Living with Chronic Orofacial Pain Through a Social Relational Lens: A Qualitative Phenomenological Exploration

by

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August 2017

A thesis submitted to McGill University in partial fulfilment of the requirements of the degree of

Master of Dental Sciences

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DEDICATION

To the millions of individuals who suffer in silence from chronic pain. Your strength is inconceivable and continues to move me. I wish there was more I could do.

ACKNOWLEDGMENTS

A warm thank you goes out to each one of **my participants** for making themselves vulnerable and opening up about the intimate details of their experiences. This project would not have been possible without your authenticity and enthusiasm. I could not be more grateful to you for taking the time to meet with me. In doing so, I learned more about myself, chronic pain, and the variety of human experiences. I am a firm believer that the qualities and knowledge I have acquired from our conversations, thanks to you, will make me a better dentist in the years to come.

I will never find the right words to express the appreciation I have for my co-supervisor, **Dr. Richard Hovey**. Not only have you encouraged and supported me throughout my graduate studies, but you have allowed me to mature as a person and taught me how to be my best self. In stressful times, you were the first to reassure me that everything will work out as they should. My acceptance into the dental school at McGill was without a doubt achieved with considerable contribution from you. I will take the knowledge and wisdom I have acquired from you and will carry it with me throughout my future studies and as a future professional. Thank you for introducing me to a research approach that I connected with dearly and for promptly responding to all my emails, no matter where you were in the world. Everything I have learned from you over the past year is invaluable.

I wish to express my sincerest gratitude to my co-supervisor, **Dr. Ana Velly** for your constant motivation and dedication throughout my graduate research. You are one of the most knowledgeable researchers I have met and your advice has been greatly appreciated over the last year. You have been kind and understanding and have encouraged me to settle for nothing less than (almost) perfect. Between the two of you, I truthfully could not have asked for a better

supervisory team.

A very special thank you also goes to **Dr. Zovinar Der Khatchadourian,** one of the kindest and most genuine women I have ever met. The rapport you build with each one of your patients is truly commendable. If every dentist strived to be as caring and empathetic as you, there would be a lot less suffering in this world. Thank you for going above and beyond and for helping me recruit participants from both the McGill Pain Clinic and the Alan Edwards Pain Clinic at the Montreal General Hospital. I can easily say that I view you as a mentor for everything I hope to embody and accomplish as a future dentist. Thank you.

Dr. Mervyn Gornitsky, your clinical expertise has introduced me and allowed me to gain interest into the world of orofacial pain. How lucky I consider myself to be taken under your wing as a master's student, receiving nothing less than your full support, guidance and most knowledgeable input.

I would like to acknowledge **Mrs. Maria Palumbo** for your patience and assistance throughout this program. Without complaint, you have always promptly and patiently responded to the millions of questions I have asked you over this past year.

A sincere thank you goes out to all my colleagues, **Mohamed Amhmed, Gurveen Gill, Sherif Elsaraj, Wafa Safour, Vimal Kothari, Neha Aggarwal and Mohammad Amin Naji Rad** for your positive contributions and astounding support throughout this process. I can easily say that I have made seven new friends this year. Thank you all for helping me with the success of my project.

To **my mother**, my strongest supporter since day one. You have believed in me in every way possible to pursue my dreams and have given up so much in your life so that I could take on the most important things in mine. All that I am or hope to be, I owe to you.

ABSTRACT

Due to the empirical nature of this topic, an interpretive phenomenological research approach was used to investigate the lived experience of chronic orofacial pain in patients with either Chronic Temporomandibular Disorder (TMD) or Chronic Trigeminal Neuralgia (TN). Individuals with TMD or TN often must alter all aspects of their food preparation and diet to avoid exacerbating their pain, which can elicit feelings of embarrassment, shame and stigma.

The objective of my study was to obtain a general understanding of what it means to live with chronic orofacial pain, while focusing on the influence of food. Since food is so pervasive in our lives, I was interested in understanding the relationship between chronic orofacial pain and emotional well-being mediated by food. This study also aimed to understand from a qualitative perspective why and how this forced change in diet in chronic orofacial pain sufferers can lead to a change in personal identity and its influence on creating the right circumstances for increased social isolation.

The research process involved interviewing seven chronic orofacial pain sufferers. Four main findings were identified: 1) Forced change in diet; 2) Experiencing loss; 3) Deterioration of social life; and 4) Acceptance. The first finding focuses on the participants' difficulty with chewing and its influence on their socializing. Some participants experienced pain and discomfort when chewing specific foods. As a result, some experienced a decline in the engagement in socializing and social activities. The second finding highlights the loss many participants experienced due to their condition, including loss of employment, loss of sleep, loss of mental stability, loss of memory, loss of intimacy, and loss of hope. The third finding concentrates on the deterioration of the participants' social lives as a result of their pain, leading to social isolation, selectively withdrawing from family and friends, feelings of depression, and feelings of shame. The last finding highlights how some participants reacted to their chronic pain condition. A few learned to accept their chronic conditions as part of their life, where some viewed their experience in a positive light or had the drive to help themselves.

Based on the lack of information about the social-relational consequences of this common condition, health professionals are not yet able to help these individuals live full and socially-healthy lives. Understanding their experience is the first step in changing the orofacial pain trajectory from isolation to social engagement. Ongoing qualitative research on this topic will contribute more to understanding this painful condition.

RÉSUMÉ

En raison de la nature empirique de ce sujet, une approche de recherche phénoménologique interprétative a été employée pour enquêter sur l'expérience vécue face à la douleur chronique oro-faciale éprouvée par les patients souffrant soit de problèmes temporomandibulaires chroniques (PTM) ou de névralgies trigéminales chroniques (NT). Les personnes atteintes de PTM ou de NT doivent souvent modifier tous les aspects de leur préparation de nourriture et de leur diète pour éviter d'exacerber leur douleur, ce qui peut susciter des sentiments d'embarras, de honte et de stigmatisation.

L'objectif de mon étude était d'obtenir une compréhension globale de ce que signifie vivre avec une douleur oro-faciale chronique tout en mettant l'accent sur l'influence de la nourriture. Comme la nourriture est omniprésente dans nos vies, je me suis intéressée à comprendre la relation entre la douleur oro-faciale chronique et le bien-être émotionnel influencée par la nourriture. Cette étude visait également à comprendre, d'un point de vue qualitatif, pourquoi et comment ce changement forcé de régime alimentaire chez les personnes souffrant de douleurs oro-faciales chroniques peut mener à un changement d'identité personnelle et de son influence à créer des conditions favorables pour une isolation sociale accrue.

Le processus de recherche a consisté à interviewer 7 personnes souffrant de douleurs oro-faciales chroniques. Quatre découvertes principales ont été constatées : 1) Changement forcé du régime, 2) Expérience de perte, 3) Détérioration de la vie sociale, et 4) Acceptation. L'accent de la première découverte est sur la difficulté des participants à mâcher et à l'influence sur leur socialisation. Certains participants ont éprouvé des douleurs et des inconforts lors de la mastication d'aliments spécifiques. Conséquemment, certains ont connu une baisse dans la participation à la socialisation et aux activités sociales. La deuxième constatation met en évidence les diverses pertes que de nombreux participants ont vécues en raison de leur état, y compris la perte d'emploi, la perte de sommeil, la perte de stabilité mentale, la perte de mémoire, la perte d'intimité et la perte d'espoir. L'accent de la troisième découverte est sur la détérioration de la vie sociale des participants en raison de leur douleur, cela entraînant l'isolement social, le retrait sélectif de la famille et des amis, des sentiments de dépression et des sentiments de honte. La dernière constatation met en évidence comment certains participants ont réagi face à leur état de douleur chronique. Quelques individus ont appris à accepter leur condition chronique comme faisant partie de leur vie où certains ont vu leur expérience sous une lumière positive ou ont eu l'impulsion d'aider leur cause.

Comme il y a un manque d'information sur les conséquences socio-relationnelles de cette condition courante, les professionnels de la santé ne sont pas encore en mesure d'aider ces personnes à vivre pleinement et de façon socialement appropriée. Comprendre leur expérience est la première étape dans le changement de la trajectoire de la douleur oro-faciale de l'isolement à l'engagement social. La recherche qualitative continue sur ce sujet contribuera davantage à la compréhension de cette condition douloureuse.

PREFACE & CONTRIBUTION OF AUTHORS

The candidate, Jessica Italia, wrote all chapters of this thesis dissertation under the supervision of Dr. Richard Hovey. Dr. Richard Hovey obtained ethics approval for this study and created the research consent form. Between April and June 2017, the candidate fulfilled the data collection for this study. All transcriptions, the data analysis, and the literature review were performed by the candidate, with Dr. Hovey being involved in all the steps. All the citations provided in this thesis are information based upon the works of others. The sources of this information are provided in the “Bibliography”.

INTRODUCTION

As someone who dedicated a significant portion of my life pursuing a Bachelor's degree in Psychology, learning about the consequences and mechanisms behind emotional and social changes that may arise in TMD or TN sufferers is something that greatly interests me. The experience I have acquired as a Psychology major in addition to my current studies in the dental field have both encouraged me to conduct a qualitative exploration of the social implications of individuals living with chronic orofacial pain. This chronic disorder is characterized by pain reported in the oral cavity and/or face and is caused by diseases or disorders of local structures or by dysfunction of the nervous system. Therefore, individuals with this disorder often must alter all aspects of their food preparation and whole diet to avoid exacerbating their pain, which can elicit feelings of embarrassment, shame and stigma in those who suffer from TMD- or TN-related pain. Since food is so pervasive in our lives, from a qualitative perspective, I am interested in obtaining a general understanding of what it means to live with chronic orofacial pain, while focusing on the influence of food. This study strived to understand the relationship between chronic pain and emotional well-being mediated by food. My goal was also to recognize why and how this forced change in diet can lead to a change in personal identity and its influence on creating the right circumstances for increased social isolation.

I am fortunate enough to be able to live my life relatively pain-free on a daily basis, however many people do not have this privilege. As a future dentist, I will inevitably be treating a large number of patients who suffer from this type of chronic pain. As many orofacial pain sufferers have received poor responses in health care settings, leaving countless feeling hopeless and in physical and emotional pain, I will indirectly experience the unhappiness that these patients feel and will respond to their desperate calls for help. For this reason, I am determined to study this cohort of chronic pain individuals from their own perspectives. This research process was carried out from a qualitative stance, where in-depth phenomenological analyses were performed in order to investigate this profound human experience and the shattering effects chronic pain can have on a human being. This scientific approach will attempt to tease away at the essence of a complex phenomenon - in this case, the social implications of a forced change in diet in chronic orofacial pain sufferers. Giving voice to the participants in this study will enrich our understanding of the effects of chronic pain- the first step towards raising awareness and potentially altering the current medical approach to treating patients with chronic pain.

Chronic pain can also provoke an extensive array of long-term and often persistent somatic and psychosocial problems [1]. The psychological side effects of living with chronic pain can be as debilitating as the pain itself. The first step in improving the pain management process for individuals suffering from chronic pain is attending to these patients' often neglected narratives. Validating their pain and suffering will pave the way towards exploring new ways in which health care practitioners understand and engage with patients with chronic orofacial pain.

Research Objectives

The goal of this interpretive exploration is to study the full breadth of human inquiry in a human manner in order to learn about the patients' lived experiences of what it is like to live with chronic orofacial pain. I seek to understand why and how a forced change in diet can lead to a change in personal identity and its influence on creating the right circumstances for increased social isolation.

Because chronic orofacial pain can have a negative effect on psychological distress levels and under certain circumstances, can lead to social isolation, those who live with this condition may feel as if they are a bother and no longer have anything positive to contribute to their family, friends or society as a whole [2]. Under such circumstances, the importance of working towards regaining a sense of purpose in life can contribute towards the healing process. Although full recovery may never be possible in such individuals, working towards the process of becoming whole again as a person, of getting one's life back on track can be the stepping stone towards living a happy and fulfilled life.

In order to surmount a personal crisis, one must reinvent oneself along the way [3]. In numerous cases, this can solely be done with the help of health care practitioners. Patients understandably seek-out and expect a fast cure for the pains they experience in their lives. Chronic pain conditions radically change these expectations, forcing sufferers to take the time to cultivate the self-discipline necessary to exercise the mind and body- an effortful process involving drastic changes [4]. However, perhaps this is the message that health care promotes; maybe if the patient and health care practitioner were made aware of how to alter their practices for the better, this would lead to a paradigm shift in the interaction between health practitioners and chronic pain patients. Biomedical approaches tend to be mechanistic and reductionist; bodies are viewed as objects which tends to obscure the person, their perspectives, and their experience of illness or impairment [5]. Thus, physicians are trained to be concerned about bodies and might fail to consider the concerns of the person. When physicians attend to the body rather than the individual, they are unsuccessful to diagnose and treat suffering [5]. Because what may be the cause of suffering in one chronic pain patient may not be in another, this study will intend to further the understanding of health professionals about the genuine experiences of TMD- and

TN-pain sufferers.

LITERATURE REVIEW

Overview of Orofacial Pain

Orofacial pain is an evolving domain within the field of dentistry devoted to the prevention, evaluation, diagnosis and treatment of complex orofacial pain disorders. The scope of this field is broadening as this specialty in dentistry still requires a better understanding in order to appropriately diagnose and provide viable treatment options for patients [6]. Orofacial pain is a collective term that refers to any pain reported in the oral cavity and/or face and is caused by diseases or disorders of local structures or by dysfunction of the nervous system [6].

As outlined by Okeson (2008), the orofacial pain classification is divided into two axes. Physical factors (Axis I) include Temporomandibular Disorders (TMD), which are a group of musculoskeletal conditions characterized by pain in the muscles of mastication and/or the temporomandibular joint [8]; neuropathic pains, such as Trigeminal Neuralgia (TN), which involve episodic and continuous pains; and neurovascular disorders, such as tension-type headaches and migraines [7]. Psychological factors (Axis II) rather include anxiety, mood, and somatoform disorders that can either prompt or affect the overall pain experience [1,7].
Select pain disorders may be influenced by one specific axis more than another; for instance, acute orofacial pains are generally more associated with physical factors rather than psychological factors. Consequently, patients with acute pain frequently respond well to therapies targeting somatosensory input [7]. Conversely, psychological factors are often very present in chronic pain patients, forcing orofacial pain specialists to adjust their treatment plans accordingly [7]. In order to successfully manage pain in chronic pain patients, knowledge of

these concepts is fundamental. This research project will focus solely on studying the social implications of chronic TMD- and TN-related pain and will not look at other types of orofacial pain.

Acute vs. Chronic Pain

The International Association for the Study of Pain (IASP) defines pain as an "Unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" [9]. Acute pain is defined as a short-lasting pain which considers a disease or injury symptom [11], whereas chronic pain is defined as pain that lasts at least three months, as IASP states that "three months is the most convenient point of division between acute and chronic pain for nonmalignant pain" [10].

Acute pain often is felt suddenly and is triggered by a specific cause such as surgery, broken bones, dental work, burns or cuts, or labor and childbirth and goes away when there is no longer an underlying cause for the pain [11]. It is generally sharp in quality, site specific and acts as an indication from the body to the individual that something is threatening the body's homeostasis [11].

On the contrary, chronic pain is ongoing and tends to be more diffuse, causing it to be more challenging to diagnose and treat as it is rarely associated with distinct events [12]. Chronic pain is a major health and economic burden worldwide. The 2007 Canadian Community Health Survey estimated that approximately 10% of Canadians between the ages of 12 and 44 experience chronic pain [13]. Due to the complexity of this type of ongoing pain, the subjective experiences of individuals with chronic pain differ from person to person [1]. These inconsistencies make it difficult to define such a subjective phenomenon, which explains the controversy concerning appropriately defining chronic pain [14]. For these reasons, I have chosen to focus on chronic orofacial pain in this study, as a better understanding of this field will help improve the standards of care and success in treatment of patients with chronic orofacial pain disorders.

In terms of treating patients for chronic pain, several treatment options are offered such as physical and occupational therapies, biofeedback, cognitive behavioural therapy, communication skills, group education, relaxation techniques and pain-coping strategies [1, 15-19]. Most pharmacological, surgical and cognitive-behavioural interventions for chronic pain intend to reduce or eliminate the painful sensation. Despite a handful of treatments having been reported to be effective in group comparison studies, many patients in the experimental group show no improvement and full elimination of pain is uncommon [20, 21]. From time to time, chronic pain treatments may even do more harm than good [21, 22], which highlights the importance of studying chronic pain with aims of clarifying the factors that improve and exacerbate one's chronic pain experience.

In the struggle to relieve it, chronic pain is often stress-inducing and frustrates the pain sufferer as well as the health care provider [23]. It has been shown that these negative psychosocial repercussions can modify the subjective pain experience itself by increasing the flow of pain signals, ultimately resulting in greater subjective pain intensities [24].

In a cross-sectional study carried out to identify clinical and psychological factors that could aid in the classification of acute and chronic orofacial pain disorders, patients with chronic pain had more frequent muscle tenderness in the temporomandibular joint (TMJ) area, constant pain and dull aches compared to patients with acute pain [25]. This tenderness often inhibited the participants' ability to properly eat specific food items. Furthermore, using the Hospital Anxiety and Depression (HAD) scale to assess anxiety and depression, this same study reported that high anxiety and depression was present in most of the chronic pain patients (57.2%) compared to 25% in the acute pain group. This disparity justifies the role of psychological factors in the maintenance and perpetuation of pain [25].

Chronic pain patients appreciate confidence-based relationships with their health care providers who listen well and communicate [1, 26]. Therefore, conducting this research project with individuals who suffer from chronic orofacial pain is important, as this discourse will aim to promote a trusting environment between the individual and myself, the interviewer, as we create a meaningful and enriching dialogue.

Painful TMD is considered the second most common musculoskeletal disorder after chronic lower-back pain [8]. Although the prevalence of TN is much smaller, the effects this chronic condition can have on a person can be devastating. This section provides an overview of the epidemiology of TMD and TN, screening, diagnosis, treatment, and reviews the relationship between orofacial pain, difficulty eating, and the psychological factors associated with such disorders.

Overview of TMD

TMD-related pain is a term describing musculoskeletal disorders characterized by pain in the muscles of mastication and/or the temporomandibular joint [8]. Pain is the chief complaint in more than 97% of TMD cases [27]. This pain is generally experienced in the jaw, face, temple, and/or ear and is frequently altered by jaw function [28]. Tenderness in the muscles upon palpation, pain with range of motion (ROM) and/or limitation of the jaw opening are common signs of TMD-pain [28]. Pain related to this disorder has a prevalence in the general population ranging from 5% to 19% depending on study populations, definitions, criteria and methodology used [27, 29]. Between half and two-thirds of individuals suffering from TMD pursue specialized care from either physicians or oral pain specialists and around 30% of these patients continue to suffer from moderate to severe levels of pain, disability, lower quality of life, and psychological distress, regardless of treatment type [30-33].

Research Diagnostic Criteria and Diagnostic Criteria for TMD

Presently, the RDC/TMD is the universally used diagnostic protocol in TMD research, which consists of two axes: (i) Axis I, physical assessment to provide a physical diagnosis and (ii) Axis II, psychological assessment and pain-related disability to identify characteristics that could affect pain management (e.g., depression, pain intensity) [34]. Three subgroups are comprised in Axis I: Group I, consisting of muscle disorders, Group II, consisting of disc displacements and Group III, consisting of joint diseases [34, 35]. Group I is further divided into myofascial pain or myofascial pain with limited mouth opening. Group II is further split into disc displacement with reduction, disc displacement without reduction with limited opening or disc displacement without reduction without limited opening. Group III is further classified into arthralgia, osteoarthritis, or osteoarthrosis.

TMD Evaluation and Treatment

Potential TMD patients generally visit their general dentist or an orofacial pain specialist upon experiencing limitation of opening the mouth, episodes of joint locking, pain while chewing, facial pain, or headache [1]. Evaluation involves a thorough examination of the patient's head, neck, and surrounding muscles, as well as the masticatory muscles, TMJs, and an assessment of the mandibular ROM and an intraoral exam. A diagnosis is made using the RDC/TMD classification.

Treatment plans are currently focused on improving pain management by reducing risk factors such as parafunctional habits (e.g. clenching only or clenching-grinding) [36-38], trauma [30, 36-38], and psychological factors (e.g. depression, anxiety, somatization) [31, 37, 40-42], as some of these psychological factors can contribute to the persistence of TMD-pain [31, 38, 41, 43]. Other treatment goals include decreasing pain and reestablishing normal ROM and masticatory and jaw function. TMD treatment may vary among practitioners, usually ranging from self-care programs, medical care, and surgical procedures [7]. Self-care treatments, also known as home care practices, such as resting, relaxation techniques, hot and/or cold packs, are often initially proposed to patients to help manage their pain and have been proven to be effective [44]. Other treatments include psychological therapy, physical therapy, pharmacological agents such as anti-inflammatory drugs, muscle relaxants, and botulinum toxin injections [45]. Occlusal therapy and the use of appliances are also considered to be effective treatments for select TMD cases for the management of pain [1, 46-51]. As previously mentioned, a significant portion of TMD patients continue to suffer in many physical and psychological domains even after treatment; it is therefore crucial to delve deeper into our current understanding of chronic TMD pain as making sense of these patients' experiences can be the first step in changing the TMD pain trajectory from isolation to social engagement.

Overview of Trigeminal Neuralgia

The second orofacial pain condition I will discuss in this research paper is Trigeminal Neuralgia. According to the International Association for the Study of Pain, TN is defined as the sudden, usually unilateral, severe, brief, stabbing, recurrent episodes of pain in the distribution of one or more branches of the trigeminal nerve [10]. Considerable evidence supports that TN is commonly caused by demyelination of trigeminal sensory fibers within either the nerve root or the brainstem [52]. Generally, this demyelination implicates part of the root involved in the central nervous system and results from compression by a superimposing artery or vein [52]. Demyelination in TN patients can also occur due to multiple sclerosis or less commonly, can be caused by a tumor compressing the trigeminal nerve. The annual incidence of Trigeminal Neuralgia is ~4.5 per 100 000 [53, 54]. A lifetime prevalence of 0.7 per 100,000 people per year is reported [54]. This pain disorder is characterized by recurrent attacks of intense, stabbing pain localized to small areas of the face, usually lasting seconds, but recur repeatedly over short periods of time [52]. The recurrent episodes are commonly hastened by stimulating trigger zones through stimuli such as light touching, wind, eating, drinking, washing or shaving. Over time, the painful attacks generally appear more frequently and the pain becomes more persistent [55]. It is common for the TN patient to leave their job due to the intensity of the pain or adverse side effects of the drugs used to treat orofacial neuropathic pain [56]. Considering the rarity of this condition and the unclear course it often follows, it is unfortunate for these sufferers, that often claiming insurance assistance can be challenging, leaving many with a financial burden [56].

Trigeminal Neuralgia Evaluation and Treatment

Opinions clash regarding the best surgical treatment for patients with painful TN [57]. This condition is treated on an outpatient basis, unless neurosurgical intervention is mandatory. Management of this condition must be tailored individually, based on the patient's age and general condition [58]. To treat TN, orofacial pain specialists generally prescribe medications to lessen or block the pain signals sent to the brain. Carbamazepine Oxcarbazepine, anti-convulsant drugs often used to treat neuropathic pain, are generally offered for pain control while Baclofen, a central nervous system depressant used as a skeletal muscle relaxant or Lamotrigine, an anti-convulsant have been shown to be useful to treat TN pain [58]. Surgical options for this condition include microvascular decompression, gamma knife radiosurgery, glycerol injections, balloon compression and radiofrequency thermal lesioning [57]. Despite the various techniques currently used to manage this neuropathic pain, patients with TN continue to suffer in a number of physical and psychological domains regardless of treatment [59]. Therefore, as researchers, our understanding of the chronic pain that accompanies TN and learning more about the patients' experiences is crucial to improving the lives of the hundreds of thousands of individuals worldwide.

Orofacial Pain and Difficulty Eating

Great meals have a way of bringing family and friends together in a way that is truly special. Unfortunately, many individuals with severe orofacial pain do not have the luxury of enjoying food the way many of us do, as chewing specific foods can be interpreted as an uncomfortable and painful act. Recent literature confirms that the clinical presence of chronic orofacial pain is associated with marked functional impairment in the jaw and surrounding masticatory structures [60-62]. One study evaluated the effect of temporomandibular arthralgia on mandibular mobility, chewing, and bite force, where twenty female patients with unilateral TMJ pain during chewing and provocation, as well as TMJ tenderness, were studied [60]. The mean pressure point threshold in the patients' painful side was significantly lower than in the control subjects. Moreover, jaw opening was also significantly less in the patients than in the controls. Maximum closing velocity and bite force were significantly lower in subjects with TMJ pain [60].

The pain clinic at King's College Hospital in London, England published a manual for people who have been diagnosed with a chronic orofacial pain condition, who are currently receiving or have received medical treatment [63]. It was noted that for most patients with chronic TN, the unpredictability of their pain was extremely difficult to manage, especially when it came to eating. Patients often develop a morning routine of getting ready and eating that takes hours longer than previously did in the hope of avoiding a painful attack [64].

There is a lack of qualitative research studying the association of orofacial pain and difficulty eating. However, Peters et al. (2015) studied this relationship by thematically analyzing audio-recorded semi-structured interviews with dentists, general practitioners and chronic orofacial pain patients [67]. In this study, participants avoided situations or activities that exacerbated their pain, for example, socializing (as it involves talking and eating) or certain foods [67]. One participant mentioned that "eating is exhausting, it takes so long to eat and the pain, it pulls me down and makes me tired" [67].

Studies have shown an association between orofacial pain, chewing ability, and common mental disorders, such as depression and anxiety. However, there are conflicting conclusions regarding the direction of the association and there is some evidence that the relationship may be bidirectional [61, 65, 66].

Orofacial Pain and Psychological Factors

While chronic pain is the overwhelming reason for seeking treatment, orofacial pain disorders may also be associated with impaired general health or psychological disabilities, such as depression, that influence the individual's wellbeing and quality of life [34, 68, 69]. Individuals with TMD pain have been shown to demonstrate higher levels of stress, anxiety, depression, somatic awareness, and kinesiophobia compared to controls [70-73]. A case-control study confirmed that orofacial pain sufferers were more likely to have higher levels of anxiety, somatization, and depression than healthy controls [70]. Studies have also demonstrated that these psychological comorbidities may contribute to the persistence of TMD pain [38, 43, 73]. Moreover, chronic orofacial pain can have a detrimental impact on psychological distress level and commonly leads to social isolation [2]. Social isolation must not be equated to solitude, where the state of one's aloneness may be voluntary.

It is common for TN sufferers to isolate themselves, as leaving the comfort and safety of one's home can be threatening and can activate or exacerbate the pain [70]. Such isolation prevents these individuals from interacting with others, which can take a serious toll of their social lives. Due to the nature of this disability, sufferers may even experience feelings of embarrassment and shame, as individuals with this facial pain often have difficulty eating and drinking, which can discourage people with orofacial pain to have a lively social life [61]. Family estrangement or being mocked from co-workers or fellow students is not a rare occurrence for individuals with chronic facial pain and can play a role in their path towards isolation [74].

In a qualitative study that looked at patients' journeys with TN through thematic analysis, emotional difficulties manifested in feelings of isolation and withdrawal from social interaction were reported by participants [64]. The study concluded that social isolation commonly surfaced from the participants deciding to withdraw from friends, family and coworkers as a direct consequence of the pain or fear of pain [64]. One participant described an example of her experience with social withdrawal as such: "Imagine, it's your daughter's birthday party… You can't speak, and you can't eat, every time you try to speak [it's like] someone smacks you straight in the mouth… so you're not going to go are you?" [64]. Another orofacial pain sufferer was very isolated in her day-to-day life, as she explained that "[she] wouldn't do social things, in case [the pain] started while [she] was out…" [64]. Depressive symptoms were also implied by two participants in this same study as they clarified the degree of their psychological grief. One mentioned that "If [she] couldn't get the pills [she] would commit suicide" [64]. The majority of participants reported that pain severity induced social isolation and even made interacting with family members difficult.

In 2011, Durham et al. qualitatively studied TMD patient experiences with health care [75]. Both TMD patients and other chronic illness sufferers experienced difficulties with "wait times" for secondary care referral. This wait prolonged and in some cases, exacerbated these patients' symptoms of anxiety [1, 75]. Moreover, approximately 73% of the sample population of a pilot study conducted to investigate the pain-related disability and psychological status of TMD patients using a newly developed, computerized on-line program (NUS TMD v1.1) was moderately or severely depressed [69].

Peters et al. (2015), also studied the experiences of patients, doctors, and dentists in the management of chronic orofacial pain. Psychological factors were believed to significantly impact the development and maintenance of chronic orofacial pain according to patients and health professionals [1, 67].

In 2012, Wan et al. studied orofacial pain symptoms and associated disability and psychosocial impact in community-dwelling and institutionalized elderly in Hong Kong [76]. Orofacial pain symptoms were correlated with significant disability and had a detrimental impact on psychological distress level and quality of life, particularly in the institutionalized elderly [76].

Studies have demonstrated that orofacial pain is a disabling condition with a high impact on psychological health in the global community. Through numerous quantitative and qualitative investigations, it has been shown to negatively impact one's quality of life and is associated with significant disability.

Chronic Pain and Psychological Factors

Not only does chronic pain have a physical impact on the individual, but it may also leave an adverse psychological footprint, as living with chronic pain is often very damaging to the sufferer [77]. A large portion of pain research is dedicated to studying chronic pain, which has given rise to copious amounts of research evidence on this topic as well as the establishment of multi-disciplinary pain centers [1]. However, because chronic pain may disturb individuals in various complex ways such as negatively affecting aspects of their self-esteem, identity, work, family and social relationships, many sufferers never succeed in escaping the painful experience [24, 78-82]. Many studies have shown that chronic pain causes substantial distress leading to loneliness, altered self-image and identity, anxiety, anger, depression, and can contribute to a lower quality of life [24, 79-81, 83-85].

Psychological factors including emotional distress have been proclaimed to predict long-term disability for many chronic pain disorders [86-88]. One study that looked at psychosocial predictors of outcome in acute and chronic pain concluded that psychosocial variables accounted for 59% of the variance in disability associated with chronic pain [89].

Durham et al. (2011) investigated the experiences of individuals living with chronic TMD [75]. The participants in this qualitative study disclosed the complications, apprehensions and insecurities they experienced due to their chronic condition [75].

There is an increasing body of evidence that justifies the significant role patients' beliefs play in chronic pain. The patient's concern about the future and the impact the pain has on his or her life have been shown to affect the chronic pain experience [85]. For example, pain-related anxiety and fear can exacerbate one's experience with chronic pain as he or she anticipates higher levels of pain, which can result in poorer behavioral performance [86, 90, 91].

If patients' beliefs are known to play such a vital role in one's experience with pain, investigating certain psychological aspects in patients can perhaps lead to new coping techniques for chronic TMD and TN sufferers. In addition to this study's main focus, it will also attempt to explore which psychological factors are associated with better or worse pain experiences in individuals with chronic orofacial pain. Doing so will help gather a holistic understanding of the lived experience of chronic orofacial pain.

Difficulty Eating and Psychological Factors

Most of us have the ability to properly enjoy a meal without having to worry about worsening any jaw or muscle pain. However, chewing specific foods can be felt as an uncomfortable and painful act for some individuals with orofacial pain. Literature suggests that difficulty eating has been linked to several psychological factors such as shame, embarrassment, anxiety, depression, and lower levels of quality of life [25, 64, 65, 69]. A qualitative study exploring the experience of living with TN concluded that many individuals with this painful condition feel incredibly anxious while cleaning their teeth in the morning and evening, or whenever they eat food, fearful that it might trigger an intense episode of pain [64]. A participant in this same study mentioned that she could not even have her tea in front of her children or her husband because she felt she "looked like a freak" [64]. This participant was constantly in pain and felt as if she was contorted [64].

In a study on pain-related disability and psychological status of chronic TMD patients, patients that were moderately and severely depressed had significantly higher scores for limitation related to mandibular functioning than normal patients [69]. The three most recurrent jaw disabilities in chronic TMD patients were: eating hard foods, yawning and chewing [69]. Kafas and Leeson (2006) also considered the implication of living with chronic TMD [25]. The findings of their quantitative study insinuate that in the case where orofacial pain affected chewing and eating, enjoyment of life was diminished in a nearly directly proportional manner.

This study outlines the implications of jaw disability not only from a health or metabolic stance, but also elucidates its impact on quality of life. Moreover, this research concluded that this reduced enjoyment of life was correlated with negatively affected mood in both acute and chronic orofacial pain groups, which negatively influenced the interest in or likelihood of positive relationships [25]. The authors illustrated this pathway for TMD patients in the following diagram:

Discussion

Using interpretive phenomenology as the approach guiding this work, it was difficult to tease apart the aforementioned sub-topics in the literature review, as each one does not exist separately from all other ones in complex human experience. For this reason, it is not uncommon for there to be considerable overlap among the sub-themes in this section.

Despite the abundance of quantitative chronic orofacial pain research, taking a holistic approach to chronic pain and understanding the lived experience of this condition remains understudied. The social implications of a forced change in diet have been studied qualitatively by Allsop et al. (2015), however, the sample only included participants with TN. Phenomenological research in orofacial chronic pain is lacking, as much of the qualitative literature in this review is limited to transparent descriptions of data as opposed to richer more interpretive analyses of the participants' experiences.

For this reason, it is important to study the social implications of chronic orofacial pain in attempt to understand why and how a forced change in diet can lead to a change in personal identity as well as its influence on creating the right circumstances for increased social isolation. Verbal and visual descriptions of patient accounts will offer the important details that are overlooked in generic criteria for orofacial pain classification [9]. This research will potentially contribute to improving the quality of treatment for chronic pain sufferers whose voices are left unheard.

A qualitative exploration of the social implications of individuals living with chronic orofacial pain continues to be a very relevant and valuable research topic as there are few studies that use qualitative methodologies to investigate this common painful experience. Specifically, using interpretive methods allows for a more in-depth analysis of a phenomenon that cannot be adequately explained solely by the quantitative measures used in most existing chronic pain studies. This research will be advantageous to the chronic pain community as it will allow them to share their lived experiences, which may eliminate common feelings of isolation among sufferers. These narratives will be disclosed in a relatable manner for both lay-persons as well as individuals suffering from chronic TMD- or TN-related pain.

METHODOLOGY

Qualitative Approach

"Qualitative inquiry represents a legitimate mode of social and human science exploration, without apology or comparisons to quantitative research" [92].

In his work, Creswell describes qualitative research as the study of human experience through a naturalistic approach, in an effort to make sense of, or interpret the phenomena in question [92]. It endeavors to grasp experiences and reflections of certain individuals through the most humanistic and interpretive approach [1]. In the realm of qualitative studies, the research continuously grows, where each researcher possesses a different point of view, and all are just as valid as the next. This scientific approach takes something complex and tries to tease away at its essence. Unlike quantitative research, which relies more heavily on a predetermined series of questions and therefore obtains more close-ended responses with little variation, the qualitative researcher rather presents open-ended questions, leaving room for elaborate and expressive responses about the person's experience [93].

In order to excel as a qualitative researcher, it is vital to understand the philosophical assumptions that underlie qualitative research. In the SAGE Handbooks of Qualitative Research, Denzin & Lincoln (1994, 2000, 2005, 2011) have clearly articulated these assumptions, which include beliefs about ontology, epistemology, axiology, and methodology [94]. In terms of ontology, qualitative researchers as well as the individuals being studied must embrace the idea of multiple realities. Evidence of multiple realities involves the practice of numerous forms of evidence in themes by presenting the actual words and different perspectives of different individuals [92]. The epistemological assumption supports the idea that it is the qualitative researcher's duty to try to minimize the distance or "objective separateness" between himself or herself and those being researched [92]. This will allow the researcher to truly understand knowledge through the subjective experience of people as subjective evidence is accumulated from individual views. Collecting extensive data in the "field" gives the researcher an important framework to work with and facilitates the comprehension of participants' perspectives [92]. The axiological assumption states that the qualitative researcher must elucidate that their study is solely one person's account of attempting to understand an individual's experience and might differ from another account. The researcher must therefore share his or her values by explicitly reporting their biases in the study [92].

In terms of methodology, qualitative research is characterized by inductive techniques and is molded by the experience of the researcher through the collection and analysis of data [92]. The inductive nature of qualitative research allows the researcher to start from the bottom and work their way to the top rather than religiously following a specific theory to answer the research question. Using a qualitative approach in research involves this time-consuming process of data-analysis which involves filtering copious amounts of data and reducing them to several themes. The eventual goal of displaying different perspectives of a certain felt experience can be carried out by integrating participants' quotations and must avoid the practice of using fixed guidelines or non-flexible procedures.

I have specifically chosen to use a qualitative research methodology for several reasons. One of the main goals of this study is to understand why and how a forced change in diet can lead to a change in personal identity and its influence on creating the right circumstances for increased social isolation. Such a study requires the presentation of a holistic description from the participants' perspectives where information can be gathered by directly communicating with individuals suffering from TMD- or TN-related pain to observe how they behave within their unique context. Employing a qualitative methodology allows for the aforementioned criteria as it gives the researcher the opportunity to gather findings that are richly descriptive through the use of in-depth semi-structured interviews.

Existing literature touches on the social implications of living with chronic orofacial pain but has yet to explore a detailed investigation into the ways a change in diet can contribute to affecting social engagement from a qualitative perspective. Approaching this research topic from a qualitative point of view provides the researcher with the opportunity to observe, record and interpret non-verbal communication as part of a respondent's feedback. This enables the researcher to reach beyond initial responses and engages the respondent more actively than through the use of scales and tools used in quantitative studies on orofacial pain. I specifically engaged in an interpretive phenomenological research approach as it introduces an in-depth understanding and report of a certain phenomenon with as much expression as possible. This philosophy has the capacity to paint a vivid picture of what it means to live with TMD while promoting descriptions of experiences in a natural setting and in the context of the suffering individual [95].

Importance of Philosophy in Scientific Research

In Hans Gadamer's exploration into the ethical and humanist issues of modern clinical practice, he emphasizes that the purpose of philosophy is liberation from all unanalyzed presuppositions, blind spots, as a kind of cognitive dissonance, which prevents us from being masters of our own thought [3]. This kind of humility is critical in a research setting, as it allows for the freedom and openness to find answers to complex questions. Although we know about the relationship between people living with orofacial pain and their emotional well-being in a health care setting, exploring this experience through philosophy introduces a reflexive analysis into this topic as an inquiry into the nature and limits of all forms of human understanding.

As philosophy and science were once tightly linked domains long ago, it is essential for us to backtrack and understand why this was ever the case and why they are no longer so closely connected. Unlike experimental scientific approaches, interpretive phenomenology does not deal with problems, it deals with questions- ones which call forth new attempts at thinking. Its purpose, is not to add to the stock of objective knowledge, but to rather challenge our beliefs and dogmas. Qualitative research, including phenomenology does not work from the starting point of a specific hypothesis, but rather seeks to explore phenomena that cannot be tested, replicated or understood using experimental methods. For these reasons, I have attempted to analyse the discourses between myself and the orofacial pain sufferers from a phenomenological perspective as this philosophical approach moves beyond the description of experiences and pursues the meanings rooted in everyday life [96].

Phenomenology

"Phenomenology, if practiced well, enthralls us with insights into the enigma of life as we experience it—the world as it gives and reveals itself to the wondering gaze— thus asking us to be forever attentive to the fascinating varieties and subtleties of primal lived experience and consciousness in all its remarkable complexities, fathomless depths, rich details, startling disturbances, and luring charms" [97].

Phenomenology was developed in the 20th century by the German philosophers Edmund Husserl and his student, Martin Heidegger, who later criticized and expanded Husserl's phenomenological questioning. It is an approach of inquiry and a study of human experience as well as the manner in which different phenomena present themselves in and through such experience [98]. It is essentially a set of "reflective descriptions" on the lived experiences of individuals as they are perceived in the human consciousness. Well-known modern phenomenologist, Max van Manen, colloquially describes it as the systematic attempt to uncover and describe structures, the internal meaning structures, of lived experience, where the lifeworld is both the source and the object of phenomenological research [99]. Specifically, descriptive phenomenology, developed by Husserl, encourages the researcher to describe a certain phenomenon while pre-existing beliefs and opinions were bracketed [96]. Husserl viewed this method as a means to achieve true meaning through infiltrating deeper into reality. In this sense, phenomenology was viewed as shifting away from the Cartesian dualism of reality being separate from the individual [100-102].

Heidegger, who attempted to broaden hermeneutics, the philosophy of interpretation, is well known for providing the philosophical conceptualization that lead to interpretive phenomenology- the methodology used in this research project. van Manen, whose process guided my phenomenological approach, characterized hermeneutic phenomenology as "a philosophy of the personal, the individual which we pursue against the background of an understanding of the evasive character of the *logos* of *other,* the *whole,* the *communal,* or the *social*" [99].

Martin Heidegger's well-known definition of phenomenology was "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" [103]. Conversely, Husserl endeavored to understand experience in its primordial essence, without interpreting or theorizing it. Max van Manen describes that to successfully pursue a phenomenological inquiry, one must understand that an analysis of a lived experience involves turning back *zu den Sachen*, to "what matters in lived or primal experience" [103]. It is a careful investigation of the relation between individual and experience, the manner in which the phenomenon is expressed (through language, art, etc.) and the understandings these accounts generate. van Manen emphasizes that using this methodology, to truly understand a "lived experience", the researcher can ask the basic phenomenological question, "What is this (primal) experience like?" [103].

Every human experience, whether that be an event, incident, occurrence, relationship, situation or feeling may become a valid topic for phenomenological inquiry. However, it is important to recognize that phenomenological analysis should not be confused with psychological analysis which rather deals with encouraging participants to make sense of their traumatic or major life experiences. van Manen reiterates that a strong phenomenological inquiry will put more emphasis on the phenomenon itself rather than focusing too much on the individual and on his or her views on personal experience. A successful researcher in this philosophical domain will "explore the eidetic or inceptual meaning structures or aspects that describe the singular meaning of a certain phenomenon or event" [97].

Husserl and Heidegger, through their development of new approaches to philosophy, have confidently influenced contemporary researchers to eagerly embrace the qualitative paradigm, specifically, phenomenology as a suitable research framework for studying lived experiences [104].

Interpretative Phenomenological Approach

This study endeavors to employ Heidegger's philosophical thinking, interpretive phenomenology, which seeks to understand the meaning of a certain phenomenon without setting aside biases. Interpretive phenomenology focuses on producing an interpretive narrative with the goal of explaining how certain individuals make sense of their own meanings and experiences. Contrary to what Husserl promoted during his time, the work of Heidegger emphasizes the interpretive process which urges the researcher to engage with the individual where pre-existing beliefs and opinions are not bracketed.

Heidegger's mindset about human nature promoted the idea that setting aside preconceived opinions is difficult as the amalgamation of one's views and experiences in life is what shapes one's idea of the world [96]. Therefore, the development of Heidegger's philosophical approach surpasses the simple description of an experience and seeks to understand the meaning of a certain phenomenon without setting aside biases [96]. Interpretive phenomenological researchers should therefore focus on how the person makes sense of his or her own life experience to attain an insightful appreciation of the participant's world. Taking part in phenomenology is attempting to accomplish the impossible: to create interpretive descriptions of some aspect all while remaining aware that the lived life is always more complex than any explanation of meaning can reveal [99].

Interpretive phenomenological reflection is retrospective as opposed to introspective, as a person cannot reflect on lived experience while living through the experience [99]. van Manen gives an example of this in his book, Researching Lived Experience, where he mentions that if one were to reflect on one's anger while being angry, one would realize that the anger has already been altered or has dissipated. Thus, reflection on lived experience is always recollective as it reflects on experienced that has already been lived through. In sum, it is a human science and is a systematic, explicit, self-critical, and intersubjective study of a lived experience.

Sampling Method

In phenomenological research, the individuals selected to participate must all have experienced the phenomenon in question and must all be willing to discuss their experience [92, 105]. The "data" gathered from the participants, in this case, people who suffer from chronic TMD or TN pain, assists the researcher to create a detailed and sophisticated description that encompasses the participants' narratives regarding their experience.

For an interpretive phenomenological analysis, unlike in quantitative research, the quality of the participants' narratives and researcher-participant conversation outweighs their quantity [106]. However, in order to gain a true essence of the lived experience of a phenomenon, a fitting number of variations is preferred, usually ranging from 3-15 participants, where a minimum of three participants is recommended [92, 107, 108). A minimum number is suggested because variations among fewer narratives would simplify the phenomenological process of grasping the individual experience of a certain phenomenon as opposed to an appreciation for the general experience of said phenomenon [1, 105, 106, 109].

Selecting Participants & Recruitment

The recruitment of participants took place through the McGill Pain Clinic, the Jewish General Hospital Dental Clinic, the Montreal General Hospital Alan Edwards Pain Clinic, as well as a Montreal chronic pain support group. Potential interviewees were contacted by the researcher either at the clinic or by telephone if the potential participant was a previous patient at the clinic. This study is a continuation of a quantitative project that sought to identify risk factors related to the transition from acute to chronic pain in TMD patients. Therefore, only patients who had previously agreed to take part in the quantitative phase of the study at the Jewish General Hospital Dental Clinic, conducted by another researcher, were contacted to set up an interview. In the case where a potential participant agreed to take part in the study, an interview date and time was arranged with the researcher.

Inclusion criteria:

- Suffers from TMD pain or Trigeminal Neuralgia pain
- Experiences pain for more than 6 months
- $\geq$ 18 years of age
- Comfortable communicating in English

Exclusion criteria:

- Experiences pain for less than 6 months

Informed Consent Form

I read over the consent form with each participant upon meeting them (See Appendix A), answering any questions or concerns they may have. Before the start of the interview, the details of the study were explained in depth including the benefits of participation, potential risks, storing and collection of data, and confidentiality. The participants were informed that their participation is voluntary. In the case that they wished to discontinue participation, their recording would be deleted at their request.

Collecting "Data"

Phenomenology does not deal with codes or objectivistic data. Alternatively, this method of research uses poetry, anecdotes, and personal narratives to gain a deeper understanding of a certain lived experience. Phenomenological inquiry avoids any calculations, coding, pattern-searching, sorting, and/or scrutinizing for resemblances or repetitions. Analysis is rather carried out through an "inceptual" process of deep questioning, reflective deliberating, attentive reminiscing, and sensitively interpreting the primal meanings of the experience [103].

Because the term "data" has quantitative overtones, it is misleading to refer to the dialogue between researcher and individual as "data" when referring to subjective information. Therefore, we can say that after using the method of conversational interviewing, when an individual has related a valuable experience to the researcher, then the researcher has gained something, even though whatever was gained may not be quantifiable [99]. These "data" can rather be referred to as personal lived-experience descriptions. Some phenomenologists such as Amedeo Giorgi use the term "meaning units" as they still retain the sense of meaning as opposed to the objectifying term “data”.

Interviews with Participants

It is typical for participant narratives in phenomenological interpretive studies to be gathered through written or recorded accounts, or face-to-face conventional interviews [106]. Because this research approach seeks to understand the essence of peoples’ lived experience of a certain phenomenon, I have chosen to perform face-to-face interviews, capturing the dialogues with audio-recorders- the more popular data collection technique. Despite being more time-consuming, this technique allows for richer discussions with enhanced depth and essence [1, 105, 110].

The months of April and May of 2017 were dedicated to conducting in-depth, semi-structured audio-taped individual interviews with each of the seven participants. These encounters all took place in Montreal, Canada in a comfortable and secure setting at the Faculty of Dentistry at McGill University or at the Jewish General Hospital Dental Clinic. Shortly after meeting each participant, I explained the purpose of the study and attended to any questions from the participants. In attempt to make each participant as comfortable as possible, I offered them a cold beverage and kept the conversation light, asking them general questions about themselves for the first few minutes, while explaining their rights as a participant and ensuring a signature of the consent form before the start of the interview. I used a semi-structured interview guide (See Appendix B) as an outline which allowed for flexibility to probe emergent topics and themes, and fostered a relaxed feel to the dialogue [110]. In interpretive phenomenology, the questions reflect meaning, which provides the participant the ability to explore their narrative in however way they choose. Therefore, it is important to clarify that the interview guide was used simply as a flexible and reflective questionnaire with questions that varied among participants, because at the core of phenomenological research, each participant needs to express themselves as unique individuals. Once a rapport was established between myself and the participant, I asked each participant the key question: “What does living with this pain condition mean to you?” The discussion between researcher and participant was very casual, where tangents were encouraged as the participant helped guide the discussion. In many cases, I asked additional questions that were not in the guide, as each unique personal experience allowed for its own set of supplementary questions.

The session was concluded once I had gone through the interview guide and all additional and relevant questions were asked to each participant. The interviews ranged from eight to fifty-six minutes and my phenomenological interpretation is based on the discussions from all seven transcripts. The shortest interview was the very first interview I conducted. The brief duration of our conversation could be attributed to my nerves as well as the succinct nature of the participant’s responses. Despite the brevity of this discussion, I believe I gathered enough information to perform an in-depth analysis of her experience with chronic pain.

Throughout this process, I followed the mindset of Donna M. Orange, author of The Suffering Stranger: Hermeneutics for Everyday Clinical Practice. As the researcher, I was required to witness and participate emotionally in the suffering of the participants. I constantly kept in mind that the process of understanding means that I place myself at risk and allow the other to make an impact on me, to challenge my preconceptions and even to disappoint and reject myself in some instances [111]. Following Orange’s approach to hermeneutics and phenomenology, I also ensured that as the researcher, I do not judge as one who stands apart and unaffected, but I rather appreciate the participant's perspective as if I too were affected [111].

Interview Transcription

As the first step in data analysis, transcribing the interviews into written form allows the researcher to engage with the participants' narratives by reinforcing their understanding and relationship with the participant [105]. Transcription entails close observation of the conversation through repeated meticulous listening and allows for the researcher to familiarize themselves with what is actually there as opposed to what is expected [112]. Consequently, realizations or ideas can be readily derived during analysis. Being an interpretive process, transcription must be detailed to capture characteristics of the conversation such as emphasis, speed, tone of voice, timing, pauses, crying and laughter [113]. Therefore, I avoided using a transcription software and transcribed the interviews myself, verbatim, and as detailed as possible, within three days of each interview to ensure ultimate accuracy. Transcribing the interviews without the help of a software or professional transcriber allowed me to include any non-verbal cues or gestures I recalled during the discussion; for example, facial expressions, feelings of apprehension, pauses, body posture, or shifts in eye contact. Once transcribed, the audio file was played a second time to correct any discrepancies between the audio and written file.

Analyzing "Data"

The goal of data analysis in interpretive research is to gain an appreciation for the individual's experience through the development of integrated statements about said experiences [1]. Because this specific research approach does not follow a meticulously guided process, data analysis in phenomenology shadows this informality. It is not strict, procedural or rule-oriented, but rather responsive and based on the research question itself [102, 114, 110]. However, because phenomenology is a research approach rooted in philosophy, it is important to use methodological approaches that are consistent with the ontological and epistemological positioning of phenomenology. Despite there being a number of data analysis techniques to this research practice [102, 110], I chose to follow van Manen's steps in his approach to see phenomenology as the study of how things appear or present themselves to us through lived experience [115]. van Manen's methodology to analyze data involves grouping similar interview excerpts, using phenomenological reflection and introspection while engaging in a process of writing and re-writing; developing findings; and listening for the substance of the phenomenon [1]. van Manen's philosophy was used as the basis for all steps throughout the research process and helped me understand and practice phenomenology in a rich and adaptable manner.

Developing Findings

The second phase of analysis, after transcription, involved van Manen's practice of three approaches toward isolating thematic aspects in phenomenology: the holistic or sententious approach, where the researcher attends to the text as a whole; the selective or highlighting approach, where the researcher reads the text numerous times and underlines segments that seem essential in describing the lived experience; and the detailed or line-by-line approach, where the researcher looks at the meaning of each sentence and notes what it reveals about the phenomenon being questioned [99]. During this process, it is important for the researcher to be attuned not to how fast he or she can understand the lived experience, not as a quick sorting of mechanical matching between words and causes, but rather relating to the holism and complexity of meaning [111].

According to van Manen, as we study the lived-experience descriptions and recognize emerging themes in the “data”, it is important to observe that specific themes may repeat as commonalities in a few of the narratives [99]. When this occurred, I ensured to make note of these recurring themes by summarizing the meaning of it into a singular statement [99]. Using van Manen’s holistic approach, I wrote a summary paragraph for each individual narrative, eventually narrowing it down to a single phrase or sentence. The highlighting approach seeks to answer if there are any peculiar phrases in the descriptions that stand out. I therefore read over each narrative many times and selected sentences that were indicative of a common theme regarding the social implications of living with TMD. I did this by selecting and highlighting specific segments of the text that seemed significant about the phenomenon [1]. After reviewing each written account numerous times, I colour-coded each statement that was directly related to the social implications of living with TMD [1]. This simplified the tracking of the different statements for each individual. I exercised the line-by-line approach in the last portion of my analysis. I perused each sentence in the narrative, which is key to grasping the true essence of the participant’s experience. I then compiled all my notes, impressions, understandings and excerpts into findings and revisited each transcript when new themes emerged [110].

As language is the key to phenomenological research, the word choice of participants can suggest significant insights into the meanings they ascribe to experiences or events [110]. Therefore, it is important that the intended meaning of each participant is conserved and that the researcher’s interpretations respect this. However, in qualitative research, each individual involved, including the participants, researchers and readers, may have a different point of view, where each is just as valid as the next, acting as building blocks by taking something complex and trying to find out its essence. This process is "a process through which one strives to understand and use [one's background or biases] because it is through heterogeneity of thought and commitment to one's discipline vis-à-vis others that sophisticated new and different understanding may be achieved" [117]. Therefore, my findings, although perhaps different from another researcher's, contribute knowledge to the social implications of living with chronic orofacial pain.

Phenomenological Reflecting, Writing, and Re-writing

Phenomenological research requires a dialectical back-and-forth between different kinds of questioning to allow for an in-depth inquiry of the phenomenon in question [99]. In order to follow van Manen's methodological approach and uphold the richness and uncertainty of a lived experience, I ensured that my interpretive writing process involved rewriting and reflecting. French philosopher, Sartre, views writing and rewriting as a way to create depth, to "construct successive or multiple layers of meaning, thus laying bare certain truths while retaining an essential sense of ambiguity" [99]. As such, I listened to each narrative many times, writing and rewriting my notes and observations, all while intending to conserve the participant's intended meaning. To gain a better understanding of the lived experience, this philosophy requires attentive reflection [1,99]. I reflected on the participants' conversations and wisely selected the appropriate words to convey my interpretations of their narratives.

Reflexivity

It is important to discriminate between reflection and reflexivity- two key aspects of analyzing phenomenological “data”. Reflection includes a distinct set of tasks involving procedure and confirmation to achieve a high-quality analysis [1]. On the other hand, reflexivity can be described as the reflection of one’s thoughts back to oneself or in other words, an authentic assessment of the self [1,118]. However, this complex term has been defined in a number of ways and its implications vary depending on the research philosophy in question [1,110,119]. Husserl’s approach to descriptive phenomenology stresses that reflexivity suggests the researcher to identify his or her particular beliefs, assumptions, biases and knowledge by “bracketing” them or setting them aside in order to see it clearly [102]. In the interpretive framework of phenomenology, the biases of the researcher are rather embedded and vital to the interpretation [102]. Having said that, Heidegger, a pioneer of interpretive phenomenology, believed that the researcher is called, on an ongoing bias, to put extensive consideration into their experience and to unequivocally disclose how their identity, position or experience may pertain to the phenomenon in question [102, 120]. In that respect, phenomenology treats the researcher’s knowledge, experiences and assumptions as indispensable components of his or her ability to understand the experiences of others [1,102, 110]. To successfully adopt this philosophical framework in a holistic manner, I practiced reflexivity throughout the entire research process by carefully considering and being transparent about the ways in which my involvement affects each phase of research. In doing so, I began to fully comprehend the nature of this exploration and of the participants’ experiences. Similar to Shaw’s description on embedding reflexivity within qualitative research, my awareness of the ways in which my identity, beliefs and knowledge interacted with the patients' narratives brought forth a co-constitution of knowledge and a fresh understanding of the phenomenon in question [110,118].

My experiences were that reflexivity involved regularly considering my status as a future dental student and current master's student in the domain of orofacial pain who previously completed a bachelor's degree in psychology, while simultaneously considering the ways in which these distinct, yet somewhat interconnected identities could and did affect this research project. Working closely alongside orofacial pain specialists throughout the past year has opened my eyes to the field of chronic pain. Interacting with orofacial pain patients, both chronic and acute, on a weekly basis for the last year, has contributed to my non-judgmental nature, as I have learned to genuinely empathize with their experiences confronting pain and disbelief. Acquiring this knowledge and belief system has enabled me to relate to my participants' feelings of distress, anger, and disbelief and to exhibit an open-minded attitude towards them, a mindset beneficial to the reflexivity of this research project.

I also considered the ways in which my presentation and experiences as a previous psychology student affected the way my participants perceived and interacted with me, and the manner in which I connected with them and interpreted their stories. Having a general background in psychological disorders and mental health were both advantageous and unfavorable in my role as a researcher. This knowledge in the field of psychology assisted my interpretation and analysis of the participants' narratives, as there were instances where I believed the accounts of some experiences (either positive or negative) of certain participants were at times linked to pre-existing mental conditions such as anxiety or depression. However, keeping in mind that interpretive phenomenology focuses on trying to understand participants from their frame of reference, I adopted a naïve attitude regarding mental health issues and did not disclose my identity as a psychology undergraduate out of concern that it would affect the way participants related to me. This allowed for a less stressful and more genuine interview experience for some participants. In retrospect, I am happy that I did not reveal my previous field of study as some individuals with mental health conditions may have entered the interview with a mindset that they will feel uncomfortable or feel as if they are being psycho-analyzed.

In instances where fellow colleagues or friends discuss chronic pain and discredit the intensity or severity of the painful experience, I feel compelled to defend my participants' struggles, which confirms my non-judgmental stance, an attitude that is favorable to the reflexivity of this project. Moreover, my supervisors' comments on earlier drafts of my work were also valuable to reflexivity.

Generalizability & Transferability

As mentioned, interpretive phenomenology is an art of understanding, emphasizing this understanding through experience and interpretation. In this research project, as in most qualitative research, the goal is not to draw general conclusions to the population at large, but instead to offer a profound understanding of a certain human experience [1,121]. In qualitative research, it is erroneous to assume that a large sample size is required to produce generalizable results [105, 110]. Although generalizability is broadly accepted as a measure of quality in quantitative research, qualitative research is based on a different epistemological framework and serves a different purpose than its counterpart. In phenomenological research, the quality of the study is achieved by prompting rich and vibrant descriptions from individuals with a certain lived experience, where it is built on the notion of essences that are eidetic- thus generalizations originate from meaning-structure of a phenomenon [105]. This study delves into the experiences of those living with chronic TMD pain and seeks to answer the question: “What is this experience like?” as opposed to the typical quantitative research question which addresses “how much?”, which requires contrasting evaluative criteria [105, 106].

What is really of utmost importance in phenomenological research is that understanding a certain phenomenon can benefit other sufferers who are learning to live with a similar condition or related experience. This is known as transferability. Transferability occurs when readers in similar contexts succeed in finding meaning in the research findings and make a connection between their own experience and those of a study [121]. It is the duty of the researcher to provide the readers with satisfactory imagery and descriptions to facilitate such a transfer to take place [1,110]. You, the readers of this particular study, are all welcome to reflect on each one of the participants’ narratives of living with chronic orofacial pain and make connections between this research and your interests, experiences and practices. It is important to note that following Heidegger’s philosophy, as I did not bracket my biases as a researcher, I was not required to verify the study’s findings by confirming if the findings are consistent with the participants’ narratives [1, 96]. I did not deem this a necessary step in my research process as I trusted the accounts to be detailed enough to confirm integrity of the data.

I believe that the conclusions generated from this research project will be pertinent for other persons living with chronic orofacial pain. This study validates the pain and suffering that these individuals experience, hopefully paving the way towards exploring new avenues in which health care practitioners understand and engage patients with chronic orofacial pain.

Interest & Commitment

I consider myself extremely fortunate to live my life relatively pain-free, however, many people do not have this privilege. Spending the last year studying chronic pain, suffering, hermeneutics and phenomenology have played a significant role in the context of my study. They have completely altered my way of thinking from a more narrow-minded perspective on people and why they do what they do, to a much more non-judgmental, genuine, and undiscriminating manner in which I now view those around me. I have learned that those suffering with severe chronic pain are often forced into isolation, which is very different from experiencing solitude by choice. Those who live with this condition may feel as if they are a bother and no longer have anything positive to contribute to their family, friends or society as a whole. Under such circumstances, I have discussed with my supervisor on numerous occasions the importance of working towards regaining a sense of purpose in life, which can contribute towards the healing process. Through discussion, I have learned that although full recovery may never be possible in such individuals, working towards the process of becoming whole again as a person, of getting one's life back on track can be the stepping stone towards living a happy and fulfilled life.

My interest in social wellness started while I was studying psychology and later being immersed in the field of dentistry was what sparked my interest in chronic pain. Examining peoples' experiences with chronic pain and learning how to positively influence these experiences for their benefit is the first step in improving public health for the chronic pain population. Exploration of the perspectives of chronic pain sufferers seemed to be a great way to better understand them and their pain, and thus to help them. As a future dentist, how could I better understand and become more empathetic towards patients who will come to me desperately seeking peace of mind and relief? What is their experience like? How could I potentially help and offer my support? Such questions about experience with pain continue to be of interest to me as a future dentist. My persistent interest on this subject and its application to practical issues has facilitated a strong commitment to my research.

Ethical Considerations

Ethics approval was granted in June 2015 by McGill University's Research Ethics Board Office, and extended to enable interviews to take place until June 11th, 2018 (see Appendix C). The informed consent form was explained to each participant and was signed prior to each interview, outlining the potential risks and benefits of the study. The goal of the study was also communicated with each participant: To understand the social implications of living with chronic orofacial pain. Each participant was made aware that there was minimal risk of psychological or physical harm in this study and should they choose not to answer any question or wish to withdraw from the study at any time, they can do so prior to the publication of the results. In order to maintain my participants' confidentiality and protect their identity, pseudonyms were used to identify participants in all work shared with others, including this dissertation, and the transcripts I shared with my supervisor.

LIFE WITH PAIN

I interviewed seven participants with the goal of understanding the essence of one's lived experience with chronic orofacial pain. In this section, I share a brief background of each participant and outline their description of their experience with pain.

Christina was the very first person I interviewed, and I was so nervous that our discussion only lasted about 10 minutes. Christina, a hospital employee in her late forties, is a TMD sufferer and has no idea what may have caused the pain. The pain began a few years ago and then tapered off, but started again last April when she was on vacation and could not open her mouth to eat. She described that "[her] mouth was like that (showing me her mouth, how it only opened about half an inch wide). Half an inch would open and I'd have to like squeeze things into my mouth." Despite her easy-going personality, she still struggled with chewing her foods, as she described the experience: "I hold…I hold my jaw when I yawn and I concentrate when I'm eating actually, how I'm going to put food in my mouth. I've gotten to the point where I'm thinking how I'm going to put it in my mouth." From our conversation, I gathered that it was something that was constantly on her mind- a nuisance and burden on her every-day life. Christina was unable to enjoy some of the foods that she used to appreciate, as she explains that "[she] won't cut into a big piece of steak and put it in [her] mouth. [She] can't get it in [her] mouth so it's cut smaller and [she] won't force [her] jaw… [she] won't take a big piece of steak like [she] used to, like a nice big chunk of steak."

She described herself as an easy-going person, which may contribute to her ability to effortlessly adapt to the manifestations of her pain. When asked whether her painful experience and change in diet negatively affects her social life and socializing, she mentioned: “I’m an easy-going person so things like that don’t bother me and I really don’t care what other people think… As I said, I’m an easy-going person and I can deal with pain and stuff, whatever happens, I deal with it”.

Kenneth, a former rapper in his early 20s has been suffering from severe chronic ear and TMJ pain for over two years. From our conversation, I discerned that his frustration with the health care system has been pending since his first visit to the otorhinolaryngologist. He had visited countless professionals before finally being diagnosed with TMD disorder and was left in limbo for many months before he could take the necessary steps towards management and recovery. He described his pain as “a stiff bothering, like an annoying… like it’s always there… you know?... It’s like uhhh, I would say like a hot, like a tight feeling, like a hot, tight feeling, and sometimes it’s just like, it feels swollen or sore.” Kenneth, despite not having to alter his diet much, reported that he suffered with isolation and withdrawal from friends as well as depression due to the intensity of the pain. When asked how his chronic pain condition has affected him, he replied with a powerful statement describing his experience:

> I would never wish this pain on anybody, I wouldn’t wish this pain on anybody. Because it’s a facial pain, you know, it’s not like your arm is broken and you know you’ll wear a cast and after a few months, you’ll be blessed again. This is something that is on you… you know and there’s just no cast, I can’t wear a cast for my jaw. Because it feels like, to me, it feels like my jaw is broken. Some days, when it’s really, really bad, it feels like my jaw is broken...

The conversation I had with **Sally** seemed like something she had been yearning to do for years. It was almost as if she had been suffering in silence ever since her pain first started three years ago. She was desperate for any help she could get and appreciated our discussion very much. Sally, worked full-time while taking care of her 94-year old mother-in-law. Being on pain-killers for the majority of the time has made her ability to focus on every-day tasks extremely difficult, as she constantly felt pain or numbness. She described her pain to me by stating that "In terms of [her] face, it's more like needles… like it's more of a throbbing, jabbing kind of sensation." Initially, the pain originated in her chin and felt almost like a numbing sensation which created a red spot on her chin. Since 2014, her pain has moved up all the way to the top of her head. She has visited a number of health professionals over the years, had dozens of unnecessary procedures and examinations performed on her before finally coming to a conclusion about her TMD diagnosis, which has caused her significant frustration, similar to Kenneth's experience in with health care. Despite her strong support from family, Sally struggled with social isolation and chronic fatigue on a daily basis.

My conversation with **Michael**, a 19-years-old CEGEP student, was not as rich and detailed as I had wished for, as it seemed like he was pressed for time on that day (or perhaps he was slightly embarrassed sharing his personal experiences and apprehensions with a female only five years his senior). I say this because of some word choices and phrases he decided to use. For example, when asked what living with this pain condition meant to him, he responded with a nonchalant response: "It doesn't impede any functionality in my life, it's just- , well I'm sure for most people it would, but like for me it doesn't because I just power through it. But I would prefer not to have it… it would be highly preferable." Although Michael verbalized that the pain was not debilitating in any sense, he went on to describe his struggle with eating due to his TMD. In terms of forced diet changes, Michael had difficulty eating in the morning, which was made clear to me when he mentioned, “my jaw would lock when I woke up, where I couldn’t eat for the first few… like hours in the morning…. well I wouldn’t eat anyways, but if I needed to, I couldn’t eat because it would lock more intensely…” Similar to Christina, Michael seemed like an easy-going young man who was fortunate enough to easily adapt to his pain. His TMD-related pain was manifested by pressure on his right eye and eye socket in addition to extreme tension and pain down near his right TMJ and neck. Despite his very blasé attitude, he disclosed the painful feeling to me as “burning and just like sharpness and pain…” His biggest concern seemed to be the annoyance of the pain and not the intensity of the pain itself, as he mentioned that “It’s… it’s honestly just annoying that’s all. I still do what I do because I have to do it… uh… but I prefer not to have it because it’s deconcentrating and it’s annoying.”

Unfortunately, it was a bit difficult for me to truly connect with **Dean**, who recently immigrated to Canada from South Korea, as I had a tough time deciphering some of the words he used, as English was not his mother tongue. I attempted to make him feel as comfortable as possible and despite his accent and moderate level of English, I emphasized that he should not be embarrassed nor hold back from expressing himself and his lived experience with chronic TMD. Dean seemed very antsy and was very talkative throughout our discussion, not from the nerves, but I believe from finally being given the opportunity to tell his story. He has suffered from extreme tension in his jaw for over ten years and similar to many of the participants I spoke to, pain killers seemed to be the only hope for Dean. His experience with chronic pain has driven him to depression and social isolation. He admitted that he has become dependent on muscle relaxants and went through loopholes to renew his prescriptions. His pain was dependent on the weather, which contributed to his reluctance towards leaving the house: “I’m scared of the winter…the… the… pain is going to get worse, I know that (looking down).”

Maria was a lovely, humble woman in her late fifties who grew up in Iran and immigrated to Canada eight years ago. It seemed as if our conversation lifted a huge load off her shoulders- a discussion very much due. Her English was moderate, but she spoke clearly and used quite a bit of gestures and props to facilitate my understanding. We connected very well and conversed for an hour about her lived experience with chronic TN and TMD. Her facial pain began shortly after she had been in a car accident and worsened after another car crash less than a year later. She described the feeling as comparable to pins and needles: “Sometimes here (pointing to gums), it’s getting…hm… you know when.. uhm your leg is getting…numb?...yes.” Her biggest apprehension seemed to be the frustration she experienced due to her dissatisfaction with the health care system. She expressed her concern about health professionals performing countless unnecessary treatments and surgeries that exacerbated her pain and did not help her condition, despite their constant reassurance. She has yet to find a treatment that worked for her, and was unable to try some common treatments such as acupuncture and physiotherapy: “Even when somebody touches me, I feel pain…” Since her pain began, her diet has suffered as she struggled to chew her food, debilitated by the constant agony. She preferred staying within the comfort of her own home as leaving seemed too risky and unpredictable. I very much appreciated my conversation with Maria, as she also viewed her pain in a positive light and used metaphors to describe the way her pain had shaped her as an individual. Despite this positivity, she was frightened of what the future has in store for her.

My conversation with **Linda** lasted almost an hour- an hour spent discussing her life experiences and the personal details and views that came along with her chronic TN pain. She was recently retired and spent 41 years working as an administrator in a high school and dedicated most of her time with her family, taking care of her newly-born grandson. Her pain started following the removal of an acoustic schwannoma six years ago. After several interventions, Linda was happy and healthy for one year and was under the impression that the tumour was removed. Despite experiencing some difficulty with balance, she was completely fine until about a year later, when, as she explained: “It came back full force…wicked. I felt it…you know, we were sitting at the table one night, I was telling my son with his girlfriend, I said I’m experiencing a sense of numbing up here next to my eye (points to left eye) …” Starting off as a slight tingling, her pain had progressed over the years: “but it’s, trigeminal neuralgia...it’s like there’s the numbness that’s there but it’s difficult to describe to someone… How can something that’s numb be so painful?” Similar to Maria, Linda expressed her concern for the future, wondering if the worst is yet to come. As she cannot chew on her left side, she has had to alter her diet accordingly, being unable to enjoy many of the foods she once enjoyed. Her forced change in diet along with the intensity of the pain has negatively affected her social life and has caused her to withdraw from friends. Despite being saddened by her chronic condition, she has, however, accepted the reality of her situation and continues to take the necessary steps towards her healing process.

Interpretive Discussion Across Participants

From this research study, life with pain was expressed in many different ways, however, most participants, at some point throughout their pain experience, described a feeling of uncertainty.

This response was manifested by either them not knowing what their condition was, which often lead to frustration, or by other people’s lack of understanding regarding their pain condition.

Study participants reported experiencing constant frustration and ambiguity in relation to the process of obtaining a diagnosis. Dean was formally diagnosed with TMD by an orofacial pain specialist years after his pain initially started: “Whenever this started, like I had so much stress, I didn’t know what it was, I didn’t even know what this was… I did all different types of tests too. Like I did blood tests, X-Ray in my head and like… I had a lot of arguments with my family at that time...” When his jaw pain was first evoked, he did not understand why and what had happened: “It drives me nuts. I never had this kind of pain before. I was so energetic, healthy…I didn’t have any diseases and like… and they do like blood tests and it’s fine, everything is fine.”

Michael shared a similar experience. He had suffered for seven months and was unsure about when and if he would ever be able to abandon his facial pain: “I’d enjoy it for it to be not be there… It would be concerning if it would be there for longer than a year. So, it’s like… will I ever lose it or not? I figured it would go away after two months, but it did not, so it was concerning …”

Participants like Maria and Sally underwent numerous surgeries and procedures with several different health professionals before finally being diagnosed with chronic orofacial pain. Sally described her story to me in frustration:

> One day I woke up and had this sensation in my jaw and I went to the dentist thinking it was the tooth because I had dental work done here (pointed to bottom 2 front teeth) […] but I thought that maybe it touched a nerve ending you know, you- you kind of just figure

> things out and then I went to the my doc- well it turned out not to be true, nothing to do with dental. And then I went to my GP…then I ended up going back to another dentist because they sent me to a specialist and he thought I had a sinus infection, they put me on medication for that… Then uh, you know with a lot of these, I've been on a lot of different kinds of pain killers which all work, but then when you, the two weeks are up (laughs) then I'm back to my regular story… So, I've seen three neurologists, I've had three MRIs… I also went to see an otorhinolaryngologist, which they put the camera down and they, he had said that there's nothing wrong with that. It's really just this, so I have seen a lot of people and nobody's really helped me (nervous laughter)…

She continued by saying: "I've had three MRIs in the last two and a half years so now, I'm scheduled for another one in 2018 because I've had too many… So, it's like you know, are they giving me cancer? (nervous laughter)".

The longing for help was often emphasized in the personal narratives- any possible assistance to rid them of uncertainty. For example, one participant explained her desperation for clarification:

> I mean the pain is lousy, there's no nice thing to say, there's nothing great I can say about it. It's crummy, it's lousy. And I would like it to go away and I would like to find somebody who can help me do that you know. And I mean I don't know, is it diet? Is it exercise? What is it? You know, is there anything that can help there? I can't exercise, I'm too tired.

She went on to mention that "Every time [she] meet[s] a new person, [she's] hoping they're going to help [her] you know. It's a psychological thing, it plays games, you know..." After reflecting on the discussions I had with each participant, it was clear to me that they were desperately calling out for help. It seemed as if our exchange was the first opportunity for many to share their experience with chronic pain.

The participants described their life with pain as being constantly faced with family, friends, co-workers and peers who did not understand them, which often created feelings of shame and frustration. When Dean first approached his family about his facial pain, he did not appreciate their reaction: “Like they didn’t understand me, they…they…they thought I was faking. But like I wasn’t faking (raised voice) … How could I fake for six months, it doesn’t make sense!” Kenneth, a former rapper, dealt with constant grief from his brothers who did not understand why he quit his passion: “Well, especially my brothers… like my brothers… because my brothers every day they’re like ‘Yo… you’re sleeping… you know, you could’ve been something… you know’… and I’ll just be like soon…soon… you know… when this goes away”. Kenneth found it difficult to properly express the nature of his condition to those around him, so he generally avoided bringing it up. When asked if he was embarrassed by other’s reactions, he responded by saying: “I wouldn’t say embarrassing, but it’s just like… You got that? What is that? … you know?” He constantly struggled to justify his condition: “Like when I tell them about it… they think it’s just like teeth, you know… I’m like nah bro… it’s just like… it’s something that’s been building up that’s not going to go away overnight...I wish it could but it’s not….” The inability of individuals around him to genuinely empathize has led Kenneth to become irritated very easily.

Feelings of frustration were also illustrated by some participants. When talking about his mother, Kenneth mentioned:

> Uhmm, just, especially when I'm… when I'm bothered by it, I go to her as if she's like my doctor, you know… and if she doesn't give me the right answer or something I just get annoyed or... I feel like if she comes home and I'm in my room and I'm just listening to music, she's bothering me… it triggers it real quick you know… like me getting annoyed or getting mad or getting like…

Another participant described similar feelings of annoyance when he stated that: "Now I feel like I'm always so uptight and mad… just like stressed…"

Summary

Meeting with my participants has opened my eyes to the chronic pain experience, allowing me to understand that there is a lot more to this lived experience than simply the pain itself. In spite of pain being subjective in nature, it is often underestimated by health professionals who may misjudge what the chronic pain patient is experiencing, as pain in medical settings is often associated with physiological signs such as high blood pressure, crying, or increased pulse [11]. The lack of physical signs makes it difficult for their pain to be acknowledged, thus resulting in feelings of anxiety, confusion, and frustration. For this reason, it is vital for health practitioners to use patient narratives as a means to better understand their patients' experiences with chronic pain [45, 46].

Four themes emerged from my findings in these narrative accounts, suggesting that it is not only just physical pain that the orofacial pain sufferer must endure, but the psychosocial implications also pose an added and often complicated challenge. These themes were as follows: Forced change in diet; Loss; Deterioration of Social Life; and Acceptance. I will begin by introducing each theme at a time and will describe each one using sub-themes. I will continue to summarize each one with some discussion about that theme. After presenting each theme, I will complete this section with a summary and concluding remarks, which will represent a more in-depth analysis.

FINDING #1- FORCED CHANGE IN DIET

Due to the nature of chronic TMD and TN, some participants were forced to alter their diet to avoid exacerbating their pain. This forced change in diet was manifested by difficulty chewing, while the social lives of some participants were negatively affected because of this lifestyle change.

Difficulty Chewing

The participants of the present study often experienced a forced change in diet due to difficulty chewing their food. Meal time has a way of bringing family and friends together in a truly special way. Literature suggests that eating family meals may enhance the health and well-being of an individual, particularly in adolescents [122]. Sadly, severe orofacial pain sufferers do not have the pleasure of enjoying food the way many of us do, as chronic TMD and TN are associated with marked functional impairment in the jaw and surrounding masticatory structures, creating pain and discomfort when chewing specific foods. The chronic pain often creates a loss in the ability to eat previously enjoyed foods. Linda described to me her inability to indulge in one of her favourite meals- steak:

> I could really handle a good steak. Give me a good T-bone or a rib steak and I could just be- I uh… the chewing aspect… of course, there was an adjustment to make there because initially how many times would I bite my tongue… how many times would I bite my cheek…

Although she missed the foods she can no longer treat herself to, she has made progress to adjust to her new diet:

> And so, I’ve had to adjust my diet because it wasn’t pleasant having to chew and just uh... sort of having a variety of… I wouldn’t say baby food, but you know…. different textures that were easier to handle. I was always a good vegetable eater so you could go with green beans and squash and potatoes and parsnips and whatever, turnips… that’s all good, but when you get into the more consistent foods that require a good chew… nope not pleasant.

Another participant mentioned: “Meat was something I really enjoyed…. Not anymore. A hamburger (laughed)… give me a sirloin tip hamburger that’s good (laughed). So I try and compensate with quality food that’s uhm… that pleases me.” She described to me her morning routine: “So I uh… you know, take a good hearty smoothie with all the necessaries in it, with some protein powder and I’m good to go.” Maria who is native to Iran, emphasized the importance of food in her culture, however, due to her condition, she was unable to indulge in many of the foods she once enjoyed. She shared her story with me:

> I lost two teeth (pointed to one of her top teeth in back). One of them is here because…it’s very important because when I’m chewing it is very hard. And this one (pointed to back bottom tooth), I went for the implants, but […] it is hard for me to do the surgery again, they pulled the teeth and they did something for the implant… but it’s still…empty…and Dr. [name] told me just let it to be like that because of the pain…

Maria did not follow through with the surgery as her orofacial pain specialist believed it would be too painful for her and might exacerbate her pain. She seemed very bothered by this, as she disclosed:

> I love to eat… you know it is very hard for me when I can't eat many things... I really enjoy, yes, when I eat…I enjoy everything…the taste, the- but now, it's difficult for chewing [….] Even for the meat, it is very hard for the chewing… For the vegetable… vegetable it is very hard…I put in the mixture (demonstrated chopping and spinning).

Kenneth had a less negative experience in this regard, as his TMD pain only prevented him from eating a few of the foods he once enjoyed: "I don't eat candy anymore… uhm… […] To be honest, I… I… I don't, there's nothing like special that I really eat that I've had to stop… Maybe peanuts, I don't eat peanuts anymore." Dean even had a positive experience with food; He mentioned that eating helped his muscles to relax and soothed the pain: "I wake up and I feel this tenseness in the jaw, but like, when I eat breakfast, it actually relaxes the muscle […] Whenever I eat, it's actually better."

Michael, on the other hand, was unable to eat breakfast, as his jaw remained locked for the first few hours upon awaking: "Well before when I had it, my jaw would lock when I woke up, where I couldn't eat for the first few like hours in the morning…. Well I wouldn't eat anyways… but if I needed to, I couldn't eat because it would lock more intensely…." Scared that the food might trigger her pain, Christina made a point of indicating that she was extremely vigilant whenever she ate a meal: "I hold my jaw when I yawn and I concentrate when I'm eating actually… how I'm going to put food in my mouth... I've gotten to the point where I'm thinking how I'm going to put it in my mouth…" When I asked her about her experiences going out to eat in restaurants, she mentioned:

> That's where I'm conscious when I'm eating… like I won't just grab something and eat it… like a sub or a big sandwich… I'll flatten in and I'll put it in my mouth slowly and take a bite slowly instead of chewing it without thinking […] Subs, sandwiches, for a sub,

> I would have to smash it down… for a burger, I'd have to squash it down […] I won't take a big piece of steak like I used to… like a nice big chunk of steak…

Change in Diet Influence on Socializing

As a result of chronic pain's effect on difficulty chewing, some of the participants experienced a decline in social engagement and activities. Linda was particularly phased by this change- she described the effect of her forced change in diet on socializing with her family: "It's really sort of sad because we used to always sit down as a family and I mean now we tend to sort of… there are many times we don't eat together… he'll grab a bite and we'll eat at different hours and it's sort of all mixed up now". Linda and I remained on this topic for quite some time, as I gathered that this particular topic was one of importance to her. Due to the chronic painful numbing sensation in the left side of her face, she has had to refrain from what was once a very active social life with friends:

> Great things happen around the table…. You know I was always an active, social… did a lot of entertaining… you know, I'd be the first to say to girlfriends 'Okay, we're getting together… it's going to be brunch time how's next uh… Saturday? Suit you?' (bit down, looked down) I don't do that anymore… I don't make big tables… Uh… all these dishes, all these… I liked to do a theme with uh, you know… if it's winter or if it's summer…prepare tables accordingly… Gee whiz I say I've got all these serving dishes and my kids don't have large homes… they can't- they're not interested… They gather more so like dust-

When Linda's pain first started, she had difficulty drinking and was thus uncomfortable enjoying her meals out in public: "You know if you're drinking, I had a lot of difficulty drinking initially because I was unable to actually grasp the actual lip of the cup or glass without it dripping or leaking… but that's been mastered. I can take a sip of water and I won't drool…" Her facial pain has caused her to be more sensitive to noise, as it exacerbated her discomfort. Due to the unpredictability of noise levels in restaurants and her inability to enjoy some of her favourite foods, Linda preferred to refrain from eating in restaurants, which led her to decline invitations from friends. When asked if this forced change in diet had affected her social life, she mentioned:

> Tremendously. I've declined now, first of all, invites to restaurants… getting together at restaurants… and recently, I've declined an invite because I just said…. it's not pleasant for me anymore. You go to a restaurant, there's so much noise, so much cling clang of cutlery and voices and I can't even have a proper conversation with someone. I recognize that I do better on one to one and if it's a quiet environment or go for a coffee in a quiet café where things are perhaps a little bit less noisy, that's feasible, however, that's really changed. You know when you had a position of leadership and you were expected to be very forthright and in charge and able to communicate with, whether it be staff or parents or students… it's a very different ball game, so now I just have to look after myself in getting my message across.

Discussion

Due to the nature of chronic TMD- and TN-related pain, participants in this present study experienced marked functional impairment in the jaw and surrounding masticatory structures [60-62]. As a result, many of them with severe orofacial pain did not have the luxury of enjoying food the way many of us do, as chewing specific foods can be seen as an uncomfortable and painful act. Some participants had difficulty chewing their foods, thus resulting in a forced change in diet. It is therefore no surprise that individuals with TMD and TN must often alter their diet to avoid exacerbating their pain. Because shakes, smoothies, and blended fruits and vegetables are usually popular among those who suffer from orofacial pain, this can, with no surprise, take a toll on their social life. Feelings of embarrassment, shame and stigma are bound to be present in situations where people with orofacial pain are invited to dinner with friends, for example. Food is more than a basic need for subsistence; it is a symbol of love, comfort and security. Being forced to resort to blended foods can negatively affect the social lives and relationships of individuals with severe orofacial pain. This outcome has ultimately lead some participants to suffer from loss, which was another commonality derived from the participants' narratives.

FINDING #2- LOSS

After extensively perusing the transcriptions, I determined that in most cases, the participants suffered from being forced into giving up aspects of their life. This loss was due to either the intensity of the pain or was a necessary step taken to manage their discomfort. The different types of losses were characterized by either having to stop work or attend school, by loss of sleep and memory, or in some participants, loss of intimacy. Having to give up or lose these key parts of their lives has led some of them to the loss of hope. I was not surprised by these findings, as the recent literature on chronic pain supports these associations [1,80,81,85].

Having to Leave Work or School

Linda humbly described her experience of having been forced into retirement due to the side effects of Tegretol, a drug commonly used to treat Trigeminal Neuralgia: "I said I'm in it for the kids, but also I think at this point in my life, perhaps a younger, more vibrant investment for that position was to be considered very much rather than just selfishness on my behalf." When asked if she felt this selfishness was due to her feeling like she was not at the best of her ability due to the pain, she nodded her head as she clenched her teeth (a habit she picked up years ago when her pain first started). Maria was forced to stop working completely: "It is very hard for me because before I did many things… I even… when I worked, I could stay for overtime and … I had some customers at home…" Unable to cope with the severity of the pain while in school, Dean and Kenneth were both obliged to stop studying after high school. While he was still in school, Kenneth described his experience as being very challenging: "Yeah, sometimes I didn't even get up to go, I just stayed in bed…" Music was one of Kenneth's passions; He used to perform in many rap competitions, but was forced to quit after his pain first started:

> Music… I used to do a lot of music… and I felt like uhh… I felt like this [the pain] has really held me back… I used to rap….and I feel like this… especially with the pain… I can't do it anymore… And uhm, I stopped doing whatever I was doing and the pain just started getting on… and then I just fell from what I was doing… and then even today people will be like 'Yo bro, you don't do it anymore?' And I'm just like nah… I don't tell them why I just be like nah… I don't do it anymore.

Kenneth went on to confess that quitting the music industry resulted in the loss of many friendships, which saddened him quite a bit: "I felt like… everybody that was that was with me left, you know? They forgot about me…"

Loss of Sleep

Some participants suffered from poor sleep quality, which contributed to their constant fatigue. Dean mentioned: "when I sit on something or lie down, it actually makes it worse… Like I have trouble sleeping… Like because I have trouble having sleep and sometimes like I end up waking… I end up like going to bed like in the morning". He went on to mention that due to his pain, his days were constantly thrown off balance. Sally, a participant who took over-the-counter painkillers all throughout the day stated: "Well, I mean I take a lot of Advil and I take a lot of Tylenol during the day because it's- and at night because it's… it [the pain] wakes me up". She laughed nervously and continued:

> I never sleep. Well I sleep a couple of hours and then I wake up and have to take more you know pills and stuff so it's kind of just like day to day zombie... After time I mean,

> it's 2017 now, I've had this since 2014, you just get used to it…. I'm tired all the time for sure because it's just constant.

She made a point to mention that she was "really, really tired" during our conversation, but she still wished to continue. As a result of her constant tiredness, Sally had given up activities she very much enjoyed, such as exercising and going out for dinner:

> Well I used to exercise, I'd go to the gym… uhh… I used to go out for dinner, I used to- I had a very big social life. I don't… I don't do anything. I work from home so I go from my office which is downstairs, I go upstairs, a couple of times walking back and forth, I'm exhausted, which is silly.

I could tell this topic of conversation was something that Sally suffered with on a daily basis, which impaired her social functioning:

> I mean I eat at 5 o'clock like I'm 80 years old. I didn't do that before. I'd go out for cocktails and for dinner. I mean really… I eat like at 5 o'clock. Like who does that?! 80-year old people (laughed)…You know…. I mean I go to bed at 7, I'm up at 8-8:30, 9 whatever…You know, back up again, back up again….

Her eyes shifted down as she continued to describe how she felt regarding this issue that haunted her every day: "I'm tired… (nervously laughed) It's a production just to go and do you know… And I feel like I'm being a baby, but you try to just keep going..." Aside from Sally and Dean's daily struggles with sleep quality, Linda and Maria also clarified that the pain negatively affected their sleep cycles, which is in line with literature that states that one of the most common complaints reported by chronic pain patients is poor sleep quality [1,123,124].

Loss of Mental Stability

"I'll start cooking and halfway through, I'll feel like throwing everything away. My family doesn't even know that this is how I feel because I control it and don't... I just carry on."

The ubiquity of the pain in these chronic pain participants unquestionably produced constant uneasiness. They expressed feeling overwhelmed by the pain, as it is an inescapable burden on them: "It's this, it's this, it's taken over everything, it really has". Sally was holding her head in distress when she continued to mention: "It's always, it's always, always, always on my mind." Much like Dean, Sally's only relief was the consistent use of painkillers, which eventually led her to an episode of mental instability: "As a matter of a fact, I had a breakdown (nervously laughed) and I've thrown everything away because they just keep giving me different painkillers and really… it is not doing anything you know…" The chronic pain seemed to be accompanied by a powerful force that took over the participant's whole entity: "I just feel like I wouldn't have a good time with whatever I'm supposed to be doing because it would be on my mind…" Kenneth expressed the bothersome nature of the pain as he described how tired he was living with his chronic condition: "It's something that I think about more like a lot during the day… Sometimes stress about it like damn… like when's this shit going to, sorry… go away […] I'm tired of living with this".

The overwhelming nature of the condition has caused even the most optimistic participants to fear the future. Maria was particularly concerned about eventually being unable to support herself:

> I'm really scared of the future because I don't know what happens... Everything is getting…every day depressed goes up […] One day I can't pay the rent… One day if I have more problems, I have to pay the dentist… Everybody wants their money you know... And I don't have any insurance…

Her fear seemed to stem from the financial burden of treatment and the inability to work:

> Of course, with the money, I don't get scared…if I can't pay my rent this month, what can I do? I'm not going like some people come please help me… And you know I'm scared, but sometimes I tell myself, I'm stupid, why are you scared? … Until now what did you do? And after that, you will do the same.

Loss of Memory

Unsure if this was a consequence from the pain itself or from the fatigue, one participant even noted that ever since her pain started, her memory had suffered: "One other thing that it really does also is it affects your memory, like I'm very, very forgetful…Yeah, yeah, very, very forgetful… So I write everything down…Yeah, so that could be very frustrating, but I keep a notebook with me, I write everything down…"

Loss of Intimacy

When I asked Linda how her chronic orofacial pain condition had affected her relationships, she disclosed that she suffered a great loss of intimacy between her and her husband:

> I would say intimacy with my husband… you know… do you think I feel like making out? Or uh… having a nice kissing session… no way! And so it's affected our intimacy… some people say, 'uch, that was long gone'… You know my girlfriends

> who're in their mid-sixties say it… well…. you know not for everybody! (laughed) We… We resort to other alternatives… just sort of satisfaction there's always hope with masturbation and with different… other alternatives, but you know… it's really… it's a bitch. I'm sorry to say that in all confidentiality… it's a wicked disease…wicked...

Linda's experience with loss of intimacy lines up with an ethnographic qualitative study that concluded that loss of physical sexual intimacy is an emerging pattern of behaviour in women with chronic pain [95].

Loss of Hope

Many individuals with chronic TMD and TN have yet to find treatment plans that satisfy them. Loss of hope can commonly be experienced by chronic pain sufferers, as pharmaceuticals are generally the only treatments that help certain individuals manage their chronic pain. Dean, who had suffered from extreme tension and pain in his jaw for ten years described the temporary fix that acupuncture provided, however, his loss of hope was implied as he admitted that the only option viable for him were muscle relaxants. When talking about acupuncture, Dean mentioned: "And I know that like muscles that are pierced, it only works temporarily…. My sister is a doctor too… She told me that only pain killers will work for me… It's not possible to help my problem." Sally similarly experienced a loss of hope, as she felt like there was no escaping this condition: "You know, I think if it was going to change, it would have changed already, right? If it was a temporary thing."

Discussion

To summarize, the participants of the current work experienced several chronic TMD- and TN-pain related losses, which each intensified their suffering. With chronic pain comes an entirety of negative responses, which affect aspects of one's social, psychological, financial and personal life. Miller and Omarzu (1998) defined loss as life events or changes that can result in someone being or feeling deprived of something valuable [125]. Numerous categories of loss are inevitably encountered during one's life, as experiencing loss is characteristic to human life. Individuals who suffer from chronic pain are more prone to experience loss, and these losses may potentially alter how chronic pain sufferers perceive their world [1, 126, 127]. Dealing with the experience of loss can be arduous, which emphasizes the importance for support and guidance [127]. During the life span, one experiences loss in different types and magnitude. The uniqueness of each individual brings forth the individuality of each person's experience, which can be dependent on personality and one's ability or inability to adapt to a novel environment. As shown in the aforementioned section, some participants had more difficulty than others adapting to their condition, thus experiencing more loss and suffering in their life than others. Many participants were forced to stop working or were obliged to discontinue their studies as a result of the constant pain. Others suffered from a loss of mental stability, where the ubiquity of the pain produced constant uneasiness and feelings of being overwhelmed. Others dealt with loss of intimacy with their partners, loss of memory or even loss of hope. The inescapable burden of the pain created numerous different types of losses in these chronic pain participants. According to the patient narratives, many of these losses negatively affected the social lives of these chronic pain sufferers.

FINDING #3- DETERIORATION OF SOCIAL LIFE

As a result of the physical pain itself in addition to the psychological setbacks of this condition, some participants struggled to maintain healthy relationships with friends and/or family. The deterioration of their social lives was manifested in social isolation, selectively withdrawing from friends and/or family, or in feelings of depression or shame.

Isolation

One of my main findings revealed that chronic orofacial pain provoked some participants into isolation as a result of the loss of relationships and a decrease in social engagement. As chronic pain victims are generally "invisible sufferers", it is difficult for them to fit in with others, as the pain can separate them from what was once familiar. Consequently, rather than reaching out for care and support, many withdraw from loved ones and succumb to isolation: "Well I don't go out. I… I rarely go out. I used to before, I was very active, so, it affects about 90%…. Not feeling like doing anything because it's (took heavy breath), it's tiring. Like I'm tired now… I could cry right now (laughed nervously). Sometimes it's emotional." As she pondered on her past life, Sally shared that story with me with tears in her eyes. She continued confiding in me as she described how her social life has suffered since her TMD diagnosis: "Well I used to exercise, I'd go to the gym… uhh… I used to go out for dinner, I used to- I had a very big social life. I don't… I don't do anything." Despite Sally's family being extremely loving and supportive, she had lost some of the "joie de vivre" she once had so much of:

> It isolates you, you become a person that stays home a lot because you're tired and you don't, you know- you don't feel like being in a room with ten people and laughing and

> having wine and enjoying, which is what I loved to do before…. So, yeah, yeah, for sure, for sure it changes, it changes who you are.

Maria emphasized that since the start of her facial pain, she much preferred spending time in solitude. The unpredictable conditions of the outside environment did not appeal to her, as she was much more easy-going in the comfort of her own home. This disdain for the outside world even influenced her willingness to see her mother who was ill: “Sometimes if I have to go see my mother because she’s sick, I don’t want to go… I’m much happier when I’m by myself”. She spent a while explaining to me the effect that her chronic pain had on her social life: “It affects it a lot… Sometimes I really want to be alone… and sometimes uhh... the noise is bothering me, I can’t stay in a noisy place and uh…even when we are gathered with my family…maybe I am staying for two hours and then I am telling them I am leaving.” Before her condition progressed, Maria loved to cook and have social gatherings with friends, but she was no longer able to enjoy these activities: “And sometimes, a friend of mine… they had party and I cooked and there were many things I did…. but now, I really…” Despite living in a small two-bedroom apartment, she felt more secure within the privacy of her household. Sometimes she mentioned that she even made up excuses to avoid having to leave: “But sometimes I tell them I don’t have time, I don’t go, you know… but I really want to be alone, I don’t want to go too much.” Despite her inability to really enjoy social gatherings the way she used to, she seemed content with her social life, and spending time in solitude was often a choice that pleased her.

At the young age of 23, Kenneth felt as if he was forced into isolation because of his condition. He told me that young adults his age should be taking advantage of their youth, spending their free time outside and traveling- two pastimes that his pain did not allow him to enjoy. He shared:

"It's kind of uhm… like I said, it's kind of… it's kind of depressing… It's kind of like sad to think about… like shit… like I got to stay home and like everybody is just doing these things... Because more or less of the time, I just stay home… just trying to not do much…" Not only has the progression of his TMD forced him into physical isolation, but it has also caused him to lose interest in social media, thus severing some ties with former friends: "I'm more isolated… way more isolated… I'm like to myself… Like I remember I used to do- I used to be on Facebook… I don't even do Facebook, Instagram, I don't do that anymore…"

Dean, also a young man in his twenties, shared a similar experience to Kenneth: "I feel like pain has made me be like… I don't want to see anybody, I don't want to talk to anybody, I don't want to do…" Dean mentioned that preceding his painful condition, "[He] was an energetic person. [He] played sports a lot and uhm, [he] went out a lot. [He] didn't stay home like for a long time. But right now like if [he] compared from that, it's so… [He's] so different […] [He]'d laugh more, you know?" Dean used to be very social, however, the constant discomfort was discouraging: "I don't even feel like going out and being with friends anymore because I have this pain... And uh yeah, like I don't even want to… For me, it's not even fun anymore… When you have like sickness, you don't want to go out sometimes, you just want to stay home". The personal narratives shared by my participants clarified that for many of them, their orofacial pain was a force that could not be reckoned with, often forcing them into solitude.

Selectively Withdrawing

Putting oneself first is an important part of sustaining a healthy and happy life when suffering with chronic pain. Some participants did not feel as if they were forced into isolation, but rather consciously chose to withdraw from the world in order to take care of their own well-being above anyone else's. When asked about the effect her pain has had on her social life, Linda took a deep breath and mentioned:

> I really have withdrawn. I noticed that uh… you know, there were people I was in touch with daily because of my work and even uh… frequently, and now… uhm… it's just evolved into being this… But it hasn't been unpleasant because I've discovered, during all the years of business and being on the ball and involved, it's really been a very comforting experience to be on my own, to get in touch with me… with my wants.

She viewed her experience with chronic pain not only in a negative light, but viewed it as an opportunity to get in touch with her own wants and needs- something she had been unable to do for many years:

> As a young adult professional and mother, you can't put yourself first… you never put yourself first because you want to give the best to your family and at your workplace… but now, I put myself first… so I ask myself a very important question: 'Is this what I want? What kind of pleasure am I getting out of this? Is this what I really want to do?' So consequently, there have been some big changes that I've respected because I say be true to yourself.

She has not withdrawn completely, but is rather very selective in who she wishes to see, which has been difficult for some friends to accept. Sally described to me how her relationship with her friends had significantly changed over the course of the last few years: "Well it's basically on the phone you know… it's not face to face … Yeah I'm missing out on things, I miss out on trips… the girls trips and things like that because I'm just not…it's not possible… I'm not going to keep up with them, you know, so yeah… I guess you can say it has... I mean, we're still friends, but you know…". Although her friendships were still intact, she felt differently about them, as she constantly would have to miss out on social gatherings: "Well I'm not included- I'm always invited, but I don't go so I miss out." Another way Sally avoided worsening her pain was by refusing restaurant invitations. When I asked her to elaborate, she mentioned: "It's the whole thing, it's the preparation of it, it's getting there, it's being there, it's being too late, it's you know…" Maria chose to spend more time in the comfort of her own home, as that is where she felt in control: "I go somewhere… I can't sit very well…and it's hard…but when I'm at home, I can lie down every time I want to sleep, every time I want to read…I feel much better." In order to look after himself, Kenneth made the conscious decision to stop partying with his friends- something he very much enjoyed doing. He described the effect his pain had on his social life and mentioned: "Uhm (put head down), that's, that's where it comes in because I feel like I'm limited to doing...like I don't drink because I feel like it bothers the pain…. I don't party as much because I just feel like while I'm partying, I'm going to have this pain on my mind…" Despite taking this stand to better himself and his physical health, Kenneth felt like withdrawing from these activities has led him to live a life of disconnect.

Feelings of Depression

"You know, it just saddens me. It saddens me and perhaps it slashed a bit of hope for years to come because I realize uh… perhaps the worst is yet to come".

During each interview, I made a point of asking each participant what their chronic pain condition meant to them. The most common response related to feelings of sadness and depression. Despite her generally positive outlook on life, Linda acknowledged the irreversible impact her pain has had on her life:

> It's… It's changed my life… It's tainted my life. I'm sorry to say, but it really has. It's… It's an overshadowed uhm… never, never expected at this time in my- I mean, of course there are factors that contribute to our health to decline, especially as we move on, but I guess I was never prepared to have such an outcome because I've always been an upbeat positive person, very optimistic…never sick… never took a sick day. I would say I'm uh… "morose".

I really appreciated Kenneth confiding in me the details of his lived experience as he seemed somewhat reluctant at first. He later expressed: "That's the most I've ever really talked about it to be honest. I've never said this to anybody." He shared how he felt about the condition with feelings of sadness and disbelief: "I'm sometimes depressed because I feel like… like… I'm the only one in the world who has this, you know? Just like… if I could fix it myself, I would fix it… but I'm just sticking to pills and waiting for it to go away…" Dean expressed his feelings in a similar manner as he took a big breath and mumbled: "It's really depressing. I hope this goes away (took another deep breath) … But no matter what… no matter what I do, it doesn't go away… (teared)…" He went through desperate measures to obtain more muscle relaxants, as he was refused the renewal of his prescription due to the pill's addictive tendency. Dean traveled all the way back to his home country, South Korea, to obtain his sole relief. He compared his past life to his life with pain: "I became like… it gets me depressed. It doesn't really change me to another person but like before, when I didn't have this, I was so much happier, so much more energetic, you know… I had so much fun too."

Feelings of Shame

Chronic orofacial pain dictates not only the physical facet of one's life, but also governs the psychosocial aspect. Some participants shared the experience of not wanting to burden anyone with their suffering as this could elicit feelings of shame and embarrassment. Maria mentioned that she preferred her condition to remain invisible to people in the outside world: "I don't tell them… I don't explain everything for them, like now I am talking to you. Because I don't like that people feel sorry or uh…the other word, what is that…" She later realized that the word she was looking for was "pity". She went on to continue stating: "I hate it…when people feel that way about me. Something we can tell…that people around you…I don't want them to feel pity and come help me and do something…no…" As a result, Maria did not want to burden anyone with her suffering: "She (referring to her daughter) really helps me, but…you know…we can't ask the people…I don't like ask the people do this one or do that one or do the other one. Everybody have their problems, you know…" Kenneth revealed that he very much disliked discussing his condition with friends. When asked why he no longer pursued his passion for music, he often replied with a vague response and attempted to change the topic of conversation: "And I'm just like nah… I don't tell them why I just be like nah… I don't do it anymore […] I don't want…I don't like explaining it to people... I don't want to be like I have jaw problems…" Michael was rather ashamed of the after-effects of the pain- intense swelling on the right side of his face. He implied that his embarrassment translated to feelings of insecurity in social situations: “It’s just the- because also accompanying the pain is like swelling on the right side… So that just kind of annoys me…like… aesthetically. I’m always self-conscious about it…”

Discussion

Feelings of embarrassment, shame and stigma are often present in the lives of those who suffer from TMD- and TN-related pain, which can lead to negative influences on one’s mental, social and relational health [61]. Many TMD and TN sufferers in this study expressed experiencing a change in identity due to the nature of the chronic pain, creating a recipe for social isolation, and feelings of depression and shame. Although these experiences are difficult to contextualize as they are lived through individual contexts and meanings, it is no surprise that deterioration of one’s social life is an impending theme in the personal narratives.

A result of loss, whether it be loss of work, friendships or intimacy, social isolation may easily creep into the life of a chronic pain sufferer. The fear of unpredictable pain-attacks, the loss of sleep and feelings of guilt from letting down friends led many of these participants unable to live the lives they once cherished. The vicious cycle of loss and isolation lines up nicely with chronic pain research. Social isolation commonly surfaced in chronic orofacial pain patients, as many have withdrawn from friends, family and coworkers as a direct consequence of the pain or fear of pain [64]. Despite some participants generally having positive outlooks on life, many admit that the pain has tainted their hope for the future due to the irreversible impact of the pain. Isolation was found to be thematic in a phenomenological study on chronic pain conducted in 2010 [128]. The overcoming feeling of pain had reset their interpersonal parameters, which created separation from the world and from family and friends [128].

From our discussions, I gathered that these negative thoughts often led to feelings of depression and sadness not only due to the pain itself, but also due to the indirect implications of the pain, such as social isolation and feelings of shame. Although a number of individuals in this study emphasized the negative aspects of living with chronic orofacial pain, positive emotions were expressed in several participants, as they had come to terms with their condition and succumbed to acceptance of their pain.

FINDING #4- ACCEPTANCE

"… I've accepted that this is going to be… it's here and it's not going to go away… There's no quick fix, there's no magical resolve."

Despite life being an emotional and physical rollercoaster for these participants, some have adopted their chronic conditions as part of their life, learning to make the best out of what they have. Some have chosen to express this acceptance by viewing their condition in a positive light, and others have acquired the drive to help themselves overcome their suffering.

Linda's mentality towards her chronic TN pain was truly admirable. The experience had taught her to be open-minded and rational with herself and her body:

> A day at a time…take it as it comes… we roll with the punches. You know Charles Dickens, the personage of Little Dorrit… well, you know… I think that you have to just open to what's… what awaits and embrace whatever comes… I'm on the downhill… little bit by little bit, so I say seize the moment … and the laughter and the good times… and the pleasantries for what life has to offer.

Since her pain took off, Linda has never been more in tune with her body. It taught her to respect her body's limits and to adjust accordingly: "The pain management... to recognize also ah, maybe this is… I have to slow down a bit… that activity was too stressful… to recognize the signs and to… to adjust." This participant accepted that her life had been simple until her initial diagnosis and understood that she was not a sole sufferer in this world: "But you know… everybody has their load, Jessica, of concern… not many people have the bright sunshine all of the time… well until I turned 57, and this… the tumour hit… man, life was a piece of cake."

Sally spoke in a more helpless manner, which characterized her negative demeanor towards her pain condition. Despite her hopelessness, she still accepted her chronic disorder: “It’s just become part of my life really.” She went on to mention: “Honestly, that’s that… I really don’t have much insight on it, it’s just what it is and you just sort of get used to it…Try to figure out what you know, to do.” Kenneth had also learned to accept and adapt to the symptoms of TMD: “Like even today, I woke up with like a baaaad headache… like right here (pointed to temples), like right now… I have a bad headache. To me, it’s kind of normal...”

Viewing Pain in a Positive Light

Despite the constant suffering that many participants experienced when living with chronic orofacial pain, some chose to view their pain in a positive light. Maria struggled to express herself in English, but when she finally succeeded, her in-depth descriptions of her experience were truly admirable. She used metaphors to portray how the pain changed her life for the better:

> You know, the uhm… stone (pointed to a sculpture figurine) …what is that…for example, this one is a stone … and when you put it like that (was referring to when you sculpt a stone), you make something beautiful… you sand it. Getting the pain sands your soul, the pain of the body sands your soul…. whatever happens to you…it makes you…makes you get better a little bit…. more, more…getting stronger, getting humble…

Maria strongly advocated that her lived experience with both TMD and TN made her into a more refined individual- grateful and appreciative of what she had:

> Hmmm, you know… I believe the pain …the pain… makes you to be more healed. I don’t know how to say… not just the body pain, the pain of the soul, the pain of the body…I think the pain makes you to be …let me find the word […] When you don’t

> have any pain you know, you don't understand many people around you…many things even… and you are not grateful for what you have.

She believed the pain experience was enriching and allowed her to thrive as an individual: "And anything I got as experience, I got it when I have pain…the pain of my soul, the pain of my body…the pain…sometimes I still thank god that if I didn't have it, I never could change anything." We also discussed Maria's personality and how it might have changed since her pain first began. She admitted to becoming a more tolerant and open-minded person as a result of the constant pain she experienced: "The only thing I can tell you… now I feel my open is getting a little bit wider…you know, before maybe I didn't pay attention to many things, but now, I pay attention…to be careful what I say, what I… you know." She used the metaphor of a sculpture to describe what her soul experienced after the onset of TMD:

> Because the person…you never can change yourself…or you never could change the other person…nobody ever change…but when you can change, you have…you know…something like that…scrape your soul… yes, it's getting like that...it's getting bright and bright and bright and bright and bright.

She clarified that she really did enjoy her pain, both the pain of her soul and the pain of her body. About mid-way through our interview, Maria shuffled through her bag to find a book, which I later realized was a journal she used to help her learn and remember English phrases and words she appreciated. She explained that she had written down an expression she very much valued, as it helped her verbalize how she felt about her chronic pain condition: "Success makes you glow, and the sour makes you human." She described the pain as being the sour part of her life- the part that made her most human, the part she was most grateful for.

Drive to Help Oneself

“I think there’s got to be a window of effort… there’s an expression in French: ‘Aide-toi, le ciel t’aidera’”.

The above quotation translates to a proverb from the bible: “Help yourself, and Heaven will help you”. Linda tried to follow this mentality throughout her life with chronic pain: “You can’t just sit back and expect things to happen for you… You have to have some input and drive and make the effort, but it’s not always easy…” Linda’s resilience was truly commendable. Despite the intensity of her chronic pain, she persevered and made consistent efforts to improve her state.

As previously mentioned, Maria was very adamant about her chronic pain condition remaining invisible to those around her, as she had no interest in others having pity for her. She demonstrated signs of independence and strength: “If I don’t help myself, who come to help me, you know? [...] I don’t want to just take the pill and stay in bed because that pill is very strong, you know… It makes me more asleep…but really…I don’t like it. I keep myself busy…when I wake up, I try to do many things.” The general consensus among participants was that keeping busy helped alleviate the suffering process. Linda mentioned: “You got to keep busy, because when you’re preoccupied, thinking of other things, you won’t even have time to think about that.” Maria also noted that keeping herself busy distracted her from the pain: “But now, I really… especially sometimes I start to do… to be busy, to get myself busy because of not thinking… When you are busy, you are not in pain…” She continued to mention:

> Keeping busy distracts from everything because the thing is… you don’t always think like the good things you know…Sometimes you think and for problems, the things like

> that… I try to keep myself busy. Now I read the book sometimes, I watch movies, TV, something like that to keep myself- But sometimes it's hard you know…

Previously trained as a pastry chef, she even expressed that she would love to find a pastry shop willing to provide her with voluntary work, just to keep herself busy: "I told them…even if they give me one day, just to not be at home […] I want to go and ask them if…just free…don't give me the salary… because I love to do the pastry, I really love to…" During our conversations, most participants revealed that keeping themselves distracted and active eased them to carry on with their daily life.

Discussion

Despite the negativity that their pain experience has brought to their lives, some participants in this study have learned how to accept their condition, viewing their pain in a positive light. Doing so has ultimately led many of them to help themselves ease the suffering. Despite the suffering still experienced by many of these participants, accepting their condition was a positive step towards relief. Findings from previous studies conducted on those living with orofacial pain suggest that pain-related acceptance is associated with reports of lower pain intensity, less pain-related anxiety and avoidance, less depression, less physical and psychosocial disability, more daily uptime, and better work status [21,129]. Therefore, Linda and Maria's positive outlooks may positively contribute to their emotional and physical health. Channeling their energy into managing the pain and learning how to regain a sense of purpose- two key aspects that stem from acceptance- are steps chronic pain patients should aim to take in order to be relieved of the burdens associated with this condition. It is important to note that, as one participant stated: "There's no quick fix, there's no magical resolve." The key to living with chronic orofacial pain, or any type of chronic pain for that matter, is learning how to manage the pain. Not everyone can acquire coping mechanisms and ways of managing pain on their own, which is why treatment options for patients with chronic pain should be readily accessible to help patients adjust to their new life situation by addressing loss as a specific experience and by leading them to the next steps towards recovery.

SUMMARY & CONCLUDING COMMENTS

The goal of this phenomenological exploration was to study the full breadth of human inquiry in a human manner in order to learn about the patients' lived experiences of what it is like to live with chronic orofacial pain and the social implications of living with such a condition. A qualitative exploration of the social implications of individuals living with chronic orofacial pain is a very relevant and important research topic as qualitative research investigating this common painful experience is lacking. Utilizing Heidegger's philosophy of interpretive phenomenology in addition to van Manen's approach allowed for a more in-depth analysis of this phenomenon that cannot be adequately explained solely by quantitative measures. Heidegger's doctrine as well as the discussions I had with participants served as the key to this study. My background in the field of psychology allowed me to empathize and appreciate the differences in each individual. Moreover, my past experience enabled me to acknowledge the disparities and different coping methods among individuals with chronic pain.

I specifically engaged in an interpretive phenomenological research approach as it promoted a detailed understanding and report of a certain phenomenon with as much expression as possible. Using this philosophy to interpret the dialogues provided a method of analysis in which the patients' perceptions of his or her own experience with chronic orofacial pain could be understood while offering deep insight into the topic [1]. Interpretive phenomenology had the capacity to paint a vibrant image of what it means to live with TMD and TN while promoting descriptions of experiences in a natural setting and in the context of the suffering individual [94]. An in-depth investigation into the participants' experiences of living with either chronic TMD- or TN-related pain deepened my understanding on the matter, allowing me to uncover undisclosed connotations or meanings within the narratives. Contrary to what Husserl's descriptive phenomenology promoted during his time, the work of Heidegger emphasizes the interpretive process, which urged me to engage with my participants where pre-existing beliefs and opinions were not bracketed.

It has been mentioned in the literature review that there is a lack of qualitative research in the sphere of chronic orofacial pain. Despite the excess of quantitative studies, the inductive nature of qualitative research allows the researcher to work bottom up rather than to strictly follow a specific theory to answer the research question. As one of the main goals of this study was to understand why and how a forced change in diet can lead to a change in personal identity and its influence on creating the right circumstances for increased social isolation, employing this methodology gave me the opportunity to gather findings that are richly descriptive through the use of in-depth interviews.

In the data analysis, four essential findings emerged: 1) Forced change in diet; 2) Loss; 3) Deterioration of social life; and 4) Acceptance.

Between forced change in diet, loss, deterioration of social life, and acceptance, the key element that stemmed from each of these themes seemed to be the experience of suffering. The works I have read by both Madison and Gadamer have taught me the many ways one could either learn to cope with chronic pain or how one could continue to live in a miserable and painful state. This is when suffering comes into play, which is not only relevant to those who live with chronic pain, but also to anyone who has ever suffered any loss. Suffering, from my understanding, is what keeps us humble; It teaches us when we must change ourselves by revising all our exaggerated expectations and desires for a “paradis perdu”. Svenaeus developed a phenomenology of suffering with an emphasis on matters relevant to medical practice and bioethics. He explained that suffering can involve many different things—bodily pains, inability to carry out everyday actions, and failure to realize core life values [130]. These repercussions of suffering have been experienced by many of my participants, as disclosed in the patient narratives above. Madison explained that pain is a neurological phenomenon, whereas a great deal of suffering is of spiritual or existential nature, “psychic pain” as he called it [131]. The works of Eric Cassell and Elaine Scarry also convey the potential estranging mood that may overcome the suffering individual as he or she struggles in the face of loss of meaning and purpose in life [130]. Suffering is essentially a feeling in itself, it has implications for a person’s entire existence: how one behaves in the world, connects with others, and understands goals and priorities in life [1, 130]. As suffering is such a unique experience, it is difficult to implement one specific methodology to studying this subject. As quantifying this subjective experience has been challenging, our job as researchers, writers and teachers is to bring the meaning of suffering into discourse and understanding through qualitative research [116]. Following a phenomenological approach to understand the lived experience of chronic orofacial pain has prevented personal narratives from becoming an alienating experience but rather an “invitation for humanizing conversations about suffering, where their unique qualities and characteristics are brought back interpretively into the world” [132]. The methodology used in this study provided me with an interpretive, humanizing and sensitive approach to gaining a deeper understanding of those who are suffering. My sense of vulnerability from my own personal experience with loss and suffering created a closeness with my participants, which ultimately welcomed a genuine exchange and allowed me to become a more experience qualitative researcher. In their exploration of the relational aspects of patient and doctor communication, Hovey and Massfeller (2012) described that becoming more experienced allows the researcher to minimize the distance between themselves and their own suffering to better recognize and appreciate suffering in the other individual [133]. In practicing these principles, I was able to suffer with my participants while embracing a "compassionate relational connection" [133]. When individuals are deprived of the opportunity to discuss their pain with those around them, their suffering is most pronounced [1, 134]. Conducting interviews with chronic pain sufferers and creating meaningful discourse may therefore contribute to mitigating patient suffering.

The first main finding in this interpretive phenomenology exploration was the forced change in diet that most of my participants experienced. Individuals living with chronic TN or TMD often have marked functional impairment and mobility in their jaw and surrounding masticatory muscles [60-62]. Therefore, it is not shocking to learn that many chronic orofacial pain patients do not have the luxury of appreciating and enjoying food in the same way many of us to, as chewing specific foods can be interpreted as an uncomfortable and painful act. One of the main research goals of this study was to understand if, why and how a forced change in diet can lead to a change in personal identity and its influence on creating the right circumstances for increased social isolation. Through in-depth analysis of the personal narratives, I concluded that every participant I interviewed with either chronic TN or TMD experienced a forced change in diet to some extent. Some, like Linda, opted to drinking smoothies as their main source of nutrients, and others, like Kenneth, only sacrificed some of their favorite foods like candy and popcorn. In the next few paragraphs, I will discuss the potential reasons of how and why I believe such a forced change in diet can lead to social isolation.

The second finding in this study was the experience of loss. Chronic orofacial pain affected many aspects of the participants' lives, resulting in numerous types of loss, such as the loss of employment, sleep, mental stability, memory, intimacy, and hope. The third finding, deterioration of social life, revealed that chronic orofacial pain provoked some participants into isolation, selectively withdrawing from friends and family, and fostered feelings of depression and shame. The last finding, acceptance, suggested that in spite of the hardships that accompany living with chronic pain, some have adopted their conditions as part of their life, viewing their pain in a positive light and having the drive to help themselves on the path to a happier and more fulfilled life. The literature review supports that these findings are not exclusive to the seven participants whom I interviewed in this study, but also apply to the larger chronic pain population, shown in previous qualitative orofacial pain research.

Participants in this present study placed great emphasis on the loss they experienced in their lives. In some cases, these losses were catalysts for social isolation, like in the case of Kenneth who felt like his social network collapsed when he was forced to quit his passion for music. Other participants like Sally, Dean and Maria were unable to pursue activities they once loved, which negatively influenced their social lives. For some, the overwhelming nature of the chronic orofacial pain has caused it to constantly take over their thoughts. Maria, for instance, admitted to at times, being halfway through cooking dinner and suddenly feeling like throwing everything away. Surely, the physical pain itself had direct negative repercussions on the lives of many. For instance, Linda, who has been happily married for over thirty years, struggled to be intimate with her husband due to the unbearable nature of the pain.

The importance of addressing loss in all rehabilitation programs has been emphasized in research in order to establish warm and considerate treatment for chronic pain patients [135]. The loss one experiences from living with chronic pain has been compared to loss similar to the grief caused by death, therefore, treatment plans specifically designed for chronic pain sufferers should work towards learning to deal with loss and viewing loss as part of the experience [136]. Those who live with this condition may feel as if they are a burden and no longer have anything positive to contribute to their family, friends or society as a whole. Under such circumstances, the importance of working towards regaining a sense of purpose in life can contribute towards the healing process. Although full recovery may never be possible in such individuals, working towards the process of becoming whole again as a person, of getting one's life back on track can be the stepping stone towards living a happy and fulfilled life.

> Because medicine is a dedicated attempt to *resist* our vulnerability to illness and disability, it can also lead us to *ignore* the fact that, in order to live a properly human life we must not reject but must learn to accept and live with our innate frailty—and the suffering that necessarily goes along with it [131].

Madison feels strongly about embracing one's suffering rather than attempting to remove it completely. One way of overcoming and accepting one's suffering is to reinstate one's quality of life and regain purpose. This can be practiced through Madison's "moral freedom" which preaches the freedom to make a new beginning and start over after things have gone wrong.

The third finding of this work confirms that the social lives of many participants suffered as a result of their pain. I have learned from my conversations with each participant that those suffering with severe chronic orofacial pain were often forced into isolation, which must be distinguished from experiencing solitude by choice. Under such circumstances, I have discussed on numerous occasions the importance of working towards regaining a sense of purpose in life, which can contribute towards the healing process.

Through discussion with my participants, I have learned that full recovery and living pain-free lives may never be possible in such individuals with chronic TN and TMD. However, like Montaigne reiterates: “Our bodies are like magnets for attracting pain, but while pain is inevitable, suffering is optional” [131]. Unnecessary suffering occurs when we elaborate on our pain and physical discomforts and allow ourselves get tangled up in avoidance responses to escape from them. Christina and Michael were the only two participants whom I interviewed who seemed to carry on ordinarily with their social lives. Although these two interviews were the shortest in duration, I gathered that both Christina and Michael had strong, yet easy-going personalities. It cannot be assumed that their lack of social deterioration can be attributed to their even-tempered personality as these two individuals also experienced less severe TMD-related pain than the other five participants, which could help explain the overall positive social lives they each possessed. Sally, Dean and Kenneth seemed to be most strongly affected by their pain and each suffered from constant isolation and feelings of depression and hopelessness. Despite the intensity of their pain being described similarly to that of Maria and Linda, their experience with social isolation and their pain’s influence on their socializing differed tremendously. The fourth main finding in this study, acceptance, may be responsible for this disparity, where one’s lack of acceptance towards their chronic condition may be the indirect variable that created the right circumstances for social isolation.

Both Linda and Maria portrayed strong feelings of acceptance towards their chronic pain condition. Not only did they view their pain in a positive light, but they also held strong views towards the importance of helping themselves ease their suffering, as supported in their personal narratives. These two women accepted that their condition was part of them and recognized that there was no escape- but there mustn't be one. They perfectly exemplified what Hovey and Amir (2013) attempted to convey in their work on the hermeneutics of suffering: "We belong to our suffering; it humanizes all worldly activities through a common 'rough-ground' from which we can become more compassionate, generous and open to the experiences of others" [132]. Maria admitted that the pain made her into a more refined individual and helped her cope with her suffering. She used a metaphorical comparison to describe a person with pain as a stone that is sanded into a beautiful sculpture. Although suffering is not pleasant, there is a positive aspect about it- it frees us from the illusion that life is a fairy tale with a blissful ending. Linda's pain taught her to respect her body's limits and to adjust accordingly. She accepted that her life changed and took an optimistic stance of understanding that she was not a sole sufferer in this world. Consequently, both Linda and Maria have made changes to their social lives, however, they did not suffer from social isolation per say in the same way as Kenneth, Sally and Dean. The two women rather selectively withdrew from activities and found alternatives to enjoy their lives, such as spending time with her Grandson, in Linda's case.

This main research question in this study aimed to understand why and how a forced change in diet can lead to a change in personal identity and its influence on creating the right circumstances for increased social isolation. After analyzing the personal narratives, I can conclude that a forced change in diet in one chronic orofacial pain sufferer may have contributed to changes in her personal identity. Food involves much more than the food itself- it includes the aroma of cooking, the "pass-me"s, the sound of the knife and fork hitting the plate, and the way it simply brings people together. However, with the inability to eat the foods one once enjoyed comes inevitable emotional repercussions. Linda could no longer enjoy meats or tough vegetables and as a result, usually succumbed to blending herself a quick smoothie for meals. Consequently, she admitted to no longer hosting big gatherings with friends, like she often used to. Since her TN pain first started, she has also spent less time with her husband around the dinner table- time they used to enjoy and cherish together. Although Linda disclosed having a great relationship with her family and friends, her forced change in diet contributed to her change in identity. Her priorities altered to a more ego-centric way of living her day-to-day, focusing on how to improve her health and happiness.

Part of my research study also aimed to focus on the influence a forced change in diet may have in creating the right circumstances for increased social isolation. I have yet to find evidence for this relationship, however, I cannot confirm that it does not exist. Despite the intensity of Dean, Kenneth and Sally's pain being described similarly to that of Maria and Linda's, the social isolation they experienced and their pain's influence on their socializing differed tremendously.

The last main finding in this study, acceptance, may contribute to our understanding of chronic pain's influence on creating the right circumstances for increased social isolation. As previously explained, Linda experienced the most drastic change in diet due to her condition but yet, still lived a socially-active and healthy life in comparison to Dean, Kenneth and Sally, who suffered from severe social isolation and spent most of their days alone. Maria also exhibited acceptance for her condition and even viewed it in a positive light. Although she tended to spend more of her time alone, she explicitly mentioned that it was her preference to do so and she was happy living in this fashion. She experienced solitude rather than forced isolation- two very distinct concepts. Other participants I interviewed who have yet to accept the reality of their situation suffered more drastically and have been guided towards a path of social isolation. This research conclusion lines up with Gadamer's views on how one may live happily despite their situation:

> If an individual decides on the other hand to live a life full of resentment, they are likely to be locked in an aggressive-defensive mode of behaviour where they fail to take responsibility for their own selves and only react to their own misery. In order to overcome this resentment, it is important to live affirmatively, despite of all the pain, regrets and suffering [3].

Maria's description of her suffering and the analogy she used to explain it is supported by Hovey and Amir's (2013) portrayal of suffering: "Sometimes suffering can be a gift because it forces us to consider otherwise and to transform our perspectives about people, other things, topics and ourselves" [132]. Both Linda and Maria have decided to live their lives according to Svaneus's mentality, where suffering may be transformed or alleviated by one's decision to alter one's core values in such a way that illustrates one's life in a new, more rewarding manner given the new circumstances [130]. It was through Linda and Maria's ability to understand their experience and power through their suffering that allowed them to re-evaluate their expectations and appreciate the new possibilities available to them given their condition.

A holistic approach to treating chronic pain patients must begin with authentic discourse. In this respect, before actively seeking an appropriate treatment plan for managing the pain, health care professionals can contribute to the healing of these individuals through non-judgmental communication with their patients. The findings in this study suggest that a forced change in diet is a common consequence of orofacial pain and may contribute to one's change in personal identity. Health care practitioners can take a step in the right direction by conversing with their patients and learning from them in attempt to avoid patients sliding down this dangerous slope.

Perhaps this change in personal identity can be avoided by introducing specific cooking classes geared towards individuals with chronic orofacial pain. In situations where they may be the food-maker at home, these cooking classes may enable them to regain a sense of purpose in their lives. Perhaps a course like this would also teach chronic pain sufferers about new foods they have yet to try, or would inform them how to properly order meals they can eat and enjoy in restaurants, permitting their social life with friends to remain active.

Moreover, this work has determined that the patients' inability to accept their condition may play a role in creating the right circumstances for increased social isolation. Therefore, it is imperative for health professionals to ensure effective communication with patients, validating their accounts by means of attentive listening. By guiding such dialogues, the sufferers will have their pain validated- a positive first step towards acceptance and ultimately improving their quality of life. A number of psychological tactics such as acknowledging the reality of pain, attending to patient experiences, and addressing suffering may help in the patients healing process [1]. Health care practitioners can help their patients reinvent themselves in order to surmount their personal crisis. In this day and age, people are seeking a fast cure without taking the time to cultivate the self-discipline that comes from exercising the body and mind as this requires changing yourself- but what if this search for a quick fix is the natural path that health care promotes? For this reason, it is important for health care to shift from reactive to proactive and predictive care.

Chronic pain is an assault on the integrity of the entire human being- on their body, mind, heart, and spirit. It is a multi-faceted phenomenon and thus requires multidisciplinary cooperation in research. Fortunately, there is an abundance of quantitative research dedicated to this field, however, qualitative studies are still lacking. Future qualitative studies related to this subject matter can positively contribute to gaining a more elaborate appreciation for the experience of living with chronic orofacial pain. Some potential studies may include:

- What is it like to live with a chronic orofacial pain sufferer?
- A health care professional's view on treating chronic orofacial pain patients
- The physical changes a forced change in diet can have on a chronic orofacial pain sufferer

In attempting to understand the unique meaning of chronic orofacial pain through in-depth interviews, this research study validates the novel insight interpretive phenomenology offers into the world of chronic pain. Because pain is such a complex domain, understanding the lived experience of chronic pain must be explored by encompassing all factors involved, including physical and psychological aspects of pain. Gaining holistic knowledge on the topic can be done through more phenomenological studies.

APPENDICES

Appendix A: Informed Consent Form

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Consent form for chronic pain research participants

The Experience of living with chronic orofacial pain and patients' experiences of its treatment, future outcomes and social implications

Research Project Leaders:

(McGill Study **No. A06-B31-13A**)

Dr. Richard Hovey, PhD.

Faculty of Dentistry

Division of Oral Health & Society

2001 McGill College Avenue, suite 537

Montreal, QC, Canada H3A1G1

Jessica Italia B.Sc.

Faculty of Dentistry

Division of Oral Health &

Society. 2001 McGill College Avenue, suite 537.

Montreal, QC, Canada H3A1G1

Introduction:

You are invited to participate in a study about understanding the social implications of living with chronic temporomandibular disorder (TMD) or Trigeminal Neuralgia (TN). Since food is so pervasive in our lives, we want to understand why and how a forced change in diet can lead to a change in personal identity. The purpose of this study is to gain insight and understanding about the experiences confronted by people living with orofacial pain.

In order to accomplish this, we plan to conduct 5-10 interviews from participants, who have been suffering from chronic orofacial 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 Ms. Jessica Italia at 514-918-1098.

Sincerely,

Richard Hovey, PhD

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
- Agree to participate in this study.

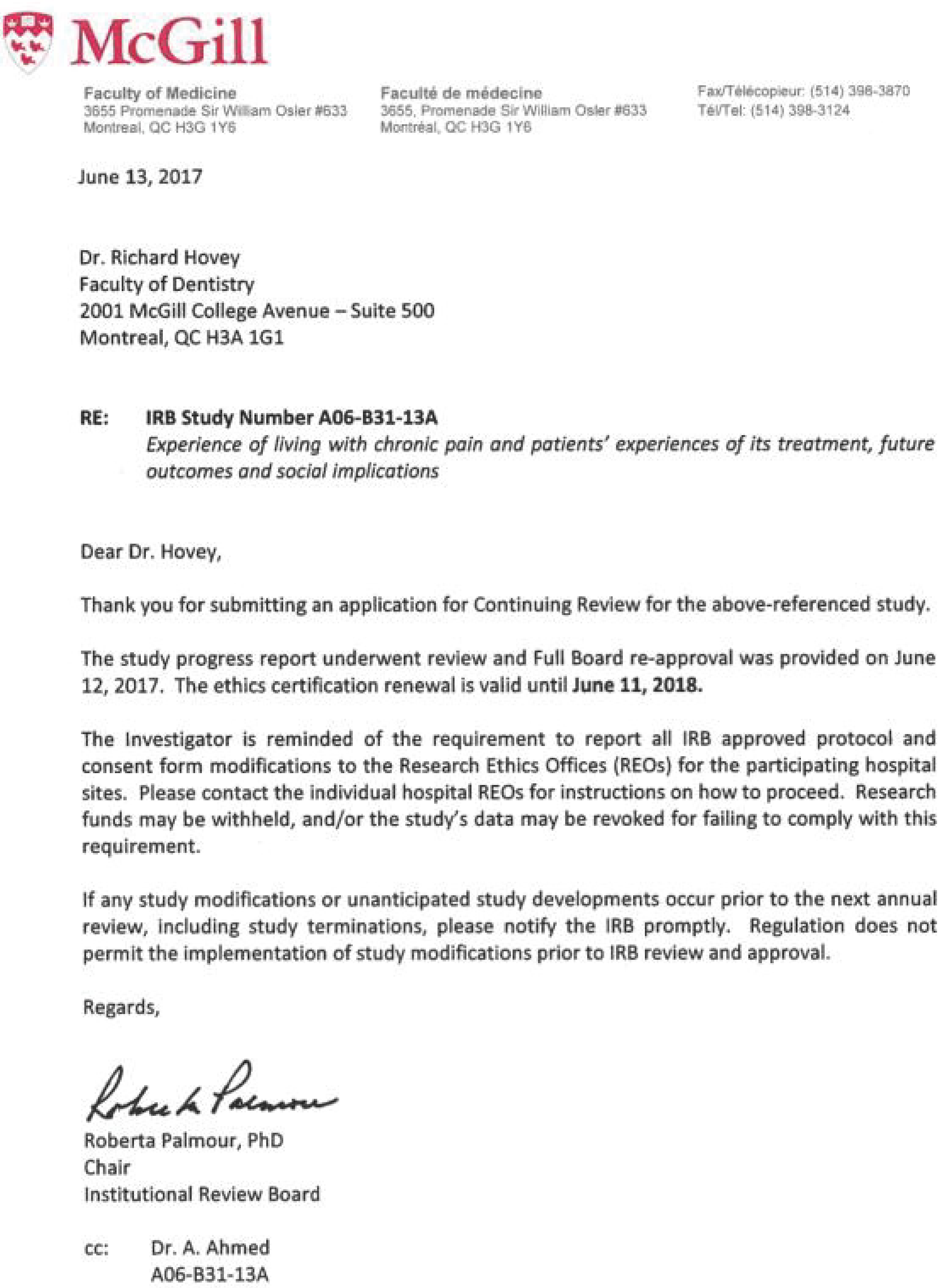
Participant's Signature: ______________ Person Obtaining Consent: _________________
Print Name: _______________________ Print Name: _____________________________
Date: ____________________________

Appendix B: Sample Interview Guide

Interview Question Guide

1. Can you describe the kind of pain you have? (severity, what does it feel like?)
2. Where do you feel the pain the most?
3. Would you mind telling me about when the pain started and what may have caused it?
4. What does living with this condition mean to you?
5. How has living with this pain forced you to change your diet and what you eat?
6. What foods do you usually like to eat?
7. How does having to completely alter your diet make you feel?
8. How has living with facial pain influenced your socializing or your social life?
9. Has this affected other aspects of your life? Relationships with family? Friends?
10. Has being unable to eat the foods you regular used to eat caused you to isolate yourself from actives you used to like to do?
11. Apart from all the treatments you have received, what helps you to cope with or manage your pain?
12. What makes the pain better or worse?
13. Do you feel like your experiences with chronic pain have changed you as a person?
14. How do you see your future? (Is it something that is constantly on your mind? Do you feel like you can’t escape it?)
15. Is there anything else you would like to talk about or that you’d like to share about your pain?

Appendix C: Ethics Approval



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June 13, 2017

Dr. Richard Hovey
Faculty of Dentistry
2001 McGill College Avenue – Suite 500
Montreal, QC H3A 1G1

RE: **IRB Study Number A06-B31-13A**
Experience of living with chronic pain and patients' experiences of its treatment, future outcomes and social implications

Dear Dr. Hovey,

Thank you for submitting an application for Continuing Review for the above-referenced study.

The study progress report underwent review and Full Board re-approval was provided on June 12, 2017. The ethics certification renewal is valid until **June 11, 2018.**

The Investigator is reminded of the requirement to report all IRB approved protocol and consent form modifications to the Research Ethics Offices (REOs) for the participating hospital sites. Please contact the individual hospital REOs for instructions on how to proceed. Research funds may be withheld, and/or the study's data may be revoked for failing to comply with this requirement.

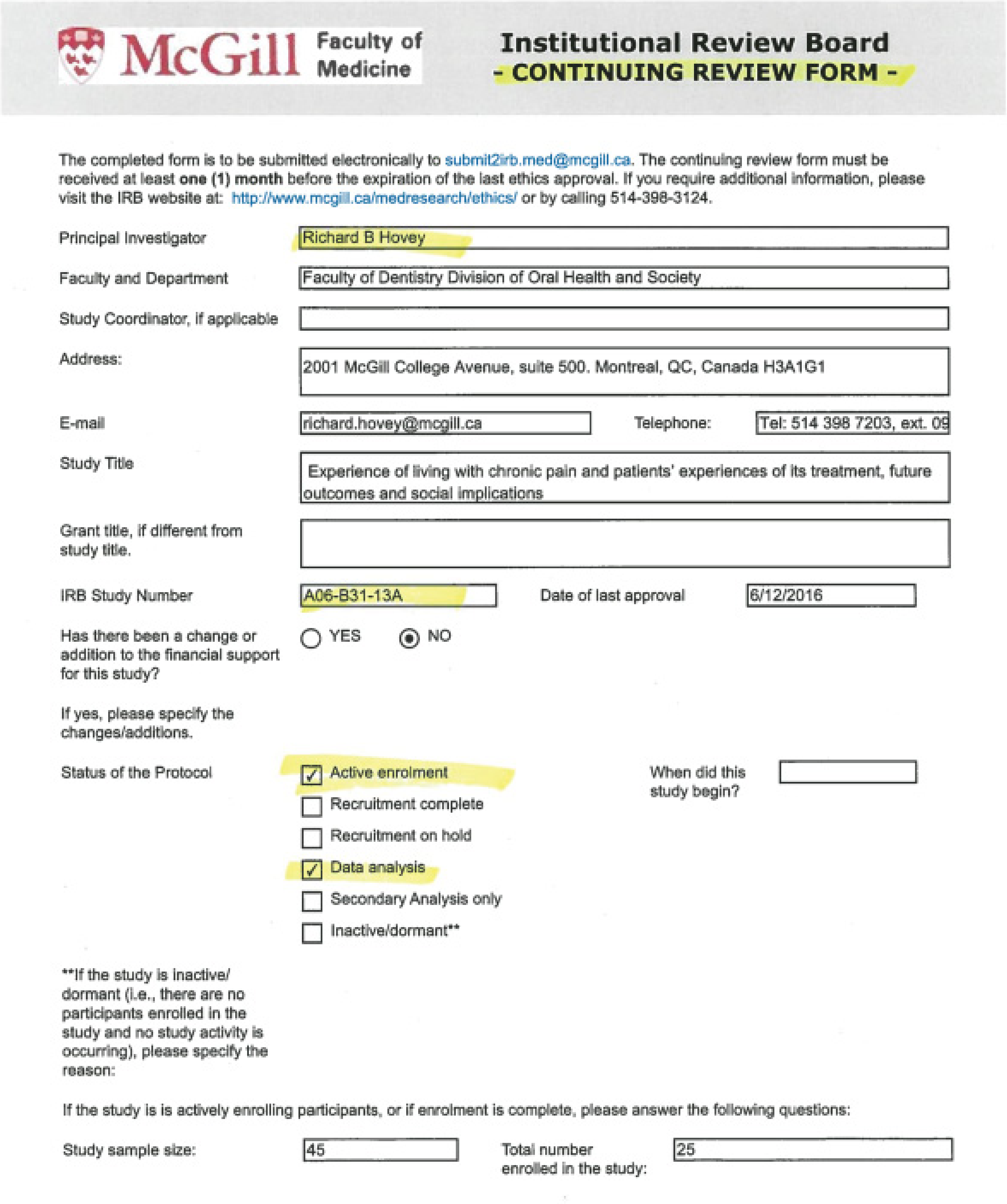
If any study modifications or unanticipated study developments occur prior to the next annual review, including study terminations, please notify the IRB promptly. Regulation does not permit the implementation of study modifications prior to IRB review and approval.

Regards,

Roberta Palmour

Roberta Palmour, PhD
Chair
Institutional Review Board

cc: Dr. A. Ahmed
A06-B31-13A



McGill Faculty of Medicine

Institutional Review Board
- CONTINUING REVIEW FORM -

The completed form is to be submitted electronically to submit2irb.med@mcgill.ca. The continuing review form must be received at least **one (1) month** before the expiration of the last ethics approval. If you require additional information, please visit the IRB website at: http://www.mcgill.ca/medresearch/ethics/ or by calling 514-398-3124.

Principal Investigator: Richard B Hovey

Faculty and Department: Faculty of Dentistry Division of Oral Health and Society

Study Coordinator, if applicable:

Address: 2001 McGill College Avenue, suite 500. Montreal, QC, Canada H3A1G1

E-mail: richard.hovey@mcgill.ca

Telephone: Tel: 514 398 7203, ext. 09

Study Title: Experience of living with chronic pain and patients' experiences of its treatment, future outcomes and social implications

Grant title, if different from study title.:

IRB Study Number: A06-B31-13A

Date of last approval: 6/12/2016

Has there been a change or addition to the financial support for this study? ○ YES ● NO

If yes, please specify the changes/additions.

Status of the Protocol:
- ☑ Active enrolment
- ☐ Recruitment complete
- ☐ Recruitment on hold
- ☑ Data analysis
- ☐ Secondary Analysis only
- ☐ Inactive/dormant**

When did this study begin?:

**If the study is inactive/dormant (i.e., there are no participants enrolled in the study and no study activity is occurring), please specify the reason:

If the study is is actively enrolling participants, or if enrolment is complete, please answer the following questions:

Study sample size: 45

Total number enrolled in the study: 25

Number of participants that have completed this study: 25

Total number of participants withdrawn: 0

Projected date of completion of study enrolment: October 2017

Projected date of study completion: June 2018

Please provide a brief description of what has occurred since the IRB's last ethics approval.
We have been actively recruiting participants and are close to completing this phase of the project.

Has the study revealed any new findings or knowledge relevant to the potential benefits and/or study risks that may influence participants' willingness to continue in the study?
○ YES
● NO
○ N/A

Has this new information been communicated to participants?
○ YES
○ NO
○ N/A

If applicable, please describe the findings.

Has an amendment(s) to the protocol been submitted to the IRB in the past year?
○ YES
● NO

What is the version date of the most recent IRB- approved protocol? 6/12/2016

Has the consent form(s) been revised in the past year?
○ YES
● NO
○ N/A

Have consent form modifications been reported to the IRB?
○ YES ○ NO
● N/A

Version date/s of the most recently approved consent form(s): 6/12/2016

Have any adverse events occurred since the last approval?
○ YES
● NO
○ N/A

If yes, how many at McGill sites?

How many at all sites?

Have the adverse events been reported to the IRB? If no, submit all adverse events with this form.
○ YES ○ NO ○ N/A

Have there been any publications?
○ YES
● NO

If yes, append list:

DATE OF I.R.B.
APPROVAL
JUN 12 2017
Faculty of Medicine
McGill University

SIGNATURES

Principal Investigator: Richard Hovey
Date: 4 11 2017

IRB Chair: Roberta Palmour
Date: June 12, 2017

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