Befriending the Enemy (foe) – A Look at How Men Navigate Chronic Pain Within Societal Masculinity Norms

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A Qualitative Phenomenological Exploration

by

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“Sorrow prepares you for joy;

It violently sweeps everything out of your house,

so that new joy can find space to enter;

It shakes the yellow leaves from the bough of your heart,

so that fresh, green leaves can grow in their place;

It pulls up the rotten roots,

so that new roots hidden beneath have room to grow;

Whatever sorrow shakes from your heart;

far better things will take their place.”

— ***Rumi***

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ABSTRACT

Pain does not discriminate in the way it makes us feel. Men do not feel pain differently than women, but they do experience it differently, perhaps due to encultured patriarchal hegemonic ideals of masculinity. Upholding ideals of [Hegemonic Masculinity] have shown profound influence on both genders in the society. However, the extent to which it affects men's health, their help-seeking behavior, coping mechanisms, therapeutic outcomes and health-related quality of life, still remains unclear. A person's wellbeing is a multidimensional phenomenon and hence reducing it to just their biology is ineffective in understanding its complexity. In order to develop a holistic approach to one's health and to free men from their incarceration created by pain in context of their masculinity, I intend to delve into their lived experiences of chronic pain. In this study, an Interpretative Phenomenological approach was used to explore men's chronic pain experiences and the meaning it held for research participants. Findings highlighted the Yin and Yang philosophy of living with pain; where although chronic pain (initially the foe) brings about vulnerability in context of masculinity, it also brings about subsequent protective coping mechanisms and resilience to live on, in spite of the pain, by re-aligning their masculine identity. Through this research, I hope to gain first-hand insight and understanding of the gaps within current literature and in turn shine light upon the factors that can help men navigate chronic pain and learn to live well.

Keywords: *Chronic pain, masculinity, hegemonic masculinity, interpretative phenomenology, health, individual experience, men, pain incarceration, resilience, vulnerability*

RÉSUMÉ

Il n'existe pas de distinction dans la façon dont le genre humain sent la douleur. En effet, les hommes ne ressentent pas la douleur différemment des femmes ; ils vivent l'expérience différemment, peut-être en raison de l'existence des idéologies reçues sur la masculinité hégémonique. La prédominance de **la-masculunité hégémonique** *a influencé profondément les hommes autant que les femmes dans la société. Cependant, la mesure dans laquelle elle affecte la santé des hommes, leur habilité à rechercher de l'aide, leur capacité d'adaptation, les résultats thérapeutiques obtenus et la qualité de leur vie considérant leur état de santé reste à explorer. Le bien-être d'une personne est un phénomène multidimensionnel et, par conséquent, la biologie seule ne peut expliquer sa complexité. Afin de développer une approche holistique de la santé et de libérer les hommes de leur concept sur la douleur qui est attaché à leur idéologie sur la masculinité, nous nous sommes plongés dans leurs expériences vécues avec la douleur chronique. Dans cette étude, une approche phénoménologique interprétative a été utilisée pour étudier les expériences de douleur chronique vécues par des hommes et obtenir les perceptions des participants à la recherche. Nos découvertes ont mis en évidence la philosophie Yin et Yang sur la façon de vivre avec la douleur chronique (initialement considéré comme l'ennemi) qui provoque une vulnérabilité dans le contexte de la masculinité. Cependant, cette douleur chronique au fil du temps, devient un allié leur permettant de réaligner leur identité masculine en créant des moyens de protection et de résilience pour continuer à vivre. Grâce à cette recherche, nous avons obtenu des connaissances de première main et comblé des lacunes dans la littérature actuelle et nous avons fait la lumière sur les facteurs qui peuvent aider les hommes à naviguer dans la douleur chronique et apprendre à bien vivre.*

Mots-clés : *Douleur chronique, masculinité, masculinité hégémonique, phénoménologie interprétative, santé, expérience individuelle, hommes, incarcération de la douleur, résilience, vulnérabilité*

DEDICATION

To my Parents,

Syed Qaim Ali Shah and Mehtab Shah Jillani,

for their unconditional love and support; for teaching me the value in hard work and to have unwavering faith in God and myself; for encouraging me to dream and pursue the path to making those dreams come true.

To my closest friends for always standing by me through various highs and lows, for motivating me, inspiring me and believing in me.

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PREFACE

As a researcher, my interest in chronic pain stems from my training and time spent working as a health care professional, along with my exposure and shocking prevalence of chronic pain at home, in my social circle, and in my patients coupled with my personal lived experience of pain.

During my time working under supervision of Dr. Richard Hovey, I was inspired by the HOMEBASE project. I became curious to uncover how the social enculturation of gendered roles of masculinity and femininity affected chronic pain and health. During my review of the literature on chronic pain, I found widely contrasting and evolving views. What became clear however was that men and women do indeed relate to experience of pain differently. There was a lack of data on men's experience of pain stemming primarily from their lack of representation and willingness to participate in focus groups. Led by my curiosity, I decided to start my research and fill the gaps here and set on a journey to explore the men's experiences of chronic pain, particularly in the context of masculinity.

CONTRIBUTION OF AUTHORS

Mona Shah Jillani was the principal researcher and wrote all sections of this thesis dissertation. Dr. Richard Hovey was the supervisory author and his work served as an inspiration to this journey of phenomenological exploration and preparation of this research. Dr. Marc O Martel acted as the academic advisory committee member.

Ethics approval for this study was obtained through the HOMEBASE project. The recruitment process and research consent forms were created with guidance from Dr. Richard Hovey. Between November 2018 and April 2019, the candidate carried out all field work and data collection for this study. Dr. Richard Hovey was involved in and supervised through all stages of the project, from the evaluation of the research proposal to data analysis, editing, and final submission.

The process of data collection (including interviews, group session recordings transcription and transcript de-identification), data analysis, phenomenological writing and review of the literature were performed by the candidate. All additional information used either for compiling a detailed literature review and/or thoughts and ideas based on the work(s) of others have been cited, and the resources are provided in the section “Bibliography”.

CHAPTER 1: INTRODUCTION

Pain is a *violent invitation* to philosophise. It plunges and invades into our lives like an enemy, unwelcomed and unannounced. Like a storm it wreaks, causing chaos, seeping into every aspect of our lives until it overpowers and casts a shadow on each and every element of our existence. Though we resist its invasion. The arrival of this unwelcome guest can potentially be a positive transformative experience as well. It provokes reflection into *Pain, Disability, Vulnerability and Suffering*. By accepting the existence of pain, one can facilitate life altering growth, resilience and courage, and change how they assign meaning to life.

> "I found that to be very disheartening, [..] When you're not seeing any improvement and things are starting to get worse again, you feel as though, there's no hope. Then you start to spiral down, and you just don't care as much. I think that's part of it too that you stop caring about all the things you used to care about. And it's not that you don't care about anymore, it's just you have to start to cut things out because you're exhausted intellectually, emotionally and physically and that's the part that people don't really realize that It's not a lack of interest. It's just you don't have any sources of energy or resources left to do anything. That's a big one." - Henry

Initially, the participants saw chronic pain as a relentless beast, one that could not be tamed. The beast cast a wide shadow on their lives, growing bigger and stronger with time. The invisible nature of this ailment cast a veil between them and the outside world. It hindered their interaction with the rest of the world, essentially constraining and isolating them. The vulnerability resulting from the chronic pain further prevented them from asking and, hence receiving help. The constant battle between their old self and their new enemy; pain, competing to be the focus of their lives cast a constant drain of energy, leaving a smaller functioning window of time to carry out daily tasks and/or engage in activities they love. This was the internal struggle brought on by the pain as pointed out by Henry. Men are encultured to be the embodiment of strength, courage, dominance and apathy. This is probably why the cascade of vulnerability and invisibility brought on by pain is particularly harder on them. The fear of vulnerability alone coupled with physical pain leads to immense suffering.

Chronic Pain is quintessentially subjective experience of one self in their pain. This project, therefore, focuses on men’s individual perspective, and takes us on a journey with the participants to explore psychosocial vulnerabilities and loss resulting from chronic pain. I will explore the symbolic meanings participants attach to their pain, and through that observe their process of proverbial re-birth (by re-defining their identity) to live a better life, with and in spite of pain.

1.1 SELF DISCLOSURE

I have known chronic pain as a patient, a care-giver, an empathetic and sometimes an unsympathetic ear, a diagnostician, a healer, a health care provider, a researcher and most importantly the culmination of all – as a ‘person’.

My acquaintance with chronic pain is an old one. I have seen its various shades, shapes and sizes. I was first introduced to Chronic Intermittent Pain when I was just 11 years old. Back then it was called **Severe Dysmenorrhea**. For me each month was the same cycle, it started with anticipation and fear of the unwanted guest – pain that came at its will and intensified at its will – affecting my basic functioning and quality of life for at least a few days. It was a transient visitor, leaving me somewhat relieved at its departure, until the same cycle would repeat itself month after month. The pain brought about a sequalae of emotional, physical, social and psychological vulnerability. Unfortunately, because of the nature of the pain, and owing to a lack of existing treatment, it was upon the patient (in this case - me) to endure and manage the best they can on their own. I felt dissatisfied and hurt with lack of compassion and the underestimation of pain’s influence on my life by doctors and others in my social circle. It was evident early on, that although people close to me sympathized, they most certainly did not understand, nor could they relate to my predicament.

According to the literature, increased sensitivity to pain observed in women with **dysmenorrhea** increases their susceptibility to other chronic pain conditions later in life. [2] I remained unaware of such facts until I was introduced to a new pain condition – at the age of 17, I developed **Migraines**. At 24, I developed **DVT** in my left leg leading to **post-thrombotic syndrome**. By this time however, I was more aware of chronic pain versus when I initially experienced pain. This gave me will and strength to live well with pain, but it hasn’t always been easy. Each time pain greeted me in its new shape and form, it presented to me as an enemy, trying to sabotage and take over my life. However, in the course of my personal journey with chronic pain, despite of the suffering I also persevered and was empowered by its manifestation. In the last 16 years, I have become an expert in my own experience of pain. I know the potential triggers and aggravators; mitigating and alleviating factors. I have learned how to manage my pain and also learned to live with it, which in turn allowed me to prevent it from dominating my life.

From my own strife with chronic pain, the prevalence of pain became more noticeable to me within my own social network; my family, my friends and the general community. My experience as a professional Dentist, working at a hospital and later on at a trauma center emergency alongside a maxillofacial team, allowed me to explore pain through a completely different lens. During my initial training, we were taught to see pain as usually a mere symptom of greater underlying illness. We were taught to focus on the biological, pathological and physiological aspects of health. Something we can treat and fix. This is probably why, we had little to offer our patients once the pain was beyond the realm of acute illness, since there's no treatment for chronic pain. From having been a patient myself and a person who had seen other people experience pain first hand, this idea did not resonate with me well. In this day and age, with all our advancements in modern medicine, no one should have to suffer at hands of physical pain. In my pursuit to uncover a more holistic view of health I turned towards phenomenological research to dive into the psychosocial aspects that influence our state of health and illness.

1.2 PURPOSE OF INQUIRY

With the ongoing evolution in modern medicine, our understanding and perception of chronic pain has evolved as well. Non-neoplastic Chronic Pain is a multidimensional disease influenced by an array of contextual factors beyond patho-physiological domains including social, cultural, spiritual, cognitive and emotional elements influencing pain.

People with chronic pain have been shown to suffer from fatigue and increased susceptibility to disease, not to mention dependence on medication and caregivers. Most cannot return to their full-functioning capacity, and as a result often succumb to social isolation and depression. This is seen to be worse in the case of men, who because of the societal enculturation of masculinity, are mostly reluctant and unable to seek help. As most studies investigating patients' experiences have higher number of female participants, management methods have also become femalecentric. Due to this, little is currently known about men's experience of chronic pain, how they cope and the kinds of support they prefer. As a result, there are no gender-specific programs to support men suffering from chronic pain. Existing literature sheds light on patriarchal expectations for men to be strong, independent and self-reliant. It highlights how holding onto these ideals make men more reluctant to seeking help in contrast to women. [3,4,5] It is therefore important to understand the meaning that men in chronic pain attach to their illness because only then can we break the social stigma, increase awareness, initiate knowledge translation and facilitate organizational change.

Therefore, the premise behind conducting a study exploring the lived experiences of chronic pain in men is rather multifold. Firstly, it is to form a deeper understanding of what people with chronic pain experience and endure, not only for the health care community and those living with chronic pain but also for their caregivers, family members, friends and colleagues. Secondly, creating awareness and visibility in the general community about this invisible disease will lead to the modifications in and development of interventions, both at level of health care providers and community. This will help people cope with the management of their pain more effectively. Further, researchers could build upon this to alleviate the stigma associated with chronic pain in the context of masculinity.

1.3 MEET MY PARTICIPANTS

Note: Names of the all the participants have been replaced by pseudonyms to protect their identity. Names of any other family members mentioned by participants have also been changed and denoted by a * sign.

Neil

Before the advent of his chronic-lower-back pain about 6 years ago, Neil was a happy 31-year-old chef, living a full life working his dream job and about to get married to his girlfriend of 5 years. His pain stemmed from a cyst between his L5 and S1 vertebrae which remained undetected for 8 months due to doctors not taking his complain seriously. This delay in diagnosis and treatment resulted in permanent nerve damage and subsequent chronic pain. Soon his pain became so severe that it took over his life. He couldn't concentrate at work, he was angry all the time, and felt like he was physically incapable of carrying out physical tasks. November of 2014 is the last time he reported to work. His relationships with his ex-girlfriend, friends and family suffered tremendously due to veil of misery casted by the pain. Him and his ex-girl-friend eventually broke up. All was lost in the wake of chronic pain – his work, his girl-friend and his friends. He had to completely re-design his identity around this new version of himself – the one with chronic pain. Over the years Neil has managed to do just that, in spite of the lingering pain. He is now happily married. He let go of the toxic people holding him back and replaced his social circle with people who understood him and shared a genuine connection with him. He also remains actively involved in different community-based health projects and support programs centered around chronic pain. He is also one of the chronic pain ambassadors at the HOMEBASE community.

Henry

Henry is one of the most compassionate people I have met through HOMEBASE. He is a pain researcher and was one even before he developed chronic pain about 7 years ago. His pain was a result of a cycling accident. He lived a very active life; running marathons and cycling, before his pain appeared. This is probably why the first year and a half after his accident were the most challenging. His accident allowed him to reflect upon various aspects of lived experiences of pain. Henry was able to utilize his prior experience of working as a pain researcher to navigate through his own experience of pain. This involved becoming active with pain groups and giving back to the community by diving further into research. Henry found a deeper meaning to life through his experience of pain as his job became his vocation. Although the pain still impacts his life in various ways, he has managed to find his way back to fitness and exercise. He leads a full life in spite of his experience of pain and is also a source of motivation for the pain community at HOMEBASE.

Paul

Paul developed chronic intermittent pain in 1992, (about 27 years ago) when he was a young adult working as a draftsman. Working on drafting tables often required leaning and a rather unhealthy posture. So naturally when his pain initially appeared, he thought it was from working on drafting tables all day. Reluctant to give-up his profession, he tried a wide range of different therapies in hopes of curing his pain. None of the exercises helped with pain, but only provided temporary relief. Eventually he switched careers, but unfortunately by this time the pain had established its territory and set its foundation. The unpredictability of his pain remains a source of distress to this day because it gets in the way of him spending quality time with his family and affects his ability to give his 100% at work. Despite that he has never given up hope. His hope motivates him to plan and adapt to the challenges of pain. He remains high-spirited and diligent by actively adopting techniques which would improve his health such as exercising, eating healthy foods, practicing mindfulness, and visiting his kinesiologist and chiropractor in hopes to improve his quality of life.

Ethan

Ethan has had pain for more than 2 decades now. His pain was a consequence of neuropathy developed after his fall on ice. Even after all this time he experiences paresthesia associated pain – ‘feeling of pricks made by pins and needles’ on his ‘entire body neck down’. Advent of his pain shook his entire world. Ethan is an engineer. Due to the nature of his pain he could no longer work with his hands as he did before and therefore retired. It also affected his relationship with his wife and kids. The challenges of pain were felt not just by him but also his family. Despite the hardships, his family stood by him, and together they managed to overcome these challenges and strengthen their family owing to adversity brought on by the pain. He also happened to be one of the participants who showed great transformation through his journey with chronic pain. Ethan was one of the individuals who, prior to developing pain, had a strong self-identity based around hegemonic traditional masculinity and yet he managed to completely redefine it over the years. He no longer defines his identity around hegemonic masculinity (things such as having a paid job), instead he focuses on being healthy and giving back to the community. He remains actively involved in different community based chronic pain projects and support programs. He has been a part of the HOMEBASE community since its inception and is also one of the chronic pain ambassadors at HOMEBASE.

Thomas

Thomas developed chronic pain 6 years ago after he slipped on ice while walking on a sidewalk. This coupled with 2 heart attacks, 3 mini-strokes and a series of physiological changes brought upon by age resulted in chronic pain. He is a friendly and calm man who, despite of pain, has managed to not let the pain affect his everyday life. His transition from a pain-free life to a life with pain was probably the smoothest among all participants. This can perhaps be attributed to the fact that Thomas was the oldest participant interviewed in the process of this phenomenological pursuit, and therefore provided a unique perspective on understanding the experience of pain. He had lived a full life and retired before the onset of pain. For the most part, he retained his regular routine and his daily rituals; such as having breakfast at Tim Hortons every morning since the past 20 years, where he meets his old friends and acquaintances. He is friendly and loves to talk. According to him the gift of life alone is enough to stem a desire to live fully in spite of the pain.

John

I met John at the Maker-Lab (by HOMEBASE). John comes across as a happy 59-year-old man, filled with enormous energy despite of having arthritis. He was the fourth participant I interviewed. I thought John’s narrative was somewhat different from the rest, because it made me reflect heavily on the idea of loss. Not just loss experienced due to chronic pain but also how previous losses such as people, relationships, and career et cetera, in life can tie into how we experience chronic pain. John began experiencing symptoms of arthritis around the age of 45. He is divorced, and after raising 4 children, he now lives alone. Most of his friends have passed away and he struggles with building new relationships. Because of his pain, he reports that he can no longer engage in physical activities like skiing and running. Through all these years, he has remained strong by pushing himself to focus on his job. But now that he is a year away from retirement, he is consumed by a strong sense of fear of no longer remaining self-sufficient and has heightened vulnerabilities, which were essentially brought upon by the pain. It seems that he wishes to incorporate other ‘manly’ activities that could replace time spent at his job after retiring, and possibly instill a sense of purpose while retaining his masculine identity.

William

In 1988, at just 32 years old William’s entire life transformed. He was hit by a drunk driver and as a result of this accident, his left hip and femur were crushed, condemning him to a life with chronic pain and walking with a cane. It was a dark time in William’s life, his ex-wife left him because of his disability and before he could get used to this new life with pain, he lost his son to Lou Gehrig's disease. Through this difficult time, he didn’t lose hope. He was a writer/journalist and continued to work until years after his accident. He engrossed himself into his writing and got involved in various community programs related to pain, rehabilitation, writing clubs et cetera. In his own words, *“I don't want to be that self-pitying person. I don't want to be that person who is not able to be of use to himself or others anymore, and I don't think I ever will be that person.”* In his case hegemonic masculinity proved to have a positive impact. His motivation was to be independent and to be an important, contributing member of the society which gave him motivation to face adversity.

Kevin

Kevin has a strong family history of Arthritis from both his paternal and maternal sides of the family. This knowledge, however, did not help him take the necessary steps to prevent/delay the onset and severity of his arthritis pain, which sneaked up on him gradually over time. Having a strong traditional masculine identity, he remained in denial about his pain and hid the extent of its intensity from his family. He tried to suffer through the pain alone, causing him to make a series of poor health choices and affecting his overall health. However, years of living with the pain later taught him to rely upon his wife and children (who also have other forms of chronic pain) for support. His favorite hobbies to engage in and distract himself from the pain include playing video games with his son Dan, meditating and listening to music.

Daniel

Daniel is a 27 years old baker. He is quiet and introverted. Even though I knew Daniel from our group engagements at the mindfulness meditation courses, it took him some time to open up during his interview. His migraines began when he was still in high school. By the time he was in college, his pain propagated by stress, and became more frequent and fully impaired his ability to perform well. He was studying Psychology at Concordia University, but he decided his health and well-being were more important and hence decided to drop out of school. He did so to pursue a different career which would be less mentally fatiguing. He decided to become a baker but unfortunately all the heavy lifting lead to pain in his joints, and spine (about 5 years ago). Daniel’s father Kevin, who I also interviewed has arthritis, which could mean that Dan is prone to develop it as well. Never the less, Daniel feels that although initially, he had a “less enriched lifestyle” due to the pain, he has now become “more comfortable with the pain”. He has learned and adopted specific tools to help with his pain, so instead of the pain being in the front and centre, he can keep it in the background most of the time. Although Daniel is not very expressive about his pain with his family or with in his social networks, a strong sense of social support deriving from his family and his passion for hobbies provide him with ways to live an “*enriched life”*”.

1.4 MEET THE HOMEBASE COMMUNITY

“HOMEBASE is not, one size fits all...
Our differences, in expression and experiences of pain are as unique as our

finger prints or our irises.
Yet, we are all wrapped in this same human condition of pain, with which we carry on our daily living.
Confronted with increasing or decreasing circles of relations.
HOMEBASE is about understanding oneself.
With support, courage and the will to change:
the way we think…
The way we do, the things we do...
The way we can do all the things we want to do...
The way we can move within our lives…
Re-thinking pain reflectively and living positively with the help of others”

– ***Shane C., Ambassador at HOMEBASE***

HOMEBASE is a community for men with chronic pain. It works on the principle of providing a safe space for men through a variety of gender-specific activities designed to help them develop social connections and in turn not just successfully pilot their life with pain but also help others in similar situations to do the same.

HOMEBASE project originated 4 years ago and was pioneered by Dr. Richard Hovey, who is an Associate Professor in the Oral Health and Society Division of the Faculty of Dentistry at McGill University. His inspiration for the project was shaped by his own personal experience with chronic pain and his years of research in person centered care, chronic illness and chronic pain. HOMEBASE is also the first McGill faculty research initiative funded by Movember.

It is designed by men with chronic pain and led by Dr. Richard Hovey (McGill University) in conjunction with partners including YMCA-NDG, Concordia University’s PERFORM Centre, and the Montreal Chronic Pain Support Group. Since its inception in 2017, HOMEBASE has designed and provided its participants a variety of activities aimed to help men in chronic pain and allow them to connect with others, exercise safely, work on community projects, and gain new skills that can help them live well with chronic pain.

Some of the activities provided by HOMEBASE included:

- Mindfulness Workshop: Stemming from research that suggests mindfulness achieved through meditation can help with intensity and suffering around pain, Laurent Caille (BSc (Hons) Ost, D.O.) lead the 12-week bilingual course on mindfulness at YMCA-NDG specifically to help participants in chronic pain. This program ran every Monday for 12 weeks beginning January 14th, 2019. Every week participants were taught and made to practice new meditation tools and methods. Depth of these workshops are beyond the scope of this paper.
- Gentle Fitness: This is an umbrella term for all the fitness activities offered at YMCA- NDG that were tailored to those who experience chronic pain. These activities included but were not limited to yoga, chair yoga, gentle spin cycling, swimming and aqua-arthritis. The trainers for these activities were well-versed in physical injuries and chronic pain. Therefore, they could design the routine around their participants' needs which provided a safe environment to exercise for those who had avoided exercise in the past due to pain and/or fear of exacerbation.
- Cooking Workshop: These were held in conjunction with the Concordia PERFORM Centre. The cooking workshop entailed creating awareness regarding healthy food ingredients and hands on preparation of recipes that can help reduce inflammation and in turn reduce pain.
- Maker-Lab: Maker Lab was a place to let creativity flow and engage with other HOMEBASE members in creating, building and renovating. Various activities were offered such as sketching, 3D printing, vinyl printing (shirts and totes), baking et cetera
- Other activities included: Music for wellness, Montreal Pain support groups et cetera.

HOMEBASE website:

https://www.HOMEBASEcommunity.com/

CHAPTER 2: BACKGROUND

2.1 PAIN

> *"The biology of pain is never really straightforward, even when it appears to be."*
>
> *— **Lorimer Moseley** [6]*

Acute pain is a protective mechanism, an adaptive trait that is essential to our survival value. Pain is a fundamental component of body's homeostatic control system that ensures the proper biological balance of organ systems in an ever dynamic and variable environment. It occurs due to potential tissue injury, which produces a reflexive retraction from the painful stimulus in an attempt to protect the affected body part until healing starts. [7]

Chronic pain on the other hand is a complex multi-dimensional disease that persists beyond the normal/expected healing time. Therefore, instead of functioning as a protective physiological nociception imperative for survival, it acts as an overly protective and exaggerated response affecting normal functions and quality of life [8].

The International Association for the Study of Pain (IASP) defines chronic pain as any pain that lasts for a period longer than 3-6 months. Chronic pain is diverse and differs from person to person – varying across etiology, intensity, frequency, and duration. [9] Chronic pain affects an estimated 20% of people worldwide. [8] Currently, 6 million Canadians (19% of the population), 25 million Americans (11%) and 20% Europeans are reported to have some sort of chronic pain. [10, 11, 12, 91, 92]

Advent of chronic pain is accompanied by physical ailment, disability and susceptibility to comorbidities. This in turn leads to depression, anxiety, fear, social isolation, suicidal ideation and reliance on caregivers and pain medication. It has become the second major cause of suicide after bipolar disorder [13]. Despite of its severity and prevalence, chronic pain still remains under-recognized and under-managed both in the health care setting and general community. [8]

2.2 CHRONIC PAIN AND MASCULINITY

In the past few years, a lot of research has gone into the needs of patients suffering from chronic pain and the psychosocial factors that impact their physical and mental recovery. [6,7] Literature shows that men and women perceive and react to pain differently. While difference in physiology certainly plays a role in this phenomenon, the psychosocial factors accounting for these differences in experience of pain deserve attention.

As children, we learn to respond to pain based on how we are treated when we experience it. Some children may be cuddled and comforted, while some may be encouraged to *'tough-it-out'* and dismiss their pain. Men are conditioned with the stereotype of masculinity early on, where they are taught to be stoic, independent and emotionless. They are reminded that 'men don't cry' and 'men are strong'. It is because of this fear of appearing weak, which does not conform to society's '*traditional masculinity'*, that many men may remain silent and are unwilling to convey their so called, '*trivial symptoms'*.[14] This gender-specific impact on men due to the enculturation of masculinity in our society makes them reluctant and unable to seek help.

On the other hand, women manage their pain far more effectively. Women often seek help quickly and are less likely to allow pain to control their lives. They are also more likely to incorporate a variety of resources, coping skills, support, and distraction to deal with pain. In a clinical setting, pain is reported more frequently by women versus men. [15] A difference in coping styles was also noted between men and women – women are more likely to use emotional coping and social support, whereas it is suggested that men seem to rely more on behaviours that portray 'problem solving' per se. [16]

Although there is evidence that men delay seeking help when experiencing symptoms of illness, there is a significant gap in literature relating to the extent to which masculinity affects men's perception when it comes to seeking help. [17]

Increasing amounts of data suggests that most often men are less likely than women to seek help from health professionals for various problems, such as depression, substance abuse, physical disabilities, and stressful life events. [17, 18, 19, 20] Empirical evidence further suggests that twice as many women visit health care professionals as compared to their male counterparts. It is important to note, however, that these numbers may be hyperinflated due to their access to family planning, childbirth and child related health issue services.[21] In contrast to these findings, many researchers argue against gender as an important factor in moulding help seeking behaviour, stating that observed differences are not attributed to gender, but rather to behaviours and attitudes associated with occupation and lifestyle choices. [22-24]

Further research, conducted in the United States, outlines that men often adopt poor health behaviours by ignoring their health needs and taking risks. Although nothing strictly prohibits a man from demonstrating masculinity differently, to do so would require that they cross over socially constructed gender boundaries, and risk danger of failing to demonstrate gender correctly (act like a man should). Instead, men often hold on to behaviors and beliefs that are rather unhealthy to demonstrate and conform to the idea of masculinity – in a patriarchal society that tends to reward such behavior. [4]

In order to understand the concept of health and help seeking among men, it is necessary to focus the investigation on men, not merely on the differences between genders. It is also important to note that not all men are the same, therefore, to generalise their behaviour is rather ill-considered. Most studies are often unable and ill-equipped to tackle this problem and hence are not able to account for this variability. [17] In contrast, to get a complete picture, a research into the lived experiences on men in chronic pain is therefore imperative as it can help understand the health and help seeking behaviours of men, and further help devise steps that can be taken to enhance their well-being.

2.3 COMPLEX NATURE AND EXPERIENCE OF PAIN

Although ubiquitous, chronic pain is an invisible ailment. This causes a major hinderance to detection, diagnosis and management. It also leads to a lack of understanding by health care providers and other caregivers such as friends and family and often hampers them to connect with people suffering from chronic pain. This means that when people with chronic pain claim they are sick, they are most often not believed and told their pain is not real, or are seen as whiners, fakers, lazy, and often left without any support from family, friends and/or colleagues. This lack of support experienced may in turn increase their dependence on health care and medications. Unfortunately, patients with chronic pain often report that they are made to feel like a nuisance by health care professionals and are often left to find their own way to handle the pain. This disappointment in the health care system along with the invisible nature of chronic pain further breeds distrust, destructive behaviour and desire to socially isolate among the patients. Most studies that investigate patients' treatments relating to chronic pain emphasize the importance of being 'believed' and 'taken seriously as a human being'. [3, 25-28]

2.4 BARRIERS TO CHRONIC PAIN CARE

Current treatment models for chronic pain care are largely based around traditional models of acute care, where chronic pain is classified and treated as a symptom, rather than a disease. This model of care revolves around a 'wait-and-see' approach, which adds substantial time between the initial diagnosis and initiation of pain management [13,29]. Instead of actively determining methods whereby further pain can be prevented or diminished, treatments are reactionary, and are only initiated when the patient complains about the intensity of pain [30,31]. Unlike acute pain, where symptoms are treated by short-term use of medication and the condition is often cured by treating the underlying cause, chronic pain requires a more consistent multi-disciplinary approach in management. Unfortunately, the average wait time for chronic pain care in Canada is up to a year – during this time, conditions can worsen which can severely affect the ability of returning to a full-functioning capacity. [8,30] Consequently, a)there are no gender-specific programs to support men; b) men are reluctant to and do not know how or where to seek help; c) little is known about how men cope and what support they prefer, d) possible need for modified more gender-specific community programs, which provide a safe place to connect, learn, and thrive together with others familiar with the experience of chronic pain.

Chronic pain also affects the cognitive and physical ability of people with pain in their workplace which results in their dismissal from workplace. A European survey of 4839 chronic pain patients indicated that of the 61% of their participants who were not able to work from outside their home 13% changed their employment and another 13% lost their employment entirely. Chronic pain is the single most common cause of disability among working-age adults in Canada. [32] In Canada, 60% of people with chronic pain eventually lose their job, incur some loss of income or resort to ergonomics in order to continue working. Under such circumstances, people in chronic pain end up succumbing to social isolation and depression. [33] [34]

People with chronic pain also have a higher propensity to develop comorbidities, which increases their financial burden and decrease health-related quality of life. [35] Costs associated with chronic pain care are more than cancer, heart disease and HIV combined. Canadian STOP-PAIN Research Group reported that people waiting to access pain clinics spent a median of $17,544 per year – this also included indirect expenditures from lost labour time and cost of private health care treatments. This demonstrates the significant financial burden of pain on the individuals suffering with chronic pain and our society. [34, 36, 37]

Chronic pain care requires multidisciplinary teams depending on the type of pain and the level of complexity. But most services offered today are fragmented, discontinuous, difficult to access, inefficient and, as discussed above expensive, leaving patients to seek help on their own. [29, 38]

Series of complementary and alternative medicine; which includes non-pharmacological approaches such as acupuncture, chiropractic care, physical therapies, mindfulness, and overall lifestyle changes through community-based pain management programs are more accessible and give people the opportunity to play a more active role in the management of their condition. [39] Unfortunately, most of these services, such as acupuncture, chiropractic care, physical therapies and mindfulness, are costly too.

Community-based support groups follow the ‘model of talk’ and ‘sharing feelings’, which does not resonate with most men. Research shows that, instead, men prefer the ability to ‘talk-sideways’, or ‘horizontally’, as seen on football pitches, or while engaged in building or working on community projects together. However, currently such programs that are specific to men’s needs are not available in a healthcare or rehabilitation program. In addition, little is known as to what activities, coping techniques and support are preferred by them. This means that even men who wish to seek help don’t know how and where to find it. Increased social engagement and reliance on community programs for synergistic pain management may produce desirable benefits to chronic pain related therapy outcomes and quality of life. These programs could be essential in helping men find a new purpose, feeling engaged and part of their local communities again.

2.5 OBJECTIVES

The objective of this study is to explore the deeper meaning of what it is like to live with chronic pain, and how men adapt and navigate through chronic pain in context of the norms posed by encultured masculinity, using an interpretative phenomenology design. I seek to understand if and how norms around masculinity affect men’s perceptions and choices pertaining to health and illness, and how in presence of pain these perceptions change to influence personal identity and quality of life.

Some of the questions I hope to answer through this research are as follows:

What does it mean to live with chronic pain?

How does pain affect one’s perception of self?

How do physicality, society and psychology interact in presence of pain to help men evolve into their new self which is stronger and lives well in spite of the pain?

What are the pyscho-socio-economic factors that influence chronic pain?

To what extent is suffering, brought upon by the pain, a choice and how one can minimise the suffering associated with pain?

What are some individual positive coping strategies by participants to live well and through the pain?

CHAPTER 3: METHODOLOGY.

3.1 QUALITIVATIVE APPROACH – Interpretative Phenomenology

3.1.1 *History of Phenomenology*

Phenomenology is the study of 'phenomena' or in simple words the study of lived experiences. Phenomenology studies what is known as 'the conscious experience', rejecting the objective view and instead exploring the subjective experiences of being-in-the-world. Modern phenomenology, which was first established by Edmund Husserl (1913/1931) and later elucidated by Pollio, Henley, and Thompson (1997), poses sharp distinctions from the Husserl's previous work incorporating the Cartesian principles. Husserl's Cartesian System essentially viewed the mind as being wholly separate from the corporeal body. In Cartesian Principle outer reality is considered a separate and distinct entity that can only be understood in rational terms through cognitive processes of deduction. This was largely because perception (being based on emotions) was considered to be a lower form of experience and a mere distortion in the process. In contrast Husserl's philosophy of Phenomenology seeks to understand the world's reality as it is interpreted by and through human consciousness by applying what he called 'intentionality to the object of study' or intentionally directing one's focus to describe realities. According to Husserl to achieve a deeper understanding of an object a researcher could quarantine their personal judgement using a process called 'bracketing' to ensure that preconceived notions do not interfere with the phenomenological inquiry. It is at this point that Martin Heidegger's approach starts to diverge from Husserl's process. [40-42]

Martin Heidegger, initially a student and later an assistant of Edmund Husserl, was critical of the existing Husserlian phenomenological ideals. Heidegger argued that Husserlian phenomenology was predominantly descriptive. Instead he employed the notion of 'Dasein' – a notion that implies a 'living being' primarily by one's activity of being in this world. According to Heidegger, since human consciousness is a construction of one's historical context, one can never (nor should they) separate an object of study from its context. Heidegger argues against the separation of an object from its context, further stating how human understanding is a product of the relationship between reality and consciousness co-existing. [43]

3.1.2 Interpretative Phenomenology

The method selected for this study is based on **Heidegger** and **Gadamer**'s philosophy of ***Interpretative Phenomenology*** which aims to provide a detailed interpretation and analysis of '*text'* through contextual features (both social and linguistic) of a person's lived experience relative to influences such as culture, gender, employment, family, and wellbeing of people or groups experiencing the phenomenon. In this case 'text' signifies any mode of language used by participants to communicate their experience, such as written and/or verbal text, poetry and/or non discursive forms of art. Interpretative phenomenology allows investigators to arrive at a deeper understanding of the experience, which is well-suited for exploring pain phenomena. [44-46]

In contrast to *Eidetic* or *Descriptive Phenomenology* proposed by **Husserl** and **Merleau-Ponty,** which focus on the description of lived experiences via *bracketing*, *Interpretative Phenomenology* (from *hermeneutics*) delves into interpretation of how participants make sense of their experiences and is upfront about the existence of those preconceptions. *Interpretative Phenomenology* addresses the impossibility of setting preconceptions aside or even knowing which will need to be set aside in each case. Interpretative Phenomenology thus consists of a double loop of interpretation; one where participants interpret their experience and then the researcher interprets that interpretation. [40, 46, 47]

The findings of this paper will therefore include both the participant's account of their experience in their own words, and interpretative commentary from the researcher exploring new insights on the experiences of chronic pain by men in context of their lives and the enculturation of masculinity.

3.2 DESIGN AND PARTICIPANT RECRUITMENT

There were two main methods by which data was collected for this thesis – focus groups and interviews. Primary findings were based on the interviews, which gave a detailed account of the participants lived experience of chronic pain. The focus groups refer to pain-specific community programs which were useful in identifying and observing the activities that could benefit and help navigate through pain on a daily basis. For simplification, detailed transcripts from focus groups were not included, and the findings mostly relied on field notes and the portion of interviews where participants retrospectively spoke about the activities, they participated in at HOMEBASE. The amalgamation of the two resulted in a deeper understanding on the phenomenon being investigated.

3.2.1 *Inclusion Criteria*

Interpretative phenomenological studies are generally conducted on a relatively small sample size. There is no specific rule about the number of participants. However, **Creswell** suggests collecting data from 5 to 25 individuals is ideal. [48] Therefore, I sought to recruit 6 to 10 individuals who met the following criteria:

i) male – since the aim is to understand men's experience of chronic pain through this phenomenological approach;

(ii) reported chronic pain (which is used as a hypernym in this research to refer to persistent or intermittent pain) for over 6 months;

(iii) 18 years old or older;

(iv) living in the greater Montreal area;

(v) ability to adequately communicate in English and no obvious cognitive imparity; and

(vi) reported pain that interfered with daily life.

3.2.2 *Focus Groups – HOMEBASE Sessions*

Men living with chronic pain were recruited into the HOMEBASE community with the help of local chronic pain care organizations (Montreal Chronic Pain Support Group, YMCA-NDG, Alan

Edwards Centre for Pain Management, and the Concordia PERFORM Centre). Verbal and written consent was received from participants to manually and digitally record the focus group sessions for research purposes. The pain support sessions included in this research were of two kinds; some activities (such as the 12-week Mindfulness medication workshop at YMCA-NDG) were digitally recorded and transcribed verbatim, and other activities, while not digitally recorded, were followed by a short group interview at the end which was recorded and transcribed verbatim (such as the Cooking Workshop at Concordia PERFORM Centre). Both categories of workshops consisted of personal field notes taken by the researcher manually to grasp the essence of the activity and it's observed effect on the participants (as seen at the Maker-Lab, Cooking Workshop, Music and Gentle-Fitness for Chronic Pain offered at YMCA). For the sake of homogeneity, only field notes taken by the researcher which were confirmed by participants' retrospective reflection of such activities were included.

Several activities arranged by HOMEBASE between April 2018 – April 2019 were included; such as the first session-cooking workshop which was held on March 2018, the 12 week meditation course which started in January 2019 and continued until April 2019, and the gentle fitness classes at the YMCA between October 2019 – April 2019. Apart from verbal and written text, two artistic drawings made by interviewed participants during Art and Mindfulness activity conducted with HOMEBASE have also been included the findings.

3.2.3 One-on-One Interviews/Individual Interviews

Participants and the researcher got acquainted through various chronic pain community programs and activity sessions arranged by HOMEBASE. After having built a good rapport during the sessions, HOMEBASE members involved in chronic pain activities were identified and approached for interviews by the researcher. This built a comfortable environment for the participants to discuss their lived-in experiences during the interviews.

Initially, twelve men were invited to participate in the interview process, out of which three participants were unable to schedule an interview due their commitments at home and/or work. Nine participants were interviewed between Nov 2018 and March 2019. They were given the option of being interviewed at a cafe near YMCA, their home, or their place of work.

The qualitative interviews conducted were semi-structured, open ended and held face-to-face. The conversation began with broad questions, about topics which were generally easier to talk about, such as asking them to describe what it means to live with chronic pain etc. The sequence and phrasing of questions was not fixed and varied from person to person. This allowed for a relaxed conversational-style interview that cultivated emerging themes and made it possible to dive deeper into participants' narrative. Participants' answers were used to ask additional questions to further narrow down on themes they hinted upon. Participants were also asked to expand on topics that might have emerged in focus groups or any topics considered important that they might have missed but seemed relevant to their experiences. Each interview lasted about an hour on average, varying from 40 minutes to 3 hours. They were digitally recorded and transcribed verbatim. Sample interview questions are provided in Appendix A.

During these open-ended conversations with the participants, I had to remain mindful of whether the narrative provided by participant was relevant to the research. Although I mostly avoided interrupting a participant's chain of thought, I had to on occasion politely interject to bring them back on track if they digressed from the topic. In such cases I had to make sure the interruption does not disrupt their comfort or trust, for example by using sentences such as, "this is quite interesting, I'd like you to tell me more after the interview" or "this is quite interesting, I also wanted to know (followed by the next appropriate question corresponding to their narrative and the research question)". This combined with the varying personalities of the participants; their degree of openness and level of comfort towards sharing their own narrative could probably explain why some of my interviews lasted longer than average. Written data and verbal communication from non-digitally recorded mediums were also used to generate relevant questions during interviews.

My phenomenological exploration was based on these 9 interviews. After these were transcribed, no new participants were further interviewed. The number of participants was within the range initially planned and hence I was satisfied moving forward with 9 participants for the given qualitative and interpretative phenomenological research. Secondly, as suggested by the name itself, qualitative research focusses on merit and quality of research, and not the sample size. In addition, the idiographic nature of the method allowed me to focus on each participant's data at an individual level. Overall the interviews met the requirements for a rigorous and comprehensive phenomenological research.

3.3 MY IDENTITY

> *"I am conscious of the world through my body"*
>
> *– Merleau-Ponty [88] (p. 122)*

The participants knew me as a chronic pain researcher from our various interactions at the community-based activities held by HOMEBASE. Being involved in these activities as a peer and observer laid down the groundwork for building a two-way connection and therefore inspire feelings of comfort and trust between me and the participants. Active listening skills and non-judgemental attitude were further incorporated to allow ease of conversation and promote a two-way communication, which was the ultimate goal during the interview process. Establishing a relationship as' one person to another' in these activities rather than a researcher, helped attain this goal. [49]

3.4 NARRATIVE ANALYSIS

> *"The individual case does not serve only to confirm a law from which practical predictions can be made. It's ideal is rather to understand the phenomenon itself in its unique and historical concreteness. However much experiential universals are involved, the aim is not to confirm and extend these universalized experiences in order to attain knowledge of a law—e.g., how men, peoples, and states evolve—but to understand how this man, this people, or this state is what it has become or, more generally, how it happened that it is so."*
>
> ***— Hans-Georg Gadamer, Truth and Method***

Unlike descriptive phenomenology, there is no step-by-step framework or requirement for Interpretative/hermeneutic phenomenology. Interpretative phenomenology avoids formulating any set of fixed procedures or concepts which would *'rule-govern'* the research analysis. Max Van Manen in his book, '*Researching Lived Experience' states,* "the method of phenomenology and hermeneutics is that there is no method!". [1, p.30] While it is true that there is no method to universally bolster such an endeavour, we do possess volumes of insight and knowledge from thinkers, authors and scholars who provide us with methodological themes and features to utilize as source and groundwork for good research practice. Van Manen further also elaborates that it is however important to note that these guidelines of methodology should not be turned into a mechanistic set of procedures but instead inspire creativity and stimulate insight to create appropriate research methods and themes for a particular problem or question they wish to answer. [1]

3.4.1 Interview Transcription

The first step in this task to analyse the text was to engage with the participant's narrated text at a deeper level in order to understand the meanings they assigned to their lived experience of pain. In order to carry out that task successfully, each interview was transcribed personally by myself. Although, transcribing was a time consuming and occasionally exhausting process, it was important to accomplish this task as soon as possible so it is easier to recall nonverbal cues such as facial expressions and body language along with the verbal content that were not necessarily perfectly audible in the recording. This in turn helped me get into right frame of mind for interpretative analysis. Interviews were transcribed verbatim, except for some word repetitions, expressions or filler words such as ‘aa’, ‘umm’, ‘and like’, ‘you know’, which did not add to instead complicated the understanding of text. Such phrases and words were only included if they signaled a break in conversation resulting from any emotional instances during the narrative. Time taken to transcribe varied upon the length and quality of audio. On average it took around 5 hours to transcribe 1 hour of a digitally recorded interview. After transcribing, I listened to the audio recordings at least twice to correct any mistakes and include additional details of general demeanour, and the tone (such crying, laughter and pauses etc.). [50,51]

During the transcribing process of hearing, writing, reading, re-hearing and re-reading each sentence, primary reflection on the narrative began to emerge along with possible themes. I also developed and improved a set of semi-structured questions that were used in each interview by observing how the participant responded to the questions. These consisted of broader open-ended questions in the beginning followed by more specific questions if needed. This resulted in each subsequent interview to reveal a more thorough data of participant’s narrative.

3.4.2 *Investigating Experience As We Live It*

> *“When someone has related a valuable experience to me then I have indeed gained something, even though the thing gained is not a quantifiable entity.”*
>
> – ***Max Van Manen, Researching Lived Experiences*** *[1]*

As a phenomenological researcher the starting point for me in this project was fueled by the natural consequence of my own lived experience. Van Manen in his book talks about how a phenomenologist is aware that the extent of his or her own experience could be possible experiences of others, and that experiences of others could possibly be experiences of one self, making it a potential universal human experience and giving it an '*intersubjective character*'. This means that being aware of and reflecting upon meanings attached in one's own experiences, a researcher can orient his or herself in the said 'phenomena'. [1]

The reflective part began when I met my participants for the first time at one of the community-based events held by HOMEBASE. This was before I conducted the interviews, even before the participants knew that they would be participating in my research. I remember reflecting upon their narrative and noticing that for some, their identity was predominantly built around their life in chronic pain. It allowed me to reflect on my own lived experience and to detect thematic presence of those narratives. It is true that hearing other people's experiences allows us to reflect upon and become more aware of our own experiences with such instances. Through exploring these experiences, I began to reflect on and view the experience of pain in a new light.

During these interactions, I also began observing the participants noticing their experience of pain as they live with it. These observations helped me frame tailored-questions for the interviews, in order to understand participants' experiences as I interacted with them during and after the interviews. This also allowed me to broaden my horizons and, in a way, experience their life as lived by them. As stated in his book, Max Manen argues, "A researcher who is involved in closely observing situations for their lived meaning is a gatherer of anecdotes". Anecdotes are highly valued by biographers and historians for their power to decipher the true essence of a person, the way of thinking and/or particular times in history or one's lives which would be difficult to capture otherwise. However, it is important to realize, anecdotes should not be used to make fallacious empirical generalisations as that is against the goal of phenomenological analysis anyway. Instead they are often used in phenomenological writings as a tool/methodological device compelling our attention to reflect and demonstrate probable wisdom and proverbial truth. Hence in my interactions and conversations I also analyzed relevant anecdotes that highlighted the appropriate themes. [1]

No written notes were taken while recording interviews. This is because writing forces one into a reflective mindset rather than experiencing the participant's narrative as immediately lived; which is imperative for the process of phenomenological research. It is not possible to experience something while reflecting on the experience. An example of such a case would be to imagine how our anger dissipates as soon as we try to analyze it during the experience. [1]

3.4.3 Reflective Methods and Thematic Analysis

The meaning of phenomena is multilayered and multidimensional and is therefore impossible to break down in one sentence. A phenomenological researcher is therefore constantly reflecting while trying to explore the meaning of 'phenomena' or 'text'. In order to encourage this reflective process, I turned towards phenomenological works by Heidegger, Gadamar and Van Manen. This helped me uncover the phenomenological style of viewing the world and it aided me in familiarizing myself to the phenomenological way.

The process of generating a theme is equivalent to the desire of finding a core meaning from the experience in question. It allows us to make sense of the said experience. Since no thematic formulation can completely unlock the enigmatic aspects of an experiential notion, it facilitates a process of phenomenological reduction. Van Manen mentions three essential ways for isolating themes of a phenomenon in a given text [1]:

1. the Wholistic or Sententious Reading Approach: In this we identify the fundamental or core meaning of text, and try to answer what significance it holds as a whole as we try to express this significance by re-formulating;
2. the Selective or Highlighting Approach: In this approach we try access which parts of a statement, sentence, phrase, or anecdote seem essential in context of the experience

being investigated – we listen to or read a text multiple times and highlight or underline such phrases; and

3. the Detailed or Line-by-Line Approach: In this we look at every sentence or sentence cluster and ask what these seem to reveal about the phenomenon in question.

Keeping this in mind, following the transcription process, I read each passage multiple times and interpreted from the participant's lens, in order to become more and more familiar with the experience and identify important patterns and themes. I began by reading the interviews line by line in order to grasp its essence, and then proceeded by marking selective passages as I began to notice and connect the various themes I found. As I analyzed the first case, I clustered some of these themes together as *superordinate concepts* and created a table of themes. The process was repeated with every participant, where I took notes of insights and noted down strong themes from each narrative and anecdote separately. By the time I started analyzing fourth participant's interview, I had already begun to see strong emerging themes and commonalities. After I analyzed each interview individually, the common themes were identified and grouped into categories, adding themes and trends as they kept surfacing. Themes which appeared the most profound were then used in framing patients' perspectives of adversity and serendipity around chronic pain. During this process there was constant reflection on whether the emerging themes were essential to the participants experience of chronic pain. I simultaneously held discussions on these themes with my supervisors in order to enhance the rigour and reliability.

3.4.4 Re-Orienting to and Writing About the Essence of Life With Chronic Pain While Considering Parts and Whole

> *Nothing exists except through language.*
>
> ***–Hans-Georg Gadamer***

In a phenomenological research, writing is strongly influenced by the reflection and research process. Writing therefore is not the final step of the project, but instead as Van Manen states, “Creating a phenomenological text is the object of research process”. Perhaps this is why, it proved to be the most challenging part of this process as well. It required me to be creative and open-minded, all the while also requiring me to re-build and enhance my scholarly tact and writing talent. Phenomenologists see writing as the way we bring an experience into a ‘symbolic form’. Language (writing and reading) are at the core of developing a phenomenological manuscript – its key purpose being to provoke thinking afresh.

Phenomenology requires ability to be sensitive towards intricacies and undertones of language and being able to hear and recognise beyond words. It reminds us to focus on not just what the text says but also on how it is said, in order to decipher the deeper meaning hidden in the text. Writing allows us to subjectify our understanding so we can truly engage in reflective praxis. Van Manen mentions a paradox of writing, where on one hand it abstracts our experiences from the world, and on the other hand it also helps us intellectualize our understanding of the world.

> *“In silence there is eloquence. Stop weaving and see how the pattern improves.”*
> ***— Rumi***

Phenomenology, like art and poetry, implicates as it explicates and reveals more through the hidden/unspoken silences and through the language beyond words to disclose the deeper meaning of our world. Therefore, the process of writing in phenomenology requires a high level of reflectivity along with dedication and patience. For me this meant that as I wrote and re-wrote my thesis, I had to maintain a critical stance towards emerging interpretations while continuing receptive and reflective questioning of my presuppositions and newly found assumptions. With overwhelming amount of data and themes I had to constantly re-orient myself to my thesis by adopting reduction, reflexivity and reflectivity while writing and re-writing. This also meant that I had to constantly move back and forth between competing ideas during the process.

The process of learning the language of phenomenology and the analysis were insightful. It not only helped understand the lived experiences of my participants but also allowed me to reflect upon my own experiences. Reading stimulated interpretative writing and the ability to delve in deeper reflection on the experiences. Writing about these experiences was also a reflexive activity in how it requires one to go through the process of recollecting and totally immersing with one's physical and mental being. Eventually I was able to group the core themes into the main essence of my understanding of the lived experiences of chronic pain in men.

3.5 PROCEDURE AND ETHICAL CONSIDERATIONS

Ethics approval was obtained from McGill University's Research Ethics Board Office before starting the project. **IRB Study No. A06-B31-13A** – under the title: *Experience of living with chronic pain and patients' experiences of its treatment, future outcomes and social implications*.

Potential participants were personally contacted through sessions and workshops conducted by HOMEBASE. Through casual conversations their eligibility to participate in the research was assessed which was followed by an invitation to set up an interview. The purpose of conducting these interviews was also conveyed to the participants during these conversations, which was to get more insight into their experience of living with chronic pain and exploring the programs and services that the pain community could benefit from. If the prospective participants showed interest, I proceeded to the next phase of scheduling the interview in the subsequent days, or in some instances, weeks. The participants were made aware of the potential average duration of the interview. They were given the option to choose where they would prefer having the interview. Usually a quiet coffee shop near YMCA-NDG, Maker-Lab or one near their home was generally preferred. The purpose of the interview was reiterated to them during this phase along with addressing any questions or concerns that were posed by the participants.

On the day of the interview, each participant was explained their right to consent and withdraw from both the interview and the research at any point in time. Since all participants chosen for the interview were already a part of HOMEBASE, they were familiar with the process of signing consent forms. Permission to recording and transcribing the interviews, while protecting their identity and their confidentiality, was also taken. Finally, written informed consent was obtained from each participant prior to the interview (see Appendix A).

Out of the pain support activities conducted at YMCA-NDG, Concordia PERFORM Centre and Maker-Lab, some were entirely recorded on audio/video such as the 12-week Mindfulness medication workshop conducted at YMCA-NDG. Some activities were not transcribed but followed by a short group interview at the end which was recorded and transcribed such as the Cooking Workshop at Concordia PERFORM Centre. In rest of the activities, personal notes were taken by me to grasp the essence of the activity and its observed effects on the participants (as seen at the Maker-Lab, Cooking Workshop and Gentle-Fitness for chronic pain offered at YMCA-NDG). Consent for this was taken at the time of signing-up for a member at HOMEBASE. (Appendix B: HOMEBASE Consent Form)

Pseudonyms, instead of their real names were used for the purpose of this research in order to protect participants' identity. Pseudonyms were used in all documented work, including transcripts, drafts and this dissertation. During our conversations, two of my participants shared information that was potentially sensitive or personal in nature and unrelated to the research topic. Audio recordings and transcripts were kept securely on a local encrypted hard drive.

3.6 TRUSTWORTHINESS AND RIGOUR

It is important to establish credibility in any form of phenomenological manuscript that seeks to understand the meaning of a given phenomenon. Credibility is established from trustworthiness of the researcher, their interpretations and their manuscript. Central to the trustworthiness of a phenomenological research is the framework employed in researching lived experience. To establish this, I tried to describe in detail the steps taken and tried to demonstrate how they were informed by research paradigm and based on inspiration from great minds in this field. [48, 52, 53] I also employed reflexivity which acknowledges presence of researcher bias within the research process. Reflexivity is also central to adding credibility and rigor to a study. (54,55). Interpretative Phenomenology argues that every researcher uncovers an underlying meaning differently, because of their own fore-notions, social and historical background. [1] Reflexivity evaluates the researcher's own experiences and presuppositions. Having experienced chronic pain myself, I could relate with the experience, not just as a researcher and health care professional but also as a person who has had a lived experience of chronic pain. This allowed for a balanced communication, from 'one person to another' instead of propagating an expert to patient disbalanced discourse. In addition, I believe that in comparison to someone viewing the experience merely from the outside, as a researcher or a health care professional, my perspective may represent a more empathetic and congruent interpretation of participants' experiences. This seems to be a valuable asset to have when conducting phenomenological research [56].

To further achieve credibility and rigour, I also employed *transferability* into my analysis, which refers to the ability to identify the meaning presented in the research findings by people in similar contexts [57] – also known as the '*phenomenological nod'* [58]. Transferability invites readers of the research to find commonalities and draw connections between this research and their interests, circumstances, questions, practices, and experiences in context of the research. To achieve this, I continued to share and discuss my findings with my supervisor and research colleagues. I did not however ask my participants to review the text as this practice is not required in phenomenological research [59].

CHAPTER 4: FINDINGS – THE YIN AND YANG OF CHRONIC PAIN

Twelve men who had participated in a variety of focus group activities hosted by HOMEBASE were invited to take part in a one-to-one interview – of whom nine agreed. Findings from these interviews delineated themes ranging from physical and psychosocial aspects of chronic pain and how they are shaped by gender norms pertaining to men's experience and expression of pain, influence on their identity, and quality of life. These findings further identified techniques used to cope and adapt to a life accompanied by chronic pain.

The core findings of this study can be described as the ***'Yin and Yang of vulnerability and resistance'*** – two primary attributes that seem to coexist along with chronic pain in lives of men. The concept of Yin and Yang arises from ancient Chinese philosophy, described as the interplay of two opposing yet counter-balancing forces. These forces exist to interact with each other to maintain balance and bring about change and life. Much like everything else in this world, all things in this life with pain exist in a similar complementary state – *if yin is stillness, yang is movement; if yin is adversity, yang is serendipity; if yin is vulnerability, then yang is resilience*. They go hand in hand. They are interchangeable. It's important to note that this concept is vividly different from the western concept of duality which reflects two opposing extremes; good or bad, black or white. Yin and Yang is about *harmony* between the two primary forces; which act together, not against each other to create a whole. Similarly, chronic pain in men brought about two such balancing forces; vulnerability from the pain which challenged their masculine identity, and resilience through pain which helped them redefine their new self and masculinity. These two opposing forces and their effects on lives of men living with pain are further explored in detail in this section.

4.1 VULNERABILITY AND RESILIENCE

4.1.1 Vulnerability of Invisible Ailment

The nature of chronic pain is such that despite being ubiquitous, the level of awareness regarding this condition in the general community is rather nominal. The average person and many health care providers lack the understanding of what it really means to live with pain every day.

What does it mean to be invisible? It is a state in which an object is present, and yet it cannot be seen. Chronic pain is an invisible illness, because most people with this condition appear visually similar to those without it and hence the disability can be easily and unconsciously overlooked. Chronic pain occurs unannounced and unexpected. For most participants, this was evident; their pain appeared unexpectedly, and without warning; whether due to unforeseen trauma, pathology or idiopathically. It was something they did not anticipate. The condition was invisible even to themselves, until it happened. This was evident in the narratives of the interviewed participants.

> "It was sort of like I was getting a cramp every 10/15seconds and this is something I really wasn't accustomed to because normally other injuries during my life just, had a beginning, and you could see it sort of transition over time, right? [pause] And it didn't do that this time..." – Henry

It was evident in Henry's mannerism that he was taken by shock and left disappointed when he discovered that this pain was unlike the one's he had experienced before. Henry mentioned how being physically active and playing sports was a huge part of his life and due to this he was used to minor injuries, pain, cramps and muscle soreness. But those were all acute in nature, the kind that transition and eventually heal. His assumption, after his cycling accident, was that similar to his previous injuries, this pain too, shall heal and pass. However, his pain took a different, unanticipated course. The shock and fear of knowing that this sharp and intense pain, which did not seem to get any better with time, and as he would soon find out was a companion for life weighed on him heavily. This initial realisation of chronic pain appeared pivotal, because this is when ‘vulnerability’ first appeared. Vulnerability – which threatens the very core of one’s masculinity by challenging one’s masculine identity was widely evident. This in turn causes a ripple of psychological and social distress in addition to the physical disability caused by pain.

Similar feelings were described by other participants who could not have predicted or been prepared for this situation.

> “There's so many intervening variables. I never thought... [pause] I was running marathons. How was I supposed to know I'd be disabled by some stupid, drunken lawyer? [Pause]” William

William spoke about his experience of a life with chronic pain, and how it began, during which he transitions between moments of animosity towards developing pain and the unpredictable nature of circumstances that life puts in one’s path. The subtle pauses seen throughout the narratives of participants, similar to those seen with Henry and William as well, were indicative of participant’s trying to mask the emotional vulnerability and adversity brought about by a life in chronic pain. The realization of the inherent oblivious nature of chronic pain and its effect on the quality of life is not truly understood until one experiences it himself or sees a loved one going through it.

> “Yeah that was... [pause] that was a tough way to work. [..] Yeah so it's not like a cold, ‘oh you're too sick you should stay home’ and don't come in. Right? It's just a sore back, sit behind the computer” Paul

Paul during the interview explained his struggle with chronic pain at work place. He mentions how the idea of chronic pain is misinterpreted due to its invisible nature and a lack of understanding by employers and colleagues. He mentions how conditions that are commonly seen and experienced, such as a cold, garner more sympathy and affection, versus a disability that can't been visibly seen. People often take it lightly and dismiss it as 'just a sore back' when in reality it is much more than that. The distress of living with a condition where one is constantly made to believe that those living with chronic pain are constantly exaggerating its intensity and disability, is evident in his tone. Paul seemed disappointed by the notion that his everyday struggle is dismissed rather easily. Paul's displeasure towards the fact that transient conditions gain more compassion compared to what he lives through every day, where regular activities are affected by pain and are a constant strain on his mental and physical energy, was evident through conversations with Paul. As the world around such patients underplays the nature of the pain they are experiencing and its effects on their daily lives drives most men into a pattern of hiding and avoiding expression of such pain. In their mind, this pain – which others assume to be 'just a sore back' is seen as a sign of weakness in men stemming from the encultured ideas of hegemonic masculinity. The invisible nature of such conditions further challenges a person's masculinity and feeds into their vulnerability.

4.1.2 *Vulnerability vs Genuine connection - Medical setting*

All the participants mentioned a sense of disappointment with health care professionals who they felt needed to be better versed in diagnosing and helping manage chronic pain. Most of them mentioned how they felt practitioners were quick to downplay the experience of patients as exaggeration. This, as mentioned earlier, is essentially refuting a disability because it is invisible to the naked eye.

> "When I first realized that it was really bad, and it took over my life, pretty much. [..] The first two doctors that I saw, didn't take it seriously. I was kind of like, in a limbo period for eight months. And during that eight months, like got no help whatsoever. The nerve was being severely compressed that entire time. So now I have chronic nerve

> damage, because of the fact that it wasn't like.. [pause] I didn't get an MRI, I didn't get it removed right away...” Nathan

Again, it was seen, that due to the invisible nature of chronic pain health care providers neither believed the patients nor understood their chronic pain when they spoke about it. *Nathan* narrated this experience of seeking help from the health care system for his severe back-aches, which were caused by a cyst between his L5 and S1 vertebrae. However, due to doctors not taking his complain seriously, the cyst remained undiagnosed for 8 months, which caused permanent nerve damage, and the subsequent chronic pain which he is suffering from. Most participants in a similar situation blame their doctors/nurse practitioners. It was interesting to see however, that despite Nathan’s visibly evident disappointment and distrust in health care system, he didn’t shift the blame of him being in pain onto the health care providers. This was evident in the way he used the pronouns ‘I’ instead of ‘they’ or ‘them’ – the doctors, when talking about not being able to get treatment. ‘I didn’t get an MRI, I didn’t get treatment right away.’ This shows immense growth and maturity in his approach to coping and living with pain. It shows acceptance of the existence of pain irrespective of why it came into being. And, it seems (most days) this allows him to look forward and take a lead on his pain instead of being trapped in it.

Other participants also mentioned their distrust in their physicians and health care providers due to their lack of ability to understand and empathise with the participants.

> Kevin: “And she said, ‘you should go to for physio’. And I said, well I don't want to for physio.”
> Researcher: “Why not?”
> Kevin: “[..] I probably should. But if I'm going to go take this... [pause] I just rather not do it. I don't know, it's just I've had physio before, hasn't done anything for me. It was enough to determine that I had plantar fasciitis, which is the tear of the ligaments off of the heel. And well the physio can't fix that. Only time can fix that. So, I've never had a positive

> experience with the medical community ever. I shouldn't say that; I had my eye operated on once and that was okay. Otherwise, I'd be looking at you like this. [laughs]"

Kevin states different incidences from his visits to clinics and hospitals, on the suggestion of his wife and unfortunately like others, more often than not he has come out disappointed with no material help for his pain. A lack of connection between the participants and health care providers is rather visibly evident. In most cases Kevin's reliance on the health care system was returned with lack of assurance and compassion.

Traits of encultured hegemonic masculinity were observed in the way Kevin navigated the conversation. These displayed an obvious presence of *yin and yang – the shifting dimensions between one's vulnerability and resilience*. The hegemonic trait where one wishes to demonstrate their knowledge to establish their credibility and in turn be seen as an expert was displayed by Kevin when he indulged in medical jargons to establish credibility for his experience in front of the researcher/interviewer who he was aware was from a health care background.

Another aspect of hegemonic masculinity observed here, is one of 'I don't want to go for physio', which hints more at 'I don't need physio' from his tone and his sudden shift posture to assume a guarded crossed arms posture for the next few minutes to follow. The way Kevin says this statement portrays his need to prove to himself and others that he is a 'real man' who does not need help or nurturing from others even health care. We see him trying to conceal a possible deeper emotion at this point. And it is not surprising that what follows next is humor, another hegemonic masculinity tool.

It was interesting to observe how most participants, like Kevin, either used humor or changed the conversation mid-sentence to try and deflect a meaningful conversation as it started to reveal a part of their personality which made them feel vulnerable. Talking about their vulnerabilities made them uncomfortable, stemming from their idea of masculinity, and use of humor allowed them to regain control of the direction of the conversation, thereby regaining their hegemonic masculinity.

The *yin and yang* were evident as participant expressed '*guarded vulnerability'* – at one hand letting go of encultured masculinity ideal and expressing some elements of their vulnerability and on the other hand regaining control by retaining and displaying other aspects of masculinity as mentioned above.

Kevin began struggling with weight gain and was diagnosed with depression soon after he developed chronic pain.

> "All of this stuff [he says, referring to his pain] is a vicious circle. You can't walk; you can't exercise. You can't exercise, you gain weight. You gain weight, your feet get worse. You know, it's yeah when you get on the anti-depressants and one of the side effects is weight gain and good lord it's hard to stop that one." Kevin

Kevin blamed chronic pain as the cause depression and his inability to exercise which collectively lead to weight gain. Weight gain in turn worsened the pain. Depression along with weight gain made him want to further avoid exercise. He felt stuck in what he refers to as a *'vicious circle'*. One could imagine that each element in this vicious polyad, resulted in a butterfly affect, magnifying the negative effects of the other, particularly on his health. When asked about Daniel's experience with the Doctor he mentioned;

> "I've been to loads of doctors, lot of them just tell me to lose weight and exercise more. Which is the standard answer." Daniel

Both participants understood that weight and pain have a proportional relationship where increase in one lead to an increase in the other. It is apparent that there is an expectation from the health care practitioners to guide the participants with a realistic and personalized plan, which they can follow and benefit from, instead of being told something they were already aware off but required guidance to achieve. In this case, the forfeiture of expectations leads to a sense of disappointment and distrust in the participants.

William too indicated his disappointment and the challenges in convincing the health care providers to pay attention and take his condition seriously.

> “not only are you disabled, but it's going to make it exponentially harder to get what you want, if you're not prepared to fight and put it on the line. It shouldn't be that way” William

All participants also portrayed a form of ‘*treatment fatigue*’, which refers to physical, mental and emotional exhaustion, occurring during and in between visits to the health care providers. Dedicating time, energy and finances for numerous appointments and diagnostic tests, just to try different treatments that don’t cure and only manage the condition partially, results in fatigue and exhaustion.

Thomas mentions his disappointment in lack of effective communication between health care providers and the patients.

> “Doctors cannot be blamed. In my experience, doctors don't know too much. They know, they cannot preach effectively. [..] you know, because you're learning the books. But do you know how to put it across to the patient? You have to feel, what you're saying.” Thomas

Thomas mentioned that in his experience the doctors, despite of knowing the medicine, are unable to effectively communicate with the patients in a way that they can understand. Participants mentioned things like doctors ‘can’t put in across’, ‘don’t listen’ and ‘don’t understand'. The desire for a genuine conversation – a conversation where the participants are given the opportunity to work alongside health care providers to take charge and become an authentic-partners in working towards their health with their doctors, was observed here. Gadamer, in his book *The Enigma of Health (1996)*, writes about treating the 'patient' as a 'person' in order to institute person-centered care in the medical community. The ability to participate in a two-way genuine communication, not *speed-patient(ing)*, where the patient is a treated as a person and an expert in their condition, enhances participant's trust in health care system and improves therapy outcomes leading to a healthier quality of life. [1]

When outlining positive experiences, a noticeable common theme from the what the participants valued in their interactions with the health care professionals was when and if they got attention from the health care professionals. Participants really valued whenever the health care professionals diligently heard and acknowledged their experiences related to their health and illness – and hence developed a *genuine connection*. 'A central feature of genuine connection is the stated desire to be understood as a person and having one's illness validated within this context before embarking on a management regime.'[77] Having their healthcare practitioner genuinely understand them as a person and the complexity of their lives, gave the participants hope in a state of hopelessness caused by vulnerability.

> "So, I started going to a Chiropractor. [..] he'd do like this, called it dynamic thrust or dynamic manipulations and cracks your back.. and I was wow, the pain was like it's like gone almost […] A lot of it also was the attention of your specialist, so like you know all of a sudden somebody's seen your pain and is dedicated to help making you better. So, that felt reassuring because at first you're by yourself with your pain, that's kind of like daunting sometimes." Paul

Paul continued to explain how a good specialist pays attention to connecting and communicating with their patients. He mentioned that they take time to convey and explain not just what is wrong but how it can be corrected in a language which is easily understood by the patients. Being understood at a personal level and having the complexity of their illness validated, helps the participant feel they won’t have to try and cope with pain alone. This is the primary expectation of a person to be understood specially in context of a patient seeking help for their health. Professionals trained to treat chronic illnesses and pain can help people who have had negative experiences previously and help them take lead on steering through their pain.

4.1.3 Vulnerability and Genuine connection – Family and Home

Some participants, particularly Neil, Paul and William subtly mentioned arduousness of family members failing to understand their pain. It was observed that parents of the adults diagnosed with chronic pain tend to downplay the experience or provide advice that is often opposite of useful, unless they suffer from chronic pain themselves.

> “So usually people understand that, believe me and all. There's sometimes, you know people… I guess my parents, sometimes they do this; why don’t you do this and do that? And they're just shooting golf because it's not with experience. A lot of times people have good wishes for you, meaningful intentions, but because they lack the experience or the resources, you know, they are just shooting golf and you have more experience because you've already done the circuit of all the self-help groups and every therapy that is out there” – Paul

Paul knew that his parents spoke from a place of concern and good intentions, but they also lacked awareness regarding experience of chronic pain. He felt that his family members, specifically his parents, who had not experienced chronic pain would push him to try things they believed would treat or cure his pain, when in his experience none of those treatments had worked nor did these treatments eliminate the pain completely, only dull it down temporarily.

There was a simultaneous interplay between two opposing ideas expressed by Paul. On one hand, he expressed grief and annoyance about not being understood by his parents when he desired their support. This seemed to offend him and resulted in him feeling resentment towards his parents. On the other hand, he also tried to reason with his negative emotions brought upon by pain by rationalizing that his parents were only trying to understand his condition and help as best they can. It remains unclear whether his attempts at reasoning affected his way of navigating through his pain. In such situations it seems, establishment of trust and validation from participant's family members could potentially aid their management outcomes and outlook of life.

Similar realizations distressed Nathan, who mentions that he limits his interaction with his parents, who don't seem to understand his pain or the choices he's made to be able manage his life through the pain.

William outlines, with a descriptive example, of how family can act as both a source of sorrow and distress, or as a strong support system that empowers you and helps one deal with pain.

> "It's a sad commentary. I think there are a lot of families that do break up because one of the one of the partners is disabled, you know that just because you're married to someone doesn't mean that they're going to help you or take care of you. I had three small children, it affected my ability to play with them or do things with them. But it also... I haven't thought about this in a long time but my oldest son, all I could do when I got out of the hospital was walk for a few feet. [..] He'd come out with me every time and he would be very encouraging. I always remember that, when he became a fairly ill and died. [..] I felt what a real loss that was." – William

His account of limitation and loss speaks for itself. In his case, family has been a source of both; sorrow in some cases and support in others. The vulnerability brought on by the pain of not being able to carry out his regular duties as a father was followed by a realization that the pain had not just taken away his ability to carry out physical tasks, but also changed the dynamics of his relationship with his wife. Not being understood and supported by his wife during one of the most difficult periods of his life caused friction, anguish and suffering.

> “How even in the middle of a tragedy, there's some family members who really man up or rise to the occasion. And others who don't. My youngest was baby, he doesn't have any memories of me walking without a cane or not being sick.” William

This was evident in William’s tone and language. Although there was a clear evidence of emotional burden in his account, his life with pain seemed to have given him an different perspective as well – one of wisdom and acceptance. In midst of adversity, there will be some people who will help you persevere through it, and then there will be those who will further add to the burden. The decisions and actions taken by an individual navigating through such characters in life is what determines the strength of one’s own character and resilience.

William does not see his kids often and stated that he felt satisfied with the frequency and quality of his interaction with them. However, from his language and comments, you could observe his underlying desire for more from his children.

> Interviewer: “Are you close to your kids? Do you meet them often?”
> William: “Well, my daughter, it's hard because of her autism. I have to go out there and sort of limited because I don't have a car and it's all the way at east-end, but she calls me several times a day.[..] My son has his own life. He is nice. He's at times as you know... at times he's very kind.”

Further along the interview;

> “And I like to think you know I talk to my children [..] I mean it's hard for.. it's hard. So my son works with his mother, for his mother. She gives him phenomenal salary. So he's walking a fine line, I'm walking a fine line and then you know we just we both make the best of it as we can” – William

In case of his daughter, he is limited by mobility and therefore unable to see her often. And in case of his son, his son is preoccupied and rather busy with his own life and does not have much time to spare. It was also apparent that him and his ex-wife have had a bumpy history, which further limits his ability to be with his children and for them to be a strong support system for him. He has found alternate social connections to rely on for support, but a lack of family presence is duly noted.

Ethan and his father Thomas seem to have a complicated relationship, but it also appears that their pain has (in some ways) brought them closer over the last few years. This was not directly expressed by them to the interviewer. Instead observed through series of interactions and conversations with each before, during and after their interviews, and in community programs they participated in. Ethan developed pain after an accidental fall and has had pain for the past 2 decades now. In contrast Thomas, developed his pain less than 5 years ago resulting primarily from physiological changes that come with aging. It was clear that due to a difference in age at the onset of pain and duration of living with pain, their experiences of living with chronic pain were rather different too.

> “There's so much empathy in that kid, [..] All his life, he was sick. [..] I knew the sicknesses he had, knew all the disabilities and things. And somewhere along, Never, saw the person he developed into…” – Thomas

Thomas is proud of his son, who he has seen struggle with pain most of his adult life. He talks about his son’s experiences and how they made him develop into someone with a strong sense of compassion for others. Thomas had a better understanding of chronic pain because being in close proximity with a family member who experienced it. His pain also began at old age. Which is why his perspective of his pain is completely different. Thomas sees his pain a consequence of life and specifically a life lived well. He focusses on the positives and does not let the pain control his sense of self or the way he lives his life. He follows the same rituals and routines he has had for the last 20 years, (before his chronic pain appeared) in order to maintain the sense of normalcy. His main motivator he says is life itself, because without life none of the other things hold meaning or matter.

When Ethan was asked about how his relationship with family changed after he developed chronic pain.

> “Family is the same. They have no choice. My wife should have left me years ago, I gave her every opportunity to throw me out. Okay. She did not deserve this in any way. She stuck by me. Like I said, no matter what. And I put her through hell and back. I guess our relationship grew stronger. We could withstand just about anything right now. But she was my rock. If it wasn't her, I wouldn't be here today. That's a guarantee. I would have blown my brains out long ago. So far –so good. Kids are doing well. It was also tense for them you know… they were babies when this [referring to his pain] happened. And they didn't know any better. So, I was miserable... right? I evolved. And now they're doing great. They're strong people. They're also an encouragement or shall I say a tremendous support system, even though they're a pain in the ass. [laughs]” – Ethan

Ethan expressed that he owes his strength to cope though his pain mostly to his wife. He mentions if it wasn’t for his wife he would’ve ‘blown his brains out long time ago’. This statement gives us an insight into his suffering. His bilateral paresthesia causes him to be in discomfort constantly, but he no longer suffers at its hands. Over the years him and his family have transformed to accommodate the pain, and in accepting his condition and befriending the proverbial enemy. He seemed to have unlocked the potential to live better in spite of the pain. In his narrative of him reflecting upon his journey, the mannerism of his dialogue outlines self-respect for having come a long way — from ‘hell and back’. Through his struggles, him and his family found a new meaning to life.

The concept of finding meaning in one’s life in search of a good living is not a new one. It was suggested by the German philosopher **Friedrich Nietzsche**. Later **Victor Frankl**, in his book, *Man’s Search for Meaning,* gives his analysis outlining his experiences and suffering in captivity and further introduces his ideas of purpose and meaning. Victor Frankl was a Jewish psychiatrist in Vienna who was captured by Nazis in 1942 and was sent to multiple concentration camps where he suffered at the hands of his captives. His family including his mother, brother and wife, lost their lives in the same concentration camps. It was in these concentration camps where he found inspiration in people's ability to carry on and find *meaning* despite of suffering from unimaginable horrors, by turning their life experiences into inner triumph. The development of character through finding purpose in life in face of adversity gives rise to a new improved version of self, one which is resilient and adaptable. A saying by Nietzsche sums this up perfectly, *"He who has a why to live can bear almost any how"*. [60] For Ethan, like most of the other participants finding meaning in the course of his suffering, proved key to a better life with the pain.

It is interesting to note that Ethan too, similar to Kevin, used humor to perhaps subconsciously deviate and regain control of the conversation. This again points towards guarded vulnerability due to classic hegemonic masculinity behavior.

Kevin and Daniel, who are the second father and son pair in this study, also demonstrated a healthy and strong social support system through their family. However, the contrast between their experiences is very vivid. They are a family of four; Kevin, his wife Jane*, and their two children; Daniel and Lucy*. Their entire family shares the ailment of chronic pain, and although for each of them it came in different forms (had separate physiology, onset, duration, intensity), it has made them more sensitive and compassionate towards each other.

> "There's not very many people who would get past the barrier - the guard - the wall. I've learned to do that through counseling. I've learned to do that with my wife. It's not always easy, we don't always agree on everything of course, that's next to impossible. If we agreed on everything, I guess it wouldn't be any fun [laughs]." Kevin

Men's natural (instinct encultured by society) inclines them to avoid situations of vulnerability. In order to avoid these situations, they set up what Kevin refers to as *'the barrier – the guard –*

the wall'. The idea is to be a fortress – an impenetrable, indestructible structure. In order to become this impenetrable fortress, one has to isolate and cut off ties from outside. That in turn weakens the settlement inside the fortress because it limits one's access to help and support. Ironically the fight to gain advantage against vulnerability, feeds into vulnerability itself. Vulnerability is often confused with weakness, just like pain is confused with suffering. **Brene Brown** a research professor who spent the past 2 decades studying vulnerability, courage, shame, and empathy defines vulnerability as *uncertainty, risk and emotional exposure* as opposed to its conventional definition of *'the quality or state of being exposed to the possibility of being harmed, either physically or emotionally*'. [61] In her book *Daring Greatly* she writes;

> *"Vulnerability isn't good or bad: it's not what we call a dark emotion, nor is it always a light, positive experience. Vulnerability is the core of all emotions and feelings. To feel is to be vulnerable. To believe vulnerability is weakness is to believe that feeling is weakness. To foreclose on our emotional life out of a fear that the costs will be too high is to walk away from the very thing that gives purpose and meaning to living."*
> *— **Brené Brown** [61]*

The only way forward through pain is to befriend the vulnerability of pain, this is not always easy to do. It is a constant pursuit. Kevin realised the fact that the only way to embracing pain is through embracing its vulnerability. The first step for him in allowing himself to do this was by counselling, followed by confiding in his wife. She seems to be the only person he relies on during the darker periods of his pain and values her perspective. This was also noted earlier, in regards to how Kevin's decisions, at least the ones concerning his health, were largely influenced by his wife. This is in line with many of the existing research which show that existence of functional relationships in men's lives lead to positive results pertaining to coping strategies and therapy outcomes of chronic illnesses. This reflects the positive affect of strong social support in men with chronic pain. [88-90]

Previous studies have shown that as opposed to women, who rely on a larger network of people (their children, friends, parents, siblings and spouse) for social support, men tend to rely mostly on their spouses. This could be attributed to a large number of factors that will discuss further in our findings and discussion. [3, 4, 5,16,90]

Kevin comes across as a well-mannered and cheerful man. Throughout his interview he kept smiling even through the uncomfortable parts where he had to talk about something personal or faced difficulty to express. On the other hand, his words, curved posture and heavy eyes constantly relayed a conflicting story.

In this way a play of opposing Yin and yang forces of pain were noted; where they compete to be brought into light and take the front seat in driving Kevin's life.

When Kevin was asked how his pain have affected his interactions with his family, he said;

> "Just being less involved and less active. So, they probably haven't been encouraged a lot… to be active outside and to do things around the house, such as maintenance or, you know, it's not something that I can physically do anymore. [..] Being more withdrawn, because of the depression means that I'm just less present in their lives. I guess, my usual struggle is to get home and I've suffered enough during work or have enough stress during the work hours. And by the time I get home. I just don't want to deal with anything anymore. I don't want to make decisions. I don't want to have to solve other people's problems. Sometimes it's a chore to help somebody else. But sometimes you force yourself into and it gets done anyway. But it's just that much harder." Kevin

Kevin displays guarded vulnerability here, where he mentions the seemingly 'manly' things he can no longer do for his family, such as maintenance and physical labour around the house. As the 'man of the house' he sees himself as someone who should be motivating his family to be more active, but instead finds himself disappointed upon not living up to his ideals of masculinity per se. This is one of the things that fuels his depression and distress subconsciously. The depression consequentially leads him to want to withdraw and build ‘barriers’ and ‘walls’.

Pain often breeds thoughts of self-doubt, challenging one’s hegemonic masculinity, and instigating feelings of vulnerability and feelings of failure. Being in pain means your time is never truly your own, there’s a constant battle between who takes the spotlight – the metaphorical driving seat of life. Kevin feels most days the pain leads and dominates his life, but sometimes his resilience pushes through to get things done. The competing nature of the tug of war between the vulnerability of pain and resistance always remains a challenge.

When Kevin was asked the reason for difficulty in talking about his pain or asking for help. His responses included not wanting to feel ‘inadequate’, ‘weak’ and justified it by calling himself a stereotypical man.

> Interviewer: “When you express to your wife Do you still feel that way?”
> Kevin: “Less. Well… after a while, we learned to trust each other. So yeah, I don't have to be a superhero.”

Kevin demonstrates a strong hegemonic masculine identity. And since the pain doesn’t allow him to live up to his ideal self, this leads to him dissociate from his pain identity in front of others. He feels shame and vulnerability in context of his identity with pain, and constantly tries to mask it. While this restricts him from completing embracing the pain, in his pursuit to living well with pain, a positive social support from his family provides a significant cushion and helps him cope in his daily life.

In contrast Daniel’s experience brings to light variant shades in contrast to his father.

> “Dealing with my pain... personally, I think it makes it easier. Because I can see other people have pain and they can deal with it on their ways. And so, when I have the pain,

> it's not just an excuse for not wanting to do something, they can actually sympathize with the pain. So, they could say, okay he's in this kind of pain, I've had that before I still have that, so I understand how it feels. So, give him a bit of slack, give him some time to himself. So if you want to do whatever he needs to get over that. Whereas, I don't have to feel like that to make up excuses to.. okay need to go lie down, just don't want to.. I don't want to talk. I don't want to play with people. I don't want to sit down. I just want to lie down. And that's good." Daniel

In Daniel experience dealing with pain is easier at home than it is outside. He mentions being surrounded by his family, who are also living with chronic pain, creates a safe trusting environment with no judgement. Since the whole family can relate with the experience of pain, an attempt to recoup is not seen as weak or a mere attempt at making excuses.

> "And the other one is computer gaming. So I'm not good at it. But my son is, that's one thing that we can do together. Daniel and I, we have a couple of games we played together." Kevin

> "Sometimes I play with that online so the games, so we play together when we're trying to relax, otherwise it's sitting down watching movie or watching the show with Amy and mom." Daniel

It was fascinating to note that when asked about activities that help them through the pain, one of the activities mentioned by both Kevin and Daniel, was spending time with each other playing video games. A typical way to bond for men, as suggested in previous literature as well, was talking sideways while engrossed in an activity. For both Kevin and Daniel, this was a soothing activity, a way to connect with each other and disconnect with the pain. Through this activity they took the lead on their pain. I will further discuss the influence of activities in the later sections of this paper.

4.1.4 *Vulnerability and Genuine connection – Friends*

Pain often dominates and affects quality of life and social interaction. Positive social interactions can potentially play a powerful role in coping with chronic pain. In the interviews and group sessions transcribed this became an evident finding.

The advent of chronic pain affected relationships of participants, at home and outside. They unanimously reported isolating from friends and activities they once loved. Neil, Paul, Ethan and Daniel mentioned a complete change in their social circle post advent of chronic pain. Kevin mentioned feeling distant from his good friends due to a lack of understanding of his invisible disease on their part. John mentioned a lingering inability to create new relationships and hold on to social relationships. In order to explore these altering social relations further, I will turn to Aristotle's work on this particular subject.

According to the Greek philosopher, **Aristotle**, most friendships can be classified into three categories according to the bases of friendship between 2 individuals. The first and the most important category is of '*friendships based on good'*. These friendships are hinged upon mutual respect and appreciation for each other's qualities and character. These are bolstered by goodwill and trust in each other's ability; therefore, this type of friendship brings about a strong desire to aid and assist one another. The second and third categories of friendship are those of '*utility'* and '*pleasure'* respectively. This utilitarian form of friendship is based upon mutual benefit, assessed by the usefulness each one brings to the table. An example would be work colleagues or schoolmates. And those based on pleasure would be accounted to common interests and befitting hobbies. Aristotle, tacitly relying on widely accepted assumptions about what makes a relationship satisfying, refers to these last 2 categories of relationships as '*imperfect*'. His argument is that friendships based on goodness consists of individuals with equal moral development, where one benefits the other for that person's sake. It is unlike the *imperfect* friendships which merely revolve around self-interested strategy and therefore are bound to fade away. [62]

Participants account of loss and gain in relationships post chronic pain, supported this view by Aristotle and uncovered a different layer within their narrative.

> “I'm not as social as I once was. I don't get involved in outdoor activities with friends anymore, which I used to do. I guess, I've been more withdrawn, it's not helped with the depression because that's what depression does to you as well. [..] I have probably less friends that I can count on one hand that I consider true friends. And most of them are far away. Some of them are in Ontario. Some of them are in Sherbrooke. There's one in Montreal, but we have our differences. So he's still a good friend, but not someone I'll turn to if I need something. [..]” – Kevin

Most of Kevin’s friendships fell into the category of friendships of pleasure, where he would engage in outdoor activities with his friends. It is understandable that the loss of being able to participate in those activities also resulted in loss of common interest thereby affecting those friendships. He felt distant from his close friends due to not only being located in different cities but also due to a lack of awareness about chronic pain on his friends’ behalf. Hence, the lost connection with old friends can also be attributed to them no longer being able to relate and be compassionate towards each other’s struggles.

> “There are a couple of people that I know who are also suffering from pain from various diseases and other things. And so, I can identify with them and just try to be sympathetic to the things they have. We know what each other has. Like one of my friends has lupus. So, he's pretty much constantly in pain. I'm more sympathetic than I would have otherwise been. Because I think that unless you experience pain, you don't know what it is. You can't empathize with somebody else that has it when you have no clue what they're feeling.” – Kevin

Kevin’s newer friendships, however, demonstrate a foundation of goodwill and trust. Not just listening to but also being genuinely compassionate towards each other. As discussed previously in Literature Review, isolation is both an effect and a cause of worsening chronic pain. Chronic pain, in conjunction with depression in Kevin’s case, points towards a strong tendency to isolate. Hence, it can be argued that cultivating genuine connection can prove to be a powerful tool in preventing the negative sequelae arising from chronic pain.

Daniel acknowledged the existence of mainly utilitarian category of friendships in his life (through work), followed by friendships based on pleasure which were in reference to his online friends who he plays video games with. It is worth noting that a constant lack of genuine connections through friendship at a younger age might have been the reason that his personality became predisposed to prefer seclusion as opposed to company.

> “What friends? [pauses and smiles] The only friends I have are people I work with at work. All the people I used to hang out with, they're gone in different countries, gone to different schools or they have no time. All I do to spend time with them at work, it's just a way get along with people at work. [..] Yeah, I have some friends online. If I see them online, then it's a chance to just relax and play with them. Otherwise, if just nobody's online or I don't feel like playing with anyone else. Then that's it. Find something to do, read a book. I'm not very social, which unfortunately. [..] It might have been part of the pain in the beginning because in the beginning it would be.. I'm not in the mood to do this, or this hurts too much or this is too much loud noise [..]. And instead of hanging out with friends most of the time, it would've been, sit down read a book or play on the computer or just do something alone.” – Daniel

Daniel has a strong social support at home. It was interesting to see that the pain made him evolve into someone who prefers solitude. He also mentions he doesn’t necessarily have friends that he spends time with, and states this was not a consequence of chronic pain but was in fact more circumstantial in nature, such as friends moving away for college and / or work. Although, in the beginning, his pain might have been a major reason for him avoiding social interactions, in his case it did not spiral into the cascade of loneliness and depression. Later in the interview he also mentions how large groups and crowds make him anxious. So, it is important to appreciate, that social interactions outside of home, did not seem to be tied very closely to fluctuations in his pain or disease behavior, nor were they a variable to loneliness. In his case they transposed into a desire to explore solitude.

Both participants in this study who developed pain earlier in life (as young adults) demonstrated higher levels of adaptation to pain and were able to re-assign meaning and purpose to their new self-identity successfully. The also seemed to have matured and adapted at a relatively faster pace.

Ethan may or may not know the different classifications of friendships introduced by Aristotle, but he too has certainly encountered them and has developed an astute understanding of these along the way, through his lived experiences.

> “I've lost most of my friends. Obviously, I'm not I'm not the party animal anymore. My view - were they really true friends? Probably not. Because as soon as the you know the situation started to get tense, they bailed on me, which is fine I got over that. And I shouldn't have expected anything. But I did. So it was a means... to evolve into a new way of life, a new path, a new direction. I've developed incredible friendships now, incredible bonding with people I never expected. It just opened up a new direction. I'm not sorry about the events that happened. I'm actually happy because it pushed me into another direction, it forced me into another direction. Which evolved through Richard, and Richard's groups. When one door closes, the window opens. It was great.” – Ethan

Ethan expressed how through the adversity of pain he discovered who his real friends were. He mentioned that he is no longer friends with most of his old friends and instead has developed stronger friendships and connections with like-minded individuals who understand him and his pain. I can sense the transition from '*imperfect friendships'* to those based on '*goodness'*. This form of genuine social connection based on goodness ignited resilience and optimism in Ethan's life which was palpable through his tone, posture and verbal confirmations. Throughout his interview, Ethan moves back and forth to reflect upon the things he loved and lost because of the pain such as his job, feelings and bodily functions. However, I could also sense an expression of gain – gain of genuine social connection, new self-identity in light of his re-defined masculinity, and a strong sense of purpose which appear as positive ripple effect of embracing his former enemy – the vulnerability and pain.

When Thomas was asked about his daily activities and how he starts his day, he mentioned he had been going to Tim Hortons every morning for years (since before he developed pain). He had managed to make acquaintances and friends there. As someone who lives in a retirement home, he found this to be a way to grow and sustain positive social interactions.

> "I come here [Tim Hortons], And I have my people who come here. Some people come here because they saw me before." – Thomas

During the course of his interview (which was conducted at Tim Hortons), many of his acquaintances and friends stopped by to share greetings and have a quick chat with him. Being in their presence was truly Thomas's comfort zone, he appeared content and the familiar environment allowed him to thrive through his pain.

Other participants too mentioned the change of social circles.

> "I was working as a chef before. So when It first started, all my friends were chefs. I kind of lost a load of those relationships just because of different lifestyle. So now I've got kind of a different circle of friends. Mostly, like musicians and chronic pain community and stuff like that." – Neil

Neil was a chef and most of his friends were chefs as well. He had a completely different lifestyle before the advent of chronic pain in his life. When he quit his job, due to his pain, he also lost those friends of *utility* and *pleasure* along the way. Like Ethan, Neil also reported to have built stronger and deeper connections now that are a source of support and comfort. Having developed pain as a young adult, he too was able to develop stronger coping mechanisms and evolve to assign new meaning to his life.

Three participants mentioned battling depression in the aftermath of chronic pain; Neil, John and William. Out of these three, John and William mentioned lingering feelings of loneliness. While some participants mentioned experience of loneliness directly, others used alternate words and euphemisms to hint to either possible depression from isolation or hinted indirectly towards loneliness through the stories they shared. This will further be discussed in Section 4.2: Loss.

4.1.5 Vulnerability and resilience - Paid work and men

All participants who had paid work spoke about how chronic pain impacted their productivity and mental capacity. Eight out of nine participants mentioned the challenges of maintaining a job while tackling a life with chronic pain. The only exception was Thomas' narrative which highlighted that since his chronic pain began post-retirement, it didn't impact his identity in the way it affected other participants. Three out of nine participants interviewed; Neil, Ethan and William, took an early retirement from work due to the unpredictable nature of their chronic pain. [Table 2] The remaining five participants expressed the desire and will to continue working. For these men, work was both seen as a way to maintain normalcy in their life and it also provided a way to cope as a man where their jobs became a mean to retain their identity in context of hegemonic masculinity – *'the bread earner'* and *'the resilient man'.*

> "I think the interesting thing for me is that I always had purpose for what I was doing. Because even though I was in pain having an academic position means that I had things to do, I had people to meet. I had a whole different way of looking at things. And I think

> it's one of the most important things is that you have something that's meaningful for you that you can continue doing." – Henry

Henry was a pain researcher even before his accident that lead to chronic pain. The experience of pain assigned new meaning to his vocation. He mentioned how having a clear sense of purpose made it easier to navigate through the pain. The gratification and strength from personal agency, while knowing people were relying on him, made him see things in a different light. In working with other men and women who share the same struggles of pain as him, he was able to turn the burden of pain into a gift for himself and for the community. During my interactions with Henry, during and outside of the interview, it was evident that he enjoyed his job and was passionate about it. This gave him a strong sense of purpose and direction in life. The passion also fueled a desire to keep moving forward in spite of the pain as he continues to help others do the same through his profession.

> "I literally couldn't walk; I would have had to have the crutches but I was in denial enough not to do that so I limped into work." – Kevin

During the interview Kevin recollected the times of extreme pain where his mobility and functioning capacity were fully affected. He mentioned one such time when he couldn't walk due to pain, but despite of such excruciating pain he decided to stay silent because being the 'man' didn't want to worry his family and didn't want to appear weak in front of his colleagues. So in hopes of maintaining normalcy and retaining his '*strong manly identity'* he limped into work without saying a word. He denied a cry for help because of his inbred traditional hegemonic masculinity ideals.

> "I feel stiff. And, I feel that it reduces my mental capacity to focus on things and to think properly. And my job as a thinking job. I'm director of infrastructure for large company. And that means a lot of thinking a lot of troubleshooting, problem solving, management skills, communications, those if you don't do them properly..." – Kevin

For Kevin his job appears to be both a source of comfort and distress. Kevin felt pride in what he does professionally. His work allows him to maintain an ideal self-identity that he can associate with by retaining traditional masculinity ideals and a feeling of control over his life. On the other hand, he also mentioned that it becomes draining to concentrate on work and carry out tasks, when his brain is often preoccupied with the pain in the background.

> "I'm going to hit retirement soon. I'm going to have a big chunk of my day gone. As far as, my routine, and I need to replace it with something concrete. So keeping an open mind. You know, I'm not trying to be a master of anything [..] I got a year and change until I retired unless I change my mind. And I can do some of this work [refers to maker-lab activities] in the labs in the garage and so I can do you bring it up to my chalet and just put it in place up there" – John

Retirement can be scary for a person regardless of chronic pain. However, it can be scarier for people with chronic pain, as they tend to tightly hold on to work when defining their masculine identity in presence of chronic pain. Hegemonic ideals of masculinity require men to be self-sufficient – they are providers and for that they need to work. It was interesting to observe however, that John mentioned filling his time post retirement with activities that involve *building* and *creating*. These were activities he can do in his garage, which essentially that give him a sense of control; these were mostly activities which are traditionally considered *'manly'*.

As seen earlier, although continuing paid work was observed as a strong coping mechanism, it was also seen as emotionally and physically draining due to invisibility of the condition and the inability of others (at work) to understand their condition. In some participants this was also confirmed by a desire to keep their pain and work identity separate, and hence, a notion to avoid mentioning their pain conditions at work entirely.

> "It's difficult to talk about is when I'm talking to superior at work. Somebody who I generally don't want to appear weak in front of. So I don't want to be the one giving them excuses like this didn't get done because of this. This isn't happening because I'm not up

> to it. So, it's usually just okay well, I guess put it in the background or focus on things that it needs to be done. Instead of admitting to not being able to do something." – Daniel.

Daniel works at a bakery. He expressed in his interview how his pain made him feel vulnerable at work. He finds it difficult to lift boxes and heavy objects which are a part of his job and end up aggravating his pain. Furthermore, stressful situations, difficult customers and rush hours tend to propagate his pain as well. Even during extreme pain, he often tries to avoid mentioning it at his workplace, especially in front of his superiors to not appear weak and incapable of carrying out tasks, or even worse in fear of appearing as someone who is lying or making excuses to get out of work. During an exercise at Mindfulness of healing pain through art, Daniel expressed this again in his drawing [Appendix C – Figure 2]. He drew himself as a bird with a mechanical wing that appears normal to others but can barely function like it should. He also mentioned that he likes to take a 5 mins break to sit down and meditate to help cope with the increasing pain before getting back to the 'madness at work'. Other participants, such as Paul, also expressed similar concerns.

> "I think everybody feels maybe it's because it's the owners and the management, that we should suck it up [..] If you're able to do stretches at home, every day working on it, I think the healing process will get faster. That's the other drawback. You have to get ready to work." – Paul

Paul mentioned how he believed that if he was allowed to work on his injuries at home and during work, they would heal faster but unfortunately that wasn't an option for him. He also mentioned how his back seizes up while working. Activities that provide relief such as stretching, or yoga help relax the back muscles are often awkward for him to try at work.

> "But everybody tries to do this here that 'oh look at me I have a bad back but I'm at my work' you know." – Paul

When Paul said these words, it was clear he felt hurt and mocked by other people's perception of men in pain, and what they should look like. Chronic pain isn't like acute pain, it is there constantly and is a part of everyday life, from the moment you wake up till you go to sleep. Paul also seemed displeased, rather hurt, to have his condition being often compared with a casual back-ache or a common cold, to the fact that others tried to downplay his experience of pain without having shared his experience of it. There was hidden dismay in his tone regarding these ill-conceived notions around pain at his work place.

William is retired senior citizen now, but he remains actively involved in multiple community programs. He feels that in all of his interactions, one constant obstacle has always been the need to assert and convince people of his disability as something that is real because people tend to instinctively dismiss it**.**

> “that because you're disabled doesn't mean… not only are you disabled, but it's going to make it exponentially harder to get what you want, if you're not prepared to fight and put it on the line. It shouldn't be that way” – William

Thomas on the other hand seemed to cope well with pain. He retains a strong masculine identity despite of being in pain. This may be due to the fact that his pain began after he retired, and by associating his pain to the inevitable evil of old age, he avoids it impacting his identity.

Early retirement due to chronic pain had a massive impact on Neil. He was only 32 when he retired from working as a chef. But after a few years of adversity brought on by pain, he adapted and re-defined his idea of masculinity. He feels comfortable and doesn’t feel the need to ‘prove himself’ and therefore can engage in activities at home and outside home such as music and being pain group ambassador without his masculinity being threatened. His ability to reject the demands of hegemonic masculinity while renegotiating the concept of masculinity and what it should look like seem to be both physically and psychologically beneficial for him.

The overarching commonality within these 8 participants was assigning meaning – those who continued to work in spite of the pain did so by finding meaning through the experience of pain and by fortifying their self-identity. However, those who retired early due to the pain, it seemed found meaning by looking for other forms of fulfillment, such as community participation, mentoring others in similar life circumstances/lived experiences or leisure interests such as music, art and writing.

4.1.6 Vulnerability and Adaptation - Mobility

Invisibility of pain unfortunately means that the condition is often missed and misunderstood, which leads to limited services designed for people in this condition. One of the everyday things that becomes challenging as a result then is transportation and mobility. Participants in pain said they don't prefer to drive because that worsens their pain. For elderly experiencing pain driving isn't an option at all. The only available option then is to use public transport, which is an entire struggle on its own.

> "I think you plan things differently, so for example, I don't come in during rush hour or leave at rush hour. Because I take the public transit […] I remember almost falling over a couple of years ago, because I couldn't feel my foot and it was so unbalanced. People look at you and you look fine, so nobody's giving you their seat just because you're in pain. And I think that's part of the issue is that you have to plan everything more carefully. I don't often go to meeting's in the evening and stuff, because just the fatigue of living with pain, I think just narrows your functional windows of doing things." – Henry

Invisibility of the disease inhibits other people from acknowledging and really understanding chronic pain. Participants also reported constant feelings of being judged by others because while they may be disabled, they appear seemingly normal. Consequently, this limits services available to those who need it. Unfortunately, this constraint felt by people suffering from chronic pain also means these people have to plan everyday more carefully. This means there is twice as much fatigue associated with living with this ailment, because one's not just physically exhausted, but also mentally and emotionally exhausted. The fatigue then further reduces the '*functional capacity'* or as Henry calls it 'functional window' of the person. Limited functional window refers to having limited energy resource to carry out various tasks each day. He explains how this means all his tasks for the day need to be accomplished before evening as by that time of the day, the fatigue of chronic pain catches up the person.

> "I couldn't drive, my foot was so... [pause] I couldn't feel it. So, it was like having a wooden block and that in itself is very frustrating, even walking is difficult, [..] and I realized that one of the worst things for me was the exhaustion because you get tired all the time."
> – Henry

Henry described his leg as a 'wooden block' in that it felt artificial or external rather than a part of his body. This made carrying out regular tasks like walking and driving frustrating. The constant distress made commute more difficult. Thus, also further fed into the cycle of exhaustion further reducing participant's 'functional capacity'.

> "Cote Saint Luc may look like it's very, you know, very convenient location. But if you don't have car it's hell on earth." – William

William's interview was one of the longest interviews I conducted (about 3hours). He spent a good chunk of the interview (about 25 minutes) going back and forth, in often a very agitated tone, talking about the poor public transportation options near his house and how the government needs to work on these issues. Poor transportation is a major source of distress for him, he defined it as 'hell on earth'. It is clear that this vulnerability in mobility along with his disability further impede his ability to carry out average everyday tasks and lead to agitation.

4.1.7 *Financial Vulnerability*

Financial vulnerability of living with pain, as described by most participants, can be divided into two components; the direct financial burden resulting from incremental costs associated with chronic pain care, and the indirect costs of chronic pain resulting from resultant disability and lower economic productivity such as lost wages due to lost days and fewer hours worked. Most participants spoke about the financial burden of living with pain. During the course of their illness, they required multiple diagnostic and medical procedures. Each demanded more time, energy, commitment and financial resources than the participants had the strength or means to provide.

> "I was fighting to get covered by my insurance company. And so, during that eight-month period, I just depleted all of my savings and everything, had nothing, I couldn't… I didn't have money to eat, and didn't money to pay the rent, I was just incurring debt." – Neil

The months following Neil's chronic pain were very difficult for him. He spoke about how he faced problems with health insurance provider despite of having coverage through his employer. This trouble with his insurance provider lead him to accumulate debt due from all the hospital visits, expensive tests and promised treatments.

> "I laughed. The first year and a half that I was trying to seek out help, I had my Manulife, (they give you a summary) and like the first year had 4 pages. And usually I have one or two things on. It had just all these different things, chiropractors, medication, everything you could imagine you could have. And I realized that some people with chronic pain who don't have insurance would be kind of stuck" – Henry

Henry's account of his first year and a half primarily conveys three important points. Henry spoke about how he remembers going through his insurance bill the first year after his accident. He mentioned it was 4 pages long, had various diagnostic tests, medications and treatments on it. These anecdotes from the participants delineate how pivotal the initial months with chronic pain are. During this time patients rely heavily on health care providers financially. Unfortunately, there is evidently a lack of medical infrastructure to support people with chronic pain and / or allow them to enjoy a smooth transition into their new life with pain.

Many people either don't have insurance or the right insurance coverage and often struggle with the process, which is why insurance coverage still remains a battle for most people with chronic pain. Many plans are willing to pay for medical treatments such as surgeries and medicines, but they’re not as keen to cover psychology and therapy services such as chiropractor, physiotherapy, massages, yoga and meditation which are essential management tools for chronic pain patients.

First few months following chronic pain also often see higher number of hospital visits and diagnostic tests. Since chronic pain requires lifelong management and care, inadequate public health coverage provided by the government and the varying extent of coverage provided by private insurance companies can lead to financial burden and stress for patients. It is obvious to then imagine how stressful it would be to not have an active insurance pan at all in such a situation.

> “I tried physiotherapy first [..] I went over and over again and it's lots of money for physiotherapy, back then it was like $45 or something. Now doesn't seem like much, but now it's close to $90 or $75 - $90. So much easier. Though each time that you go there's this kind of like anxiety that how many times am I going to have to go? And they're not exactly sure, you know? And sometimes they'll (say) well you should be coming six to eight sessions this year. You end up paying like hundreds if not thousands of dollars and it's fine if you have the money and you're not thinking of the cost. But when you’re money conscious and all of a sudden, it's a never-ending cycle. Because you have no idea, [and they say] "well come back and we'll see how it goes” – Paul

Paul talked about his experience of physiotherapy over the years. For Paul, it never proved to be a perfect solution. There was a level of uncertainty around sustainability and benefits of the therapy. Again, this uncertainty stemmed from a lack of proper communication and genuine connection between health care providers and patients (as discussed in earlier sections). Paul also mentioned the financial burden that his treatment posed. These treatments are often not sustainable because, as discussed above, chronic pain requires lifelong management. In the long run one ends up spending lots of money towards a temporary source of relief, and that too if you are lucky. However, if one has financial constraints, they are unfortunately further limited and cannot even access temporary relief.

Other participants, such as Kevin, also mentioned how some management strategies like massage helped him but he limits himself since they are costly and therefore not financially feasible.

4.2 LOSS as 'ADVERSITY', HOPE as 'SERENDIPITY'

> *"Grief is like the ocean; it comes on waves ebbing and flowing. Sometimes the water is calm, and sometimes it is overwhelming. All we can do is learn to swim."*
>
> ***– Vicki Harrison***

Loss and grief are an inherent part of chronic diseases. Unfortunately, while much has been written on grief associated with death, grief and losses accompanying chronic pain have received relatively little scholarly attention. Grief associated with death, although excruciatingly painful, is followed by a sense of finality, which can eventually bring about resolution and closure. In contrast grief for participants who are chronically ill, consists of multiple permanent losses and therefore is difficult to resolve. Since these losses, known as *infinite losses,* are unending, they can severely and permanently affect an individual's quality of life. [63]

Speaking to participants made themes of loss vividly evident. Categorized experiences displayed themes surrounding loss of health, loss of trust in the health care system, loss of social connections (family, friends and colleagues), loss of fun, loss of ambition (school and work), and loss of dreams. These losses further gave rise to feelings of hopelessness, emptiness, loneliness, anger, disbelief, sadness, depression, anxiety, and a lack of any sense of control in life.

While participants’ stories mostly displayed themes of loss, their stories often also spoke of hope, adaptation and evolution simultaneously. This fortifies our yin and yang philosophy of the contrasting forces at work – loss and hope. Hope for the future often included the notion that chronic pain would either subside or become more and more manageable. Participants also believed in achieving a meaningful life despite their circumstances, and spoke about multiple ways of staying motivated or finding meaning in life.

4.2.1 Former Loss - Death of Loved ones

Pain and Loss have an interesting relationship, there is a lack of research on how former bereavement may impact one’s perception of loss from chronic pain and therefore how that may be associated with suffering or helping them power through. Three participants; John, William and Daniel expressed loss of loved ones. These participants were also the ones who seemed to prefer solitude but (in their own words) *‘forced’* themselves *‘to be a part of’* different groups for their well-being.

> “I always remember that, when he became a fairly ill and died. I felt what a real loss that was. [..] People check in with me every day, I'm very blessed in that regard. [..] I don't, I don't get very close to a lot of people who are late because they die. I mean, they're that age, they're in the mid 80s, they're going to expire. And it's you know, be nice to them but I don't really have a terrible [need to] find this intimacy with them. Because, you know, it's hard to let go. I mean, I had my best-friend Brendan there, she died last year. She was 89 which is amazing. An amazingly nice person.” – William

William lives in an elderly home. He makes a conscious effort to avoid creating meaningful social interactions there as it is followed by an unavoidable sense of loss. He elaborates how he has lost many of his friends and family members to death either due to old age or misfortune. He gave an example of his best friend and neighbor who was 89 years old when she passed away last year. He also mentioned his first wife who was murdered and his son who died due to Lou Gehrig's disease (aka. ALS). William is very talkative and friendly, but he hesitated and appeared overwhelmed by grief when he spoke about his son. Although William remains actively involved in multiple groups, including pain support and writing groups, he hints toward being lonely. His loneliness became more pronounced after he retired and moved to the elderly home.

> “This is very painful to admit. [..] I guess until I moved into here [senior citizen home] and became single again, I was sixty years old. I never realized how easy it was to get isolated.” – William

Serendipity – ‘One day at a time’

> ‘The pain has changed my life it's made me somebody didn't used to be, so I have to think you know, what's really doable? what's really feasible? […] It’s like they say in my program ‘One day at a time’.” – William

Previous loss extenuates the experience of pain. William’s philosophy to ‘push through’ his loss is by living each day as it comes. He explained how he sees each day as different in terms of the intensity of pain, subsequent energy, quality and quantity of sleep, and therefore is required to accommodate every day accordingly. He mentioned that he likes to plan but the feasibility of planning changes due to the everchanging nature of his pain.

> “My best friend committed suicide two years ago. But by this point, I've never... [pause] never really let myself fall into that dependency of a good friendship. Relationship is fleeting for me! It doesn't last and there's death involved. My best friend on the female side was my cousin and she died of cancer four months ago. Time flies when you're not having fun. Anyways, she died. And I found is it that it may be positive in its own way. But at the same time, mortality rings. So, I try and go into, into friendship without any expectations. [..] So I'm sort of lost in that department. Like most of them are dead.” – John

John further elaborated that coming from a lower socioeconomic status, a lot of the people he thought of as friends, took to addiction, drugs and crime. Some of them ended up in prison, some in drug rehabs and most are no longer alive. Death, though inevitable, is a traumatizing experience. One needs to go through different stages of grief to eventually accept its reality. John is trapped between the repeated sense of loss arising from losing loved ones and losses resulting from his pain. The sense of loss will only get worse as he loses more activity as a consequence of his arthritis. He struggled forming meaningful relationships which he refers to as *"fleeting"* due to past experiences. Instead, he prefers developing acquaintances. His narrative highlights loneliness, and the fear of vulnerability at the thought of working towards emotional connection. This feeling of continuous loss and fear of further loss isolated him even further – moving him further away from recovery.

> "I have good health, got projects, I've got a chalet that has to be either fixed up, renovated, then sold or fixed up, renovated and lifted. And a lot of people don't have that" – John

On the other hand, to compensate for the loss and lack of strong support system, I saw John relied on other activities and projects to find meaning in life. He mentioned focusing on maintaining a healthier lifestyle to motivate himself to live well. I also noticed him engaging in a downward social comparison behavior as a coping mechanism. He mentioned having relatively good health and projects allow him to look forward in life compared to others who may not have these privileges.

Hope - Through Faith/Religion

> "I know that the answer can be in people, I wouldn't put all my money in people. more money in God than other people." – John

And also;

> "Take care of yourself first, give thanks, give praise, sit back and try and help somebody." – John

John was the only participant who mentioned coping through faith and belief in a higher being. Nevertheless, it was worth mentioning in this section that since he didn't have access to a strong social support system, a strong connection to religion helped him attach meaning to his life and suffering.

> "Now there are tools, what not to do, what to do, what I can't do, that's much easier. [long pause] Although I still don't deal with death well enough... My dog passed away two years ago so it was, right before I went to work because in that morning of sitting down with the dog. Having a doctor come over to put him down. Amy crying... I don't remember if I cried. And now with our grandmother passing away this weekend. It was pretty tough." – Daniel

Daniel is introverted and not very expressive, but as the interview progressed, he eventually opened-up about his experience with loss and death. The weekend before our interview Daniel's grandmother had passed away. Although he remained calm, composed and a little distant throughout the interview, reflecting on loss allowed him to lower his guard. Speaking about previous losses allowed him to reflect on his recent loss, and helped him channel through the distress. It was also evident that each new experience of loss no matter how big or small, reminded participants of their pervious pain and sufferings, which often further amplifying the intensity and impact of emotional and physical pain.

4.2.2 Loss of Self

> "It was turns out I wasn't as smart as I wanted to be. With the pain and family issues going on. The anxiety was too much, so my GPA suffered I got kicked out." – Daniel

There was a loss of seeing oneself as capable or talented in certain areas, such as professions, hobbies, and physical endeavors that once made up participants' sense of pride and were no longer possible. Since these were tough to carry out with pain, these activities were mostly replaced by others.

Hope - Accepting Pain as a part of one's Being

Hovey et al., in their paper, refer to this as a sort of ballroom dance – where sometimes pain leads the person and at other times the person leads the pain. This metaphor outlines that to incorporate pain into our life and our story we can align ourselves with the pain in a coherent way. Thereby, allowing us to manage our pain and live a good 'enriched' life. This is described by Daniel who mentioned that during the initial phases of his chronic pain he experienced a 'less enriched' life, where the existence of pain had taken over his entire life. Over the years however, he managed to *accept pain as a part of his being.* This allows him to lead the pain in his dance of life and live his life well in spite of the pain. [64]

> "I find, it's mostly the same as it is now. Before I had a less enriched lifestyle. Now my lifestyle is such that I'm more comfortable with the pain. I know how to manage it better. I can, I can feel it enriched more than I was before. And I can actually enjoy myself sometimes without the pain being in front and center. Now it's usually in the back, in the back burner. So, I can relax, and I can focus on other things." Daniel

Guilt and Self – Blame

Participants expressed feelings of having failed as a strong male figure (father, husband, son) in their social settings. This can be seen in narratives of Kevin, Paul and John. These participants blamed themselves for their chronic pain, and the subsequent disability, anxiety, depression, and how their pain affects them and their family.

> "Yeah it's a bit of a crisis sometimes, it will just be a potential slight pain and other times I've been worse. The last year was supposed to go to Niagara on the lake. I'm not sure if I mentioned, and I was supposed to this was for vacation set up everything. And the day before, it was on a Sunday, I think I was cleaning (was wiping down the tiles in the shower) and it's just cold and I was like, 'oh no...'. It came and so right away I thought okay, let's

> schedule physiotherapist’s appointment, they got to do something. Even if I feel a little bit better, it'll be manageable. But this was like seven hours drive. And driving is the worst. […] So, it effects people around, so my wife and daughter had to postpone their vacation because of that. I felt bad. Sometimes you feel that if you had planned it correctly or if you had gone to the gym a little bit more, you would have been more flexible. And this wouldn't have happened, we feel like the bad money's worth all the time. So, you can't take care of yourself. I feel like there's a lot of self-criticism.” – Paul

Paul’s story is used as an example here as a unique interpretation of one’s disability and perception of their own disability and how they interact with the world. Paul told us about the time when he planned a trip with his family, which he had to cancel due to the sudden onset of his pain. He explained how during this, he wondered whether he could’ve prevented the pain episode if he had altered the events that led up to it. He mentioned things like ‘should’ve done’, ‘should’ve done things differently’ and ‘bad money’s worth’ while acknowledging the underlying unnecessary self-criticism and guilt. He also mentioned how he tried to think of ways to salvage his family vacation by thinking he could schedule a physiotherapist’s appointment or that he could manage driving as soon as he feels a little bit better before finally accepting that driving for such long durations would only make the pain worse. Again, the yin and yang of denial and acceptance are seen here as Paul recognises the unfair self-criticism.

> “It's like the mindfulness where they said that you shouldn't use the words should have, ‘I should have done this’, ‘I should've done that’. You're there now and you're dealing with it. [..] Yes, I'm going to do avoid it from now on.” Paul

Paul referred to one of the positive cognitive techniques he learnt from mindfulness workshops held at HOMEBASE and spoke about incorporating them to avoid the cycle of guilt and self-blame and associate a more positive outlook instead of suffering at hands of the pain.

Hope - As a way of looking forward

> “I'm kind of fortunate. I'm not as bad as some, who are feeling it of all the time. I don't know how that must feel. You need to feel as if there's some hope, when you're in the dark all the time... I don’t know.” Paul

Paul mentioned the need for hope as a means to look forward. He compared pain to ‘darkness’ and hope to light. For someone with intermittent pain, moments of relief act like light and a beacon of hope for how his life should or could be – this motivates him. He felt thankful and happy to experience bursts of pain-free moments. He also compared his pain to those who are worse off in terms of chronicity and intensity of pain. In this way, the incorporation of downward social comparison as a coping mechanism becomes evident yet again.

4.2.3 Loss of Physical Activity

One of the first things that happens when someone develops chronic pain is the immediate loss of activity, often due to the fear of further injury and further intensification of one’s pain. Consequence of that is seen in the form of weight gain which further propagates one’s pain.

> “For the first year to year and a half I could hardly do anything. And you start to not even recognize yourself, it just feels that you have changed so much.” – Henry

Henry was extremely active before his accident, this changed after he developed chronic pain. The lack of physical activity lead to feelings of loss and weight gain which changed his perception of ‘self’. Contrary to the fear of exercise increasing and furthering the pain, research has shown regular exercise can help people manage symptoms and improve their health-related quality of life. Most interviewed participants confirmed previous findings in that regard. Although they had to modify their physical activity by taking their pain into account, they reported an overall benefit on the experience of pain through exercise.

> “I mean the interesting thing is that the physical activity helps me the most, so I try to do that as much as I can [..]. The closest I have come to being pain free is when I’m exercising.

> I can feel the back of my leg and it feels normal, like the other one. And I think it's because the circulation. [..]endorphins and blood flow. Normally the leg that I have pain on, it doesn't feel, gets colder quicker. So, there's something going on there and that feels really good because there's this sense of accomplishment. And so even a few hours after that and the endorphins, the sense of accomplishment stay with you." – Henry

Henry's narrative confirmed that exercise physically helps with the pain by increasing blood flow, releasing endorphins and reducing inflammatory agents. [65, 66] But more importantly, in short term it gives a person sense of accomplishment which allows for more positivity energy going into the day and makes one more capable on taking a lead on their pain. In this way it helps people retain their strong self-identity in the form of dominant masculinity. Due to existing pain, it's physically and emotionally painful to exercise at first, but it is imperative to find a way to it. Participants with chronic pain are prone to other chronic diseases (diabetes, coronary and pulmonary diseases) that can be prevented by exercise. So, when you chose a healthier lifestyle through physical activity and diet, you are not just trying to reduce pain, but also improve your quality of life by preventing others chronic diseases.

4.2.4 Isolation and Depression

> One of the questionnaires I was asked when I this program – on loneliness. I don't… [pause] Where did that come from? That's what got me hooked on. It actually prompted you to 20 questions anonymously […] I looked at it for a minute and thought 26 and a half years of marriage, and I'm lonely." John

Isolation was thematic in all interviews. Participants essentially described their pain as literally 'crippling' and figuratively, 'incarcerating' and 'entrapping'. Pain modified their interpersonal relationships by separating and distancing them from the world, their previously normal hobbies, activities, ambitions, friends and even family members. As seen in the previous section (4.1 Vulnerability vs resilience), they no longer felt they 'fit in' or had much in common with people in their social circle. Participants described feeling lack of genuine empathy and trust from pain-free individuals in their social circles. The participants reported growing tired of explaining themselves and yet being misunderstood which resulted in social withdrawal.

> "And a lot of that confines you so sort of call it the "Pain incarceration" where your world becomes smaller and smaller and smaller over time, to the point where you just start giving up. I'm getting better at it but for a long time I didn't feel like going to parties or doing anything like that because I didn't know what to talk about. You know I just didn't want to talk about my pain. But It was there all the time and it was very frustrating for a long period of time." – Henry

Henry narrated how the strong shadow cast by pain takes over one's life by using up all available energy, and thereby confining them and isolating them by claiming dominance over mind and body. It's hard to break free of the control that pain imposes on life because, a) other people do not understand and therefore cannot help, b) being misunderstood makes one irritable and upset, c) loss of normal routine and activities handicaps the ones suffering d) loss along with disability caused by pain generates self-doubt and puts one's self-identity in an existential crisis, e) one does not feel like other pain-free individuals can relate to their experiences or vice versa, and f) experience of pain is too overwhelming which does not allow spending any more than a few minutes speaking about things other than the pain.

3 participants mentioned battling depression and/or had sought therapy in the aftermath of chronic pain; Neil, John and Kevin. Some participants, such as John and William, also mentioned lingering feelings of loneliness. Unlike the aforementioned participants, who mentioned experience of loneliness directly, others used alternate words and euphemisms to hint to either possible depression and isolation or hinted indirectly towards loneliness through the stories they shared.

> John: "I'm not really a joining type. I forced myself to become part of. I like solitude. Then this reality that I have to be able to get out of bed every morning starts. To make sure of

> that, requires exercise even going to the longevity and you know you have to avoid these things called depressions and sadness. [..] Because I've been there and I used to take pills, and I don't want to take pills. I don't want that. I want a sober existence and I want to die in peace, I don't want to die in chaos. But I don't control that right I have to turn that over to something stronger than me and say okay but what's my plan for today and my plan for near future is to do 16 more months (at least) of work, of my routine and then help! help! [..]" – John

John, like William, believes in taking in one day at a time. Some participants also used the word solitude as a euphemism for loneliness.

> "I take two medications for depression. [..] that's probably been, four years at this point. I got myself into trouble and didn't realize what was going on and I had some harmful thoughts and my lovely wife sent me off to a to a CLC the session and when they heard what was going on a quickly admitted me into a program. Then sent me to Jewish general for follow up and then it was a quick entrance to the medical substance do to fix that and you try for years to get the right one, to get the right balance the ratios. This one works. That one doesn't work. This one has side effects that you can't stand. You know. It's ridiculous." – Kevin

Kevin reported diagnosed depression, which occurred 4 years ago, most probably as a consequence of chronic pain. Kevin too, throughout the narrative, used euphemisms for depression, such as 'got myself into trouble', 'that', 'not feeling too great' etc.

4.3 PURSUIT AND ART OF LIVING THROUGH AND WITH BEREAVEMENT OF PAIN

The changing constructions of self, though varied in nature, represented a loss of parts of their former self. Participants mentioned a defined change in their behaviors because of their changed interactions with others. For instance, some participants mentioned that they were able to empathize with others more than they would've otherwise. Some reported otherwise. Some reported seeing themselves as less likely to take risks and being less fun or less active. Accordingly, there were also changes in their way of thinking. The initial shift came from being stuck in the past and being trapped by the pain. However, later there was a shift in the participants' orientations to either the future or the present as they moved towards accepting pain as a part of their life.

4.3.1 *Pain is inevitable, Suffering is optional.*

> "The pain is there. So, it's up to me that you want to sit back and die or you want to live. And if you want to live, you have to live with pain. And the pain is really a mental pain. You can live with pain. But you have to, want to do live" – Thomas

One of the main motivators and coping mechanism in life with chronic pain according to Thomas was *life* itself. His narrative resonated with the popular saying, 'pain is inevitable, suffering is optional'. He mentioned his pain is inevitable, but he can actively choose to either suffer at its hands by being trapped by his pain or accept it as imminent and find some way to live on in spite of it.

4.3.2 *Pursuit of Healthy Lifestyle*

Hope for the future often included a notion that chronic pain would either subside or become more and more manageable with time. Participants also seemed to believe in achieving a meaningful life despite of their circumstances. They spoke about multiple ways they stayed motivated or found meaning in life. Most participants reported a strong want to live a healthier life because of the pain. Living with an illness made the participants hold higher regard and appreciation of their physical, mental and emotional health. Henry, Neil, Paul, John and William became more health conscious by wanting to exercise, eat healthier, sleeping better and putting their health and well-being at the center of their focus. They recognized self-care as the core to leading a happier life.

> "All of these exercises and meditation are going to help me. Because I have anxiety and movement is very good." – Paul

Along with wanting to lead a healthier life, there was also hope regarding improved techniques to manage and possibly cure the pain eventually.

> "I don't have a choice. I have to continue doing this otherwise it's just going to get worse. I think you know, anything that comes my way, saying this is going to help; a new discovery out there, 'hey we found this exercise... a few movements that you do remove it right way. I'm looking. I think I'm always looking for things, being curious about things. Because, I think the other option is worse. If you're in pain and you're saying I'm not going to do anything. I don't know if that's acceptance, but while yeah, I'll accept that it comes and goes, I'm going to do whatever I can to make my body as healthy as possible. It's difficult." – Paul

Paul discussed how although he accepts that pain is a part of his life, he is adamant on eventually making himself healthier and hopes to be completely rid his body from being under control of the pain.

4.3.3 Purposeful Existence – Through helping others

The idea of participants' experiences being helpful to others in similar situations enabled them to associate positivity to their own experiences.

> "It helps me when, I see other people benefit from it. It gives me a rush [..] While I'm there, it helps my pain. When I leave in my pain comes right back. So, it's a distraction." – Ethan

Ethan mentioned getting tremendous pleasure when he wishes to accomplish something or when he's accomplished something. To him seeing other people benefit from his experiences creates the same level and pleasure of accomplishment. It provides a temporary relief and acts as a distraction from the pain. The feeling of purposeful existence is in line with hegemonic masculinity, where men possibly act based on acting responsibly, solving problems and being in a position where they can provide help rather than receive it. This is seen in subtle forms, such as Daniel and Kevin's decision to join mindfulness workshop was influenced by Jane* (Daniel's mother and Kevin's wife). They initially joined not because they wished to help themselves but instead wanted to provide emotional/moral support to Jane. Similarly, William and Henry also thrive through remaining involved, providing their expertise and support and playing their part in chronic pain related community programs.

4.3.4 *Using Activities and Hobbies as Distraction*

> "I did a lot of reading to kind of distract myself and did a lot of different kinds of treatments in the beginning like osteo, massage, and acupuncture. I also started doing a lot of meditation self-hypnosis to deal with pain. [..] Just kind of always distracting myself." – Neil

The most common coping strategy practiced by participants was of distraction. By immersing into activities and hobbies that took their focus away from pain, they were able to move their pain to the peripheries. These distraction techniques included various activities and hobbies ranging from cooking, baking, reading, working, playing video games, listening to music, practicing meditation, exercising and socializing. The different techniques used by participants are highlighted in Table 4.

> "Otherwise, I'll just sit down and read a book anyway. Reading is a really central part for me." – Daniel

Some participants found it easier to find solace and maintain normalcy by engaging in familiar activities. For many participants, some of the old hobbies were no longer feasible as is, hence they added modifications to fit their abilities and disabilities better. For some activities, this included adding more breaks or changing the posture for some activities. For participants who wished to remain healthy and exercise after their chronic pain, they had to modify their routine and regimen to accommodate their physical limitations. This will be discussed in the next section (4.4) in further detail.

4.3.5 Age

Participants who belonged to younger age groups at onset of pain, experienced a loss of innocence. Experience of pain and loss accelerated and facilitated the process of rapid adult-like maturity. This demonstrated a greater initial struggle with the existence and acceptance of chronic pain in the months following its onset. There were greater feelings of associated loss relating to profession, hobbies and physical activity. In replacing these activities, they re-defined their self-identity, whereby they developed stronger coping mechanisms compared to other participants who developed chronic pain at much older age.

The other spectrum of the age group that coped well with the pain was elderly group (over 80 years) – participants who developed pain at an old age, such as Thomas.

> “For the pain I'm taking their medications of course but as he said that cuts the pain but doesn't take it away because it's there. And I'm old enough to know that it just won't go away. Because pain causes pain. And nothing really takes away pain, even if it takes away one pain. It is replaced with another pain. So you have to live with the pain” – Thomas

Resilience to live on came from being aware of and acceptance of aging and death as a consequence of life. Their strategies talked about having to live with pain as that’s the only way forward. This age group seemingly came to terms with their circumstances faster, hence experienced least amount of changes in their personality to accommodate and incorporate the pain. Pain did not influence them in the same way as it affected other groups. Having experienced loss in the past played a significant role in perception of and subsequent actions pertaining to their pain.

4.4 FINDING SELF THROUGH HOMEBASE COMMUNITY PROGRAMS

Participants unanimously reported that they wished to put their well-being first. This was the resistance brought upon by pain – the will and motivation to live with enhanced health-related quality of life by being more mindful of self, their condition, their limitations and their strengths. Most participants also explained that paying attention to the interplay between their mind and body, in terms of thoughts, feelings and subsequent actions, provided insight into the ways of achieving happiness and healthier life goals.

Most participants discussed altering their schedules and habits to adapt to their new lifestyle (one with pain). For instance, I discussed how Henry altered his schedule in the previous sections. This involved avoiding transportation at certain hours of the day and travelling during particular times to avoid any stress related to public transportation. Other participants reported adjustments made at work and/or home in terms of help-seeking behaviors, relying on social support, re-directing themselves to positive course of actions (with re-defined masculinity) opposed to damaging ones (such as poor health behaviors, increased anger, isolation, dependence on medications or substance abuse et cetera). Participants also talked about looking forward by focusing on their motivation of not being stuck in the negative experience of pain or being stuck in the nostalgia of past self (pain-free days).

HOMEBASE seemed to provide a sustainable platform for those in chronic pain to achieve these goals – to find tools to navigate through their pain in order to have a better life. This was to be achieved in three steps:

- ***Connect*** – By providing variety of activities including pain specific programs ranging from mindfulness meditation workshops and gentle fitness such as yoga and swimming to music, art, photography, cooking and nutrition;

- ***HOMEBASE Shed*** – To promote personal agency and sense of purpose by providing a space where men get together and work on projects (Maker-Lab) and/or volunteer for community initiatives;
- ***Mentor Corner*** – To provide a space for men living with chronic pain to connect with others who are seasoned veterans of this experience. It is about men helping men live through and with chronic pain.

> “I like it because it has a variety of things, it's not like the same things where you're doing the same thing over and over. Now we're here at the YMCA, I come in to do my exercises, I do my aerobics, and I do my saunas and today I mean they're doing meditation. Next week, if I have time on Saturdays, they have yoga meditation. There's also the maker lab, together with something different something new... the cooking classes also. There are things out there that very easy, very tasty and they help with inflammation. I think all of those things coming together. And also, the people, they're sharing their stories, they're doing better, they have a sense of humor, that helps. [..] They're all very supportive. They have interesting stories, and they're genuine.” – Paul

Paul, in his interview, touched upon how HOMEBASE has been a helpful platform for him. Since one size doesn’t fit all, having a variety of activities are therefore beneficial as they aim to provide something for everybody. Paul also mentioned that in addition to the activities provided as a tool to seeking healthy behaviors and navigating their pain, HOMEBASE also brings together a group of individuals who can truly relate and empathize with each other. Everyone in pain has a unique experience and perspective that allows them to be supportive, express genuine concern and learn coping techniques from lived and learned experiences. This helps with building a genuine connection between people who can relate to and thereby help each other.

4.4.1 Mindfulness Meditation

One session was held every week for 12 continuous weeks. Each session focused on different dimensions of pain. Sessions focused on being mindful about pain and other factors that influence pain intensity, and the aspects of life that are influenced by chronic pain. These included sleep, exercise, nutrition, music and art amongst other things.

> "I mean, I've taken meditation courses and mindfulness meditation, but I hadn't really done something that's explicitly connected to pain management." – William

All participants who participated in this workshop mentioned how it was benefiting them. More than half of the participants mentioned that they had previously tried meditation but it hadn't been as beneficial because the practice did not acknowledge their pain, whereas since this workshop was specifically designed to help them navigate through the pain it allowed them to incorporate new and improved set of tools to work through their pain.

> "I think mindfulness is a very good tool. I've had a little bit of experience and started with yoga and, and some of those mental exercises were what introduced me to the subject. [..] It's not the same technique that we're learning now. [..] When I did this before, there was no intent to connect it to pain. This time, there's an intent to examine what it does with pain. And while I don't think it's a miraculous solution, there's no question that it helps. Part of the pain lives in your brain. And if you can even briefly, do something which dulls it or minimize it, or changes that in some way that it becomes acceptable, then that's a good thing." – Kevin

Participants mentioned how through the variety of techniques they were able reduce the onset and intensity of distress caused by their pain. The practice enhanced their awareness of the way they perceive pain and how they can modify that perception to associate more positivity to the experience.

> “Every class we're becoming more aware, he is showing us, look this is how you can do it...” – Paul

Insomnia:

> “I don't want to go get up in the morning, because usually I don't sleep the night before the pain is waking me up, so I'm not very rested I don't want to go out, but I have to go.” – Ethan

7 out of 9 participants who were interviewed were a part of the mindfulness meditation workshop. Sleep disturbances were unanimously brought up and reported by all 23 participants during Mindfulness meditation session (on sleep, chronic pain and mindfulness). Although all participants mentioned it during Mindfulness meditation session, only 3 participants mentioned sleep during the interview. John (who wasn’t a part of the meditation workshop) actually reported to get a good sleep at night regularly. Daniel reported diagnosed sleep apnea, which along with his pain affected his quality and quantity of sleep. Ethan reported being awoken multiple times in the night due to the pain.

Art - RISING FROM THE ASHES LIKE THE PHEONIX

One of the mindfulness sessions comprised of asking participants to make drawings to express their life in pain. Since contemporary phenomenological approach uses all forms of text including works of art as expression to understand a phenomenon of lived experience, I decided to include one such drawings in my phenomenological pursuit.

Neil’s image (Figure 1 – Appendix C) gives us an insight on the dynamics between himself and his pain. In order to understand his lived experience through his art, I will allude to the previously introduced concept of ‘dance between the person and their pain’. In his artwork he depicts three primary states, each of which simultaneously represent presence of pain (in red). Green in painting represents his responsibilities, tasks, motivations and dreams on the other hand. The first state shows a circular scatter pattern of both the him and pain, both coexisting yet competing for the same space, both completing to be the epitome of his being – or wanting to lead the 'dance'. The scatter pattern represents chaos and intersection of each force with one another.

The second depiction or state represents a circular pattern again, where both forces begin at the center equally but slowly the person (green) starts to regain control leads the pain in the 'dance' – i.e. one learns to live with the pain. Though the pain still exists, it moves to the background majority of the time so that a person can take back control in leading their life.

The third depiction demonstrates a state where the person (green) and the pain (red) exist side by side in a sort of what appears like a Venn diagram, where most life exists at their point of intersection. Thus, in surrendering to the existence of pain one truly accepts it as a part of self, instead of treating is as a separate entity to be fought with. This sums up the ball room dance metaphor as it reiterates that although the pain and person co-exist, with one taking the lead sometimes versus the other, but for most part they co-exist in harmony with one another, existing and moving as one through the dance of life.

The struggle between control and surrender to pain is constant. Although Neil is in pain and has lost many things due to chronic pain, including his career, old friends, old relationships and physical activity, the pain also allowed him to remediate his priorities in life. Neil has managed to completely redefine his identity to live a better life despite of chronic pain, and in doing so he has emerged stronger and happier.

4.4.2 Exercise

> "It's amazing with what the gym does because the stress level reduces. It also improves your heart rate. You feel that you're more active, you are capable of doing things. You sleep better! It has a lot of benefits." – Paul

As I discussed above, physical activity helped participants with their pain in the longer run. HOMEBASE provided activities specifically designed to cater to the people with injuries and chronic pain, allowing them to indulge in physical activity in a safe environment. Exercise helped participants sleep better, reduced their pain intensity, and made them feel more active and positive. There is evidence which links physical activity to reduced anxiety and depression [65, 95]

> "I am glad this is another reason why I joined this chronic pain group. I find now that the spin cycling helps immensely with the arthritis" – John

4.4.3 Cooking

First time I met William it was at the cooking workshop held by HOMEBASE. I welcomed him into the class as he struggled with his cane to walk through the long hallway that stretched from the entrance to the area where the workshop was being conducted. I asked him to fill out the required forms, he observed his surroundings grumpily and gave me a very judgmental stare. A few minutes into the workshop his attitude began to transform completely. He warmed up to the activity at hand and the people around him and began engaging in the activity fully. I remember his words clearly;

> "I was really unsure about coming to this event today. I woke up with a really bad pain and the thought of getting out of my house seemed… but you know what? I'm glad I'm here." – William

One of the earliest workshops arranged with the HOMEBASE community was the cooking workshop at the Concordia PERFORM Centre. It was easy to pick up on the change in the participants body language and attitude, and the overall change in atmosphere from before and after the activity. Participants seemed skeptical and worn down by their pain when they came in (similar to William). Some were unsure about being able to remain engaged during the entire two hours of the activity and had negative ideas regarding pain getting in the way. However, during the activity, they loosened up and became truly engaged in the activity and began engaging with the group of individuals they were working with. After the activity they all reported to have either forgotten about their pain completely or were able to put the pain aside temporarily for the task at hand. The activity made them feel fulfilled and put them in a good mood. The effect lasted weeks following the activity as reflected later in the interviews of some of the participants, since the recipes from the cooking workshop taught use of healthy anti-inflammatory ingredients that help reduce pain intensity.

> "[…] the cooking classes also, things out there that very easy, very tasty and they help with inflammation". Paul

4.4.4 Music

One of the most important motivators in Neil's narrative regarding his way to navigate through the pain was music.

> "Well, for me, it's just, there's, there's so much joy coming from music. And it's something that I'm very devoted to. So, it's like, it's always on my mind as something positive that I need to, sink my energy into, even if, you know, I'm in crazy amount of pain." Neil

Neil mentioned that playing music keeps his mind off of pain. He becomes completely engrossed and does not think about his pain at all. Music also improves his mood and gives him an overall positive outlook which leaves a lasting effect. This makes it easier for him to deal with his pain when it returns up to hours after the activity. Other participants such as Kevin and Daniel also mentioned music as a major source of distraction from pain.

Regarding Music workshops held at HOMEBASE:

> “We had a music for wellness workshop last week. And it was amazing. [..] They've set it up so that we can have free personal training sessions at the Y [YMCA]. Benefiting from that and the maker lab also. It's such an amazing place. And just the vibe in these workshops – there is just happiness. It's all people just there and like nerd-ing out! Exactly. I walked in. And I was like, this is the place where I belong, where I should be.” Neil

4.5 IMMERGENCE OF RE-DEFINED MASCULINE SELF- IDENTITY

> *"Long before we understand ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society and state in which we live."*
>
> ***— Hans-Georg Gadamer***

I previously discussed how chronic pain causes loss of one’s identity and threatens their hegemonic masculinity. In this last section we take a look at the re-negotiation of masculinity and self-identity which emerged from our phenomenological exploration.

Raewyn W. Connell in her book ‘*Masculinities’* talks about the multiple masculinities – Hegemony, Subordination, Complicity and Margination, brought about in society due to the interplay of gender, race and socio-economic class. Hegemonic masculinity is constructed in relation to what she identifies as the other four nonhegemonic masculinities: *subordinate* masculinities are constructed as lesser than or aberrant and deviant to hegemonic masculinity, *complicit* masculinities do not actually embody hegemonic masculinity yet through practice realize some of the benefits of unequal gender relations, *marginalized* masculinities are trivialized and / or discriminated against because of unequal relations, such as class, race, ethnicity, and age, and finally, *protest* masculinities are constructed as compensatory hyper-masculinities that are formed in reaction to social positions lacking economic and political power. It is however important to realise that since both hegemonic and non-hegemonic masculinities come into being under specific settings and situations (varying among local, regional, and global levels), they are subject to change. Therefore, hegemonic masculinity constantly evolves and is replaced by newer versions. [67,68]

Specifically, in context of chronic illness and chronic pain, where traditional hegemonic masculinity is often threatened, research shows wide typologies of immerging masculinities; including types that ‘retain hegemonic ideals of masculinity’ and those that ‘try to renegotiate masculinity’. According to Buchbinder, the changing construction of masculine identity is constant in one’s lifetime, men unconsciously (re)negotiate their concepts of masculine identity as they navigate different relationships and attempt to ‘fit in’ or ‘pass’ as ‘one of the boys’. [69,70]

Every participant reported impact of experiencing chronic pain on their self-Identity. The modifications in self-image were explained either as negative, positive, confusing, all-encompassing, or as a personality change. Most participants reported that the onset of chronic pain shook up their sense of self. This destruction of their previous self-identity was usually followed by successful or unsuccessful attempts to renegotiate, rebuild, recreate, and/or modify parts of their identity.

8 out of 9 participants identified changes in themselves which, were negative in their view, post chronic pain diagnosis. The participants reported feelings of destructive habits, poor health choices, lack of confidence, feeling angry and/or bad about themselves, desire to socially isolate and feelings of worthlessness. Participants also reported feeling weaker, lethargic, unhealthy, out of shape and dissatisfied with their physical appearance further hampering their self-esteem. In contrast, 6 out of 9 participants also spoke about some positive changes in their identity simultaneously. For example, these participants felt stronger as they had managed to persevere through the struggles of pain which further also helped them regain their masculine ideals of self. For most participants, these difficult circumstances led to a healthy change in point of view and friend circles, which in turn helped them attach new meaning and purpose to their lives. For instance, Neil, Ethan, Paul, Daniel and William underwent complete change in their social circles and found their own unique calling. Similarly, some participants, such as Ethan, who previously

had very strong ideals of tradition masculinity and viewed himself as an independent and purely self-reliant person, became more accepting of help from others.

4.5.1 ‘Retain hegemonic ideals of masculinity’ to navigate through pain

The Self-reliant and sometimes risk-reliant man

Some of the risk reliant attitudes included those discussed earlier – ones of poor health seeking behaviors. One such example was of Kevin and Daniel who both mentioned avoiding seeking help from a health care professional until Kevin’s wife, and Daniel’s mother, pushed them to seek treatment. In contrast self-reliance was based upon the gendered assumption that asking for professional help makes men too weak. This any/or all problems should and could be dealt by being on their own and without the need of help from anyone. Many men’s narrative acknowledged either direct or indirect awareness about their reluctance to seek help was tied to their sense of masculine identity. Hence, this notion became a key typology in this section of the discourse. One such example of Ethan’s narrative;

> “I got up and I felt a really sharp pain in my knee which I smashed but I've done that a million times so it's no big deal. After a while like we're talking hours, my left hand started to get pins and needles. Didn't think anything of it, I'm a guy, right? Didn't go away. Okay, no big deal, It's going to go away.” – Ethan

Ethan walked me through his initial days with chronic pain. He stated that initially, at the onset of his injury, being a man, he didn’t think his injury was ‘a big deal’. He also recognized the enculturation of masculinity as being responsible for his self-reliant behavior by stating that such behaviour was because “I’m a guy”. And that as ‘a guy’, acceptance of pain and vulnerability may be seen as weakness in those who upheld traditional ideals of masculinity.

The Responsible Man – (Treatment-Seeking as Responsible)

As we know, masculinity defines men to be self-dependant and responsible. Looking from a different lens, disclosure and conveyance of treatment seeking behaviour is also strongly aligned with hegemonic masculine identity, but in an action-oriented way. In participants with chronic pain there was a loss of seeing oneself as independent, which was then accompanied by a realization that reliance on others was therefore necessary.

> “I would have hidden it until I couldn't run anymore because it was too bad and then she would find out that my feet hurt and I couldn't run. She'd wonder why I wasn't going running. But later on, about two years ago is when I killed my knees again, and she knew about that right away because I was hurt enough that I had to say something.” – Kevin

The discourse of ‘treatment-seeking as responsible’ is also strongly aligned with hegemonic masculine identity, but in an action-oriented way. Men feel a regain in control of their hegemonic masculinity by taking charge of their health by using words like ‘doing’ and ‘deciding’ in relation to their own help-seeking, as opposed to outright asking for help. Reasoning behind this that only when things are so bad that one cannot deal with it on their own, and have no choice but to seek help, should they be asking for help. Here desperation and/or reason conclude the action of seeking treatment as *responsible.* Similarly, Ethan also spoke about his initial days with pain in a similar tone:

> Didn't think anything of it, I'm a guy, right? Didn't go away. Okay, no big deal, It's going to go away. All of a sudden, my right hand goes completely dead. Dead! No feeling! And again, the pins and needles, excruciating pain, going up. So I decided to finally go to my doctor...” – Ethan

He mentioned how only when it got out of hand, he decided to visit the hospital – ‘my right hand goes completely dead. Dead! No feeling!”. Similar to Kevin, and other participants as well, Ethan felt the need to imply the *severity* of his as the reason for seeking help. His expression implied that being a man, he is strong enough to bear pain and deal with it. But also that in this case, he had no other choice but to seek treatment or visit a doctor only because it was beyond his control and had become truly unbearable (which he expresses by using words like 'Dead' and 'No feeling' when describing his hand).

Masculine - Guarded vulnerability

Guarded vulnerability reflected the paradoxical state in which when men began to express the feelings of vulnerability brought upon by experience of pain, they also coincidentally held back from revealing information. They shared cautiously and while limiting their extent of felt vulnerability as the mere expression which made them feel weak and what threatened their hegemonic masculinity.

> Kevin: "[..] Stereotypical man, not wanting to appear weak."
> Interviewer: "Opening up isn't necessarily… Do you believe it's a weakness?"
> Kevin: "Just sometimes it's hard to admit things. I don't know… that could be perceived as a weakness. Maybe sometimes not wanting to admit the obvious, I think just admitting it makes you feel like you're not as capable or something like that."

Kevin admitted, in third person, that for a 'man' expressing one's vulnerability brought on by pain could make him feel like he was inadequate or 'not as capable'. He also knew that his views were based on the stereotypical representation of what a man must feel and appear like. But these are also ideals upheld by other men in the society and swaying from them would mean being seen as lesser than adequate (falling into subordinate masculinity category) by other men and women. Contrary to what we, admitting vulnerability is the first step to accepting it as a reality. This would mean rejecting pre-existing notions of hegemonic masculinity, and in turn being emotionally and intellectually lost by completely losing one's existing identity. The fear of facing this existential crisis further holds them back from accepting their pain completely and being vulnerable.

> "Sometimes you see somebody worse of and think I'm grateful, it's not that bad, after three weeks I'm okay." Paul

Some participants protected their masculine identity by adopting a downward social comparison; whereby comparing their conditions to others in chronic pain who are worse off or less fortunate than themselves. This was evident in the above statement by Paul, where he stated how he felt grateful that he has intermittent pain rather than those who are in worse situations and in constant chronic pain.

Men also displayed guarded masculinity during focus group sessions in the beginning. In more private settings, such as interviews, it seemed men were more comfortable drifting away from expectations of behaving in a way that conforms to hegemonic masculinity. They were more comfortable diving deeper into their narrative of life with pain vs in group settings. This was specifically seen in case of Daniel who was relatively quiet during focus group sessions. This was also true for John, Paul, Kevin and Ethan. It was also observed that over the course of the 12-week meditation workshop, participants developed friendships, compassion and trust within the group and slowly became more comfortable in expressing compared to the earlier classes.

The Solitary Man

Although most participants had a strong socially supportive environment, they also mentioned how they preferred solitude. They were motivated to preserve their ideals of hegemonic masculinity pertaining to confidence, self-dependence and unemotional self-image. Their solitary lifestyle choices were a result of wanting to hide their vulnerabilities and from a fear of appearing fragile (therefore 'unmanly'). Daniel mentioned his choice of solitude by stating that he felt 'on the peripheries', like he doesn't belong in groups and people in groups don't understand his life.

> "I just feel like I'm on the peripheries. I'm there, I participate a little, but that's it. I don't like talking much, especially on groups. Yeah, I'm quiet, not social, I can listen, but don't want to talk." – Daniel

It’s also important to note that iconic forms of traditional masculinity glamorized solitude as enigmatic; denoting wisdom and other manly virtues. Participants who preferred solitude additionally based it on another hegemonic ideal of *rationality* where they highlighted that their decision to seek solitude was to avoid stressful social situations, anxiety, public embarrassment, rejection, judgement and (as in John’s case) depression. However contrary to their belief in most cases it also fed into reported loneliness, isolation from friends and family, and increased intensity of pain. While some like Daniel reported to be (for the most part) happier being this *solitary man,* others like John mentioned being stuck because of it and their struggles in creating and maintaining new relationships.

4.5.2 ‘Renegotiating Masculinity’

Genuine Connection

Genuine connection relies on establishment of mutual understanding. It speaks to men’s willingness to talk openly and seek guidance and about their condition with friends, family and/or healthcare providers. As discussed previously, a central feature of a genuine connection is the desire to be believed and understood in the context of their pain narrative – being ‘seen’, ‘visible’, ‘belonging’ and ‘in a place where I should be’ – such words were often used to display the perception of a genuine social connection. In this way it provides a contrasting alternate construct of masculinity – which focuses on not just reliance on self but encourages help seeking through genuine support from the community and does not fear emotional expression.

> “So you feel like you're not there by yourself. It's difficult for other people to imagine, they're like, they'll try to make recommendations to try this. Have you tried acupuncture? Have you tried that? But it's just on the surface. You know want you want is for it to go away. So being in a group of people that has pain, they are listening, and they understand. You could see it. They're not anticipating that you're exaggerating. In that sense it's reassuring [..] Knowing you're not the only person that has this, that it's not unique to you and there's other people that are similar, [..] that helps.” – Paul

Men also spoke about genuine connection in relation to health care providers as discussed above. One reason why men were dissatisfied with their health care providers and avoided seeking professional help could be attributed to not wanting to take on a subordinate masculinity typology as a patient. Rather, men desired a collaborative partnership with their healthcare providers, which enhanced their *personal agency*, made them feel listened to, understood, validated and empowered in their relationship with the healthcare providers. This was more in line with their desired renegotiated masculine identity.

DYNAMIC IDENTITY – Vulnerable Self with Pain vs Retained masculinity

(The Negotiation Act: Foregoing and regaining control of life to pain.)

All participants mentioned a dichotomy between their sense of self before and after pain. They kept going back and forth between their previous identities of self without the pain and their newer self with pain. Participants who appeared to have strongly embraced their pain in focus groups and social circles also demonstrated contrasting emotions behind closed doors. They portrayed a persona that celebrated their challenges while covering up inwardly hurting emotions. They used phrases like 'it won't go away' and wanting for it to 'go away'. This reflected a dynamic identity in participants where they went back and forth on negotiating their acceptance of vulnerability and pain and retaining their previous subconscious ideals of masculinity.

Paul acknowledged that he had gotten accustomed to and had accepted his pain but only in the hopes that one day soon there will be a cure which will 'take the pain away', which is somewhat contrary to definition of true acceptance.

> "But it's just on the surface. You know all you want is for it to go away." – Paul

Struggle between fully acknowledging their life with pain while rejecting its vulnerability became evident as participants relayed disassociated identities from before and after pain. This is seen in a statement made by Neil. He distinguished his life before pain as ‘normal’ – a life he could no longer have because of the pain.

> “I couldn't do them. Like, I couldn't have my normal life when I have chronic pain – Life I had before chronic pain.” – Neil

Sometimes participants used euphemisms or third person in their narratives while describing their pain or distress caused by pain, using words like ‘you’ or ‘they’ or ‘one’ while telling their personal experiences instead of ‘I’, ‘me’ or ‘we’. Most like Kevin and Daniel tried to keep their identity of their life with pain separate from their identity at work in order to retain their sense of control and not change people’s perception of them.

> “My arms and my legs came back to some degree, but the pain was excruciating, but I say pain it's burning pins and needles, burning sensation, spasms in the shoulder blades actually never stop - 24 hours a day. And through 12 years of the consecutive nonstop narcotic roller coaster rides, being titrated off, and weaned off of 11 most powerful medications on a planet, I finally came to terms with my life that, I have to live it versus kill it. It was either going to kill me or I was going to learn to deal with it. And that's where we are today” – Ethan

Ethan talked about his journey through a life with pain. He spoke about the unfathomable physical, emotional and mental suffering caused by pain. The most important part of his account to me however was its epilogue to acceptance. Surrendering to this new life, rather than being paralyzed by the nostalgia of a past painless existence, allows us to overcome our resistance to change. This is turn, gives a way to living our life regardless of the existence of pain. [r] Ethan’s story about his journey with pain reflected upon how it took him 12 years to come to a realization that the best way of out-living the suffering brought by pain is actually through acceptance of pain. The words he used for his life with pain included ‘live it’ vs ‘kill it’, this teaches us to learn to live with pain. It allows us to settle into our new story by not fighting our pain but by embracing it in order to regain our sense of lost control in the life with the pain [64]

The change in participants mindset to realize that certain aspects in life are dictated by our circumstances beyond one’s control, lead to true acceptance. Therefore, in order to learn to live with pain, they realigned their identity, where they no longer tried ‘fix’ their pain but rather integrated the limitations and vulnerability of pain into their life.

CHAPTER 6: DISCUSSION AND CONCLUDING REMARKS

This study provides a phenomenological analysis, which to the researcher's knowledge, is the first qualitative study in Canada specifically exploring the lived experiences of men with chronic pain in context of masculinity and tries to understand to what capacity, this encultured masculinity affects their perceptions, health seeking behavior and quality of life (QOL).

Previously conducted studies on chronic pain have not been gender-specific. [71-76] The closest gender-specific studies in context of pain have either looked at general chronic illnesses in context of masculinity or have looked at the relationship between psychological distress such as lived experience of depression in men in context of their masculinity. [77,78,] In Europe few researchers have looked at masculinity and in context of chronic pain. [30, 69, 79-81]. These studies discuss the sequelae of experiences chronic pain; starting with loss of function, discomfort, feelings of vulnerability and weakness, in some cases loss of livelihood all of which lead to a loss of self-identity, fracturing self-esteem. Lack of social support and compassion from health care further incapacitates patients, fueling distrust in health care system, negative perceptions of pain and isolation from family, and friends. Some studies also found how men modify their masculine identities to incorporate and cope with pain. My study confirms and builds upon all these findings.

My study finds that hegemonic masculinity influenced the way men viewed their self before and after the event of chronic pain. Their masculine ideals both had positive and negative effects on their health. On one hand, hegemonic ideals limited them from displaying vulnerability, seeking help from health professionals and/or social support which according to previous research have proven to be essential in developing higher level of adaptation to pain. On the other hand, by modifying and redefining hegemonic masculinity men were able to use masculine ideals to justify positive health behaviours, treatment and help seeking and community engagement as responsible, stoic and therefore 'manly'.

"How one encounters reality is a choice." ~ Martin Heidegger

For most participants it was a struggle to incorporate the ‘self in pain’ into their wholistic self-identity, often creating two distinct identities until the participants accepted and adapted to the reality of their pain. For some participants’ like Daniel and Frank the depersonalisation of and dissociation from their pain identity was important in coping with the accompanying distress felt, however, for some other participates more subtle themes of ‘endurance and resilience’ or themes of ‘hope’ in face of the physical pain and loss experienced were more evident. The accounts showed the transition from being trapped by the pain which is more commonly depicted in previous literature when discussing chronic pain to looking forward to live life by accepting and tolerating pain, so that life can be experienced in spite of pain and the implication having community support when dealing with the diagnosis of chronicity of an illness.[30, 71, 75]

Genuine connection played a significant role according to my findings. Previous researchers found that positive social interactions do not seem to change the intensity or progression of pain, nor disease behaviour however if affected their outlook towards pain and helped them adapt better. [66, 82, 83] I discovered that men in chronic pain desired to be understood and have their experience validated, to know they’re not alone and to no longer feel guilty or be ashamed of themselves and/or others for not representing the stereotypical depiction of a man. This validation needs to originate first from practitioners well-versed in dealing with chronic pain. A genuine and empathetic communication between health care providers and their patients is imperative as it increases health care utilization and compliance. [49, 84] The next step is generating awareness within the community about this invisible disease. This in turn cultivate a more compassionate and educated community, which will help alleviate the masculinity stigma that currently deters the management of chronic pain. This will aid men in associating positive interpretations to their pain experience, cope with and manage their pain more effectively and therefore enhance the intensity and depth to their life.

Some studies also talk about suicidal ideation as a consequence of this cycle. [85-87] This was not seen in the participants of this study. The interviews and focus groups revealed that the participants saw their life with chronic pain as one requiring constant struggle between vulnerability due to the distress of pain and resilience through hope. Studies including both men and women have compared coping styles, they have been inadequate at highlighting men's experiences and needs due to a smaller representation of men in these studies. This is why little was known regarding best management modalities specific to men in chronic pain. The study therefore also helps to identify both real and perceived barriers to their care and QOL. Through this study, I was able to reiterate what Shane said, 'No one size, fits all'. Since each person is unique, they had different preferences and coping strategies that benefitted them, while some preferred meditation, others preferred exercise and/or engaging in community activities that required complete immersion.

Some participants reported avoiding physical activity due to fear that exercise will increase and intensify their pain. Research has proven otherwise. Regular exercise (tailored mindfully of one's injuries) can help them manage symptoms and improve their health-related quality of life. The literature suggests that the two conditions being overweight and chronic pain are significant comorbidities which adversely impact each other. Although relationship between them is not a direct it is mediated by various factors. These factors include biological changes, inflammatory mediators, mood disturbance, poor sleep, and lifestyle issues. [65, 88, 95] All treatments require patients to internalize adaptive eating habits and staying active, which are not easy tasks. In general, weight loss and exercise appear to be beneficial for pain and associated QOL. In this case creating awareness isn't enough, in order to help participants safely engage in beneficial health behaviors, they need to be connected with instructors well-versed in chronic pain who can ensure positive outcomes. [65] This can be accomplished by inter-disciplinary efforts leading to tailored management programs with the help of community initiatives and areas to reintroduce *personal agency* to men allowing them to take control of their own health.

One of the limitations identified through this exploration was encouraging men to help themselves and increasing their representation in groups. This has been unanimously reported in studies in the past as well. [17] Findings from interviews and previous studies showed that convincing and motivating men to accept help for their own benefit proved difficult, which ties into their hegemonic masculinity ideals. Through HOMEBASE community initiative we were able to partially achieve their participation at a small scale and got a glimpse of beneficial activities agreed upon by men to navigate their pain. However, more research, is required to identify men's preferred activities and coping techniques in order to encourage them to take the first step towards living better with their pain.

Those living with chronic pain struggle to return to their jobs, passions and every-day living and in turn have to restructure their entire life around the circumstances they're imbedded in. This adversity asks from them to assign new meaning and purpose to their life. It asks them to focus on strengthening and redefining a new self. This brings about the desire to connect through mutual suffering by helping each other thrive through it together. And it instills the ability to look beyond suffering, to find happiness in concepts greater than self, and to find elation in accomplishing moral joys in order to experience deeper satisfaction in life.

One of purposes of this study was to give this population a voice, because they often feel silenced, delegitimized, and isolated by society when/if they try to express their vulnerability. By utilizing interpretive phenomenology to reflect the subjective nature of emotional and physical pain; I was able to better the understanding on how realms of physicality, society and psychology interact in presence of pain to warp self-image, which although initially negatively impact their self-perception and life, eventually through the right opportunities, and coping and management techniques can allow men to re-define their identity and settle into nay evolve into their new narrative story through pain and it's adversity. Eventually I hope that this research assists practitioners in the development of effective interventions and quality treatment protocols for individuals with chronic pain and its related co-morbidities.

APPENDICES

Appendix A: Sample Interview Guide

Recording Time and Date ______________

Name of Participant ___________________

Thank you for consenting to participate in this study. I would like to record the interview so the study can be as accurate as possible. You may request that the tape recorder be turned off at any point of the interview.

1. Please describe how your chronic pain and how and when it originally began.
2. Please describe what life with chronic pain is like, and how/if has it changed from before your diagnosis.
3. Do you work? How has pain affected life at work?
4. Please tell me about your relationships at home; (follow up question: How has your relationship changed after chronic pain)
5. Please tell me about your relationship with friends; (follow up question: How has your relationship changed after chronic pain)
6. What helps with navigating/coping and/or diminishing the pain (activities, medicines, other coping techniques)
7. Please tell me a little bit about the treatments that you have sought for your physical pain and mental health concerns. Do you think any treatment was particularly helpful? Or unhelpful?
8. Have you attended any activities at HOMEBASE, and how helpful or unhelpful were they?
9. What else would you like to tell me about your experience of living with chronic pain?
10. How are you feeling right now? (Asked to ensure the safety and wellbeing of participants)

*Other follow up questions came up according to participant narratives.

I want to thank you again for your participation, please feel free to contact me if you have any questions, queries and/or concerns.

Appendix B: Research Consent Form

McGill

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Consent Form for chronic pain research participants

Experience of living with chronic pain; Psychosocial implications and Quality of Life

Research Project Leaders:

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Introduction:

You are invited to participate in a study about understanding the experience of people living with chronic pain. The purpose of this study is to gain insight and understanding about the experiences confronted by people living with chronic pain to enhance the interactions and reduce barriers between the patients and clinicians.

In order to accomplish this, we plan to conduct 8 to 10 interviews from participants, who have been suffering from chronic pain. Each interview may last approximately 30 to 60 minutes. Participation is completely voluntary, and you may stop the interview at any time during the interview process. The type of questions you will be asked will relate to your chronic pain experience in the past days/months/years.

The data both audio-recoded and transcribed will be deleted / shredded approximately 36 months after its analysis.

Possible Risk and Discomfort:

There is no known risk for the participants who will participate in this study. Should the participant become unable to continue the interviewer will immediately stop the interview and ensure that the participant is comfortable.

Potential Benefits:

Participants will not benefit directly from participation in this research study but will make a meaningful contribution to understanding the unexplored aspects of chronic pain.

Cost and Reimbursement:

No compensation will be offered for participation in this research project.

Confidentiality:

Any personal information obtained during this enquiry will be kept strictly confidential. In order to protect participants' identities, their names will be removed from the written transcripts. Only the researchers will have access to any identifiable data. This data will be stored in the researchers' personal password protected computers at McGill University. Moreover, although the results of the study may be published and presented at research meetings and conferences (including direct quotes) participants' direct identity and/or identifying information will not be revealed in scientific publication, presentation, or report.

Voluntary Participation and / or Withdrawal:

Your participation in this study is completely voluntary. You may refuse to participate or may discontinue your participation at any time without explanation, and without penalty or loss of benefits to which you are otherwise entitled. The interview will be digitally audio-recorded with your permission. This recording will be destroyed once it is transcribed. If you decide not to participate, or if you discontinue your participation, you will suffer no prejudice. In the case of withdrawal, information collected to this point will be used to preserve the integrity and quality of the project.

Questions and Contact Information:

This research has been reviewed and approved by the McGill University Institutional Review Board. If you have any questions about your rights as a research participant, please contact Ilde Lepore, Senior ethics Administrator of the Institutional Review Board at 514-398-8302. If you have a question about the research itself or wish to report any adverse event, you may contact Dr. Richard Hovey or Dr. Mona Shah Jillani.

Sincerely,

Dr. Mona Shah Jillani

Declaration of Consent:

☐ I have read this consent form and have received the following information:

☐ My participation in this project is voluntary; I am free to withdraw my consent and to discontinue my participation in this project at any time without explanation.

☐ My decision regarding whether or not to participate will have no effect on my status. Refusal to participate would have no penalty or loss of benefits.

☐ The results of this study may be used in research publications and meetings.

☐ Confidentiality of any verbal and/or written feedback I provide will be respected, as all identifying information will be removed from the written interview transcripts, and my name will not appear in any published documents.

☐ I have had the opportunity to ask questions, and all of my questions have been answered to my satisfaction.

☐ I have been given sufficient time to consider the information and seek advice should I choose to do so.

☐ The individual interview will be conducted by the researcher and will be audio-recorded and transcribed.

By signing this consent form, I:

☐ Do not give up my legal rights,

☐ Acknowledge that the study has been explained to me and my questions have been answered to my satisfaction, and

☐ Agree to participate in this study.

Participant's Signature: _______________ Person Obtaining Consent: __________________

Print Name: ________________________ Print Name: ______________________________

Date: _____________________________

Appendix C: Participant's Art Work

Figure 1 - Neil's Drawing

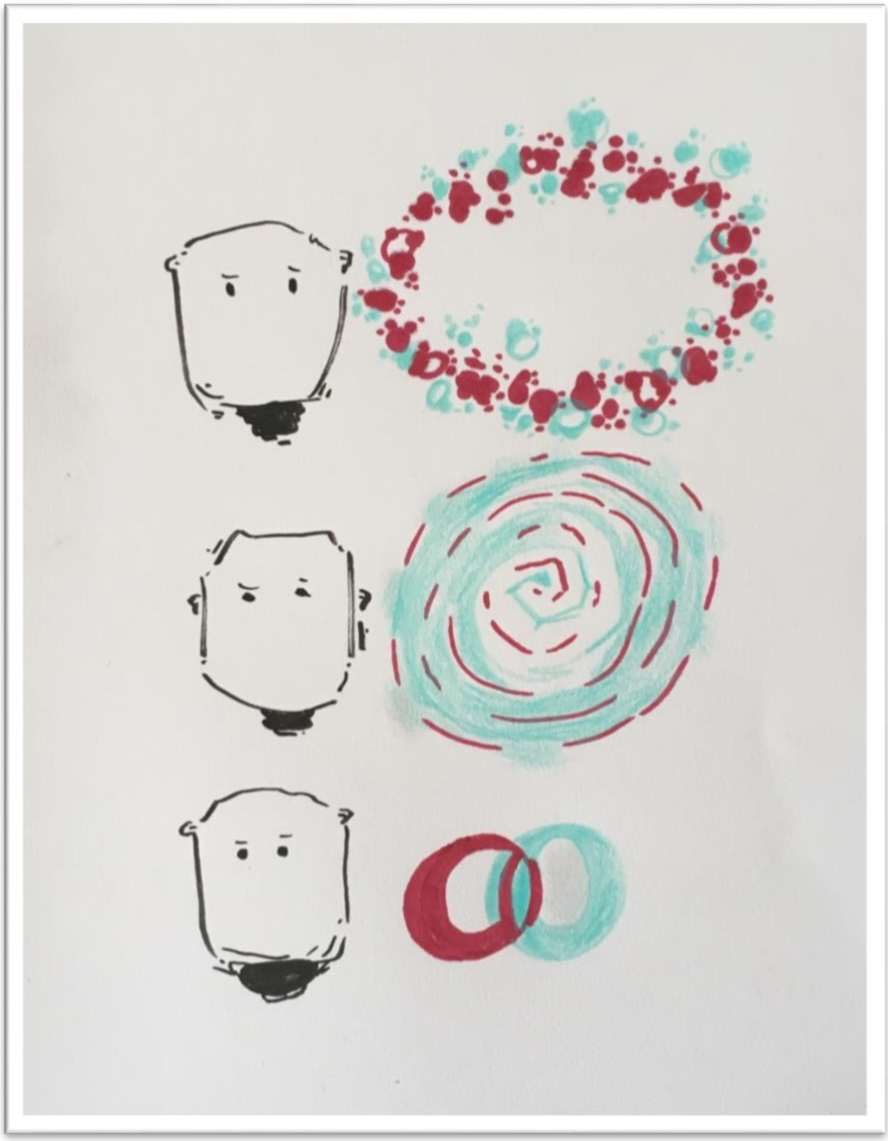

Figure 2 – Daniel's Drawing

Appendix D: Tables

TABLE 1: INCLUSION CRITERIA

INCLUSION CRITERIA
GENDER: Male
AGE: Over 18 years old
Reported chronic pain for over 6 months
living in the greater Montreal area
Ability to adequately communicate in English and no obvious cognitive imparity
Reported pain that interfered with daily life

TABLE 2: PARTICIPANT CHARACTERISTICS

PSUEDONYM	*AGE GROUP*	*DISEASE DURATION*	*EMPLOYMENT STATUS*	*LIVING SITUATION (alone or with someone)*
Neil	20-39	6 years	Early Retirement *	Married
Henry	40-59	7 years	Employed	Married
Paul	40-59	27 years	Employed	Married
John	60-79	25 years	Employed	Divorced – lives alone
Ethan	40-59	22 years	Early Retirement *	Married
Thomas	>80	6 years	Retired**	Widowed – lives alone
William	60-79	31 years	Early Retirement *	Divorced – lives alone
Kevin	40-59	10 years	Employed	Married
Daniel	20-39	9 years	Employed (switched his career)	Single – lives with family

* Still working when they were diagnosed but eventually took early retirement due to their chronic pain.

** Pain developed post retirement.

Age groups: 20-39; 40-59; 60-80; >80

TABLE 3: MANAGEMENT STRATEGIES FOR CHRONIC PAIN

Management strategies for Chronic Pain	Number of participants who used each strategy (out of 9)
Physical Therapy	7
Medication	5
Chiropractor	4
Massage	7
Exercise, Stretching, or posture	4
Relaxation or Mindfulness	8*
Acupuncture	3
Psychotherapy	3
Spinal Decompression or Traction	1
Alcohol or Medical Marijuana Use	2
Use of distractions	9
Reliance on Social Support	8
Faith/Religion	1
Mentoring others	4
Paid Work/ Ambition	4

Note: Variables may be underreported.

*more participants reported meditation as a result of their participation in mindfulness workshop conducted by HOMEBASE

Glossary of terms

Being: is the most universal concept of Heidegger's hermeneutic phenomenology (1962) and may be seen not an entity but rather fundamental term of his ontological analytic. Thereby asking about the being of something is to ask of its nature and its meaning. Therefore, this term is rudimentary to phenomenological research and its process.

Being-in-the-world is a Heideggerian phrase which signifies the way we exist, interact and get involved in and with the world.

Bracketing: is setting aside of one's preconceptions to reduce their impact on the interpretation of the data.

Dasein: is a Being who understands that it exists, and what is more the Being of Dasein is, in part, shaped by that understanding.

HOMEBASE: HOMEBASE is a community for men with chronic pain. It works on the principle of providing a safe space for men through a variety of gender-specific activities designed to help them develop social connections and in turn not just successfully pilot their life with pain but aid others in chronic pain do the same.

Hegemonic Masculinity: This term was coined by Raewyn Connell in 1987 as part of her Gender order theory which sheds light on multiple masculinities. Hegemonic masculinity is premised on the existence of a dominant form of masculinity. Traditionally, it indicated how men maintained dominant roles over not just women but amongst other men. The ideal dominant masculine traits revolved around being stoic, aggressive, competitive, in control and successful while displaying a restraint to flow of *vulnerable emotions*. The pressure to conform to these internalised codes of behavior which men position themselves in relation to, have been used to explain men’s health behaviors and therapy outcomes.

Treatment Fatigue: A term coined by Dr. Hovey to explain the exhaustion and fatigue –physical, mental and emotional, which occurs during and in between visits to the health care providers, it is a combination of designating time and finances for numerous appointments and diagnostic tests just to try different treatments that don’t cure only manage the condition partially.

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