, as well as the first sub research question exploring the value of modern approaches to phenomenology for new researchers. This methodological approach was chosen because of its ability to both describe and interpret the lived experience of those who are self-employed or teleworking with a chronic pain condition. The specific ability to interpret the descriptions of the participant experiences is of benefit, especially given my background as a researcher with a chronic pain condition myself. Autoethnography was the methodology used for the second sub research question exploring my own experiences with chronic pain and how they have influenced my viewpoints on chronic pain as a whole. Autoethnography was chosen as a methodology for the second manuscript, as it serves to both share my individual experiences with chronic pain as a young adult, connecting these experiences to the broader chronic pain community and by doing so allows the reader access to understand the nuances of chronic pain conditions and how they relate to the broader literature in these fields. Throughout the rest of this chapter, these methodologies were explored in greater depth to identify exactly how they were used to explore the research objectives within each of the research questions being explored.

#### **3.1 Background on Phenomenology**

Prior to discussing Interpretative Phenomenological Analysis and its uses, it would be first prudent to discuss the origins of phenomenology as a methodology and how it has been developed over time. By first developing an understanding of the history of phenomenology, it should be easier to see how this approach can be used to study issues such as chronic pain and chronic pain in the workplace, as well as seeing the added value of more contemporary approaches to phenomenology.

At the core of every form of phenomenology, the researcher is trying to explore the lived experience of a concept or phenomenon (Creswell, 2013). In most cases, this means that the researcher is trying to describe the common experiences of individuals who are undergoing a

particular phenomenon. In doing so, the researcher is identifying what is at the core, or essence, of that particular phenomenon through a composite of descriptions by the participants who have experienced that phenomenon. The way that this phenomenology is performed and the focus of it varies dramatically based on whose version of phenomenology is at the core of what is being experienced.

## **3.2 Theoretical and Philosophical Foundations in Phenomenology**

Phenomenology itself started as a philosophical exercise, rather than a research methodology. The philosophers who created the field of phenomenology wanted to understand the lived experience and created rules to do this study. The development of the philosophies of phenomenology emerges through the philosophies of Edmund Husserl, Martin Heidegger and Maurice Merleau-Ponty. Through these various philosophers, it is possible to develop a greater understanding of the nature of phenomenology, which can provide a necessary starting point for a discussion of its application as a methodology as a whole. That said, it is also important to identify some of the areas in which each of these philosophical approaches may be not as suitable for practical applications to research, which should open the door for more contemporary approaches to phenomenology to bridge the gap to more useful adaptations for research purposes.

### **3.2.1 Edmund Husserl**

Edmund Husserl is seen as the father and creator of phenomenology. Prior to developing phenomenology, Husserl was primarily a mathematician, however he attended philosophy lectures by Franz Brentano, which led to him studying some of Brentano's work in detail. Brentano's work on the study of consciousness and how one views the world provided the impetus for Husserl's creation of the phenomenological approach (Gallagher, 2012). Husserl believed that the study of consciousness was completely different from the study of nature, and as such the scientific method could not be directly applied to its study. The difference in this area of study is that everything in the study of nature can be explained by scientific principles. The exploration of consciousness is trying to develop more of a description of the phenomena of the world, rather than an explanation of why the phenomena exist. This shift away from a positivist ontology required him to develop a new foundation that did not rely on these classic scientific techniques. Husserl was not trying to question the existence of the world itself, but was trying to determine, fundamentally, how one senses and experiences the world around them.

The goal that Husserl was trying to accomplish in establishing phenomenology, was to create an eidetic science, whereby one can study the essential nature of consciousness and experience (Welch, 1939). This eidetic science was achieved through performing what Husserl called an “eidetic reduction” (Crowell, 2013). This eidetic reduction consisted of probing and/or modifying the essence of an experience until the limits of its variability can be determined. This reduction had an almost imaginary component to it, whereby the researcher would modify the object, or experience in their consciousness to determine whether or not an aspect of a phenomenon was vital to its definition. An example of this eidetic reduction can be explored through the consciousness of an apple. One can change the characteristics of an apple to a multitude of colours, shapes, textures and tastes, however one cannot change that it is a fruit with a core that grows on trees. This eidetic reduction isolates the core essence of a phenomenon, removing any potential variability in the experience, leaving one with only the key elements. In performing this reduction in phenomenology, Husserl believes that one can determine all of the necessary and sufficient conditions for a phenomenon to exist (Crowell, 2013). In addition to determining the outermost limits of a phenomenon, an eidetic reduction makes it possible to understand all of the intricacies and variations that can exist in a phenomenon’s numerous forms.

In developing phenomenology, Husserl utilized the concepts present in the field of intentionality through the works of Brentano. Intentionality is the concept whereby the key characteristics of a phenomenon are assigned to a particular object (Ströker, 1993). An example of intentionality can be identified through the perception of this printed page, whereby Husserl would not only differentiate the act of seeing and the object being seen, but would also discuss the ways in which consciousness synthesizes the various elements of the page to form a complete experience (Spiegelberg, 1975). Through the understanding of intentionality, Husserl defined terms of Noesis and Noema, which formed part of the foundation of phenomenology (Gallagher, 2012). The term Noesis refers to the act of experiencing an object or phenomenon, whereby one attributes characteristics to the object or phenomenon in question (Bernet, Kern, & Marbach, 1993). Conversely, the term Noema denotes the intentional object, or in more simple terms, the object or phenomenon that is being experienced in the intentional act of the Noesis (Bernet et al., 1993). To place these terms in reference to each other, one is experiencing a Noema through the act of Noesis. These terms are important to identify in the foundation of phenomenology as they help to clarify the processes of how one perceives objects and phenomena in their daily lives.

In discussing the evolution of phenomenology, it is not only important to address the underlying philosophy at its core, but also of importance to discuss how Husserl's phenomenology can be utilized as a methodology. The overarching purpose behind Husserl's phenomenology was to acquire the detailed descriptions of an experience or phenomenon in question, and from these descriptions develop an essence of the experience or phenomenon. Husserl's phenomenology was attempting to find the objectivity inherent in an experience, allowing the researcher to gain understanding of what is at the core nature of experiencing a phenomenon.

In searching for the essence of an experience a researcher must be careful so as not to confuse the experience with any judgment or preconceived notions that they may have. This concept, called the phenomenological stance or bracketing, requires the researcher to put the phenomenon in question in a set of epochè, which means that they must set aside any existing knowledge and judgment about the object or experience and focus specifically on the core description of the phenomenon (Sadala & Adorno, 2002). The idea of bracketing is one of the key features of Husserl's Transcendental Phenomenology and it is his belief that only through proper bracketing is it possible to achieve the true essence of an experience. If a researcher is unable to achieve bracketing, the description of the phenomenon becomes clouded and that which is unessential may inadvertently become a part of the core essence of the phenomenon (Sadala & Adorno, 2002). It is here that the naming of Husserl's Transcendental Phenomenology becomes clear, as one must transcend beyond the preconceptions about a phenomenon in order to understand what is truly at its core.

Husserl's Transcendental Phenomenology certainly has some interesting uses in the discussion of chronic pain as a topic. The goal to attempt to find the essence of the experience of the phenomenon of chronic pain is certainly an interesting one, but it begs the question as to whether or not it is actually attainable. Is it possible to find the true essence of chronic pain among many individuals who experience it, or are we boiling down this experience too far and beginning to lose some of the nuances that exist within it? Certainly, transcending beyond any preconceived notions to focus in on the true core of the experience is admirable, but for chronic pain this may not be achievable, particularly for chronic pain in the workplace. The experiences of chronic pain are incredibly complex and nuanced that the individual experiences and context has significant value in understanding issues of chronic pain. By honing these experiences down to the core essence, as required by Husserl, we may be in fact losing a great deal of valuable information that could be useful in understanding the complexities of chronic pain.

### 3.2.2 Martin Heidegger

The concept of bracketing and the phenomenological stance is one that differs Husserl from his immediate disciples in phenomenology. When Martin Heidegger started to explore phenomenology after Husserl's works were published, he decided to modify some of its fundamental principles and change the overarching focus. Heidegger was never a formal student of Husserl, however he studied his teachings on phenomenological reduction while they were both teaching in Freiberg, Germany (Lavery, 2003). Using Husserl's Transcendental Phenomenology as a foundation, Heidegger developed Hermeneutic Phenomenology, which similarly focused on the human experience as it is lived. Heidegger wanted to develop an understanding of the details of everyday experience. He separated himself from Husserl, however, in the method of how the lived experience is explored. Husserl was focused on understanding the phenomena themselves, separated from the constructs in which they were situated. Heidegger felt that this was lacking vital information, that the circumstances of the phenomena are necessary to understanding the intricacies of the lived experience. This led to Heidegger developing a more interpretive form of phenomenology, where the context of the phenomenon was determined to be an important element to discuss.

Unlike Husserl, who believed that understanding a phenomenon requires one to bracket out all prior context and history that one has, Heidegger asserts that one is not able to completely isolate the context of a phenomenon prior to discussing their experience with it. The comprehension of an experience cannot be separated from the background and context that exists around it. In performing this type of phenomenology, Heidegger posits that one must actively engage in disclosure, in that one must uncover all of the facets of an experience to truly understand it (Annells, 1996). This can be applied to Heidegger's viewpoint that phenomenology should not employ bracketing, as the context of a phenomenon is of crucial importance to its disclosure and without disclosure phenomenology is impossible.

In developing Hermeneutic Phenomenology, Heidegger established the concept of 'Dasein' which means "'the mode of being human' or 'the situated meaning of a human in the world'" (Lavery, 2003). The notion of Dasein is first discussed in detail in Heidegger's seminal work titled *Being and Time* (Heidegger, 1962). In order for one to be involved in phenomenology, one must first develop an understanding of their own existence or being, as well as an understanding of the existence or being of others (Haugeland, 2013). Here, Heidegger is asserting that the ability to understand one's own existence and the existence of others is an imperative first step in achieving an understanding of

an experience. Dasein has a secondary meaning as well, that in order for one to be, one must be open to understanding and engaging with other beings (Heidegger, 1962). This additional meaning takes the concept of Dasein further than its initial assertion in that not only must individuals observe and understand themselves and those around them, but also, they must actively seek out this understanding and strive to uncover and disclose that which is unknown. The notion of Dasein is at the core of Heidegger's approach to phenomenology, whereby one is constantly investigating and analyzing everyday experiences and phenomena to achieve a greater understanding of the world around them. In this approach to phenomenology, Heidegger is essentially an ontologist, where his development of the term Dasein is working to understand both what existence is and what is the nature of existence (Dicenso, 1990).

In order for one to understand Heidegger's approach to phenomenology, it is imperative to discuss what Hermeneutic Phenomenology means. At the core of hermeneutics, is the concept of language and its necessity in phenomenology. The importance of language in Heidegger's phenomenology is discussed in his concept of logos. The most literal meaning of the term logos, refers to the importance of words. However, Heidegger extends that meaning to incorporate the use of words and talk to clearly identify and discuss an experience (Haugeland, 2013). Heidegger's phenomenology allows the phenomenon to show itself, or to be pointed out. Words are a key aspect to allowing a phenomenon to be described in enough detail. A detailed description of a phenomenon through words leads to the secondary part of the concept of logos and that is talk, or interpretation.

Heidegger's Hermeneutic Phenomenology relies heavily on interpretation as an integral part of understanding. The concept of hermeneutics, involves an interpretive process designed to achieve the full understanding of a phenomenon through the use of language and discussion (Lavery, 2003). The interpretive process of hermeneutics uses a hermeneutic circle at its core, wherein the researcher moves from specific parts of an experience, to the experience as a whole and repeats the process in a cyclical manner (Earle, 2010). The hermeneutic circle allows the researcher to focus on specific elements of the experience while regularly being reminded of the importance of context in the interpretation of the experience. This approach helps to develop a complete understanding of the experience in question, as the researcher is able to shift back and forth between the phenomenon and the context (Earle, 2010). The cyclical nature of the hermeneutic process forces the researcher to interpret the experience at great depth, which in turn allows for a more complete description of the phenomenon. The concept of hermeneutics presented by Heidegger seems to divide the world of

phenomenology in two, separating future disciples in the field into following a more descriptive phenomenology, as seen in Husserl's Transcendental Phenomenology, or a more interpretive phenomenology, as seen in Heidegger's Hermeneutic Phenomenology.

Aside from the belief in bracketing, the main point where Hermeneutic Phenomenology significantly diverts away from Transcendental Phenomenology is in the end point of the phenomenological process. Husserl, in his development of Transcendental Phenomenology, believed that an understanding of a phenomenon occurs when its pure essence is discovered and described. In contrast to this, Heidegger believes that this level of phenomenology is not achieving a complete understanding of the experience and in order to achieve a full understanding one must also interpret the experience as well (Dowling, 2007). The nature of this interpretation is inherently grounded in the subjective experiences and context of the interpreter, which makes this form of phenomenology significantly less generalizable. This demonstrates a shift in overarching goals between Husserl and Heidegger, as one might argue that Husserl's Transcendental Phenomenology provides a more generalizable result at its conclusion. In utilizing Husserl's approach to phenomenology, one is rigorously determining the essence of the experience and is effectively forming an objective fact out of a subjective description. Conversely, Heidegger does not aim for objectivity or generalizability, rather, his principal goal is a greater understanding of a phenomenon. Heidegger believes that the context and subjective descriptions and interpretations of an experience can lead to that level of understanding. While the foundation of Husserl and Heidegger's phenomenology is similar in that they are seeking the exploration of experiences and phenomenon, their approaches and goals could not be more different from one another. This is not to say that one approach is categorically better than the other, but rather it is to say that they serve different purposes.

In the realm of using these approaches to study and explore chronic pain, Heidegger's Hermeneutic Phenomenology is certainly of greater benefit to exploring these experiences. By shifting the focus to allow for consideration of context, Heidegger is allowing for an understanding of the complete picture of the experiences of chronic pain, specifically chronic pain in the workplace. For researchers, this additional process of contextualizing the experience can be incredibly valuable and allows for the concept of subjectivity to exist within the discussion of the experience. The fact that this philosophical approach veers away from the others in its acceptance of subjective experiences and allows for a level of interpretation makes it somewhat superior to the other approaches being mentioned. That said, where this approach is lacking is in its inaccessibility, due to its heavy



philosophical leanings, and its lack of a clearly defined methodological approach. Given that Heidegger's Hermeneutic Phenomenology was not designed to be a methodological approach, but rather a philosophy, it cannot be directly faulted for this gap. That said, its approach certainly does serve as a starting point for some of the more contemporary methodological approaches that have been mentioned and discussed later in the chapter.

### **3.2.3 Maurice Merleau-Ponty**

The final philosophy relevant to this dissertation research is that of Maurice Merleau-Ponty. Merleau-Ponty, unlike the other philosophers discussed in this dissertation, did not follow directly in the line of German phenomenologists. Where Heidegger was a successor of Husserl, Merleau-Ponty developed his form of phenomenology more recently in France. This is not to say that Merleau-Ponty did not use any of the works of his German predecessors in developing his phenomenology, but rather he was not a direct disciple or student. Merleau-Ponty's version of phenomenology is often associated more as being an evolution of Husserl's Transcendental Phenomenology. However, there are some aspects of Merleau-Ponty's approach that align with Heidegger's philosophies. Merleau-Ponty's phenomenology is seen as simultaneously being a philosophy of essences, while at the same time being a philosophy of existence, following Husserl and Heidegger's overarching philosophies respectively (Macann, 1993). Merleau-Ponty believes in a phenomenology, which starts with reduction, while at the same time believes in a world that already exists, another point where Husserl and Heidegger fundamentally disagree (Macann, 1993). While these contradictories may make Merleau-Ponty's phenomenology seem muddled and confused, it is his assertion that Husserl was actually heading in this direction in the later works of his career. Therefore, Merleau-Ponty's conception of phenomenology is more of a true derivation of Husserl's Transcendental Phenomenology, the concepts of which appear throughout the description of his approach.

Merleau-Ponty's approach to phenomenology is situated in the belief that a true form of phenomenology cannot be situated in empiricism or intellectualism (Macann, 1993). That is to say, that the scientific and intellectual breaking down and interpretation of an experience or phenomenon is actually distorting the true essence of the experience in question. Merleau-Ponty asserts that to perform phenomenology objectively, the researcher must approach it from a pre-objective realm, whereby the individual attempts to understand an experience or phenomenon before it has been influenced by science, knowledge, and experience (Macann, 1993). This pre-objective state is almost viewing the world from the perspective of a child, in that the individual is seeing the phenomenon for

the first time and is able to describe it without any value-laden knowledge interfering with its core description. In this pre-objective realm, Merleau-Ponty is essentially creating a new form of bracketing, as the individual is attempting to simplify their perspective on the phenomenon.

In Merleau-Ponty's development of an existential phenomenology, he discusses four key existentials, which are considered to form the foundation of the lifeworld. These existentials include: lived space (spaciality), lived body (corporeality), lived time (temporality) and lived other (relationality) (Dowling, 2007).

The lived space existential explores a phenomenon through the way we experience a given space or location. Examples of this might be a feeling of freedom that one might have in a large open field, or a sense of being trapped when being in a large crowd of people. This existential is seen to be quite challenging at times, as these experiences are not often reflected upon and are generally only felt for brief moments (Van Manen, 1997b).

The lived body existential states that an individual's physical body is always present in the world. When one meets an individual, the first thing that is experienced is the introduction of a person in one's physical space. In experiencing one's lived body, there are certain attributes that may be noticed. These attributes can include a discussion of movement, whereby one might be more graceful or more awkward in their movements (Van Manen, 1997b). Another example might be the size of an individual, as someone larger might seem more physically imposing or potentially threatening.

The lived time existential discusses the experience of subjective time and how one experiences time. A simple example of this is when one is having a good time, it seems as though time passes quickly. Conversely, when one is performing an undesirable task, time seems to extend forever (Van Manen, 1997b). The existential of temporality also refers to the much longer-term nature of the passing of time, such that when one is younger they are always looking forward to the future, eager to get there, or when one is older, they reflect on past experiences (Van Manen, 1997b).

Finally, the lived other refers to the relationships that one has with others and how they manifest themselves in everyday life. An example that can be considered when discussing this lifeworld, is the proximity and demeanor one has, dependent on whom they are talking to and what their relationship may be. One who has a relationship with another person will appear to be physically closer to a friend, as compared to a complete stranger. This can be seen even more in individuals who are in an intimate relationship as compared to a simple friendship. The lived other can also be seen in

differences in body language dependent on relationship as well. One who is just meeting someone may appear more guarded, as compared to someone with whom one is familiar (Van Manen, 1997b).

These four lifeworlds provide a foundation and a simply defined way of viewing and understanding the world and the phenomena that exist within it. This existential perspective allows for a structured way of how one can go about analyzing a particular phenomenon. It is in this structure and in the approach to pre-objectivity, that Merleau-Ponty differentiates his work within the field. This structured approach to descriptive phenomenology is able to minimize some of the barriers to entry that exist in Husserl's heavily philosophical, Transcendental Phenomenology. This simplification of Husserl's work allows a researcher to enter into the world of descriptive phenomenology with greater ease.

Merleau-Ponty's form of phenomenology creates a fascinating approach and structure to understanding an experience such as chronic pain or chronic pain in the workplace, by implementing the "lifeworld" concept as a structure to describing an experience. Unlike Husserl's Transcendental Phenomenology, Merleau-Ponty is taking the experience a step further by outlining a number of the different elements that make up a particular experience. These four "lifeworlds" can be applicable to the experience of chronic pain. The lived body, the most obvious of the connections, can discuss how one experiences the physical space in the body. The lived space is particularly applicable to those with mobility issues in how they navigate the space around them and the challenges that might exist in doing so. The lived time, might discuss how one perceives the passing of time when one is undergoing a pain flare up, as opposed to when one is not experiencing pain. A personal example I can give for the lived time, is the experience of time passing incredibly slowly when one is having a sleepless night as a result of persistent pain. In this circumstance, it feels like every minute is an eternity and you simply want time to pass faster. The lived other "lifeworld" allows for the inclusion of a discussion of the relationships that an individual with chronic pain has with those around them and starts to explore some of these experiences outside of the individual. While these four "lifeworlds" do provide a useful structure for the development of a methodological approach to exploring an issue like chronic pain, the overall philosophy also carries with it the fundamental limitations of Husserl's Transcendental Phenomenology, as well as Heidegger's Hermeneutic Phenomenology. The limitation from Husserl's Transcendental Phenomenology is that the experiences are meant to be as objective as possible, and are to remain primarily in the descriptive realm. This philosophy also aligns with the fundamental critique with Heidegger's Hermeneutic

Phenomenology in that there is a heavy philosophical requirement to utilize this approach as a methodology. What Merleau-Ponty is able to offer to someone considering these classical approaches is a level of structure. This “lifeworlds” structure could be comforting for a researcher and may allow for a detailed description of a phenomenon through a number of different lenses.

### **3.3 Interpretative Phenomenological Analysis – Phenomenology in Practice**

These origins behind phenomenology provide a solid foundation for discussions on more modern approaches to using phenomenology as a research methodology, specifically Interpretative Phenomenological Analysis. Interpretative Phenomenological Analysis (IPA) was developed in the United Kingdom by Jonathan Smith as a methodological approach to answer research questions about psychology using phenomenology. Smith, however, did not want to simply describe the phenomena or experiences that his participants were undergoing, but rather he believed it was important to interpret the descriptions based on a variety of factors. Smith wanted to develop a double hermeneutic, based on Heidegger’s phenomenology, whereby the participant is trying to make sense of their world, while the researcher is trying to make sense of the participant trying to make sense of their world (Smith, 2004a). This leads to the two primary aims of Interpretative Phenomenological Analysis. The first aim is to understand the ‘world’ of the participant and describe the nature of a particular phenomenon, experience, or process (Larkin, Wells, & Clifton, 2006). The second aim of IPA is to develop an interpretative analysis, allowing the researcher to explore the data and analyze its meaning, considering why the participants responded the way they did (Larkin et al., 2006). In developing IPA, Smith set out to develop an approach, which clearly delineates the various steps necessary to perform an Interpretative Phenomenological Analysis successfully. While Smith did not set out to design a “cookbook approach” to phenomenology, a researcher may use his basic design to develop a clear methodology for their research (Smith, 2004a).

Interpretative Phenomenological Analysis (IPA) was used to address two out of the three research questions in this dissertation research. The primary research question, exploring the lived experiences of those with chronic pain and are teleworking or self-employed, used IPA as its methodological approach. IPA was utilized as the methodology of choice for this research question, as it not only describes the lived experience of the phenomenon in question, in this case those with chronic pain who are teleworking or self-employed, but also allows for the analysis and interpretation of these lived experiences. This methodology choice allows for both of the objectives of the primary research

question to be addressed, extending beyond the basic description of the lived experience, to add an extra layer of analysis and interpretation.

In addition to the primary research question, IPA has also been used as a key component of the first sub research question mentioned, which explores the benefits and challenges to using contemporary approaches to phenomenology for new researchers. In this research question, contemporary approaches to phenomenology including Smith's IPA and Maxwell Van Manen's approaches to phenomenology have been described, critiqued, and reflected upon for their usefulness for new researchers, particularly examining their effectiveness in exploring issues such as chronic pain in the workplace. This research question provides the background and knowledge behind IPA as a methodology to provide the background for its utilization in the third manuscript. In terms of the actual implementation of this methodology, a number of areas need to be discussed, including: data collection strategies, sample, sample size, recruitment strategies and data analysis approaches.

### **3.4 Data Collection**

The data collected for this dissertation research program entirely consisted of semi-structured interviews. Semi-structured interviews allow the researcher to adapt and modify the initial questions based on the responses of the participant and probe areas that arise over the course of the interview (Smith & Osborn, 2008). An interview guide was developed in advance in order to consider areas of the topic that should likely be explored, although this guide was not so rigid so as to not allow for digressions and tangents from the participant. This interview guide can be found in Appendix A. The topic of self-employment is often a fairly individualized experience with specific nuances occurring in each particular situation. While there may be commonalities that exist between the experiences of the participants, focus groups, or other forms of data collection would not be appropriate to achieve the level of depth and discussion that is necessary for this sort of analysis. This study underwent a research ethics review by the University of Waterloo (#21950) and received approval in December of 2016.

#### **3.4.1 Sample and Sample Size**

The other aspect of data collection that is important is sample and sample size. Given the depth of description and analysis that should take place with each participant, sample sizes for Interpretative Phenomenological Analysis tend to be kept relatively small (Larkin, Watts, & Clifton, 2006; Smith & Osborn, 2008). For this particular research the ideal sample size was to be somewhere between 5-15

participants, and ended up being a total of four participants. This sample size enables a level of feasibility, in order to achieve the depth required in completing the work, and also to complete the research itself in a reasonable time frame. The inclusion and exclusion criteria for this study was left fairly open ended to allow for the largest number of potential participants. The primary selection criteria were that participants were over 18 years of age, experienced some form of diagnosed chronic pain condition, and were either self-employed or teleworked. As will be discussed later, the sample size for this study fell beneath the 5-15 participant ideal and consisted of younger, white, unmarried/childless and middle-class participants. This was not sought out intentionally in the sampling, but may be indicative of the nature of this population.

### **3.4.2 Participant Recruitment**

Participants for the study have been recruited primarily through my involvement at the Waterloo Region Chronic Pain Initiative (WRCPI). This newly formed initiative acts as a central organization in the Waterloo-Wellington region to support those with chronic pain conditions. In the year before the study, the WRCPI had developed a recurring workshop series on a number of topics related to chronic pain, and had been working on a number of other projects designed to help and support those in the community with a chronic pain condition. As the WRCPI has established itself, they had accumulated a list of e-mails of participants who attended their events and wished to be notified of other chronic pain related work happening in the Waterloo-Wellington region. The WRCPI was involved in sending recruitment materials via e-mail to their participants, which formed a total potential subpopulation of approximately 200 people, as well as we had members of their committee mentioning this research to potential participants they may know in the community. By using these pre-existing contacts, it was possible to find participants to discuss their conditions for an hour to ninety minutes.

### **3.5 Data Analysis**

The analysis process begins with a thorough reading and re-reading of each transcript, writing comments on areas of note in one margin on the first read through, and documenting potential theme titles in the other margin on subsequent readings (Smith & Osborn, 2008). These themes should be close enough to the participant's words and experiences, but should also be flexible enough to allow for academic, specifically theoretical, discussions (Smith & Osborn, 2008). Once the themes are derived from all of the transcripts, they are listed on a single page in the order they appeared on the

transcript, from this list it is possible to cluster themes together into relationships and some sort of structure. As this clustering occurs, the researcher must go back to the original transcripts to make certain that the clustered themes still work and relate to the words of the participant. This process is then repeated for each transcript and once the themes are identified for each, similarities and differences can be acknowledged. These themes would be written up in a results section of the paper, identifying each one and supporting it with relevant quotes from the participant's own words. Following this, the discussion section would examine the implications of these themes, unpack the similarities and differences between them, and connect the findings back to the academic literature on the topic. Using this structure, it should be possible to develop a greater understanding of the area of self-employment and/or teleworking with a chronic pain condition.

### **3.6 Qualitative Methodological Trustworthiness**

After discussing how the IPA approach was implemented in this research, the final discussion on this methodological application was to discuss the qualitative methodological trustworthiness of this approach as defined by Guba and Lincoln (1985). Methodological trustworthiness consists of four primary questions including issues of: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985) Credibility can be defined as internal validity and is asking the question of whether or not the data sources find the analysis and interpretation to be credible, as compared to that which they shared. IPA does allow for a credibility check by allowing the researcher to return to the participant and make certain that their description of the phenomenon is accurate, however this can be taken a step further wherein the interpretation and analysis findings can also be shared with the participants to add extra insurance that everything aligns properly and is credible. Transferability inquires that the data collected from the sample is somehow representative of the general population which it is discussing. While pure transferability is impossible given the nature of the population and approach that is being taken, there are certainly some aspects of the experience that can be generalized beyond this sample of the population. It is in the interpretation and analysis portion of the IPA, where some of the transferability and generalizability has been found. Dependability, or reliability discusses the concept of whether or not a study is repeatable under the same circumstances. Given the nature of personal experiences with a given phenomenon, the exact same results are unlikely to be found in future implementations of this research question and methodological approach. That being said, it is likely that some commonalities exist in themes and experiences in addition to the unique experiences that occur in the replication of the study. Finally, confirmability,

which asks the extent to which the results can be confirmed by others, and are not simply based on the researcher's bias and experiences. This aspect of methodological trustworthiness is particularly challenging, as I do have a foundation of experiences that align with the target population and it is very easy for my bias to potentially creep into the research as a whole. To combat and offset these challenges, I was highly reflexive before and throughout my analysis of the data, and also attempted to confirm my interpretation with the participants to help ensure that it is reflective of what they were saying, rather than being reflective of my own experiences and potential biases.

### **3.7 Autoethnography**

As mentioned at the beginning of the chapter, autoethnography is the second of the two methodologies selected to address the research questions and objectives identified in the first chapter of this proposal. Autoethnography was used to explore the second sub research question which explores my experiences with chronic pain, and how they have influenced my perception and viewpoints on chronic pain as a whole. Before addressing how autoethnography was used employed in this research question, it would be prudent to first discuss what autoethnography entails as a methodology itself.

Autoethnography is that which connects the “autobiographical and personal to the cultural and social” (Denzin & Lincoln, 2000; Ellis, 2004). In doing an autoethnography, one is analyzing a personal experience in order to better understand a cultural experience. Essentially, what this approach is doing is causing the writer to openly share their world and story and allow it to inform and shape how the world is viewed as a whole, or a particular aspect of it. This field was developed by Ellis, Bochner and others whose approach veered away from the attempted value-free work (Ellis, Adams, & Bochner, 2011a). While this is certainly something that can be seen as a deviation from the traditional ideas of what research is and how it is conducted, it is something that can provide a great deal of value, as it provides a very different look at a given phenomenon (Ellis, Adams, & Bochner, 2011b).

In doing an autoethnography, the author is retroactively and reflexively looking back on past experiences and assembling them in order to reflect on more societal issues as a whole, in this case the societal issue is the experience of living with a chronic pain condition. In this case, the author is acting more as a storyteller, with their end products being stories (Bochner, 2012). These often appear as epiphanies or key facets of a story, rather than the more mundane aspects of a person's life. These



more individual experiences can then be unpacked and analyzed to understand the larger, or more societal issue. The writer using the autoethnographic approach can use a variety of storytelling conventions, either taking a more plot-based approach, or going more chronologically, or fragmented in the progression of the story or the experience (Ellis et al., 2011a).

There are a wide variety of approaches to autoethnography in the existing literature on a number of different topic areas (Ellis et al., 2011a). These varieties include: indigenous ethnographies, narrative ethnographies, reflexive interviews, reflexive ethnographies, layered accounts, interactive interviews, community autoethnographies, co-constructed narratives and personal narratives (Ellis et al., 2011a). In this thesis, the autoethnography was written as a personal narrative, wherein my own experiences and stories were shared to reflect on the nature of living with a chronic pain condition. The autoethnography being presented followed somewhat of a chronological pattern in its design, wherein it started with the stories that go along with the initial diagnosis and continued to progress in a logical time pattern. The primary structure of the autoethnography, however, was thematic in nature, wherein the experiences were grouped and clustered based on various aspects of my life and chronic pain condition, including: treatment, relationships and work experiences.

After understanding the underlying concepts behind autoethnography, it would be prudent to also unpack why it is that I did this autoethnography. The reasons behind this autoethnography are multifaceted. On the simplest level, I believe that autoethnographies on the topic of chronic pain can be very important to share with both the academic community and those who extend beyond it. This discussion of my experiences with chronic pain can help to identify and explore facets of the condition that other approaches may not be able to get at. As a researcher writing an autoethnography, I am sharing my lived experience for the reader to have a deeper understanding of some of the intricacies of living with a chronic pain condition. Another benefit to this autoethnography is that I was able to share an authentic and genuine account of my experiences as a young adult with a chronic pain condition, as the nature of these experiences is unique in that my chronic pain condition has had clearly defined impacts on various relationships in my life, as well as implications on my work and experiences in the workplace.

This issue of authenticity can often be challenging for researchers to achieve when interpreting and assigning a voice to their participants. As much as we, as researchers, strive to be as authentic to our participants as we can, there is still a barrier, whether we attempt to avoid it, or not (Richards, 2008). This is particularly true when discussing concepts of illness and disability, wherein we are having

conversations about those who may be marginalized by society. In being an insider, and sharing my own story, I was hopefully able to provide an accurate representation of the nature of living with a chronic pain condition as a young adult, or at least touch upon some aspects of it. This is not to say that the interpretation of an outsider would be definitively inauthentic, rather that there is an added level of authenticity given my insider knowledge and experience. The in-depth understanding that one has going through a particular experience adds a level of depth that wouldn't otherwise be present. Finally, the autoethnography serves the benefit of putting my experiences and viewpoints on chronic pain out in the open, for everyone to read and understand, such that my future work in the field can be looked at within the context of my experiences and backgrounds. Oftentimes, in phenomenology, the researcher works to bracket their prior experiences in order to stay close to the essence of the experience, in other times, the researcher embraces their background to interpret these experiences. In either circumstance, I will be able to use this written description of my experiences with chronic pain in any future work I do with phenomenology in the field of chronic pain.

Following the discussion of how these methodologies were used in the research questions and objectives, the next section reviews how these research questions formed three primary manuscripts and how they add to academic literature on issues of lived experiences of chronic pain in the workplace, particularly among those who are teleworking or self-employed.

### **3.8 Contributions to the Literature**

Based on the three primary research questions identified in this thesis proposal, the aim was to develop three manuscripts for publication. While each of these manuscripts work separately in their own right, the combination of the three works flows together to form a singular discussion from multiple facets and perspectives, all of which have built towards addressing the primary research question discussing the lived experience of those who are teleworking and self-employed with a chronic pain condition.

#### **3.8.1 Manuscript 1 – Contemporary Approaches to Phenomenology**

As identified earlier in this chapter, classical approaches to phenomenology are likely not the best suited methodologies to be chosen to explore issues of chronic pain and chronic pain in the workplace. While their approaches have been critiqued, it would be prudent to discuss more modern approaches that have been developed from these classic philosophies and how they may in fact be quite appropriate to explore the lived experiences of those with chronic pain. In this manuscript, two

of these approaches were identified, explored and critiqued, in order to demonstrate their effectiveness and use for new researchers in the field.

The first research objective under this sub research question is to describe and critique Maxwell van Manen and Jonathan Smith's approaches to phenomenology and explore how they can be used effectively by new researchers in the field. It is in this section of the manuscript where the key facets of each of these approaches were identified and explained. Following this description, a comparison and critique of these approaches highlighted the ways that these methodologies were used to study issues such as chronic pain, or chronic pain in the workplace.

### **3.8.2 Manuscript 2 – Autoethnography of a Young Adult with Chronic Pain**

The second of the three manuscripts addressed the second sub research question identified in chapter one of this thesis proposal. This question asks: What are my experiences with chronic pain, and how have they influenced my perception and viewpoints on chronic pain as a whole? As discussed in the previous chapter, these personal experiences have been explored using an auto-ethnographic methodological approach. This approach allowed for a detailed exploration of both of the research objectives that pertain to this research question. The first research objective explored my personal narrative about my ongoing experiences with chronic pain and provides the reader with my own perspective on living with chronic pain as a young adult.

The second objective of this sub research question was to critically reflect on my own experiences with chronic pain and to identify and discuss how these experiences are situated within our current understandings of chronic pain. It is here where I related my own experiences to the existing literature on chronic pain, identifying the areas in which my story aligns and differs with common perceptions of chronic pain.

### **3.8.3 Manuscript 3 – Interpretative Phenomenological Analysis of Chronic Pain and Self-Employment and Telework**

The final manuscript addressed the primary research question, which asks what are the lived experiences of those who have chronic pain and are teleworking or self-employed and what can we learn from these experiences using an Interpretative Phenomenological Analysis (IPA) approach? Using the IPA approach, the two primary objectives of this research question have been presented in

this manuscript. After setting up the research in the manuscript, there was first a description of the lived experiences of the participants living with chronic pain, which identified the commonalities that exist in those who are teleworking, or self-employed with a chronic pain condition. Following this description, the second objective of this research question has been addressed, whereby these lived experiences has been interpreted and analyzed in depth. This analysis phase combined with the description of the lived experiences should allow for a far greater understanding of the overall nature of being self-employed or teleworking with a chronic pain condition.

## **Chapter 4**

### **Contemporary Approaches to Phenomenology**

#### **4.1 Abstract**

Contemporary approaches to phenomenology can help to offset the daunting and challenging task of using phenomenology as a research methodology as a novice researcher, or one unfamiliar with these approaches. Jonathan Smith's Interpretative Phenomenological Analysis and Maxwell van Manen's contemporary approaches to phenomenology provide simple and manageable approaches to understand and apply to research. For novice researchers, modern approaches are beneficial as they reduce or eliminate many of the barriers to entry that exist in more classical approaches to phenomenology. This paper details each of these approaches and provides critique on the strengths and limitations of each, focusing on their application to new researchers. Following this review, the application of these approaches has been explored through the lens of workplace health issues. Through the discussion, critique, and application of Smith's Interpretative Phenomenological Analysis and van Manen's approach to phenomenology, may be considered by novice researchers, or researchers who are new to phenomenology.

Keywords: Phenomenology, Interpretative Phenomenological Analysis, Workplace Health, Contemporary Methodology, Smith, van Manen

#### **4.2 Introduction**

The contemporary approaches to using phenomenology as a research methodology, while still rooted in classic philosophies, have begun to ease the burden on new researchers to implement these methods. These methodological approaches have been in development for the past twenty to thirty years and are, for the most part, fairly easy to implement for a variety of research questions. While there are a number of methodological approaches, this paper highlights two approaches ideally suited for researchers who are new to phenomenology: Interpretative Phenomenological Analysis by Jonathan Smith and Maxwell van Manen's approach to phenomenology. The following paper outlines these approaches and critiques them identifying their strengths and deficits, with a particular focus on their application to new researchers. From these general critiques, the author draws specific lessons that applies to research in the health and workplace fields.

Interpretative Phenomenological Analysis (IPA) as developed by Jonathan Smith in the mid-1990s, provides a helpful set of guidelines to implement phenomenology. Originally conducted in psychological research settings and further expanded to other domains, while focusing on an interpretive element in addition to the more standard, descriptive approach to phenomenology (Smith, 1996a). Maxwell van Manen also developed a set of guidelines and instructions in the development of his form of phenomenology as a research method (Van Manen, 1997b). Both approaches provide a useful introduction into the realm of phenomenology and in particular provide helpful instructions to novice researchers, or to experienced researchers new to phenomenological approaches, to apply key overarching concepts to their methodological framework.

The choice of using the approaches of Smith and van Manen was an intentional decision based on a number of considerations. Both Smith and van Manen are prolific in their work and explain in great detail discussing their approaches to phenomenology, which in and of itself makes their approaches to phenomenology more accessible for novice researchers. This foundational methodological discussion enables researchers to not only review the original methodological approaches, but also exposes the original author's critique to applications of these approaches. The increased popularity along with frequent publications by both Smith and van Manen allow for a novice researcher to better develop an understanding of these approaches within a contemporary viewpoint. Another rationale to focus on Smith and van Manen was that they deviated from each other in their approaches through their inclusion of an interpretative element, or specific focus on a descriptive approach to phenomenology. This deviation is the continuation of a debate that started in the classic philosophies of Husserl, Heidegger and Merleau-Ponty on phenomenology and both interpretative and descriptive forms of phenomenology are present in contemporary approaches. Based on this debate, options for either should be discussed when reviewing possible methodological approaches. Additionally, these particular approaches to phenomenology were chosen due to the ongoing back and forth debate between the authors as to whether the other approach could be considered phenomenology (Zahavi, 2019). In his critique, Zahavi (2019) argues both approaches, leading up to the conclusion that neither approach, is appropriate to utilize as a form of phenomenological research. Zahavi's criticisms for both Smith's IPA, in its use of an interpretative element, and van Manen's phenomenology in its approach to describing what a phenomenon is like, seemingly deviates too far from the classical philosophical origins of phenomenology. While the debate between interpretative and descriptive forms of phenomenology will be addressed in the critical examination of the approaches, unlike Zahavi's conclusion, making the assertion that one should not utilize

phenomenology in these methodological forms is overly restrictive. While these methodologies may have deviated and built upon the original philosophical underpinnings, they still hold many of the values that phenomenology originated from and in doing so still create valuable phenomenological work (Williams, 2021). While Zahavi might argue otherwise, particularly in naming either of these approaches phenomenology, in my view qualitative health researchers could easily turn to either of Smith or van Manen's approaches to engage with phenomenology and in doing so, critically select the methodological approach that best serves the purposes of the research project.

### **4.3 Jonathan Smith – Interpretative Phenomenological Analysis**

Interpretative Phenomenological Analysis (IPA) was developed in the United Kingdom by Jonathan Smith as a methodological approach to answer research questions about psychology using phenomenology (Smith, 1996b). Smith, however, did not want to simply describe the phenomena or experiences that his participants were undergoing, but rather he believed it was important to interpret the descriptions based on a variety of factors. Smith wanted to develop a double hermeneutic within his approach, whereby the participant is trying to make sense of their world, while the researcher is trying to make sense of the participant trying to make sense of their world (Pietkiewicz & Smith, 2014; Smith, 2004b, 2009). This leads to the two primary aims of Interpretative Phenomenological Analysis. The first aim is to understand the 'world' of the participant and describe the nature of a particular phenomenon, experience, or process (Larkin et al., 2006; Smith, 1996a). The second aim of IPA is to develop an interpretative analysis, allowing the researcher to explore the data and analyze its meaning, while considering why the participants responded the way they did (Larkin et al., 2006; Smith, 1996a). In developing IPA, Smith created an approach which clearly delineates the various steps necessary to successfully complete an Interpretative Phenomenological Analysis. While Smith did not set out to design a "cookbook approach" to phenomenology, a new researcher could use his basic design and suggestions to develop a clear methodology for their research (Smith, 2004b).

In conducting an IPA, a researcher must first identify both their sample and data collection method. Sample sizes in IPA tend to be very small, generally in the range of five to ten participants (Pietkiewicz & Smith, 2014; Smith, 2004b). These samples are purposeful in nature, as the data being analyzed tends to be particularly detailed, as opposed to approaching it from a more surface level. IPA requires that the researcher delve deeper into the phenomenon to understand its meaning (Larkin et al., 2006). The sample chosen for IPA is not randomized like other approaches in health research but rather IPA requires the researcher to select a purposive homogenous sample of

participants to understand the nature of the experience from multiple, similar viewpoints (Pietkiewicz & Smith, 2014). This means that the results of IPA will not necessarily be generalizable, but that is acceptable within the goals of this research approach. Much research in applied health sciences relies more significantly on generalizable data that can be applied to the population as a whole. However, the nuances of an individual or small group's experience with a condition like chronic pain can be valuable to help increase understanding of that condition. By going into a level of depth, a researcher is able to unpack some of the intricacies of a given phenomenon and make it more approachable to the reader. The preferred data collection method for IPA is semi structured interviews, however focus groups and diary entries can also be analyzed with a level of effectiveness (Larkin et al., 2006; Smith & Eatough, 2008). Semi-structured interviews are considered to be ideal, as they allow the participant the freedom to discuss their viewpoints freely without the strict procedures of an interview structure, while at the same point allowing the researcher to guide the participant back in the right direction, in the event they go on a tangent, or veer too far away from, the purpose of the interview (Pietkiewicz & Smith, 2014; Smith & Eatough, 2008). Caution is required while navigating the interviews, as some tangents may in fact be useful to analyze. This creates a delicate balance for a new researcher to understand and apply in practice.

The process of IPA at its core includes a systematic analysis component to review the transcriptions collected from the participants. Each transcript is read and analyzed until fully understood, which could mean a number of readings based on the individual researcher. With each read through the text it is annotated with comments (Chapman & Smith, 2002; Pietkiewicz & Smith, 2014). These comments can either remain as initial understandings, or they may be developed, or honed, through further readings. After this initial stage is completed, these comments are transformed into themes, which are used to capture the essence of the participant's experience (2002). Following this, these themes are explored and connected with each other, forming a complete thematic account of the experience as seen through the particular participant (2002). It is only at this point, after each participant's transcript is fully analyzed, that connections across cases can be explored, at which point superordinate themes are developed (Pietkiewicz & Smith, 2014). These themes can then be translated into a narrative account, which describes the themes, using verbatim quotes from the participants to support and enhance the emergent themes (Chapman & Smith, 2002).

Smith breaks down the characteristic features of IPA into three key facets: idiographic, inductive and interrogative (Smith, 2004b). IPA is idiographic as it analyzes a single case until a sense of



closure is found, as it goes into depth on each individual participant's experience before attempting to analyze themes across cases (Pietkiewicz & Smith, 2014; Smith, 2004b). This allows for the individual reading the final version of the analysis to both understand the nature of the experience from each individual who experiences it, while at the same time seeing the cross-case similarities and differences. The second facet of IPA is that it is inductive, wherein it allows topics or themes to emerge from the transcripts. The researcher in IPA is not trying to accept or reject a particular hypothesis based on the existing literature, rather, they are simply trying to engage with the material provided to them by the participant (Pietkiewicz & Smith, 2014; Smith, 2004b). Finally, IPA is interrogative in that it is trying to explore a given phenomenon with the express purpose of adding overall understanding of how the phenomenon works and how individuals experience the phenomenon (Smith, 2004b). Smith's IPA is one of a number of contemporary approaches to phenomenology. The following section will explore another of these approaches in Maxwell van Manen's phenomenology.

#### **4.4 Maxwell van Manen**

A second contemporary approach to applying phenomenology to a research methodology can be seen through Maxwell van Manen's discussion on phenomenology. Van Manen argues that phenomenology is at its core a study of the lived experience. This means that as researchers who are utilizing this approach have the goal of understanding the world as it is experienced, rather than looking at how it might be conceptualized or theorized (van Manen, 1997c). The lived experience is more about the clear descriptions of the world, rather than trying to develop an insight into the world through the formation of theories (Van Manen, 1982, 2007). Phenomenology does not follow by traditional rules of scientific inquiry, in that it is not objective and does not allow for generalizations (van Manen, 1997c). In this, van Manen believes in practicing phenomenology, one is not trying to understand how or why a phenomenon happens, but rather what makes the phenomenon unique, or in other terms what is the nature of the phenomenon (van Manen, 2017). Van Manen's approach to phenomenology consists of six key activities: (1) turning to the nature of the lived experience; (2) investigating experience as we live it; (3) reflecting on essential themes; (4) the art of writing and rewriting; (5) maintaining a strong and oriented relation; (6) balancing the research context by considering parts and whole (van Manen, 1997c).

The first activity involves turning to the nature of the lived experience, in which the researcher orients themselves to the phenomenon, formulates their phenomenological or research question and

finally unpacks any assumptions or preconceptions they may have about the phenomenon (van Manen, 1997c). The initial step within this activity is to orient oneself to a particular phenomenon and determine what phenomenon the researcher wants to investigate and explore with this particular analysis. In doing phenomenological inquiry the researcher is questioning the essential nature of a lived experience. In undertaking this type of inquiry, it is important to identify why it is we are doing so and the position it is we have relative to the phenomenon. Essentially asking, who is this particular researcher who is exploring and inquiring about this phenomenon (van Manen, 1997c). Following this, the researcher must begin to formulate their research question, which basically follows a structure of what is X really like? Or what is the nature of the lived experience of X? (van Manen, 1997c). The research question needs to remain open ended enough to allow for a variety of areas to explore and examine, and should act as a starting point for the researcher to begin their work in phenomenology, but also to provide a starting point for the reader to think about the phenomenon before delving into the lived experiences as written by the researcher (van Manen, 1997c). The final step of this first activity is to identify and reflect upon the assumptions and preconceptions one might hold about a particular phenomenon. Similar to many of the philosophical constructs that came before this, it is important for the researcher to bracket their preconceptions prior to describing their phenomenon (van Manen, 1997c). In stating what the researcher initially thinks about the phenomenon, it forces the researcher to fully reflect and consider how they view and understand it, prior to delving into a pure description of the phenomenon from the lived experience of the participant.

Following this, one begins to investigate the phenomenon as it is lived, wherein the researcher begins to delve into the exploration of the phenomenon itself by using their own experience as a starting point, tracing etymological sources, and most importantly obtaining experiential descriptions from others (van Manen, 1997c). By looking at the personal experiences that the researcher has with the phenomenon in question, one should be able to see similarities in the experiences of others. By being aware of one's own experiences with the phenomenon, there is a clear starting point for understanding the basic structures of the experience (van Manen, 1997c). The researcher begins by focusing attention onto the etymological origins of the titles of the phenomenon in question. It is in this that one pays attention to the origins of the words that are being used in relation to the lived experience. In doing so, the researcher is able to reflect on how the words themselves help to inform the experience of the phenomenon and add layers of meaning and depth to it (van Manen, 1997c). Obtaining experiential descriptions from others is the primary section discussing data collection for

phenomenology. This section is the key facet of data collection for phenomenology. Obtaining this data could be in the form of: protocol writing (written descriptions of lived experiences); interviewing (an open-ended conversation about the lived experience of the topic); observation; descriptions in literature, biographies, or journals; or representations in art and literature (van Manen, 1997c). The researcher's role at this point is to direct the participant to describe the phenomenon, rather than try to explain or conceptualize it.

In the second reflection activity of van Manen's phenomenology, the researcher works through conducting a thematic analysis, isolating thematic statements to determine the overarching essential themes of the descriptions (van Manen, 1997c). Van Manen defines essential themes in phenomenology as the structure that comprises a particular experience, however these themes are not conceptual or categorical in nature, rather, they are used to provide a level of structure behind the description of a particular phenomenon (van Manen, 1997c). These themes are described like knots in a web of experiences, whereby the experiences are spun around the themes. By grouping different statements into themes, it is possible for the researcher to provide a clearer description of the phenomenon under analysis. Themes are isolated from text in one of three ways: wholistic, selective, and line-by-line (van Manen, 1997c). The wholistic approach involves reading over the text in entirety to make certain that the theme takes on the overall meaning of the text (van Manen, 1997c). The challenge in this approach is that different readers may ascribe different overall meanings to a given text. The selective approach consists of identifying 'stand out' phrases that seem to be indicative of the overall experience (van Manen, 1997c). Finally, the line-by-line approach means a researcher reads each sentence or sentence cluster carefully, writes what each sentence means and starts developing themes from these meanings (van Manen, 1997c). This process has quite a few similarities to the variety of coding processes generally found in general qualitative methodologies. After this, it is the role of the researcher to determine which themes are essential to the description of the phenomenon. This is done through reading and re-reading the original transcripts to determine which themes should be eliminated, added, or potentially reworded or redeveloped (van Manen, 1997c). This thematic analysis provides the researcher with a level of structure to analyze the original transcripts and provide a clear, structured and accurate description of the phenomenon.

The final activity of van Manen's phenomenology is phenomenological writing. It is here where the researcher becomes part scientist and part artist. It is important that the researcher paint an accurate picture of the phenomenon from the descriptions provided by their participants. The

researcher needs to be thoughtful and considerate about what themes are identified and how they are structured and supported throughout the paper. It is imperative here that the researcher selects appropriate quotes to support each theme and clearly identify the connections between the examples and the themes. Van Manen identifies five ways to structure one's description of a phenomenon: thematically, analytically, exemplificatively, existentially and exegetically (van Manen, 1997c). Thematically focused papers structure everything around the emerging themes found in the research, with each section of the paper discussing a particular theme (van Manen, 1997c). More complex phenomena may be broken down into subordinate themes, which provides further structure to the paper. An analytic approach reworks the information found from the hermeneutic interviews into reconstructed life stories, or anecdotes to help provide a more thoughtful understanding to a particular phenomenon (van Manen, 1997c). The exemplificative approach identifies the essential nature, or essential theme, of the phenomenon and then further explains it using different examples that fall within that essential nature (van Manen, 1997c). An exegetical approach uses the prior phenomenological literature that exists on the topic in question and then expands by filling in any gaps that may be missing in their writing (van Manen, 1997c). Finally, the existential approach uses the four lifeworlds: lived body, lived space, lived time and lived other, to provide the structure behind the phenomenological description of a particular experience (van Manen, 1997c). Each of these approaches could be effectively used to structure a phenomenological paper, and it is up to the discretion of the writer and researcher to determine one that suits best for their particular topic. The final task that van Manen sets for the researcher is to work reflexively and constantly be able to rewrite and adapt ones' work (van Manen, 1997c). A researcher must constantly strive for a truly thoughtful and insightful description, which requires the researcher to articulate the best and clearest description possible.

The approaches discussed above by both Smith and van Manen provide a clearer path to adopting and using phenomenology as a research method rather than using a more traditional, or classical, philosophical approach. There is value for a new researcher to understand the questions and discussions that these early philosophers and creators of phenomenology put forward in their initial discussions on this philosophy. However, it is also possible for a new researcher to perform a perfectly acceptable phenomenology, while working through the guidelines of researchers like Smith or van Manen. These guidelines are more user friendly, and easier to understand and apply on a relatively short time frame, as is often a limitation presented to new researchers. The approaches by Smith, van Manen and others can be seen as very attractive and feasible options by new researchers

and are certainly a way to demystify and ideally ease the transition to apply these techniques and approaches.

#### **4.5 Similarities and Differences of the Contemporary Approaches**

In analyzing and critiquing these contemporary approaches it is important to identify the ways in which these methodological approaches are similar, and how they divert away from one another.

Smith's Interpretative Phenomenological Analysis and van Manen's Phenomenology are seen as being similar in some of their data collection approaches, approximate sample sizes and the overall way in which the researcher needs to carefully read through and analyze. Additionally, both approaches similarly value the importance of hermeneutics and researcher reflection. The role of the researcher in the process is pivotal in both of these approaches, yet this is also a point of divergence. As such, Smith's Interpretative Phenomenological Analysis delves deeply into the perceptions and interpretations of the researcher on the experience of the participant and the nature of the participant experiencing the phenomenon in question (Smith, Jarman, & Osborn, 1999). While Van Manen's Phenomenology suggests the researcher reflect and think about the phenomenon, but then asks the researcher to bracket these experiences and reflections in order to stay closer to a more accurate description of the phenomenon from the participant perspective (Van Manen, 1997a). The role of the researcher exemplifies the key difference between these two approaches, in that Smith is focused on both the descriptive and interpretative elements of phenomenology, whereas van Manen relies more heavily on the descriptive aspect in the exploration of a particular phenomenon with the interpretive element used more to inform a clearer description. It is primarily this difference that new researchers to phenomenology will either thrive, or falter. The final section of the article will unpack the benefits and challenges to each of these approaches for new researchers attempting phenomenology for the first time along with some of the specific benefits and challenges to work in the area of workplace health issues, specifically in the area of chronic pain.

#### **4.6 Critique of Contemporary Approaches to Phenomenology**

In examining the benefits of contemporary forms of phenomenology as a useful approach for new researchers, there are a number of factors that must be taken into consideration. It is imperative that new researchers understand both the benefits and the overall challenges of implementing these contemporary approaches.

Both Smith and van Manen's approaches to phenomenology can be useful to new researchers attempting to understand the concept of these approaches, while at the same time being able to apply them easily enough to their own projects. For both Smith and van Manen, one is able to apply these methodological approaches while simultaneously working towards and understanding the foundational philosophy. It is manageable to read the seminal works of Smith and van Manen to gain sufficient understanding of the nature of the approach and to learn how to effectively apply it. This in comparison to the more classical approaches to phenomenology, removes one significant impediment for using as a methodology. Instead of trying, and likely struggling to understand the complexities of the classic philosophies, in considering concepts like epoche, Dasein, and the lifeworlds, one is able to understand either of the overall approaches of Smith or van Manen through an applied lens and in doing so, can begin to develop an understanding of some of the differences between their philosophical approaches. As seen above in the discussion about the differences between these approaches, Smith is following the guidelines of Heidegger's approach to phenomenology in that he is concerned about interpretation and the context behind the descriptions of the experience, compared to van Manen who is more closely following the philosophies of Husserl and Merleau-Ponty in that phenomenology should only be concerned with the description itself and any interpretation by the author should be bracketed and not included in the final work. While this debate about the differences in philosophy are still continuing today, it is now possible to understand both of these approaches through their practical application within research thus reducing, or eliminating significant barriers for researchers to utilize either of these phenomenological approaches. This elimination of a barrier to entry increases the possibility of popularization and increased usage of either of these, or other, effective approaches to studying and exploring a phenomenon.

A second, equally strong, argument for the adoption of contemporary approaches to phenomenology for new researchers, is in the overall clarity and straightforward nature of both of these approaches. Smith's Interpretative Phenomenological Analysis provides the researcher step by step instructions with detailed guidelines to follow, in order to properly adopt and implement this methodological approach for their particular research projects. Similarly, van Manen structures his approach with key activities that researchers can implement while undertaking a phenomenological approach. Each of these activities have a number of sub activities to direct the overall methodology. This guides the researcher through the phenomenological process and, if followed in detail, makes certain that the researcher addresses all of the key facets of the approach. While these approaches are certainly different from one another, their overall approach in building in accessibility for new

researchers is an important common ground that is shared between them and adds value for either methodology.

While these approaches are both strong, and useful for new researchers trying to adopt phenomenology as an approach, each is not without deficits or challenges in their application. Smith's Interpretative Phenomenological Analysis requires the researcher take an additional step in the research process to interpret and analyze the data beyond the simple descriptive approach. That said, in phenomenology, the description is key, and Smith's take on this approach is a significant deviation from the original tenets of phenomenology by Husserl. This deviation can be a significant point of contention for more traditional phenomenologists and has been critiqued directly by van Manen and Zahavi (van Manen, 2017; Zahavi, 2019). In doing so, van Manen argues that IPA is more of an interpretive psychological analysis as the researcher is seeming to take on a role of being a psychotherapist (van Manen, 2017). While there is certainly a possibility in IPA for a researcher to go too far in their interpretation and deviate from the essential meaning of the participant's description, the added level of interpretation may be beneficial to add meaning and context of a particular phenomenon, something that Heidegger ascribed to in his philosophies on phenomenology.

Both Smith and van Manen's approaches to phenomenology use semi structured, or open-ended interviews as one of the primary methods of data collection, and this method of data collection can be challenging for newer qualitative researchers. For more experienced qualitative researchers, the nuances of semi-structured interviews will not be so foreign to them. However, researchers new to qualitative methodologies may find it challenging to provide the participant with enough leeway to share their experience, while at the same time potentially restrict and direct the participant to keep them on topic and discuss their experiences within the confines of the area of focus. For new researchers, there may be a level of comfort in structure and fixed guidelines. Van Manen's approach to phenomenology provides an additional challenge along the data collection and data gathering lines through the exploration of the phenomenon in question through different sources other than traditional participant interviews. There is already an inherent challenge that exists in extracting data from interview transcripts. The added burden of using other sources, where their initial design was not meant for data analysis, may be particularly onerous for newer researchers.

## **4.7 Applications of Contemporary Approaches to Phenomenology in Workplace Health Issues**

The approaches of Smith and van Manen can be useful in studying issues of workplace health, specifically chronic pain in the workplace. Smith's Interpretative Phenomenological Analysis can be particularly useful to the field of workplace health, in that it moves beyond the descriptive nature that most approaches to phenomenology rely upon and adds an element of interpretation. In workplace health, this added interpretation can be valuable to explore the complexities and nuances of the workplace environment and health issues that occur within it, as one is not only considering the health issue at face value, but also considering issues such as relationships with other co-workers, or management concerns. The standard approach of using descriptive phenomenology may be helpful, but to a far lesser extent in workplace health issues, as does not take advantage of the added level of interpretation, analysis and context. This added level of interpretation is valuable while exploring issues in the area of chronic pain, since the description of these conditions may be valuable and the nuances may be lost in the simplicity of the approach. Through the interpretation and the analysis of a complex phenomenon like chronic pain, it is possible to achieve a greater understanding of the intricacies of these complex conditions. This increased understanding can be particularly valuable for some of the stakeholders, such as employers, unions or organizations such as the workplace disability insurers and workers' compensation agencies. By adding a depth of interpretation and analysis in addition to the descriptive components, the increased accessibility of the lived experience is made that much more valuable.

In my view, Van Manen's approach to phenomenology has one key benefit for the study of workplace health and/or chronic pain issues, in its' potential use of existential analysis and the lifeworlds in structuring the description of the phenomenon being studied. Due to the complexities and intricacies of workplace health issues, particularly chronic pain in the workplace, the lifeworlds approach helps to provide a tangible and simplified approach to break down and understand what is going on at the essence of a particular phenomenon. For example, this can be seen through the lived time lifeworld when looking at chronic pain in the workplace. Lived time looks at how one experiences the passing of time, giving meaning to the phrase "time flies when you are having fun", or having time seem to pass incredibly slowly when one is doing something unenjoyable or unpleasant. For chronic pain and workplace health issues, this conceptualization of time as moving at a snail's pace while one is in discomfort or is ill, but can't do much about it because they are at work,



helps to explain and describe more fully the phenomenon of workplace health issues or specifically chronic pain in the workplace.

As discussed earlier, both generally and specific to workplace health and chronic pain, the methodology and philosophy behind phenomenology can be valuable and thought provoking, but it is not without its challenges and difficulties. However, it is important for new researchers not to be discouraged by these challenges, but rather to work through them to apply this useful approach to conducting research. The various approaches and concepts behind phenomenology can be applied to many different topics within health research, workplace research, or a multitude of other topics, it simply requires a bit of tenacity on the part of the researcher and additional support from those around them to effectively use this methodology to explore a variety of different phenomena.

This paper set out to provide background and critique on two of the significant and modern approaches to phenomenology. Both Smith's Interpretative Phenomenological Analysis and van Manen's phenomenology can be useful approaches to novice researchers, or researchers who are new to the field of phenomenology. Both of these contemporary approaches act to simplify the processes that are seen in the classical forms of phenomenology. The benefits to using these contemporary approaches are greater than any challenges that may exist, and while there are some issues that may slow down new researchers to phenomenology, they are certainly able to be worked through to develop new research.

## **Chapter 5**

### **Autoethnography of a Young Adult with Chronic Pain**

#### **5.1 Abstract**

Personal experiences of chronic pain conditions are of key importance in understanding the nature of these conditions and what these individuals face on a daily basis. This article aims to use autoethnography to help to explore the personal experiences of the author in navigating their chronic pain condition as a young adult. These experiences will explore topics of initial diagnosis, medical interventions, personal relationships and navigating the workplace with a chronic pain condition. From the narrative of these experiences three major themes will be reflected upon through the existing literature in the field, including: interactions of young adults with health care providers and advocating for their own care, impacts by and on caregivers in supporting a loved one with a chronic pain condition and the challenges of reduced capacity in the workplace. These themes will be explored to ground the autoethnography in the existing research.

Keywords: Autoethnography, Chronic Pain, Caregiver, Patient Decision Making, Identity, Workplace, Relationships, Health Care Providers

#### **5.2 Introduction and Methodology**

In starting this autoethnography on my lived experience with chronic pain, I feel as though it is prudent to discuss why it is I am writing this paper and what it may contribute to the given field. As a fairly novice researcher, I was debating what I might offer to my field, that other more seasoned and experienced researchers have not done already. In part, the answers to this question lie within my own personal experiences with chronic pain. While there are a number of articles that currently exist on various individuals' experiences with chronic pain, I believe there is a specific and unique experience of a young adult's lived experience with chronic pain that has not sufficiently been discussed. The other unique facet of this paper that occurred not by design, but rather by happenstance is its' longitudinal perspective on chronic pain. While the original goal was to isolate my experiences to my late teen and early twenties, life has certainly had other plans. Prior iterations of this paper ended at points in my mid-twenties, but plans changed and the paper evolved to include new elements of my life that were just as relevant to discuss. The overall experience is key to

understanding not only the nature of this chronic pain condition with the specific population of young adults, but also the nature of chronic pain in general.

Autoethnography as a method is the combination of autobiographical and ethnographical elements. It serves as both an autobiography, wherein the author writes about past experiences and is recalling moments that have in some way impacted their life moving forward, but also an ethnography, where one studies cultural practices, values, and beliefs (Ellis et al., 2011a). In doing an autoethnography, the author is writing about and analyzing their experiences in being a part of a particular cultural group or identity. It is in this facet of the methodology of autoethnography that the aspect of narrative and storytelling comes to the forefront. Previous literature in the field of writing narrative works in health care focusses on the standpoint of the storyteller, wherein one reflects on their own unique experience and reflects on this experience as a member of the broader community that they are a member of, in my case this is reflecting on my unique experiences as a young adult with chronic pain, in the broader shared cultural experiences of the community of those with chronic pain conditions (Frank, 2000). It is in telling my story, in the way that I am choosing to tell it, I am hopefully bringing a sense of authenticity to the description of the lived experience of chronic pain, particularly among young adults (Frank, 2000). As an academic methodology, where autoethnography as a methodology is able to add to the existing literature is taking some of the emergent themes or concepts and analyzing them relative to the existing research and literature that currently exists (Ellis et al., 2011a). I am also bringing a level of reflexivity to the underlying literature that exists by tying it back to my own lived experience and through this analysis, highlighting for the reader that which is particularly relevant and prescient to my experiences while reviewing the literature (Frank, 2000). These connections to existing research will be incorporated throughout the discussion where appropriate.

In taking some cues from another of Frank's works (1998), the choices and structure of the discussion somewhat follow his Quest story structure, although not as rigidly as described. My story is not based in any way in the restitution or chaos of the primary aspects of the events happening to me, but rather in the overall quest for achieving a new sense of normalcy. My story may start in the chaotic sense, with my life being thrown into some version of turmoil both in my relationships with others and my workplace. Both of these areas being predominantly positive areas in which I have navigated my life back to a manageable level of normal (Frank, 1998). This concept of navigating illness, particularly chronic illness can be valuable, as often individuals with chronic illness are not

realistically seeking that miraculous cure, but rather are searching for a sense of normalcy and a respite from chaos. It is my hope that this autoethnography serves to demonstrate this role.

### **5.3 Identity**

Prior to discussing my story, it would be prudent to discuss who I am and the facets of my identity that may play some form of role with my chronic pain. While there are aspects of my experience that should be common and relatable among those with chronic pain, and particularly young adults, there are aspects of my experience that are specific to my identity. Some nuances that are specific to my experience and background, may not be apparent to others with chronic pain. Similarly, I may not have faced some of the structural barriers that others have faced based on elements of race, culture, ethnicity, socioeconomic status and education. I am quite fortunate that in many ways these did not play as significant of a role in my story. That said, other young adults with chronic pain may struggle with these particular barriers, which complicate an already challenging experience. This should serve to emphasize the importance of sharing these experiences of people of different backgrounds in order to unpack the specificities of the impacts of these conditions across varying backgrounds.

The primary aspect of my identity that is discussed throughout this autoethnography is my age. I started this journey with pain when I was 17 years old and continue struggling with this in present day at 34 years old. My experiences with chronic pain have made up half of my chronological life so far, and all of my years of adulthood. This concept of age, is central to this manuscript. Much of the work that has been done in the area of chronic pain is focused on older adults and by shining the spotlight on the experiences of a younger adult, it should help to demonstrate some of the nuances that are unique to this particular subset of the population with chronic pain. This connects specifically with the work by Bury (1982) on identifying chronic illness as a form of biological disruption, as he is specifically focused on rheumatoid arthritis. In this work, Bury (1982) wanted to explore the concept of illness at the earliest point of one's life cycle to examine how life circumstances and relationships are impacted by the development of a chronic illness. Chronic illness, and chronic pain in particular is a disruptive event in one's life, and one's structures of everyday life are inexorably changed. An individual who develops a chronic illness or chronic pain condition is forced to recognize a world that involves pain, suffering, and potentially even death, when previously these concepts may have been considered to be foreign and unfamiliar. This is particularly true for a young adult who is trying to find their footing in the world and seeking a sense of autonomy and control that otherwise was not really present. Some may hold that this disruption may be more

difficult for someone older, who is already more established in their life with set schedules and routines. It is my assertion, that the difficulties for younger adults are significant as they disrupt the development of this schedule and routine. This creates a concept of adulthood that normalizes pain as part of one's self-concept and identity, rather than it being an aberration of the norm.

The next aspect of my identity that would be important to discuss is that of my gender. While I do not regularly see being male as being an integral aspect of my identity with pain, it is still something that should be acknowledged in the entirety of the scope of who I am. Much of the literature on pain focusses on women more than men presenting with symptoms of pain, and openly discussing their conditions (Meana, Cho, & DesMeules, 2004; Rustoen et al., 2004). Being male was not an aspect of my identity that in any way seemed to interfere with either my management of my chronic pain condition, or discussing it with others. This could perhaps be connected with my age and overall openness about my condition, but in general it was not an element of interference. In an article by Charmaz (1999) on suffering, she discusses a 61-year-old man who was suffering through a pain condition and as such wanted to maintain control of himself and his autonomy. While I certainly felt the challenge with maintaining autonomy as an individual once my chronic pain condition took hold, I did not find that my struggle with lack of autonomy was directly connected to my gender identity, but rather was more interconnected with my age and the disruption of where I was supposed to be in my life (Bury, 1982; Charmaz, 1999).

The final area of my identity to discuss is my ethnicity and cultural background and in turn my racial identity and socioeconomic status. My ethnicity and cultural background are strongly rooted to form my Jewish identity. Prior to writing this autoethnography, I had not really considered my ethnicity and culture as being a significant part of my pain condition. Certainly, there are those who say that pain and suffering may just be a part of the Jewish identity and experience, but I do not know that I would make such assertions. What I do know from my experience of having chronic pain and being Jewish is that my pain condition was always taken seriously by my family members and those within my community. I have likely always taken this for granted up until now, but am aware that ethnically and culturally this viewpoint may not be shared in those who come from different backgrounds (Holt & Waterfield, 2018; Morais et al., 2021). That said, there are some ways in which I have followed the trend of one who is Jewish in managing their pain condition, in how open and up front I can be about my pain condition, but simultaneously there are other ways in which I have deviated from this norm in an element of attempted stoicism, which I would not say is part of the

standard Jewish identity (Encandela, 1993; Peacock & Patel, 2008). More often than not, I try to deal quietly with my pain condition, as will be alluded to in the narrative to follow. This deviation from the norm in actively discussing my pain condition regularly may be an interplay between my culture and my gender roles. This interplay is not something that is touched upon further in this autoethnography, but may be the source of future work in the field. Within my ethnic identity is also my racial identity, which is Caucasian from mostly Eastern European lineage, also known as Ashkenazic Jewry. My lineage mostly affords me a level of freedom from (racial) discrimination, although sadly I have still faced some as a result of my Jewish identity. As such, managing my chronic pain condition has had one less impediment compared to those of other racial and ethnic backgrounds. Finally, within the discussion of my ethnicity and culture, is also some connection to my socioeconomic status. I am grateful to have been raised in a financially stable home focusing on high levels of educational attainment and with a background of financial security. Thankfully, for the most part, my socioeconomic status has served as a benefit to managing my chronic pain condition. Also playing a role in this is living in Canada, which has fewer structural impediments built into their health care system as compared to other nearby countries. Even with that being said, there are times where despite having a stable financial background that my treatment options would have been unaffordable. This situation would only be made worse by those in either worse financial circumstances than me, or in other countries where the cost of medicine can be that much more expensive. This interaction between socioeconomics and health is one in the realm of chronic pain and chronic pain self-management that should be discussed in depth at some point, and it is my hope that elements of this discussion still resonate in others' lived experiences where these issues have impacted the ability for one to manage their treatment. I am grateful that these impacts have not become a significant factor in my experience, but am certain that others with differing socioeconomic backgrounds can continue provide valuable insights as a jumping off point to critically reflect on that discussion.

#### **5.4 Initial Diagnosis, Reactions and Suggested Medical Interventions**

My story with chronic pain begins roughly at the age of 17, turning 18 years old. Naturally, the recollections of these early experiences will be far less vivid and detailed than those which have occurred more recently, however, they should still provide some insight into one's early days with a chronic pain condition and how someone with chronic pain reacts and handles their diagnosis. The initial onset of chronic pain occurred in my first year of university. I recall that I woke up one day

and was barely able to move. I tried to get up out of bed and could not apply pressure to my foot to get up. Any time that I attempted to do so, resulted in a great deal of pain and discomfort. Being a relatively young and naïve individual at the time, and never having faced this sort of pain before, I figured that it was simply a rolled ankle or a bad sprain. I simply stayed put that day and asked my roommate to bring some ice when he could, but figured that only time would make it better, so it would likely be best to stay off of it until it improved. Even while I was resting, I was still in a significant amount of pain, so I tried to keep it as still as possible and elevate it, as this is what the internet ‘experts’ said I should do. After a few days, my foot began to feel better, and I began to hobble along with my daily business. My internal logic was that my foot was improving and I needed to get back to classes. This initial interaction with pain, especially at a relatively young age tends to be unexpected, and this leads to an overall sense of denial that the pain is anything more than an acute response to something that happened, rather than the start of an ongoing chronic condition. It is unfathomable, especially for young adults, that any sort of pain felt, is anything life altering or a potential start to a consistent struggle.

Months passed, I celebrated my 18th birthday and during my travels, I went to the campus health centre to get a clear answer as to what was going on, which was followed by a number of tests and a suggestion to see a local rheumatologist for more information. I had never been to a rheumatologist before and trekked downtown to meet with them, in the hope of receiving a clear diagnosis and information on how I should treat my foot. While there was hope in finally solidifying some sort of answer, it was also combined with feelings of apprehension and anxiety, as there was now an escalation to a specialist who needed to review the circumstances.

The rheumatologist diagnosed me as having psoriatic arthritis, given my history with psoriasis and the likely connection between these conditions. I remember him saying that I would have this condition for the rest of my life and the pain might come and go, but would dramatically increase as I grew older. This was hard to hear; however, I did my best to keep a level head and try to clearly gather as much information as I could. That being said, when one is given a life altering diagnosis, it is not necessarily the easiest thing to be completely level headed and rational, especially at such a young age. The rheumatologist proceeded to review my treatment options, which included invasive surgical procedures and/or side-effect laden pharmaceutical interventions, all of which were my “only options” to try to offset the impacts of my arthritis pain. The surgeries suggested by the rheumatologist had significant risks and did not have the best chances for effective outcomes,

whereas the pharmaceutical interventions were more likely to be effective. However, most of the effective pharmaceutical treatments would likely make me infertile, eliminating any chance of me having a child someday, along with a large number of other unpleasant side effects. To me, neither of these options seemed even remotely feasible, as each carried significant risks and downside without any proven chance of effectiveness. This is one of the challenges that is specific to those who are younger with chronic pain conditions, compared to others who traditionally tend to be diagnosed with chronic pain conditions, some of the side effects may be more reasonable and manageable being further along in their life course. For me, the feeling is that I could live with this occasional pain and try to manage it whenever it came up, while not mortgaging my future on risk-laden interventions with little chance of success. In expressing my decision, the rheumatologist vehemently disagreed with me, saying that I was being incredibly short sighted (taking some slight license here and replacing the more jarring words that he had chosen at the time) for not taking a chance on these invasive procedures and stating that I was essentially damning myself to a life of pain and discomfort. I was appalled by his lack of understanding and empathy in these life altering decisions that I had to make for myself. I was a grown adult by this point, fully capable of making decisions on my own health and weighing the potential risks and benefits behind my treatments. I tried to explain to the rheumatologist that I was not like many of his other patients who may be trying these treatments. I was not someone who already had children and who could easily eliminate that possibility moving forward. It was clear that we were at an impasse moving forward and this doctor/patient relationship was not a good match, so he gave me a prescription for some stronger anti-inflammatory medication and I left his office never to return again.

This initial interaction with a health care provider certainly soured my opinion of how I would likely be treated moving forward. I asked myself questions in the realm of, is this how health care providers will view and treat me moving forward? Will I simply be lumped in and treated like the majority of arthritis patients who are generally older and have different viewpoints on life and treatment? At 17 or 18 am I considered too young to make an informed decision about my own health care and as such, will my decisions not hold nearly as much weight as the decisions of those older than me? On the other hand, is it possible that this interaction with a health care provider was an anomaly and moving forward other health care providers might start to match my understanding and expectation of how a health care provider is supposed to communicate with their patient? Suffice it to say, at that point I was a bit frightened and disconcerted. I knew that I had a lifetime of pain awaiting me, not entirely certain of how it would be managed or treated and was left reeling from my



first interaction with a health care provider on my newfound condition. Thankfully, this experience was more of the exception than the rule, but as will be seen later on, there are still a number of trends that carried over through my interactions with other providers.

The theme of youth and young adult decision making on health care decisions is not particularly uncommon in peer reviewed literature, however, this concept specifically related to chronic pain conditions is not significantly discussed. The likely reason for this is that there is not a large population of young adults with chronic pain conditions as there is with other, more impactful chronic conditions. Much of the literature that exists on youth and young adult decision making on health care decisions is in the realm of Cerebral Palsy. While some of the specifics and nuances of Cerebral Palsy are not relevant to the discussion of Chronic Pain, some of the more general themes still seem to appear across the literature. The general concept of ‘rule your condition, don’t let it rule you’ is one that appears regularly in literature on chronic illnesses and conditions in general and particularly in youth and young adults. It is found to be imperative for those to control their conditions themselves rather than having parents or doctors do so for them (Heaton, Raisanen, & Salinas, 2016). From the outset of my condition, it was of key importance to me to manage my condition on my own, and take the primary role in my healthcare. This was something, thankfully, my parents and physicians mostly respected, despite being just on the verge of adulthood. I needed to actively manage my medications regularly on clinical trials, including self-injections, which were initially terrifying. Mastery of one’s condition is vital in successfully managing a chronic condition, and it can be particularly challenging and daunting in doing so as a youth and young adult. These challenges are amplified when there are difficulties in successfully advocating for oneself in health care decisions. In the literature, there are discussions on how the parental role in health care decisions can at times be overbearing in the area of youth chronic conditions (Grande et al., 2019). Thankfully, in my particular situation, I was a bit older and my parents allowed me the autonomy to manage my own care and health care decisions. This support allowed a greater overall feeling of control and management of my own condition. Starting with this autonomy and control from the beginning of my condition, technically still as a youth, has allowed me a sense of ongoing confidence that likely would have taken longer to build had a more active role been originally taken by my parents. The one significant deterrent in the building of autonomy was in my consultation with a rheumatologist in diagnosing and setting up treatment for my condition. The challenges I faced in this instance, seem to be common themes in youth management of health care decisions with their physician. In an article on perspectives of adolescents and young adults with Cerebral Palsy, there is a discussion of common participant responses on

challenges faced during health care consultations. Some of the recurring themes include: lack of listening; lack of optimism, hope and willingness to find new solutions; lack of trust of the physician in the patient; lack of interest in the patient, and belittling the patient (Lariviere-Bastien, Majnemer, Shevell, & Racine, 2011). The initial feeling of disrespect and lack of willingness to find new solutions from the rheumatologist managing my condition was deflating at the outset and minimized my self-management of my condition. That said, thankfully this experience was more of an outlier and while I do not believe that the communication from my direct physicians was often best and sufficiently supportive, as will be reflected upon shortly, at least it was at the point where I was respected and my decisions were valued.

After this preliminary struggle with the rheumatologist, I was referred to a dermatologist in my hometown, who was known for running a research centre that participated in clinical trials to potentially treat both my psoriasis and psoriatic arthritis. I was leery about participating in clinical trials, as I knew I was getting involved in something potentially risky, with absolutely no certainty of effectiveness. I approached these trials as level headedly as I possibly could, reading through the consent forms carefully, weighing the potential risks and benefits and in general trying to make certain that it was the right fit for me. As far as I was concerned though, the risks present in these clinical trials were certainly outweighed by the potential benefits and were also far fewer and less serious than those presented to me by the rheumatologist.

My first clinical trial was using a self-injectable treatment along with an oral medication a couple of times a week. The inclusion of self-injection was in and of itself an incredibly frightening component to my first clinical trial. I thought to myself, “How am I going to be able to steady myself to give an injection? I don’t like needles at the best of times (who does?), how am I going to now inject myself regularly? Is this my life now?” However, as I got used to the injections, it became second nature. It would not really faze me that I would need to do an injection on myself in a given day. That said, despite the fear and significant lifestyle change, the treatment that went alongside it demonstrated minimal impacts on either my psoriasis or my psoriatic arthritis. After the trial ended, I was offered the option of proceeding with the injectable for a period of time free of charge. This was an option that for some reason I had accepted, despite the medication being mostly ineffective. I knew that I was not planning on moving forward with this medication on the open market, both for its ineffectiveness as well as its cost, (many thousands of dollars per year that would not be covered by

insurance). In trying to rationalize my decision now, I was holding out hope for the medication to become effective and potentially relieve me from the conditions that plagued me.

It was after stopping the use of this medication that I faced my first significant surprise in dealing with clinical trials. In order to participate in a second clinical trial, I needed to “wash out” of the original treatment for a period of multiple months. For those unfamiliar with a wash out, this meant that I was not able to take any prescription treatments for my psoriasis or psoriatic arthritis. Unfortunately, my body reacted to the lack of medication by my arthritis ‘kicking into high gear’, where I was basically immobilized for days or weeks at a time. It was as if for the past year the trial medication was doing its best to hold off an onslaught of an attacking army, even though they were taking losses and were not as effective as they should be. Once the medications stopped, the defenses were down and the arthritis army invaded my system with extreme force. I remember that I was in so much pain that any pressure placed on my foot, or even the slightest movement of it in the middle of the night resulted in such pain that I was barely able to sleep. This lack of rest and constant discomfort was one of the most miserable times in my life. I felt completely disabled and debilitated. I needed help with basically everything in my life, I couldn’t easily make it to the bathroom, dress myself, and more. This inability to do the most basic daily tasks in life wears on an individual very quickly, especially someone like me who had up until this point prided himself on independence and autonomy. I very quickly realized how disabled I was when I started to think about the effort it would take me to simply walk across the hall to go to the bathroom. This transition to losing my complete autonomy, particularly at a stage when I was starting to gain more autonomy than ever is a unique added challenge for those who are diagnosed with chronic pain at younger ages. Losing autonomy, and needing to heavily rely on others for basic tasks is a challenge for most with chronic pain, but the jarring transitions of shifting autonomy for those who are younger with chronic pain is a significant added challenge.

I was so heavily reliant on my parents at that time that they essentially were caregivers for a twenty-year old. This is something that they certainly didn’t sign up for, and while they didn’t complain once, it was an incredibly difficult to really need my parents in order to get through that time. I was extremely frustrated and angry. This was the point in my life where I was supposed to have complete freedom and independence, to be able to come into my own and explore the world in new and exciting ways. Instead, I was forced to be far more dependent and more restricted than I had been for many years.

Throughout my numerous appointments to check up on my psoriasis and arthritis, nurses were my primary point of contact, they were the ones who spent the time with me, listened to my concerns and genuinely seemed to care about them. The physicians would drop in, for three minutes or less, check only the most relevant aspects to them and move on. This is not to say that I needed more care from the physicians, as I received plenty from the nurses, but the physician was there to oversee the overall treatment and follow the study guidelines, which at times led me as the patient to identify more like the conditions that brought me to the physician, rather than an actual person who was trying to deal with these conditions. I do understand and am aware that part of this had to do with the fact that I was participating in a series of clinical trials, but in some respects, I wish the physicians could have showed a greater level of empathy and understanding with their knowledge of my condition. While I am happy to be treated for my conditions, I am far more than the sum of my symptoms. There are times when it feels like a brief discussion of the impacts of my condition on my daily life would go a long way to coming to terms with them, especially from those who have some sort of concept about the impacts of my condition. This lack of compassion is a significant deficit that still exists in our health care system, which is something that I feel is regularly lost in that the physicians often forget that there is a person in front of them that they are treating and that extra effort of compassion and listening could potentially go quite a distance in helping their patient.

As alluded to earlier, this first trial was followed by a number of additional trials, at least up until this point. It was in the fourth and fifth clinical trials when I started to write this paper, and sadly my writing has taken up the entire time of the fourth trial and has brought me well into the fifth trial. I had originally written that I was very hopeful that the new medication would be effective in managing my condition, and it definitely was not. Thankfully, the wash out for the fourth trial was not nearly as debilitating as past wash outs, but my psoriasis and arthritis took over my body. Going onto the fifth and now current trial, I have had some positive outcomes for the first year or so, and am going onto an extension phase of the trial. However, I am starting to feel the efficacy of the treatment diminish. While my symptoms may be gone most of the time, I still have an ongoing baseline level of pain, and occasional flare ups to remind me that I still have arthritis. These flare ups are increasing as my time on the trial continues, so while I have some faith in the future success of this medication, it is tempered by the dips in efficacy of late. The lack of consistency in the efficacy of treatments to manage chronic pain is certainly a challenge for those living with these conditions on an ongoing basis. With every new treatment, there is the buildup of hope that this will be “the one to finally get my condition under control” and bring me back to some semblance of normalcy. This hope is not just

on me, but on my wife and parents as well. The extent of the impact of a chronic pain condition goes far beyond the patient themselves, but has a ripple effect to all those around them. It is for this reason that taking a more holistic approach to understanding a chronic pain condition is incredibly important, moving far beyond the basic physiological impacts of pain.

## **5.5 Personal Relationships and Interactions**

This is likely the element of my condition that I am both most intrigued by, as an academic, and most challenged by, as a person with a chronic pain condition. Regardless of what people say, there is always incredulity in looking at me when my chronic pain is flaring up. People automatically tend to assume that I have broken or sprained my ankle when I am hobbling around with my cane, as that is the most logical explanation to them. For a twentysomething, now thirtysomething, it does not compute that someone my age would have a chronic condition, let alone chronic pain. This is a frequent occurrence for those who are younger with chronic pain conditions, that it is often unfathomable to others that a young person would have a condition beyond a simple injury that requires time to heal. In keeping more general to start with, interactions with others tends to start with disbelief, then shifts to some level of sympathetic response and then eventually transitions to advice about how I should manage my condition. While I completely understand the train of thought and approaches that people are taking towards my condition, it yields a level of frustration on my part and from what I have heard from others with chronic pain, I am not alone in my frustration. There are many times when I don't particularly want my condition to be brought up and discussed with me, I would rather talk about nearly any other topic. I am certainly at the point where I no longer want to hear others' advice about the best way to manage my condition. I cannot even count how many times people have advised me about my diet, how I walk with my cane, and how to best protect my foot. So much so, that earlier on in my condition, I was hobbling along in the local mall and a stranger started staring at me and decided it was appropriate to come up to me and chastise me about how I was holding my cane and how I balanced myself on it. I thought to myself throughout the rest of the day, what business was it of his to come up to me and either discuss my condition or try to tell me how to manage it. This was infuriating. I know my own health and body and I am perfectly aware at this point what the best ways to manage my conditions are.

Now that I have discussed the common stranger reaction to my condition, I feel it is best to talk about my regular interactions with my family, friends, and significant other. In discussing my relationships and the impact that my chronic pain has had on them, I feel it is likely best to start with

my family, specifically my parents. My parents have been helping me manage my condition the longest, and aside from my wife have had the most interaction with me while I have been dealing with my condition. While my parents have been aware of my condition since I found out about it, they do their best to let me handle it to the best of my ability. My parents have been fantastic about not being overbearing, or overly worrisome. They have allowed me to make all of the key decisions about my treatment and simply ask follow up questions after each step and hope for the best. I would imagine that some of this has been incredibly difficult on them. Knowing the type of people they are, I am certain that they want to be involved with every step of the process and do whatever they can to help. However, the best thing that they have done is to let me take charge of my own condition, even from the earliest stages. Having my autonomy taken away from me as my condition developed would have been the worst thing that could have possibly happened. I think that would have dramatically impacted how I went about my daily life. In referring back to a previous story, when I was on wash out from my first clinical trial and was still living at home, I knew that it was likely a great challenge for my parents to face. They had their only child at home and almost completely incapacitated, writhing in pain and needing their help in performing even the simplest tasks. My parents were obviously incredibly concerned during this time and did all they could to check in on me and help me with everything. I even recall an instance where I was in so much pain that they went out and brought in a physician friend of theirs to check in on me and see if there was anything he could do or suggest. I believe that the primary point of the discussion on my parents and how they handled my chronic pain condition is that the impact of these conditions extends far beyond the patient. It is imperative to consider and reflect upon the impacts that it has on relationships, especially those who are in immediate proximity of the individual with the chronic pain condition. In this circumstance, the impact was primarily a positive one, my parents did whatever they could to support me, while at the same time not impacting my autonomy or decision-making processes. In other relationships, it is a distinct possibility that a chronic pain condition could negatively impact one's relationship with their closest loved ones. The individual with chronic pain is essentially thrown out of their equilibrium and forced to redefine their being. If one's family, or loved ones, are not able to understand or cope with this change in dynamic, significant impacts are bound to occur on their relationship.

Despite all of the challenges mentioned above faced by my parents, my wife is the person who is most impacted by my chronic pain condition. While my condition was present from the start of our relationship and she was aware of the drawbacks that came with it, the impacts on her are still something I feel bad about regularly. There is always an inner feeling that she is essentially stuck

with a defective product, one which would be very difficult to return. She certainly has never shown any indication that this feeling is accurate, however I still am hampered by letting her down most. I am frustrated with myself that she needs to pick up extra slack at times because I am unable to do things. I feel bad that there are times when I am unwilling or unable to go out to do something because I cannot easily move around. There are limits to what I am able to do, and now she is limited by association. I particularly feel bad when I see the look on her face when I am in pain. I know that it in and of itself causes her some level of pain and anguish to see me that way. These are not small things for a married couple to deal with, let alone a married couple with a toddler. We do our best to handle everything in stride, but the impacts of this chronic pain condition certainly weigh heavily on both of us in very different, but equally important ways.

On a daily basis, we do our best to manage and offset the impacts of my condition when it rears its ugly head. I work hard to try to deal with as many of the chores as possible when I am mobile and able. I believe strongly in participating in the cooking, and cleaning around the house. When my pain is so severe that I am couch or bed ridden it bothers me and weighs on me that the burden of the house is lying solely on my wife. She says that she doesn't mind, but I still do feel bad about it every time that I am not helping out to the capacity that I should be, if I were able.

In addition to my inability to regularly share the workload in the house, there is an added pressure on caregivers to take care of someone who has difficulty moving from point A to point B, even around an apartment, and now around a house. We have tried to be innovative in coming up with solutions and fixes for each of the problems I face. These solutions are not able to completely address every problem that I come across, but they certainly do make things easier. One example of this sort of solution would be how to get me onto the bed or couch. I was able to fall down easily enough onto either the bed or the couch, but would significantly struggle in lifting, or swinging my legs onto the same surface. My legs do not easily bend and lifting them with my own power would often be accompanied by a large burst of pain. So much so, that there were often times when I would sit for hours trying to gather the energy and courage to lift my legs up onto the bed or couch because I was either afraid of the pain, or used up too much energy to try to do so previously. To offset this issue, my wife figured out that she could easily wrap my legs together in a blanket and then pull and swing them from the floor onto the bed or couch. This solution allowed me to more easily transfer between rooms, albeit with significant effort and challenge still, and provided me a bit of additional comfort in either place while eliminating the dread and fear of pain in initiating movement for basic tasks.

One of the other significant struggles that my wife faces is in the uncertainty of my treatment and the elements of my treatment that may not be as ideal or easy. The earlier treatments that I was using primarily involved topical ointments or pills that I would need to take on a daily basis. The newest treatment being an injectable is certainly an adjustment for her. While it has become somewhat second nature for me to inject myself, there is some difficulty for her in me doing it. We have worked together to make her more comfortable in the process, however it is still not something that she is fully comfortable with. Another example of a treatment process that made her significantly uncomfortable happened a couple of years ago, when an increase in my pain levels lasted a number of days and required a trip to the hospital. I was putting off the visit to the hospital for as long as I could, because I knew what it would inevitably entail. Regardless, we went in search of some relief for the pain in my knee. On a fairly quick diagnosis by the attending physician it was determined that the best course of action to provide me some relief would be to drain my knee. While I told my wife about my past experience with this, I obviously did not do it justice. For those of you unfamiliar with the process of draining one's knee, I will save you from the majority of the gory details, but to use my wife's words "there was a VERY big needle going right into your knee." I was working on breathing slowly, unsuccessfully at that, and my wife was near my head and I was strongly suggesting she not look at the procedure that was occurring at my knee. As people often do, she disregarded my suggestion, lost most of the colour in her face, and was breathing even more deeply than I was, and was crouched underneath the hospital bed. This example and the others stated are not to diminish or make light of what my wife and other caregivers go through in helping their partners manage their pain, but rather it is to emphasize the difficulty in the responsibilities that they have taken on.

To conclude the initial section with my wife, I feel as though it is important to circle back to our living situation, which has been a significant challenge and also an important detail in our lives, and specifically my life with chronic pain. As it often happens with married couples living in an apartment, my wife and I had felt the need and urge to settle down further and buy a home. We brought on a supportive real estate agent to help us with our search. One of the significant challenges that we faced was to find a home that was at least somewhat designed to help with my chronic pain, but also fit the rest of our needs in the features it had, along with its overall budget. Our real estate agent, along with my wife, struggled regularly to see me hobble up and down stairs in a number of these homes. I knew that it was likely that we were going to want a multi-level home, but would be sufficiently content with some room on the main floor that could contain some form of convertible bed where I could sleep if I was unable to make it up and down the stairs. To my wife and real estate



agent, this compromise was more of a last resort, and sought to find a better fit. Fortuitously, there exists a concept of a bungalow, although these are certainly few and far between. While this wasn't my number one priority, our real estate agent tirelessly looked for a home that would suit us and my condition permanently. We were very fortunate to eventually find a home that ticked nearly all of the boxes and had a main floor primary bedroom wherein I only needed to walk about five steps to a washroom, ten steps to the living room and about fifteen steps to the kitchen. In my pain flare ups I am most grateful for the luxury of being able to live primarily on one floor and not have to worry about making long and arduous treks up and down stairs to sufficiently live in my own home.

As was hopefully clear above, the impacts of my chronic pain condition are far from limited to just being on me directly, but also significantly impact my spouse as well. There is a great deal of literature in the field, focusing on a variety of different aspects of the spousal experience supporting one with a chronic pain condition including impacts on sleep, depression, anxiety, and life satisfaction (Ascigil, Uysal, & Saracgil Cosar, 2019; Leonard & Cano, 2006; Martire, Keefe, Schulz, Parris Stephens, & Mogle, 2013) Two particularly interesting areas in the literature on spousal interactions on chronic pain are related to how a spouse perceives their partners pain and the reaction that they have to this perceived pain. In general, research indicates that one indicates they were more disabled in terms of physical and psychosocial disability than their spouses tended to rate them (Cano, Johansen, & Geisser, 2004). While it is certainly true for the most part that my wife is not always able to accurately determine my level of pain when it is somewhat less severe in nature. However, when my pain is more pronounced, my wife is often able to anticipate this and take certain proactive steps to help me manage my day and offset my pain. In terms of one disclosing their pain condition to their spouse, research indicates that spouses will more often respond with validation of these concerns, as compared to invalidation and these responses tend to mix as there are more disclosures of pain symptoms (Cano, Leong, Williams, May, & Lutz, 2012). This communication of pain symptoms is common among partners and often leads to a communal coping with pain. Reflecting on my own experiences, for the most part, my wife was validating the feelings of pain that I was undergoing, but as the disclosures of pain increased over time the validation of symptoms often shifted to be more concern as to why the newest form of treatment was ineffective. This was still a validation of my pain symptoms, but the nature of the validation changed somewhat to include a critical element of concern for my ongoing pain management.

Alongside my wife who is of the utmost importance to discuss, is someone who did not exist when this paper was first conceptualized and the initial words were on the page. My son, was born over a year ago as I am writing this section of the paper. This is the son who would not exist if I had taken the advice and guidance of a certain rheumatologist many years ago. When people say that having a child changes everything, they are certainly telling the truth, but these changes are even more so when navigating these new challenges with some impediments of a chronic pain condition. There were certainly a few challenges in the early days of my son's life with balancing some of the side aspects of my condition while balancing an infant's needs, things like a frequent need for rest and not always being able to easily move him wherever he needed to go led to additional feelings of guilt and added imbalances where my wife needed to pick up extra slack when I was unable to do all that I wanted to. In some ways, we had found a new balance over the first months of our son's life, in other ways, we have new challenges on the horizon that may prove to be even more difficult than anything we have faced so far. Of particular concern is how fast our son was able to crawl and eventually walk around the house. Even at my best, I don't move particularly quickly, and with his agility and quick movements it is difficult at times to protect him in the ways that are needed. I am certain that this will only get worse when he starts to walk more and run around, which will likely be at the time that this paper is in publication. While I am hopeful for the future, and will forever be trying my best, I will perpetually feel ongoing guilt for the extra work that I am putting my wife through. She is certainly as gracious as she could be about this additional effort, and our son is worth all of it, there are days in which I wish that I could ease this burden by being fully able to run after him and keep up with his now constantly growing energy reserves. I will forever do all that I can for my son, and hope that it will be enough moving forward. Despite my limitations, he will always know that he is loved and supported and I will do everything I can to limit or reduce the impacts of my condition on his life, even though I know that this will not necessarily always be the case.

## **5.6 Navigating the Workplace as a Young Adult with Chronic Pain**

One of the significant life changes that occurs when one becomes an adult is the shift to entering the workplace and beginning to take care of oneself financially. In many ways, fortuitously, I have primarily stayed within the sheltered realm of academia for the majority of my working career. That said, whether in academia or not, working adds an entirely different dimension to the discussion of chronic pain that certainly needs to be discussed. I started my working life in earnest during the summers of my undergrad, where I worked as a mailroom clerk for a government organization. In

doing so, I needed to sort incoming and outgoing mail, and go on mail delivery/pickup runs throughout the office. Yes, it is exactly as glamorous as you are thinking. However, with this job came one of my first unique challenges in the workplace, as this job mostly required me to move around and be on the go multiple times per day. While I was occasionally able to balance my activities with my co-workers, I still needed to find ways where I could sufficiently offset my pain in order to get the job done. Even with my chronic pain condition, I was still as efficient as most of my co-workers, even though I may have moved around a bit slower, I also did not have as many friends in the workplace environment. On days where I was slower than my co-workers, they often did not mind, and found ways to accommodate me. Much of the time, this led to me pushing through the pain to fulfil my responsibilities at work, even if it meant that I might need some additional downtime at home after work. These were the formative years for me in the workplace, where I had begun to figure out exactly how to balance my work and home life while maintaining a level of professionalism and not burning out completely over time. The additional impact of this first job is that it forced me to reconsider and reevaluate the types of jobs that I would take on. No longer could I take on jobs that had a physically demanding component to them, but rather it was important for me to find jobs suitable for both my career progression, but also my health condition. This level of consideration is often an important element for those with chronic pain, as considerations of work-life balance must now shift to include a health element. This transition can be incredibly difficult for many who are coping with chronic pain as the workplace can be an even more challenging environment to try to manage one's condition than at home.

The impacts of the reduction in capacity in the workplace, particularly in a physically demanding workplace is apparent in the existing literature in the field. A systematic review in the field explores some of the impacts of knee pain and arthritis on presenteeism and absenteeism (Agaliotis et al., 2014). While I would not say that my particular pain condition led to either absenteeism or significant presenteeism, I certainly faced some reduced productivity in my work, even though I made efforts to reduce these impacts. Much of the literature in the field of chronic pain in the workplace is situated in accommodations being made and particularly in ergonomically adjusting one's workplace (Amick et al., 2003; Loisel et al., 2001). Given the nature of my employment being temporary in nature, investing in ergonomically adjusting my work environment for a pre-existing work condition did not necessarily make sense at the time, as I was still sufficiently productive. That said, reflecting on the experience in hindsight, I likely should have advocated for myself in some respects to find some easier ways to more effectively manage the physical aspects of my job. This role of self-

advocacy for one's pain condition in the workplace is something that is also a common issue among workers with chronic pain and is often times a challenging conversation to be had (Jakobsen & Lillefjell, 2014).

Eventually, in doing various work in academia, I have had the benefits of working at a university level along with the challenges that exist. The primary significant benefit is that much of my work can happen in a basic office setting, by an adjustable desk rather than other forms of employment that would require far more movement or potentially strenuous activity. Thankfully, my office has truly become my domain, where I have set up a standing desk for when I need it and have plenty of space to either move around, or rest somewhat in order to do my job at maximum efficiency. The aspect of my job that is particularly challenging is when I have meetings elsewhere, or classes to teach. As one tends to do with a chronic pain condition, I trudge along and wince through the pain when it occurs so that it does not impact my work in any capacity. I fully understand that this is not expected of me, but achieving a high caliber of work is very important and any impact on what I am able to do is unacceptable. Most are understanding of the issues that I am going through, but the main challenge faced is often the students that I teach. It is often inconceivable to them that their relatively young professor would have arthritis and would be hobbling around at times with a cane, and as such it must have been something more glamorous like a skiing accident that has caused me to limp my way into class. While these particular interactions with students are few and far between, they are certainly a regular reminder of the judgmental nature of strangers. I work to offset this in class and in meetings by clearly stating any issues at the outset, just that someone will know and not be taken aback by it, but that doesn't fully eliminate experiences of judgement from others in the workplace environment. These judgmental experiences are not limited to students, and are certainly not limited to an academic work environment. Even if it is not overt by nature, it is a frequent occurrence that someone with chronic pain will face some form of adversity in the workplace, either due to the nature of their job or from co-workers, managers or clients. While thankfully these experiences are often few and far between, it is yet another dimension to the chronic pain experience that one must navigate.

## **5.7 Reflection**

The process of revisiting these experiences has run the gamut of emotions as I have written various sections of this manuscript. I have regularly oscillated between feelings of frustration, sadness and occasionally gratitude. The fact is that while discussing and analyzing my historical experiences with the chronic pain condition, many of the issues that I have faced in the past are still as prevalent today

as they were when I first encountered them. I still have the occasional challenge in best advocating for my health care, albeit these are easier to manage at 34, rather than when I was first diagnosed at 17. I continue to struggle with the balance of getting support from my family and friends, while still regularly feeling as though I am letting them down. Even as I write this section, I am internally debating if I have the strength and energy in my knees and ankles to get up and do our weekly grocery shopping after I have finished. This struggle to achieve balance extends to the workplace and my work on this manuscript and other projects. Many days, my energy reserves are depleted because of the pain in other areas of my body, such that even moving the relatively short distance from my bed or couch to the dining room table to have dinner with my family becomes an arduous journey that takes some time to recover. As a result of this lack of energy, I find that I must carefully balance my workload, both in getting small amounts of work done every day in order to achieve my goals and also to set reasonable goals and timelines in getting things done. Where I usually would be able to get many things done by myself and relatively quickly, I am finding that I now need to rely on others far more in order to help offset these challenges. This is not an easy thing for me to do, but it is something that I work on daily.

From all of these issues that have occurred throughout my journey and that I continue to struggle with today, there is one facet that continuously flows between these challenges and that is a disruption of my independence and autonomy. I am now 34 years old and I should be a fully capable and contributing member to my family, friends, workplace and society, but this is not necessarily the case. While I regularly do what I can, sometimes it may just not be enough and it is in these times where the chronic pain continues to strongly define who I am. This disruption in independence could be as simple as not completing my daily tasks to the extent that I am hoping to, or even more simply in not being able to get to my son's room to say goodnight before bedtime. On a surface level, this may seem relatively miniscule, but the inability to manage and complete my to do list frequently weighs heavily. More than anything, I want to be the best husband, father, friend, teacher and academic that I can be, but at the same time, I am also regularly aware that my ability to succeed and thrive in these areas is often impeded by my chronic pain condition. I continue to work to achieve a level of consistent independence and autonomy to do my best in most aspects of my life, but am also very aware of the fact that unless I am able to find some sort of stable treatment for my condition, I will be struggling with elements of independence and autonomy for the rest of my life.

## **5.8 Conclusion**

There are three key themes that emerged from this autoethnography that were expanded upon and linked into the current state of the field in academic literature, they are youth and young adult control of their health and decision making on health care decisions, and the impact of chronic pain on caregivers. Each of these areas alone could and should be expanded upon for research papers in their own right, something that perhaps will be worked on moving forward. Additionally, there are a number of other themes that could have been discussed at greater length, but unfortunately would not sufficiently work within the confines of a manuscript of this length. My hope is that those who have read this paper so far will either have a greater understanding of the inner nature of chronic pain conditions, particularly in young adults, or, if one is a young adult with chronic pain hopefully some of these themes and stories will ring true and work to validate that which is currently being experienced.

## **Chapter 6**

# **An Interpretative Phenomenological Analysis of Chronic Pain in those who are Self-Employed or Teleworking**

### **6.1 Abstract**

For many individuals with a chronic pain condition, traditional work environments are not nearly as appropriate for ongoing success in the workplace due to difficulties with accommodations, and the continued potential of discrimination based on one's condition. As a result, many of those with chronic pain are looking to alternative forms of work including self-employment and telework in order to best achieve their goals in ongoing employment. While there has been some work completed in the United States and Europe about self-employment and telework for those with chronic pain, this work has not explored the lived experience of individuals transitioning to these forms of employment and what this may mean for others under similar circumstances. Using Interpretative Phenomenological Analysis, the lived experience of individuals with chronic pain who are self-employed and teleworking was examined and analyzed. Some of the common areas of discussion among the four participants who completed the semi-structured interviews for this research include: issues that existed in their traditional work environment; their shift to self-employment or telework; strategies that were adopted to manage their chronic pain in their new work environment; and benefits and challenges to self-employment and telework with a chronic pain condition. All of the participants strongly believed that self-employment was the necessary approach for them given their chronic pain condition, despite the number of challenges that they faced.

Keywords: Interpretative Phenomenological Analysis, Chronic Pain, Self-Employment, Telework, Young Adults, Work, Autonomy, Self-Control

### **6.2 Introduction**

In the modern employment landscape, alternative forms of work are becoming increasingly prevalent and commonplace in our society. This is particularly true for individuals where the standard work environment is in some capacity unsuitable for them. Over the past number of years, a trend has been developing wherein people with various disabilities are turning to self-employment or telework to find ways to support themselves and to succeed and thrive in their fields of work. In general, research has shown that people with disabilities tend to have lower wages and benefits than those without and

are found to be restricted in their path to promotion and career advancement (Gouskova, 2019; Yamamoto, Unruh, & Bullis, 2011). As a result, it appears that self-employment and telework has become a viable employment option for the disabled population at even higher rates than for non-disabled populations (Gilman, 2014; Pagán, 2009).

There are a number of reasons why the disabled population is turning to self-employment, when possible, as a means to support themselves, and find financial stability and work satisfaction. The reasons for the shift to self-employment could come from a variety of sources both positive and negative. The more positive justification behind shifting to self-employment from traditional forms of employment include: being able to best accommodate one's own disability, (Jones & Latreille, 2011). Some of the more common negative reasonings include: discrimination in their past employment, fear of losing employment, or unsatisfactory employment (Ashley & Graf, 2017; Gouskova, 2019; Jones & Latreille, 2011; Yamamoto et al., 2011). This is not to say that self-employment and telework completely eliminate the negative aspects mentioned, but rather these work environments eliminate or reduce the impact of the employer serving as an impediment to managing one's pain condition in the workplace.

For those who are able to undertake self-employment and telework there are a number of benefits and challenges mentioned in the literature as to how this may have impacted their disability. Some of the key benefits include: having more flexibility to manage work alongside other responsibilities, eliminating one's commute, increased control along with self-worth and self-reliance, increased possibility for career advancement and wage increases (Ashley & Graf, 2017; Gilman, 2014; Jones & Latreille, 2011; Yamamoto et al., 2011). While there are a number of benefits to self-employment or telework, there are also challenges and barriers that exist, including: reduced government benefits, societal prejudice, increased need of support from others, educational, technological or funding barriers (Ashley & Graf, 2017; Yamamoto et al., 2011).

The association between disability and increased levels of self-employment and telework has been clearly identified and discussed within the existing literature, as well as some of the justifications behind this association along with the impacts of self-employment on the disabled population. That said, while there has been much work that has already been completed, there are key gaps in the literature that would be beneficial to explore and understand. Currently, much of the research has been completed in the United States and Europe. Exploring some of the impacts of self-employment in other areas throughout the world, would be valuable in order to expand upon the nuances that exist



in other geographic regions. The concept of self-employment has primarily been explored within the area of disabilities or work limitations, without exploring the contexts and distinctions that exist within certain types of disabilities. Thus, the focus of this research will be primarily in the realm of chronic pain, while this is still somewhat generic and covers a wide range of pain conditions, it is a starting point to honing in on the specific experiences of different dimensions of disabling pain conditions. This article will attempt to expand the discussion on self-employment, by exploring the lived experiences of those who are self-employed or teleworking with chronic pain conditions.

### **6.3 Methods**

This research utilizes Interpretative Phenomenological Analysis (IPA) to explore and understand the lived experiences of those who are self-employed with chronic pain conditions. In undertaking IPA, the researcher is trying to explore the participant's personal world and gain an "insider's perspective" on the particular experience in question, from which the researcher can then interpret these experiences (Smith et al., 1999). This method of IPA is considered to be a double hermeneutic, wherein the researcher is trying to gain an understanding of the participant who is trying to gain an understanding of their own experience (Smith, 2011). At its most effective, IPA is both identifying the shared themes across the data collected, but also identifying and discussing the ways in which these themes are important for these individuals (Smith, 2011).

Data collected in IPA studies are usually through detailed personal accounts, usually done through audio-recorded and transcribed semi-structured interviews (Smith, 2011). IPA research generally consists of relatively small sample size, to enable a more detailed reading of the participants' accounts to try to develop a more detailed understanding of challenging conditions (Smith & Osborn, 2015). In performing IPA, the researcher codes the data, identifies shared themes across the transcripts, and explores and unpacks the meanings behind these shared themes (Smith et al., 1999).

In this particular project, semi-structured interviews were conducted with four individuals in the Waterloo Region who identified as both having an ongoing chronic pain condition, as well as being self-employed or teleworking. These individuals were recruited to participate in the study from a local community group called the Waterloo Region Chronic Pain Initiative, which consists of a number of individuals with chronic pain, along with their caregivers, who attend events and programming related to their conditions. Inclusion criteria for this study consisted of those who were 18 years of old or older, had a diagnosed chronic pain condition, and were either self-employed or

teleworking. Individuals who met the inclusion criteria for the study, were interviewed at their convenience using a semi-structured interview guide. This guide was designed to explore and unpack the experience of being self-employed with a chronic pain condition along with understanding past potential work experiences. The types of questions inquired into work experiences before self-employment and telework, current work processes, managing chronic pain and work, interactions with others, impacts on relationships and stress management (a full copy of the interview guide is included in Appendix A). Being semi-structured in nature, the guide included a number of general probes in order to guide the participant into certain areas of reflection, but for the most part, participants were given the ability to examine their own experiences at length and to guide the discussion accordingly.

The role of the researcher in the process of an Interpretative Phenomenological Analysis is important in multiple ways, both through the data collection process and through their interpretative lens that is helping to shape the experiences of the participants. In the data collection process, the researcher must work to gather enough of the experience to fully understand the phenomenon, while giving the participant a level of freedom and flexibility to share their experiences in the way they see fit. The semi-structured interview approach helps with this process, but the role of the researcher as an interviewer is also significant. Developing a level of rapport with the participants to allow them to openly and comfortably share their work experiences, and especially some of the challenges that they endured, can be particularly important. It is here where this researcher had his first advantage of being an insider in the chronic pain community, having a chronic pain condition himself and discussing his pain condition openly through the Waterloo Region Chronic Pain Initiative events. This 'insider' status likely allowed participants to feel more at ease in sharing their experiences as they knew that the person interviewing them had some similarities in their experiences and would be able to sufficiently understand what they were going through. That said, this role has the possibility of being used inappropriately and taken advantage of, by blending the researcher's experience with the participants and in doing so veering away from the initial intent and meaning of the participant's experience. Great care was taken in the interviewing process to identify the commonality of experience, but to not share too much about their own experience to remain focused on the participant themselves.

It is through the data analysis and interpretation process where somewhat of a delicate balance takes place, as the value of the participants words is significant and should not be distorted by the

researcher's interpretative lens. A number of protective measures were put in place in the data analysis process to ensure that the participants' experience as captured in the analysis was staying true to their actual experience. To begin with, in the interview coding and thematic grouping, the themes were developed and extracted in as close to the participants original wording as possible. By keeping to the words of the participants, at least for the initial results section, it was possible to ensure that the original themes did not deviate much, if at all, from the participant experience. To reinforce the credibility of the analysis relative to the participant experience, member checking was performed with two of the participants who I was able to follow up with when the manuscript was being developed, the other two participants did not respond for follow up. This allowed for the participants themselves to indicate whether or not their experience with chronic pain and self-employment and telework was reflected in this analysis. As indicated previously, in the results section the role of the researcher was to stay as close to the experience of the participants as possible, in the analysis section of the paper the interpretative lens of the researcher comes to the forefront. It is here where the researcher on the project is uniquely situated to analyze this data, as he has lived experience with chronic pain and employment himself. This lived experience was used to ensure a level of authenticity throughout the entirety of the manuscript, by internally reflecting and self-checking as to whether the analysis rang true and was representative of the overarching experience with chronic pain. Effort was made to first and foremost focus on the experiences of the participant, but the added value of the researcher knowledge and experience added some level of value to the interpretation in the analysis.

## **6.4 Results**

As previously mentioned, there were four participants who agreed to participate in this study. Of these participants, three were female and one was male. These participants ranged in age between 25-45 at the time of the interview. All of the participants were White, and primarily middle class. Below is a more detailed prescription of each of the participants.

Participant 1 was approximately 40 years old at the time of the interview and is a psychotherapist. She had transitioned into a self-employment role in the past three years by developing her own private practice where she has been able to manage her own patient load. This participant works hard to make sure that her business and client base is thriving, often to the detriment of her physical health, although she works hard to self-regulate and find balance between thriving at work and managing her health and well-being.

Participant 2 is the youngest participant at 25 years old and is a research assistant and coordinator. Participant 2 transitioned to a telework role in the past two to three years by finding a job that would allow her to work remotely, while still capitalizing on the skill set that she had developed. This participant benefits greatly from the flexibility afforded to her by working from home, while being able to manage her workload and manage her chronic pain condition.

Participant 3 was the only male participant in the group and in his mid-30s. He had an accident while on vacation which led to permanent nerve damage and an ongoing chronic pain condition. Of the participants, he is the only participant to completely change his career path as a result of his chronic pain condition, being forced out of his prior employment as a Personal Service Provider to owning his own landscaping company. This participant struggled with medication usage, resorting to seeking out narcotics to help manage and reduce his ongoing pain.

Participant 4 was a female graphic designer who was in her mid-40s. She had shifted to self-employment within the past two years after trying to work for a year full time with a chronic pain condition and struggled to keep up with the workload and effectively manage her condition. The two primary challenges for this participant included the difficulties of keeping up with deadlines set by clients, especially if they were rush jobs, and not being able to fully use physical activity and sports as a significant part of her daily life. While this participant used the gym, stretching and working out as a primary way to manage her chronic pain condition, it was still not the same level of physical activity that she was previously accustomed to.

#### **6.4.1 Issues in Traditional Work Environment**

There are a number of key issues that were identified about the traditional work environment. Half of the participants indicated a common struggle with the daily commute into work. The drive to get to work was often times nearly as bad as getting through the work day as one was unable to make themselves comfortable in the car for any extended period of time. Participant 4 described, “By the time I’d drive home, I was in so much pain that there was nothing going on through the evenings.” Similarly, Participant 2 discussed their commute in the following way, “I was having to go in and drive in with chronic pain a lot of the time. It would get to the point where it was about a 35-minute drive to school and about 20... 20-25 minutes, I would start getting uncomfortable and having trouble driving. So, it was definitely a slog just to get up and have to drive.” The elimination of the need to commute can be an incredibly important facet to considering the shift to self-employment or telework.

Once in the workplace itself, generally co-workers were found to be supportive and understanding. While one's chronic pain condition was not often a topic of conversation in the workplace, it was found to be difficult to completely hide the pain from others. Conversely, employers or supervisors would often verbally support their employees in their struggle with chronic pain, but their words did not match their actions. Chronic pain conditions in their prior workplaces led to poor performance reviews, lack of support, and functional impediments in supporting their health challenges. Participant 1 talked about the challenges of employers reviewing her performance and its' impact her potential future contracts "I definitely felt pressure from the employer...Often the line of work that I am in, it's a lot of contract work. So, if you don't perform well or you have to take days off it's like an easy way to not renew someone's contract." The lack of support from employers, combined with the rigidity, requirements and accountability within the traditional workplace environment led all of the participants to leave this work environment, and seek out a better situation at home, that said, for many others, this is not inherently an option.

#### **6.4.2 Shifting to Self-Employment**

All of the participants were able to transition from traditional work environments to contract positions, three of four participants moved onto full self-employment, while one participant continued contract work through teleworking. All participants strived to achieve some sort of daily routine, but often times struggled to achieve it. Of the participants, half of them worked nearly 12 hours a day and managed this by either taking regular, lengthier breaks, or working consistently for a few days straight before needing extended respite. The other half of participants worked about 5-6 hours straight, while taking frequent shorter breaks and exercising. This variety of approaches in managing one's workday while having a chronic pain condition demonstrates how the flexibility of self-employment or telework is key for the ongoing sustainability in the workplace.

#### **6.4.3 Strategies for Self-Management**

There were many approaches to self-management of chronic pain during the workday that were commonly identified across multiple respondents. Half of the respondents identified using some form of meditation or mindfulness approach in order to try to ground themselves to minimize their pain and focus on their work. Participant 1 described starting her day with meditation and mindfulness, "it takes me quite a while to get moving in the morning, and I take special time in the morning to like do meditation and mindfulness", whereas Participant 3 uses meditation to reduce their pain while it is

occurring, “I tried to meditate a lot actually, because I’m very spiritual. I find like the healing energy... I try to just focus on that a lot of times if I’m having a crisis.” The other half of respondents utilized exercise and stretching to try to physically relieve their pain condition. Participant 4 described her use of exercise in pain management as follows, “as soon as the pain starts a little bit and gets to the point where it is burning, then I know to stop and do something else. Then I usually put the gym in the middle of the day to break it up... whatever happens at the gym, tends to get the blood flowing and just makes the pain kind of subside a little bit and then I can go back to work.” The respondents indicated that they used a variety of time management strategies to manage their workload while having chronic pain. These strategies included: detailed project planning, taking regularly scheduled breaks so as to not burn out, taking administrative days weekly to catch up on non-urgent work and focusing on more difficult tasks earlier in the day. All of the respondents indicated that they would either need to take regular naps to recuperate, or if they pushed through their pain it would often lead to an entire day of bedrest and sleep. From this, all participants discussed days which they knew were not going to be productive as a result of significant pain, and all participants identified the need to make the decision to ‘wipe the day clean’ and reschedule their tasks to a day when they were more functional. This led to a day in bed to reduce the impact of their chronic pain, but sometimes it was just to the point that pain was leading to a lack of mental clarity, which would significantly impede their work. Two respondents identified ergonomics as a key facet to managing their chronic pain condition, either through utilizing chairs or foot rests, or repositioning their computer monitors so as to not exacerbate their pain. Participant 4 went into detail about how her ergonomic set up was helpful in managing her pain condition, “I got a very high-end chair that is very ergonomic.... It actually moves with your body, it is sort of the best chair you can find for the issues I am having with my back. I find that it is the best investment for sure... That and my monitor moves back and forth, and up and down, so that you are not slouching, and the foot stool. Just being in a proper position, for sure helps.” Medication was mentioned by three out of four respondents as a key component to managing their chronic pain condition, but two of these respondents also indicated that they were struggling with effectively managing their pain through medication. Finally, one respondent indicated that nutrition was an important facet to regularly managing their chronic pain condition.

#### **6.4.4 Benefits to Self-Employment or Telework**

Respondents found a multitude of similar benefits to self-employment or telework in being able to find employment while managing their chronic pain condition. Most respondents discussed the lack of external responsibility and firmly set deadlines as being of significant benefit to being able to manage both work and chronic pain. Even with the instance of telework, where there is some external responsibility, being able to work at home independently allowed all of the respondents to set their own timelines while being able to factor in their own concerns based on chronic pain. This self-empowerment as a benefit to either self-employment or telework is of vital importance, as those with chronic pain may have little control over their daily status, at least there is an ability to have some amount of control over their work. Another benefit found by most respondents was that the current state of connectivity and technology allows one to manage their work more easily and successfully from home and thus at least mostly eliminate the need to commute, which was found to be a major deterrent in more traditional work environments. Participant 2 summarized this by saying, “All I need is a computer, a telephone and an internet connection and I can do everything.” The one respondent who regularly needed to both commute and do physical labour did struggle a bit more with their chronic pain condition, but when capable they found the work to be relaxing, which offset many of the challenges in managing their chronic pain.

#### **6.4.5 Challenges to Self-Employment or Telework**

While the benefits to self-employment or telework are significant, there are a number of challenges that exist to working in these capacities. For all of the respondents who were self-employed, there was a regular fear of potentially losing clients and as a result losing necessary income. This fear often led to respondents putting their work before their pain condition, pushing through the work week to have sometimes non-functional weekends, or working through the weekends to catch up. Participant 4 noted, “If a project comes in... the only problem with freelancing is that if a project comes in and there is a deadline, a major deadline, then you tend to, you have to finish it, and then it is usually crashing for three days after.”

An additional challenge expressed by a couple of respondents was that the financial limitations in being self-employed led to them not being able to buy the necessary tools or technologies that they needed to help them best manage their work. Participant 4 was unable to afford some upgraded tools to make their job that much easier because the government support they were receiving was not enough, “So that’s my biggest challenge... I’m just trying to find ways to get like maybe a better cart

like a dolly or something. Like one that can hold more weight, perhaps. One I can pull... well I probably could if the funds were there. Because now I'm on ODSP, which makes money super tight because they only give you enough to survive." For many of these jobs it means that the work will take more time, and this is something that is identified at the outset with the clients, but for some clients the deadline can be very important so it requires one to work through their pain in order to get the job done and get paid in order to sustain oneself.

One final challenge that existed across all of the participants was an ongoing struggle of work-life balance. Three out of four participants indicated that their partner was incredibly supportive, often taking on additional work at home, or facing the brunt of the participant's irritability when pain is flaring up. The final participant lost their partner due to this increased irritability and aggression that often coincided with this irritability. Participant 3 said, "Apparently I'm more irritable. Because I lost my partner of five years because of my chronic pain." Nearly all participants identified that while many friends are supportive when they can be, it is often a struggle to make and keep social plans with friend groups and as a result this can lead to increased strain on friendships.

## **6.5 Discussion**

For the purposes of this study, self-employment and telework were grouped together in an area of non-traditional work environments to help those with chronic pain manage their pain condition more effectively while continuing to work. Through the experiences of the participants, it was found that either and often times the combination of self-employment and telework offered the greatest support for managing one's chronic pain condition. That said, there are three permutations of self-employment and telework that are represented through this study, including: self-employed and teleworking; self-employed and not teleworking, and not self-employed and teleworking. Participants 1 and 4 experienced self-employment and telework, Participant 2 was not self-employed and teleworked, and Participant 3 was self-employed and not teleworking. While there were certainly advantages found to all of these non-traditional work environments, greater benefit was found in the participants who were teleworking. This allowed participants to work from their home environment which in most cases was maximized to suit their needs and maintain a level of comfort while still managing their workload. In future work in the field, it would be beneficial to intentionally target these permutations to better represent some of the nuances that exist between them, although some of the specific benefits to telework are highlighted below.



The commonality in themes that emerged from the interviews with the participants tended to align with many aspects of the existing literature. Most of participants left their prior work experiences as a result of restrictive work schedules or fear of losing their employment (Yamamoto et al., 2011). One challenge mentioned by participants that was not as common in the existing literature was the importance of the daily commute in making decisions about employment with chronic pain (Gilman, 2014). For at least half of the participants, the ability to reduce or completely eliminate the need to commute was a significant contributing factor for the shift to self-employment or telework. This conversation is increasingly important today, given the current state of the world, more people than ever are teleworking at least in some capacity. The question for those with chronic pain shifts to whether or not there is a reasonable amount of autonomy and control within the job to continue to report to someone else, while eliminating or reducing the in-person elements, or is it still important to transition to self-employment to completely eliminate the need for a higher authority to be involved in managing one's chronic pain condition?

The majority of the discussion about self-employment or telework for those with chronic pain lies in the balance of benefits and challenges in taking on this particular work situation. For all of the participants, they would clearly identify that the benefits of self-employment or telework in being able to manage their chronic pain far outweigh the challenges, even though the challenges may be significant. The aspect of having control over how they approach their work and their work day is more significant than any of the additional challenges that are faced. This is particularly true in a North American context, where one's identity is often strongly rooted in their job and career, by reducing control over one's capacity in the workplace, it could significantly impact one's overall self-worth. This increased control and increase in self-worth and self-reliance while being a theme mentioned in the existing research and literature, yet one that requires further exploration (Ashley & Graf, 2017; Prottas & Thompson, 2006; Yamamoto et al., 2011). In living with a chronic pain condition, one has many aspects of control over their life taken away from them. The desire is often present to maintain a sense of normalcy and approach daily tasks in the way one is used to, but the pain prevents this from happening, or at least happening to the fullest extent. This was demonstrated through the experiences of Participant 4 who, prior to the onset of their chronic pain condition, was very active and participated in a number of sports. If given the opportunity, Participant 4 would still eagerly go out and play sports regularly, but her body and chronic pain condition do not allow it to happen. These themes of autonomy appear in the literature, but focused more on either end of the age spectrum, either in adolescents or the elderly (Matos, Bernardes, Goubert, & Beyers, 2017;

Riggenbach et al., 2021). The lack of focus in the literature on issues of autonomy related to working aged adults with chronic pain conditions demonstrates both a gap in this field, but also a systemic inclination to study issues of chronic pain predominantly through the lens of the elderly, or in some cases children and adolescents. While the elderly certainly make up a large portion of those with chronic pain, the nature of their condition and the issues that they face do not extend to everyone with chronic pain. These difficulties in consistently searching for autonomy and independence are particularly apparent in working aged adults who would otherwise be accustomed to having their full autonomy and struggle in having at least some of their autonomy taken away as a result of their chronic pain condition. By having such a level of autonomy and control taken away, it becomes that much more important to find this autonomy elsewhere, especially in work, which increases the value and importance of self-employment and telework as an option for those with chronic pain.

It is also important to note the challenge of struggling to maintain clients as a result of deficits rooted in one's chronic pain condition. This challenge, while isolated specifically to those who are self-employed, is one that is not commonly discussed within the literature. While one is certainly able to navigate their day in the way that best suits them, there are still external demands and stressors that need to be managed in order to successfully be self-employed and grow one's business (Saarni et al., 2008). The ability for one to have the control to determine ways to address these challenges is of vital importance and mostly offsets these challenges, it still does not mean that these challenges are not as important and do not act as a significant impediment to successful self-employment while managing a chronic pain condition. This delicate balancing act between the benefits and challenges of self-employment must be taken under consideration by all who are considering this shift in the nature of employment while managing their chronic pain condition. In the case of the participants of this study, which is supported by the literature, most individuals state that the benefits are significantly outweighing the challenges, that said, this type of work may not be ideally suited for everyone with chronic pain and more traditional work situations may still be most suitable.

The complexities of managing a chronic pain condition in the workplace are all encompassing, and these challenges are not solely limited to traditional work environments, but rather extend to telework and self-employment based work. In looking to understand the nuances of a chronic pain condition and how one manages it, it is important to use a biopsychosocial perspective to explore all facets of the condition, but also to effectively manage the condition, in this case particularly manage the condition while being self-employed or teleworking (Lambeek et al., 2010; Wynne-Jones & Main,

2011). While this research showed that the biological aspect of their chronic pain is being better managed under self-employment, the psychological and sociological facets may not be benefitting as much. Those who are self-employed may not have the psychological challenges of needing to report to another, or ask for accommodation, as a result of their chronic pain condition, but are still likely struggling with the demands of growing their business and in many cases keeping their clients happy. In working to maintain their business, often one of the requirements is social interactions with others. For some, who determine that at least their closest relationships are of key importance, they will work hard to achieve some sort of balance with at least their primary relationships. For others, social relationships of any kind may be a casualty of seeking success in self-employment, particularly true for casual friendships and sometimes true for loved ones. The impacts of self-employment and telework are significant on those with chronic pain conditions, but there are other effects to consider on those who are close to these individuals.

For this study, there were three significant limitations. The first of these limitations is in the number of participants and overall sample recruited for this project. While the literature on Interpretative Phenomenological Analysis identifies that the ideal sample size for this methodology is 5-15 participants, in this project four participants agreed to participate. The slightly reduced sample size is likely due to the fact that at the time of recruitment, there was a smaller percentage of individuals with chronic pain who were self-employed or teleworking and specifically being centered in Waterloo and using the Waterloo Region Chronic Pain Initiative as the sample frame may have further contributed to limiting the overall sample. Additionally, the participants who agreed to take part in this research were relatively homogenous in nature in a number of ways, specifically in that all participants were younger, Caucasian, middle class, predominantly female and mostly working in less physically demanding fields and with their job were able to work from home. The homogeneity of the sample, while useful in discussing the general lived experiences of individuals who are self-employed and teleworking with chronic pain conditions, misses out on some of the specificity inherent in the nuances of aspects of one's identity. The literature indicates that differences in age, race/ethnicity, socioeconomic status and gender all play a role in how individuals experience chronic pain and are treated as a result of these differences (Morais et al., 2021). An individual's age may have impacted their interest and ability to shift to a teleworking or self-employment nature of employment, as one may be more situated in their work environment and as a result may be more reticent to make a dramatic change. One's race/ethnicity is shown to impact both how pain is experienced and managed. (Dubois-Mendes, Sa, Meneses, De Andrade, & Baptista, 2021; Meints et

al., 2018; Morales & Yong, 2021). These differences might impact both whether someone makes the decision to shift to a telework or self-employment work and even whether or not that option is available to them. (Job Flexibilities and Work Schedules - 2017-2018 Data from the American Time Use Survey, 2019). Socioeconomically, there are some inherent financial risks to shifting to self-employment and to a lesser extent teleworking. In branching out on one's own to be self-employed, it must be noted that not all businesses are successful, and while some may be financially stable enough to take that risk and make a self-employment work situation work for them, others may need the stability of consistent pay to sustain themselves. Additionally, socioeconomic status may play a role in the types of job that one is in and whether or not that job may even be suitable for a telework based environment. More physical based labour, which generally is more associated with lower socioeconomic class, does not allow for one to have the option to telework, which precludes them from being able to benefit from this work approach with chronic pain. Finally, there may be an underlying element of potential discrimination that must be considered by individuals with chronic pain, especially those of different backgrounds. As indicated by the participants, there was often subtle or less subtle discrimination directed to them at their workplace as a result of their chronic pain condition. Given the state of the world currently, it is quite possible that this discrimination may be compounded by other facets of one's identity, such as one's race and socioeconomic status. This additional layer of discrimination may limit one's ability to successfully negotiate a telework accommodation, or if self-employed may limit one's ability to effectively grow their business. These aspects of identity were not a key variable at the time of data collection and this study was focused more heavily on the general lived experiences, that said it would be important moving forward to factor in these elements of identity, not only to determine what is consistent across individuals with chronic pain of all backgrounds, but also to discuss what about the experience differs as a result of one's identity.

Another significant limitation was in the timing of when data collection occurred, as original interviews were completed in 2018, before the pandemic that changed the nature of work and caused most workplaces to shift to some form of telework. Given current circumstances, it would be much easier to find additional people with chronic pain conditions who were self-employed or teleworking; although this would change the nature of the study as the intent was to recruit individuals who balanced various factors and made the decision to become self-employed or telework to better manage their chronic pain condition. The ease of adding to the sample, may also eliminate some of the barriers to identity that were mentioned previously, particularly that of age., race/ethnicity and

socioeconomic status. Shifting to telework or self-employment may have originally been more of an option for younger populations as they may not be as established within their field, and may also be more technologically nimble to adapt to a home-based work environment. Similarly, those who are White and of higher socioeconomic status may have had greater opportunity and fewer systemic barriers to make this shift to telework or self-employment. As much of the population has now forcibly been shifted to a telework based modality, these barriers may be significantly lessened. This may be an interesting expansion of this original project at some point, given the current pandemic environment. These new workplace dynamics that have developed out of COVID-19 are not represented in this current project, but would be an interesting area of exploration in the future.

A final limitation exists in the lack of specificity of the nature of the chronic pain condition and where the condition originated. In this study, there were no distinctions made as to the type of chronic pain and where the pain originated. These nuances to chronic pain conditions could be important to unpack in a number of ways. The origin of a chronic pain condition either being in the workplace, or not, could shape the willingness of the employer to accommodate a worker with a chronic pain condition, thus potentially making it either more feasible to remain in the workplace in a manageable capacity, or to shift to some form of telework accommodation. Additionally, the type of pain condition and how it may impact one's ability to work or the accommodations needed was not an area of focus of this particular study. In future work, it would be valuable to focus on smaller subsets of the larger chronic pain population to explore particular nuances of mobility reducing pain, versus a migraine like pain condition.

## **Chapter 7**

### **Conclusion**

#### **7.1 Summary of Manuscripts and their Contributions to the Field**

Prior to discussing the connections of the manuscripts and future directions and implications of where research in this field is able to progress moving forward, it would be prudent to briefly summarize and review the three primary manuscripts of this dissertation and what they have individually added to the field.

The first manuscript (Chapter 4) was a methodological overview of two contemporary approaches to phenomenological research. This manuscript detailed how both Jonathan Smith and Maxwell van Manen developed their guidelines towards phenomenology, how these approaches were similar and where these approaches differed from one another. Similarities in these approaches included: data collection, sample sizes and careful analysis of the participant descriptions. The primary difference between their approaches was that Smith includes an interpretative element in his analysis, whereas van Manen relies solely on the description. Following this description of the methodologies and comparison between the approaches, a critique was included to review the benefits and challenges in utilizing these contemporary approaches. Both Smith and van Manen allow researchers to understand and apply their approaches without fully understanding the intricacies of the classical philosophies of phenomenology. This allows a researcher to use applied forms of these approaches while working to understand their philosophical underpinnings. Additionally, by taking on a more applied approach, researchers are given more detailed guidelines and instructions as to how to successfully utilize these methodologies. This level of accessibility for researchers is of significant benefit in utilizing these approaches. The challenges to these methodologies lie in the nature of open-ended data collection and the interpretative element of Smith's Interpretative Phenomenological Analysis (IPA). Both of these challenges rely on the researcher having the ability to either successfully extract all of the pertinent information in the interview process, while allowing the participant to sufficiently share their experiences, or in the analysis and interpretative aspect of IPA to properly interpret what can be drawn from the participant descriptions of their experiences. These contemporary approaches to phenomenology can be successfully applied to workplace health research through either the inclusion of an interpretative element in IPA, or by using a lifeworlds structure to help accurately describe issues in the workplace and their impacts as seen in van Manen's methodology. This manuscript both

helps to set the stage for the third manuscript where IPA was used to explore the topic of chronic pain in those who are self-employed or are teleworking, but even more generally, it serves as an open introduction to these contemporary methodologies for researchers who are new to phenomenology and may want to utilize it in their work.

The second manuscript (Chapter 5) was an autoethnography of my lived experiences with chronic pain. This manuscript explored my experiences with chronic pain, highlighting some of the key facets to my life with chronic pain particularly focusing on my time as a young adult, but also in reflecting and analyzing how these experiences connect with other younger adults with chronic pain conditions and with the overall chronic pain community. This autoethnography covered three main areas: initial diagnosis, reactions and suggested medical interventions; personal relationships and interactions; and navigating the workplace as a young adult with chronic pain. My issues with my initial diagnosis and interactions with health care providers was reflected upon in the literature with adjacent health care issues where adolescents and young adults may find challenges in advocating for their own health with physicians despite being completely capable of making informed decisions on their own behalf. In discussing the impacts of chronic pain on my relationships, I focused primarily on my parents and my wife who have both served as my caregivers at one point in time or another. The role of caregivers and the impact that a chronic pain condition has on them is important to explore and was linked to existing literature in the field. Finally, my experiences of chronic pain in the workplace were discussed, not only because it is my field of study, but also because work is a significant aspect of my life and the interactions of my chronic pain and work has led to my interest in this field and focusing on this area for my dissertation. The autoethnography concludes with a reflection of the impacts of sharing these experiences and the common theme that emerged across all of the areas of discussion being that of disrupted independence or autonomy. This autoethnography served a dual purpose, both in sharing my own personal experiences as a young adult, and reflecting on these experiences in how they may impact others in similar circumstances, but also in setting up my analytic frame for future work in this field, something that will be discussed further in the next section of the thesis.

The third manuscript (Chapter 6) utilized IPA, as discussed in detail in the first manuscript (Chapter 4), to explore the issues of chronic pain in those who are self-employed or teleworking. IPA was used to explore the lived experience of these individuals who are self-employed or teleworking and to interpret what these experiences mean to them. The common themes that emerged from the

interviews with the participants included: issues in traditional work environments; shifting to self-employment or telework; strategies used to manage and balance chronic pain in their new work environment; and benefits and challenges to self-employment and telework with a chronic pain condition. In interpreting the themes presented there were some key overarching concepts that were at the core of managing chronic pain and self-employment or telework, including: eliminating the daily commute; autonomy and control; managing demands and stressors of a successful business particularly in self-employment; and understanding the wide-ranging impacts of a chronic pain condition while being self-employed or teleworking as compared to a more specific physiological perspective. The concepts of autonomy and control appeared in multiple areas and themes in the lived experiences of the participants. The combination of lack of control as a result of their chronic pain condition and lack of control in traditional workplace environments often led to participants' desire to shift to a self-employment or teleworking based employment in order to try to regain some of their lost control. This combined with a key element of reducing or potentially eliminating one's commute were contributing factors to the participants making this transition. One of the more significant challenges among those who were self-employed with a chronic pain condition was the management of stressors in meeting clients' demands and timelines. Under traditional work environments losing a client by not meeting their deadline is a significant setback and may lead to a reprimand from a supervisor, but it does not necessarily hamper the overall success of the business, or whether or not you will be paid. In self-employment, managing clients and their needs is key in order to grow one's business to survive, thrive and be financially viable. This additional stress can be significant, but was found to be mitigated by having the control over the strategies of managing these challenges. Finally, while the physiological or biological aspects of chronic pain may be better managed while teleworking or being self-employed, there remains lingering psychological and sociological challenges. The psychological impact, as mentioned earlier is in the stressors of growing their business, which in turn leads to the sociological impacts of challenges in social interactions with others, as these interactions may need to be set aside to either focus on business or to spend the necessary time recovering from the additional work. The intricacies and nuances of the lived experience of self-employment and telework with a chronic pain condition are particularly important to understand both as these work options are becoming increasingly common and even more so now with the majority of people working from home as a result of the COVID-19 pandemic, which will be discussed later in the chapter.



## 7.2 Manuscript Connections

The three manuscripts contained in this dissertation all add something unique to the existing literature on chronic pain and chronic pain in the workplace, but they also work together to add far more than the sum of their individual parts. There are some connections that can be made between combinations of two of the manuscripts, along with some connections that work across all three manuscripts.

The methodological manuscript on contemporary approaches to phenomenology is directly linked with the direct research manuscript on Interpretative Phenomenological Analysis among those who are teleworking and self-employed with chronic pain, as it serves to identify the thought process and research that was employed in selecting the appropriate methodology to utilize for my first foray into primary research in this specific field. One of the primary challenges for many new researchers is in picking the most suitable methodology to help guide their research. This is particularly true for qualitative methodologies in general, where the choice of methodology has a strong direction and impact as to how the research is framed. The same can be said for quantitative methodologies, however the process is somewhat more directed in nature as compared to qualitative approaches. For example, the work on teleworking and self-employment could have taken a grounded theory, narrative, or other qualitative approach to explore this topic deeply. Instead, the decision was made to utilize phenomenology, and then narrow down specifically to contemporary forms of phenomenology, versus more classical approaches and finally to select Interpretative Phenomenological Analysis. Each step in this process has a level of importance in its own right. Phenomenology was chosen specifically because the lived experience of teleworking or being self-employed with chronic pain conditions was more valuable to unpack for readers to better understand the nature of working with these conditions. Once within the field of phenomenology, the decision was made to utilize more contemporary versus classical choices both to provide a set of clear guidelines and foundations to appropriately undertake phenomenological research, while at the same time not being limited by some of the specific philosophical requirements of each of the classical approaches. Finally, Interpretative Phenomenological Analysis was chosen specifically because it goes beyond the step of describing the lived experience of the participants, but also interprets these experiences for the reader. This added step of interpretation can be of key importance to the audience of the manuscript as it further distills the lived experience and connects some facets of it to the current state of literature. The methodological manuscript ends up serving as a logic behind the final

steps of the decision-making process in narrowing down the appropriate methodology for analyzing the area of self-employment and telework among those who have chronic pain.

There are also a number of ways in which the autoethnography manuscript can be connected to the third manuscript on Interpretative Phenomenological Analysis of those who are self-employed or teleworking with a chronic pain condition. The autoethnography manuscript serves multiple purposes as a foundation and bridge within this thesis. As a foundation, the autoethnography situates my analysis in the field of chronic pain and chronic pain in the workplace by clearly delineating my history and experiences with chronic pain in general, but also chronic pain in the workplace. Through the inclusion of these experiences, and reflecting on how these experiences both impacted me and likely impacted others under similar circumstances, it allows me as an author to have the ability to define my analytic frame and perspective. Delineating this analytic frame is particularly important for the third manuscript using Interpretative Phenomenological Analysis at the forefront as it positions any interpretations that I am making relative to my own experiences and highlights my value in the interpretative process by situating my ‘insider’ status and experience with chronic pain. Had I taken van Manen’s approach to phenomenology and employed a more descriptive approach to the third manuscript, the autoethnography would have been able to serve as more of a bracketing exercise. Allowing me, as the researcher, the ability to clearly identify and discuss my own experiences and then bracket them to focus on the descriptions of the lived experiences of the participants. Being a researcher with a chronic pain condition myself, the autoethnography was able to serve in these multiple capacities, both in sharing and reflecting on my own experiences, but also in setting up my analytic frame when analyzing and interpreting others experiences as well, as seen in the third manuscript.

The final connection that works across all three manuscripts is the use of qualitative methodologies to examine issues of chronic pain and chronic pain in the workplace. While qualitative methodologies are being utilized by researchers to study these issues, they are certainly not the predominant set of methodologies in the field. The place of quantitative methodologies is clear in these areas as they help to set and define the scope of the issues present in these fields, but these quantitative methodologies are lacking in their capacity to fully understand the details of chronic pain in various workplace environments. Qualitative methodologies may also be more approachable to employers and other stakeholders in the field, which may lead to greater understanding of the nature of chronic pain and in turn lead to increased cooperation in creating a cooperative work environment.

The qualitative approaches utilized in the manuscripts of this dissertation help to increase the overall understanding of the nuances of chronic pain and specifically chronic pain among those who are self-employed and teleworking, which up until this point has been a mostly understudied area, particularly in Canadian research. By discussing and critiquing contemporary approaches of phenomenology for novice researchers in the first manuscript, then demonstrating how IPA is successfully implemented in the third manuscript and finally using autoethnography as a complementary qualitative approach in the second manuscript this dissertation helps to demonstrate the utility of qualitative methodological approaches in the field of chronic pain in the workplace.

### **7.3 Future Directions and Implications**

There are a number of different directions that can be explored following the work in this thesis and the manuscripts contained within it. These directions can be grouped into three overarching themes: methodology, chronic pain and specifically chronic pain in the workplace.

The choice of utilizing qualitative methodologies throughout the various manuscripts of this thesis was a calculated decision. While there has certainly been qualitative work previously done in the areas of chronic pain and chronic pain in the workplace, there is more of a focus on quantitative methodologies to explore these topic areas rather than qualitative approaches. In many ways, this is a logical decision as the statistical and epidemiological assessments of the chronic pain conditions themselves, their impacts on work and interventions designed to mitigate these impacts are of key importance to make further improvements for those with chronic pain in the workplace. However, in doing so, the detailed understanding of the lived experience of working with chronic pain conditions is not as much at the forefront. By exploring the area of chronic pain in the workplace using a qualitative lens and shining a light on the intricacies of the lived experience of these conditions this increased understanding can lead to better designed and targeted interventions and policies. For example, in exploring some of the nuances of the lived experiences of teleworking with a chronic pain condition, detailed policies and procedures may be developed and implemented in order to better help individuals manage their conditions in a teleworking environment. Additionally, based on the lived experience of those who are self-employed with chronic pain, it may be possible to develop targeted support programs and groups to further help individuals with chronic pain find a working balance within their self-employment. While there has certainly been a great deal of work completed in the area of chronic pain in the workplace, there is still far more that can and should be done. Using qualitative methodologies to explore the lived experience of these conditions continues to be of key

importance to accurately capture the essence of these experiences in order to best adapt to an ever-changing work environment.

One of the ways in which the research completed in this thesis has deviated from the majority of research completed in the area of chronic pain, is the focus on younger individuals adapting to chronic pain conditions in their work environment. This is seen through both my personal experiences with chronic pain in the autoethnography manuscript, but also through the experiences of those who participated in the telework and self-employment study, with the age range of the population falling between 25-45 years of age. While focusing on a younger target population was not by design, nor was it a primary goal within the research design, it is still an important facet to investigate in future research. Chronic pain is often seen as a condition that impacts older adults and those who are younger often face a lack of understanding, or even discrimination when addressing and managing their condition, particularly in a work environment, but also at home and in social groups. Exploring the nuances of chronic pain and its management among younger populations is an important future direction of research. The prevalence of chronic pain conditions is regularly increasing in society, and while originally research on chronic pain conditions were more heavily focused among older adults, there are increasing numbers of younger age groups who are developing these conditions and face regular stigma due to the misconception that chronic pain is limited to older populations. This mostly underserved population needs more research to be completed in order to fully understand what they are going through and how to best accommodate them. By increasing the knowledge base about chronic pain in younger populations through research, this should reduce and mitigate some of the stigma that they face, which should help with their day-to-day management, let alone if functional systemic changes could be made.

In the main area of chronic pain in the workplace, there are a number of avenues that can be explored following this preliminary work in the field. Since the original research was completed, the world, and particularly the nature of the workplace has changed significantly as a result of the COVID-19 pandemic. Starting in March of 2020, much of the world transitioned from their traditional work environments to more telework based approaches in order to comply with stay-at-home orders and keep the population safe and healthy. In doing so, many industries and businesses needed to fundamentally rethink how their work is completed and to quickly adapt to have their employees work from their home offices. Very quickly, teleworking, at least to some extent, has become a new normal in how some people are going about their work and for some this transition to

telework may extend beyond the pandemic. Both employees and employers are seeing some of the benefits of telework firsthand and have enjoyed the process to the extent that discussions are taking place to make some form of telework permanent (Wrycza & Maślankowski, 2020). Employees who are teleworking are appreciating the newfound flexibility of working from home and eliminating their commute. Employers are facing a reduction in facilities costs in not having to pay to heat and cool their office spaces, and in some situations, businesses are eliminating their office spaces entirely to reduce their costs (Wrycza & Maślankowski, 2020).

The transition to telework during the pandemic, while primarily positive has not come without its challenges. Some workers are struggling to adapt to working from their home environment, especially given that in many cases their family members are also working from home and as such balancing home and work tasks becomes that much more difficult (Rodriguez-Nogueira et al., 2020). The nuances of this transition to telework are an important area of exploration for workplace researchers, but the specific intricacies of combining this transition with having a chronic pain condition adds a new and important direction for future research. While the standard dynamics of teleworking with a chronic pain condition may provide its own set of challenges, adding a dynamic that multiple people in a household may be teleworking simultaneously, may make the balance between working, familial responsibilities and managing one's chronic pain condition that much more challenging. Additionally, with a greater proportion of the population teleworking, there is also an increase in the number of virtual meetings. In some cases, the virtual meetings could be of benefit to individuals with chronic pain as they may have the flexibility to call into the meeting, or only use voice chat. In other instances, however, the requirement of video chat may be difficult for someone who is either trying to not display their pain levels, or may potentially be working from their bed because that is the most comfortable position for them given their chronic pain condition. There is a possibility that the biopsychosocial elements of teleworking with a chronic pain condition may have shifted as a result of most of the population transitioning to a telework model and these elements should be explored with further qualitative research.

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## Appendix A

### Interview Questions

1. How long have you worked from home, or have been self-employed?
  - a. Have you ever worked in a standard workplace, or worked for others?
    - i. Why did you make the transition from a traditional workplace to working from home, or working for yourself?
2. What kind of work do you do?
3. What does a work-day look like to you?
  - a. What are your responsibilities?
  - b. How many hours do you tend to work?
  - c. Do you take many breaks?
4. How do you manage your chronic pain at work?
  - a. Is it easier, or more difficult when working at home, or for yourself?
    - i. Please explain
5. Do you work with others at all?
  - a. How are your interactions with them?
6. Does chronic pain and your employment have any impacts on your relationships?
  - a. Family?
  - b. Friends?
7. How stressed are you at work and after work?
  - a. Based on employment?
  - b. Based on your chronic pain?
8. Do you enjoy working from home, or being self-employed (particularly as it impacts your chronic pain)?