What Does It Mean to Live with Orofacial Pain?

- An Interpretive Phenomenological Exploration

by

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DEDICATION

To my mother and sister and to the millions of chronic pain sufferers, who don’t live with pain, but live in spite of it.

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ABSTRACT

An interpretive phenomenological research approach was chosen to explore the meaning of living with chronic orofacial pain. Individual interviews were conducted with 6 participants experiencing chronic pain and undergoing treatment at a pain clinic. The interviews were transcribed verbatim and interpreted phenomenologically. Interpretive phenomenology is a qualitative research approach that attempts to investigate people's experiences to reveal what lies 'hidden' in them. This approach was used because of the empirical nature of the present topic.

Three essential findings were identified: 1) Suffering from loss, 2) Disbelief, and 3) Dissatisfaction with health care. The first finding highlights the effect of chronic pain on the lives of participants. This includes loss of relationships, employment, the ability to enjoy eating, engaging in social activities, and culminating in a loss of self-identity and isolation. The second finding highlights disbelief among the families and the medical community of pain participants in this study. This is possibly due to the invisibility of their chronic pain in their surroundings. The last finding suggests participants felt dissatisfaction with their journey through the health care system.

Previous studies have focused on chronic pain mainly through quantitative methods based on measurements, such as questionnaires. The biomedical aspects of pain are important, but the emphasis on this can result in lack of attention to the experiences of living with chronic pain. In qualitative studies, patients are considered on a patient level, not on a group level, and allowed to discuss their personal experiences with pain. Thus, qualitative methodologies are important in order to achieve a more profound understanding of the unique, individual patient. It is hoped that the findings of this study will benefit other sufferers learning to live with chronic pain and also guide healthcare providers to approach these patients with more compassion and empathy.

RÉSUMÉ

Une approche de recherche phénoménologique interprétative a été choisie pour explorer le sens de vivre avec la douleur orofaciale chronique. Des entrevues individuelles ont été menées avec 6 participants souffrant de douleur chronique et ayant suivi un traitement dans une clinique de la douleur. Les entretiens ont été transcrits textuellement et interprétés de manière phénoménologique. La phénoménologie interprétative est une approche de recherche qualitative qui tente d'enquêter sur les expériences des gens pour révéler ce qui est «caché» en eux. Cette approche a été utilisée en raison de la nature empirique du présent sujet.

Trois constatations essentielles ont été identifiées: 1) souffrir de perte, 2) incrédulité et 3) insatisfaction à l'égard des soins de santé. Le premier constat met en évidence l'effet de la douleur chronique sur la vie des participants. Cela comprend la perte de relations, l'emploi, la capacité de manger, de s'engager dans des activités sociales et de culminer dans une perte d'identité et d'isolement. Le deuxième constat met en évidence l'incrédulité parmi les familles et la communauté médicale de la douleur participants à cette étude. Cela est probablement dû à l'invisibilité de leur douleur chronique dans leur environnement. Le dernier constat suggère que les participants se sentent mécontents de leur voyage dans le système de santé.

Des études antérieures ont porté sur la douleur chronique principalement par des méthodes quantitatives basées sur des mesures, comme des questionnaires. Les aspects biomédicaux de la douleur sont importants, mais l'accent mis sur cela peut entraîner un manque d'attention aux expériences de vivre avec la douleur chronique. Dans les études qualitatives, les patients sont considérés au niveau du patient, et non au niveau du groupe, et sont autorisés à discuter de leurs expériences personnelles avec la douleur. Ainsi, les méthodologies qualitatives sont importantes afin de parvenir à une compréhension plus profonde du patient unique et individuel. Il est à espérer que les résultats de cette étude seront bénéfiques pour les autres personnes souffrant de souffrir de douleur chronique et guider les fournisseurs de soins de santé à aborder ces patients avec plus de compassion et d'empathie.

PREFACE & CONTRIBUTION OF AUTHORS

The candidate, Mahta Hosseinkhani Hazaveh, 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 October 2016, 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

"If you would give me two pills…one that would get me to die and the other keep on living while having the pain… I think I would take the one…at my age… take the one that would end this off. Just because I'm afraid that the pain would come back again."

This quote comes from one of my research participants who like millions worldwide, has experienced an episode of severe pain that has developed into a chronic condition adversity affecting his quality of life. He uses the metaphor of two "pills" to describe his decision between life and death. Although he is free from pain for the moment, he lives with the fear of the pain returning. If he had to choose between a life with pain or death, he would select the latter.

As for myself, I have seen two close family members suffer from various types of chronic pain. In addition, in my role as a general dentist, I have had numerous interactions with chronic orofacial pain patients. This experience has encouraged me to conduct an exploratory research investigation on the topic of chronic pain. I have observed the sorrow one feels about the limited circumstances dictated by pain and inefficient treatment options available, along with the poor response from the medical community. This has left me sad but motivated to investigate this phenomenon from the perspective of pain sufferers.

During my research investigation, I will explore the experience of living with chronic orofacial pain. This work will take an in-depth qualitative approach to report on this profound human experience and its many devastating effects. The focus of this interpretive study is to obtain a deep understanding and so give a voice to the participants' experiences of living with chronic pain.

Chronic pain creates a wide range of long-term and sometimes persistent somatic and psychosocial problems. Due to the nature of chronic pain, as a potentially lifelong condition, one must learn how to manage it more efficiently. Listening to the narratives of these patients is a fundamental step in approaching the pain management process. Even if pain is considered a pathological condition, it is also an experience to live through each day. While the medical voice is essential, this research addresses the often neglected voices of the chronic pain patients attending pain clinics. It is vital to investigate new ways to understand and to engage patients in their own pain management.

Research Objectives

The purpose of this phenomenological study is to explore the experiences of living with chronic orofacial pain, and to gain a deeper understanding of the common elements that affect the life of chronic pain sufferers.

This study may benefit those living with chronic pain, because sharing similar experiences may help sufferers feel less isolated in their pain. I intend to report these experiences in such a way that victims of chronic pain and lay-persons can understand and relate to. The findings of this study also intend to further the understanding of health care professionals about the experiences of pain sufferers, so that such patients are treated with more compassion and empathy.

The focus on living with chronic pain is an appropriate research topic as there is a lack of data on this unique yet common experience, particularly that of orofacial pain. An understanding of chronic pain through an interpretive phenomenological approach is suitable, because I believe that quality of life cannot be adequately understood or explained through the scales and tools employed in the majority of existing studies on chronic pain.

LITERATURE REVIEW

Overview of Pain

First attested in English in 1297, the word *pain* originated from the Old French *peine*. The Latin *poena* meant “penalty, punishment, retribution, indemnification” and, in turn, the definition of the Greek *ποινή* (*poine*), was “retribution, penalty, quit-money for spilled blood” [1, 2]. According to The International Association for the Study of Pain, the widely used definition of pain states: "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” [3]. In certain affluent countries pain is the most frequent patient complaint in physician consultations [4, 5]. It has become clear that pain and its many manifestations are complex human conditions which influence all aspects of a person’s life.

Various early theories among ancient philosophers address pain. Both Aristotle and Plato saw pain as emotions rather than sensations; Avicenna, on the other hand, in the 11th century, suggested that pain was a separate and distinct sense. [6]. More recently, the advanced Gate Control Theory of Pain, described by Melzack & Wall in 1965, explains the physiologic mechanisms for psychological factors in pain perception, including learning and emotional responses [7]. According to this theory a “gate” is present on the dorsal horn of the spinal cord that controls noxious stimuli introduced by the small diameter afferent nerve fibers. The gate can be closed by competing stimuli, thus preventing the noxious stimuli from entering and enabling the patient to not feel pain [7]. Massage, acupressure or electrical stimulation are examples of competing stimuli.

Pain Assessment

Health care professionals have predominantly used numerical scales (0-10), visual analogue scales or diagrams, in order to “accurately” measure the intensity of pain [8]. However, the assessment of pain remains a contentious issue. Although pain is a subjective experience, it has been associated with physiologic signs, such as increased pulse, the inability to sleep, high blood pressure, groaning, and crying. However, other patients in pain may not demonstrate any objectively measureable signs or symptoms. This lack of expression sometimes results in the underestimation of pain by health care professionals, who might think that the patient is not in pain as there would otherwise be demonstrations of expected pain behaviors [9]. The subjective nature of pain and the importance of believing patient reports make up a definition commonly used in nursing, which was introduced by McCaffery in 1968: "Pain is whatever the experiencing person says it is, existing whenever he says it does" [10].

Acute versus Chronic Pain

Acute pain is described as pain lasting less than 6 months and acts a signal from the body to the person that something is wrong. It helps to determine a diagnosis and can be used to evaluate healing and recovery. The definition of chronic is pain lasting for more than 6 months and may not be correlated with a known injury or illness [9]. However, there is some controversy regarding the definition of chronic pain [11]. Due to the complexity of pain, it may vary significantly from one person to another. Therefore, as a subjective phenomenon, defining pain has been a challenge [12]. According to results from the 2007/2008 Canadian Community Health Survey, about 1 in 10 Canadians aged 12 to 44, 9% males and 12% females, in other words an estimated 1.5 million people, experienced chronic pain [13].

Chronic pain not only has a physical impact on the sufferer, but also a psychosocial one. Living with chronic pain can be a tremendously negative experience [14]. According to Cassidy et al, patients with chronic pain, particularly low back pain, have double the risk of depression than those without [15]. Chronic pain affects all aspects of a patient's life and causes significant distress leading to anxiety, anger, depression, loneliness, altered self-image and identity, along with a significantly lower quality of life. [16-22]. These negative psychosocial repercussions can essentially alter the subjective pain experience itself by increasing the flow of pain signals, thus resulting in greater intensities of pain [22]. Chronic pain also causes sleeping disorders which, in turn, reduces the ability to function effectively for employment, education, and socializing [23]. Chronic pain is often stressful and frustrating to pain sufferers and their health care providers in their struggle to relieve it [24]. Chronic pain patients appreciate a confidence-based relationship with a health care provider who listens and communicates well [25]. Since the cause of pain remains invisible to outsiders, sufferers are often believed to be weak, lazy or unsociable individuals [26].

For the treatment of chronic pain, many components have been used and evaluated together with conventional medical care, including cognitive behavioral therapy, physical and occupational therapy, biofeedback, communication skills, group education, relaxation techniques, and pain-coping strategies [27-30].

Previous research studies have concentrated on the roles of depression, anxiety, somatization, catastrophizing, and other psychological factors in the pain experience, with the conclusion that, in order to achieve effective pain control, health care providers need to consider and address all aspects of this complex experience [31-35]. However, despite the abundance of research evidence on this subject and the establishment multi-disciplinary pain centers, many chronic pain sufferers remain significantly affected by pain in various ways [25]. Living with chronic pain can threaten a person's self-esteem, identity, family and social relationships, and work roles. If not treated effectively, pain becomes an overwhelming life altering entity that affects individuals in profound and complex ways. [14, 16, 18, 20, 22-23, 25,30].

Overview of Orofacial pain

Orofacial pain is a term that refers to pain perceived in the face and/or oral cavity and is caused by diseases or disorders of local structures or by dysfunction of the nervous system [36]. The orofacial pain classification, summarized by Okeson [37] , is divided into physical (Axis 1) and psychologic (Axis 2) factors. Physical factors include temporomandibular disorders (TMD), which are comprised of disorders of the musculoskeletal structures and disorders of the temporomandibular joint (TMJ); neuropathic pains, which include episodic and continuous pains; and neurovascular disorders, such as migraine and tension-type headaches. Psychological factors include mood, anxiety and somatoform disorders that can either produce or influence the overall pain experience. [37].

The focus of literature review will be on TMD as a research topic. For a more extensive discussion about the pathology and diagnosis of the disorders in the aforementioned classification and other painful disorders of the face and oral cavity, there should be further review of literature.

Overview of Temporomandibular disorders

Temporomandibular disorders or TMD are considered to be a sub-classification of musculoskeletal disorders that include a number of clinical conditions involving the masticatory musculature, the temporomandibular joint, and associated structures. These affect approximately 5 to 12 % of the population [38-40]. TMDs are the most common cause of facial pain and considered to be the second most commonly occurring musculoskeletal conditions causing pain and disability after chronic low back pain. [40]. TMD-related pain is characterized by pain in the jaw, temple, ear and face. The most common signs include tenderness in the muscles and/or TMJs upon palpation, joint clicking, and/or limitation of jaw movement [41].

Assessment and Treatment Options

TMD assessment include a general examination of the head and neck, a detailed examination of the masticatory muscles and the TMJs, an evaluation of the mandibular range of motion (ROM), and a detailed intraoral examination. TMD patients usually visit the clinician when experiencing pain and dysfunction, such as limitation of opening the mouth, episodes of joint locking, pain while chewing, facial pain, or headache. The treatment goals for TMD include decreasing pain and reestablishing normal ROM and masticatory and jaw function. The main treatment options include a self-care program, medical care, and surgical procedures [37]. The self-care program, also known as home care, is generally used as an initial approach to manage TMD and it has been proved to be effective. Patient education is a crucial aspect of home care. Informing and supporting the patient regarding their condition may relieve a great deal of anxiety and so improve treatment outcomes. [42]. Physical therapy, massage, warm compresses, as well as pharmacological agents such as anti-inflammatory drugs, muscle relaxants, and botulinum toxin injections, have also been used in the treatment of TMD. [43]. Occlusal appliances, which are processed acrylic devices, have been employed for the management of TMD for years. Studies have reported a reduction in TMD symptoms and presented sufficient evidence to support their use [44-48]. Occlusal appliances are still regarded as an effective assistant therapy for some TMD cases, according to a review by Klasser et al [49].

Living with orofacial pain: A review of qualitative research

The intention of this chapter is to increase our understanding of the experiences of patients living with orofacial pain. To achieve this by a summary is presented of the empirical qualitative work that has been published on the topic.

A search of Medline (Ovid) databases was conducted using a combination of free text terms and other relevant synonyms or subject headings. Search terms specific to qualitative research were utilized with the guidance of a liaison librarian. This was supplemented by manually searching specific journals, including the British Journal of Pain, Social Science and Medicine, Pain, European Journal of Pain, and the Journal of Orofacial Pain. In addition, the reference lists of the articles selected were searched for further potential studies which might have been missed. Eligible for inclusion were fully published qualitative studies exploring the adult experience of orofacial pain. Titles, abstracts, or full texts were screened to exclude articles that did not meet the inclusion criteria. The search produced 1,293 articles, of which 1,278 were rejected due to not meeting the inclusion criteria. This left 15 articles which met the inclusion criteria. These 15 articles were reviewed and categorized into two broad themes:

1) Understanding the experience of living with orofacial pain (6 papers)

2) Pain management and treatment seeking behavior (9 papers)

Understanding the experience of living with orofacial pain

For the purpose of broadening the understanding of patients and their condition, in 2006 Wolf E [50] conducted a qualitative study on chronic orofacial pain from two perspectives: the clinical view and the experience of the patient. The patients participating in the study had experienced disbelief and rejection at their orofacial pain consultations. These patients also expressed feelings of hopelessness and a lack of faith in the future. For the dental management of these patients, it was concluded that developing constructive strategies is vital as dental care is sought due to pain.

Two years later, Wolf et al [51] conducted an additional analysis of the same group of patients by using a qualitative strategy based on phenomenology. The findings revealed difficulties in understanding and communicating pain. The essence of chronic orofacial pain, as expressed by the patients, eluded perception and comprehension. For the sufferers, the pain affected all aspects of their life, including the social, practical and emotional aspects.

In 2010, Durham et al [52] explored the experiences of sufferers living with temporomandibular disorder. The interviewees gave clear accounts of the difficulties, concerns and uncertainty they experienced due to their illness. A lack of diagnosis negatively impacted their daily lives and they experienced anguishing “uncertainty” upon failing to receive a diagnosis. The ongoing symptoms and constant pain were regarded as harmful to close personal relationships, social activities, and job performance.

In 2014, Mienna et al [53] conducted qualitative thematic interviews with Sami women with and without TMD so as to gain an insight into their thoughts, experiences, and beliefs. The purpose of this work was to generate a hypothesis regarding factors associated with a long-standing TMD. The study concluded that women with TMD, its associated headaches, and neck-shoulder pain may benefit from promoting the use of their own abilities to reduce stress behavior, tension, and disuse of the jaw. Women without TMD were found to rely on strong social support, which seemed to be lacking in women with TMD symptoms. The study suggests that group rehabilitation strategies can lead to increased social support and a sense of belonging among women with TMD.

In 2015, Eaves et al [54] qualitatively studied the life experience of TMD sufferers. In contrast to earlier ethnographic studies on TMD sufferers’ experience of stigma and the search for diagnosis and legitimacy, this study reported a greater initial acceptance by TMD victims of this condition, in addition to their awareness of the nature of the diagnosis and acknowledgment of the improbability of successful biomedical treatment. These narratives of illness focused on remaining observant to pain triggers and maintaining a tolerant, present-oriented identity in the face of pain, rather than focusing on the search for diagnosis and legitimacy.

For the first time, in 2015, Allsop et al [55] studied patients' qualitative experiential accounts of trigeminus neuralgia. The findings indicated continued delays in diagnosis, persistent side effects from medication, and a lack of psychological support.

Pain management and treatment seeking behavior

In 2006, Wolf et al [56] conducted a phenomenological study on the experiences of patients with nonspecific chronic orofacial pain with respect to consultations for their pain. The patients expressed dissatisfaction with these consultations due to poor communication and understanding on the part of the health care professionals, along with experiencing a limitation in their ability to develop a personal coping strategy.

In 2010, Vuckovic [57] conducted in-depth interview with women with temporomandibular joint disorders in order to evaluate these patients’ perceptions of illness, the healing process, and the experiences and effects of shamanic treatment. Evidence from research participants indicated they all observed some type of positive effect from the shamanic treatment. They underwent both physical changes and changes in self-awareness, acquired a capacity for coping, underwent improved relationships, and took better care of themselves. Shamanic treatment also led to altering their relationship and experience with pain.

In 2011, Durham et al [58] undertook a qualitative research study of TMD patient experiences and their health care journey. In conclusion, the experiences of patients with

TMD were similar to those of other chronic illness sufferers. Both experienced difficulties in primary care and recalled the wait for secondary care referral. During this wait these patients continued to experience symptoms and anxiety which compounded the already negative impact of the illness on their everyday lives.

Another qualitative study was conducted by Rollman et al [59] in 2013 for the purposes of exploring treatment for temporomandibular disorder pain complaints. The study included 16 subjects with TMD pain: 8 care-seekers and 8 non-care seekers. It was observed that the non-care seekers sometimes did not receive treatment because of inadequate referrals. Additional aspects distinguishing care seekers from non-care seekers were mainly of personal characteristics, such as catastrophizing, assertiveness, critical attitude towards health care, confidence in medical care, and recognition.

In 2014, Bonathan et al [60] conducted pre-consultation and post-consultation interviews with patients experiencing orofacial pain as a study of their journey through care. Their findings revealed that patients’ fears and beliefs about chronic orofacial pain are dominated before consultation by worry and the search for reasons explaining the pain. Findings also underlined the critical function of specialist consultations in achieving a shared accurate understanding of pain and options for treatment.

Another qualitative research study in 2014 by Au et al [61] investigated the treatment seeking behavior of Southern Chinese elders with chronic orofacial pain. It was indicated that participants desired seeking professional treatment, yet multiple barriers to accessing care for chronic orofacial pain discouraged them from doing so. These sufferers often experienced dismissal and disinterest from the medical community. It was also observed that these elders resorted to numerous ways to manage their pain, including traditional and complementary approaches.

In 2014, Eaves et al [62] also qualitatively evaluated use of Traditional Chinese Medicine (TCM) for temporomandibular disorders by exploring the role of hope in participants' assessments of their expectations, experiences, and treatment outcomes. The findings suggested that researchers interested in measuring expectations and understanding their role in treatment outcomes should consider hope as a factor it was found to implement a multifaceted and vigorous influence on the participants' reporting of expectations and their experiences, in addition to treatment assessment.

In 2015, Peters et al [63] conducted a thematic analysis of the experiences of patients, doctors, and dentists when managing chronic orofacial pain. It was revealed that clinicians and patients believe psychological factors play an important role in the development and maintenance of chronic orofacial pain, but that management and self-management strategies are largely limited to biomedical interventions. The general practitioners and dentists participating in the study considered chronic orofacial pain as a non-dental issue and felt poorly equipped to manage the condition. The resulting ineffective and unsatisfactory management of chronic orofacial pain often lead to patient frustration and conflict in the clinician-patient relationship. There is a need for improvement in the cooperation between medical and dental services. Further training is a key to supporting primary care clinicians as they facilitate the management of chronic orofacial pain.

Recently a qualitative study by Goldthorpe et al (2016) [64] was published, which explored the acceptance of a cognitive behavioral-based intervention to manage chronic orofacial pain. It was concluded that patients suffering from unexplained chronic orofacial pain are willing to accept a CBT-based intervention to manage their condition. The results of this study can be applied to interventions for patients with other medically unexplained symptoms.

Discussion

The number of qualitative research studies on chronic orofacial pain are low. Despite the empirical and ontological nature of the topic, most studies on chronic orofacial pain are quantitative. Only two phenomenological studies were found. Individual interviews were the data collection method of choice in these studies and the most frequently employed. However, it is often difficult to adequately understand the manner in which these researchers developed their arguments and to reach their conclusion as the studies' methodology section was often neglected.

Several studies included in this review limited themselves to a simple description of the data, rather than a deeper interpretative analysis that would demonstrate a rich account of the participants' experiences. However, there were a few studies that made a valuable contribution to my understanding of pain.

In conclusion, there is a lack of qualitative, particularly phenomenological, studies on chronic orofacial pain. Thus, more qualitative researchers should carry out empirical qualitative pain research in the future. Likewise, a more interpretive engagement with the data and more accuracy in describing the methods used are required.

Research Questions

By bringing the life experiences of chronic pain patients to light, the current study endeavors to go beyond the contemporary understanding of how chronic orofacial pain affects sufferers. In offering a rich and detailed description of these experiences, I hope that health care professionals interacting regularly with these patients will acquire a better understanding of how to best support bearers of chronic pain. While gathering data, the study was guided by the following question: What does it mean for the pain sufferers to live with chronic orofacial pain?

In phenomenology, it is methodologically correct to have a small number of participants in contrast to in-depth interviews. Hence, the richness of data, not sample size, is essential to gain a deep understanding of the participants’ experiences and to present these in an informative manner which will benefit future studies.

METHODOLOGY

Qualitative approach

Qualitative research has been metaphorically described by Creswell (p. 42) as *"an intricate fabric composed of minute threads, many colors, different textures, and various blends of material."* [65]. Qualitative research studies human experience through a naturalistic approach, in an effort to make sense of, or interpret the phenomena in question [65]. Qualitative research mainly attempts to understand experiences and reflections about those events in a humanistic and interpretive approach. The qualitative researcher focuses on participants by offering richly textured responses to questions about how they have understood experiences. Conversely, quantitative researchers rely on a set of limited questions in order to obtain forced-choice responses with little limitation on open-ended responses to questions as is the practice in qualitative research [66].

While there are multiple types of qualitative research approaches, all of which share some similarities: qualitative researchers tend to work in a natural setting, where information can be gathered by interacting directly with participants and observing how they behave within their context; the recognition of the fundamental role of the researcher as a primary tool for data collection and analysis; findings that are richly descriptive gathered from multiple sources of data including interviews, observations, and documents; and the presentation of a holistic description from the participants' perspectives. Qualitative research approaches may also be employed when quantitative methods are inadequate for the topic [65].

Qualitative research goes hand-in-hand with the most rigorous quantitative research approaches and should not be viewed as a replacement for quantitative study. Conducting a qualitative research study requires the researcher to be strongly committed to a methodological approach and to spend countless hours in the field collecting extensive data and gaining access to the participants' perspectives. It involves being engaged in the multifaceted, time-consuming process of data analysis, narrowing down large amounts of data to a few themes or categories, and writing extensively to validate claims and to illustrate various perspectives. The researcher must also incorporate quotes by the participants in these long reports and overall participate in a type of human and social science research that does not offer any fixed guidelines or exact procedures and which is constantly evolving [65].

I chose to use a qualitative research methodology for this study because I endeavored to explore the topic of living with chronic orofacial pain in greater detail than previously reported in existing literature. As such, a qualitative research approach can offer insight into the pain experience which cannot be adequately understood or explained through the scales and tools used in the majority of existing quantitative studies on chronic pain. To best investigate this topic, I employed an interpretive phenomenological approach, because it allows for a deep and careful understanding of the sentiments expressed by participants. Such an approach gives space for descriptions of experiences in a natural way and positions the perspective of participants in the context of their world [67].

Phenomenology

The term “phenomenology” originates from the Greek *phaenesthia*, which means “to show itself”. Thus, phenomenology is the study of phenomena, which might be considered anything that presents itself [68].

The term *phenomenology* first appeared in the works of Immanuel Kant, George Wilhelm Friedrich Hegel, and Ernst Mach. However, phenomenology, as a novel approach to philosophy, was officially introduced at the beginning of the 20th century by Edmund Husserl, a German philosopher and mathematician. Husserl became inspired by the project of Franz Brentano and adopted his view that philosophy is a rigorous science and consists of description rather than explanation [69]. Husserl developed descriptive phenomenology, in which everyday conscious experiences were described while pre-existing beliefs and opinions were set aside or bracketed. Martin Heidegger (1889-1976), Husserl’s student, developed interpretive phenomenology by broadening hermeneutics, the philosophy of interpretation. Heidegger emphasized that setting aside preconceived opinions is not possible since one cannot escape the fact that personal beliefs and experiences shape the way one views the world. Hermeneutics moves beyond the description of experiences and pursues the meanings rooted in everyday life [70].

In spite of the number of themes describing phenomenology, it did not develop into a system, but rather into a practice. It is best known as a radical and non-traditional way of approaching philosophy which attempts to make sense of phenomenon in the manner in which it appears and manifests itself to one experiencing the phenomenon. Phenomenology initially prevents all misconstructions placed on an experience in advance [69]. Interpretive phenomenology is used when the researcher's intention is to explore the meaning of the phenomenon and so does not bracket biases and previous engagement with the study question. Conversely, descriptive phenomenology employed when the researcher attempts to describe the phenomenon in question, bracketing her or his biases [70].

Notwithstanding the different philosophical and epistemological standpoints, all phenomenologists share a similar goal, which is to investigate the life experience. Through their phenomenological work, both Husserl and Heidegger developed philosophies rather than producing methodologies. Hence, these philosophies have been used as outlines to support methodologies and research [68].

Interpretative Phenomenological Approach

An interpretive phenomenological study attempts to create an interpretive narrative-story which explains how participants make sense of experiences and their meanings. Interpretive phenomenology is based on the work of Heidegger, who believed that a phenomenological study is an interpretive process. Interpretive phenomenology recommends an in-depth analysis of the accounts and encourages the researcher to engage with the participant, as opposed to bracketing as was practiced by Husserl. Due to its concern with exploring the human experience in detail, the interpretive phenomenological approach has seen increased application in the field of health psychology over the past decade [67].

This study intends to employ Heidegger's focus on language to understand the participants' perceptions. Researchers of an interpretive phenomenological study should concentrate on the participants' life experiences and how they make sense of those [67]. The purpose of the interpretive phenomenological approach is to gain a profound understanding of the participants' world and to describe what that world is like. "*The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world.*" (p. 53) This is called "double hermeneutic" in interpretive phenomenology [71].

Sampling Method

The selection of participants is the primary step in the process of data collection [72]. A phenomenological study needs to include several individuals who have all experienced the phenomenon in question and who are willing and able to talk about it [65, 72]. The researcher collects data from these individuals and develops complex narrative accounts of the essence of their experiences. These accounts include "what" the participants experienced and "how" they experienced it [65].

Samples in phenomenological studies are usually small and can vary in size from 3 to 4 participants to 10 to 15 [65]. However, it is recommended that at least three participants be included in the study, not for statistical reasons, but because the differences between them would simplify the process of distinguishing the individual experience from the more general experience of the phenomenon [72, 73, 74,75]. Furthermore, in order to uncover a characteristic essence, a satisfactory number of variations are required. Nevertheless, the researcher would still have to assess the quality of the data and not simply rely on the number of participants. The quality of the narrative accounts is more critical than their quantity [74].

Participant recruitment

The recruitment of participants took place through the McGill pain clinic and Montreal General Hospital. All participants were undergoing treatment for orofacial pain. Consultants identified potential interviewees and asked if they were willing to participate in the study and for their permission to be contacted by the researcher. Potential participants were followed-up by the researcher, who communicated with them in person or by phone for the purposes of arranging an interview.

Inclusion criteria:

- Suffering from orofacial pain
- Experiencing pain for more than 6 months
- ≥ 18 years old, inclusive
- Communicating easily in English

Exclusion criteria:

- Children and adolescents
- Experiencing pain for less than 6 months

Informed consent form

Once a patient expressed interest in participating, the details of the study were fully explained and the participant was asked to sign an informed consent form (See Appendix A). This document explained in detail the benefits of participation, the potential risks, confidentiality, and how the information would be collected, stored, and potentially distributed. Each participant was informed that her or his participation in the study is completely voluntary and that she or he may refuse to participate or discontinue participation at any time without any explanation. In which case, their information and narrative data is permanently deleted.

Data collection

Generally speaking, there are two techniques for collecting data from a subject when the researcher is exploring the life experience of a phenomenon: a conventional in-person interview and a written or recorded account of the experience [76]. Since interpretive phenomenological researchers are interested in the meaning of a phenomenon experienced by others, they typically choose the interview [72]. I chose to conduct face-to-face interviews with my participants because interviews, in spite of being more time-consuming, offer more in-depth and richer accounts [72, 75].

Between April and October 2016, I conducted six in-depth audiotaped individual interviews with each of my six participants. All interviews took place in Montreal, Canada in secure and confidential offices at McGill University or at Montreal General Hospital. At the beginning of each interview, I explained my role as an interviewer and their rights as participants. I began with a few minutes of light conversation in order to put the participant at ease and to build trust. I re-explained the purpose of the study and answered any questions that were posed by the participant. Prior to beginning the interview, I asked the participant to give a verbal consent. I used an interview guide (see Appendix B) as an outline for the questions that were to be asked during the interview. However, in order to provide a relaxed atmosphere, I tried to keep the interview flexible and open to allow naturally topics to emerge, while allowing the participants to guide the conversation's course. I began the interview with less sensitive topics, often asking the participant to tell a little bit about themselves. During the interview, all participants were asked, "What does it mean to live with chronic pain?". I asked follow-up questions to comments they had made. When the participants seemed to have said their fill, I asked additional questions from the interview guide to gather more details about their experiences. The interviews would continue if the participants had more to offer; if not, I would bring the session to an end. The interviews lasted from 60 to 120 minutes. My phenomenological interpretation is based on the data from the six transcripts.

Data Analysis

In phenomenology, the goal of data analysis is to gain an understanding of the participants' experiences by developing integrated statements about these experiences. There are multiple ways to approach data analysis in phenomenological research [77, 75]. To analyze my data and develop my research findings, I chose to use the methodology of Max Van Manen. This approach consists of creating texts highlighting narrative accounts; 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.

Interview Transcription

In qualitative research, the transcribing of recordings into written form is the first step in data analysis. Transcription is an interpretive process rather than just a technical practice, since it can lead to the observation of unexpected phenomena [78]. It is recommended that the researcher perform this work alone, as it provides an opportunity for the researcher to gain an enhanced understanding of the experience and so facilitate the transition to the first step in data analysis [72]. Thus, I chose to transcribe the interviews myself without the aid of transcription software. I transcribed the interviews verbatim and as detailed as possible, since elements such as pauses, crying, and laughter, can be crucial for interpreting data [78]. After each interview, I typed each of the transcripts as soon as possible. It took an average of five hours to complete each transcription. As I am not a professional transcriptionist, this was a very time-consuming part of the process. However, as mentioned earlier, there are numerous advantages to doing one's own transcription, including the ability to recall what a participant said if the audio did not capture a comment and a chance to remember non-verbal parts of the interview, such as body language and facial expressions. I tried to note these parts in the transcript to the best of my recollection. These notes were useful during data analysis when details such as body posture or shifts in eye contact indicated that part of the story was not captured by the words spoken. I revised the document following transcription to correct any misspellings or mistakes. This involved listening again to the audio file interview while reading along with the transcript.

Developing findings: The Wholistic and the Selective Approach

The data analysis involved several steps. The first stage of analysis included listening to each audio recording while reading the transcript to check for accuracy. In the second step, I used van Manen's reading techniques, which consist of three reading approaches: the wholistic or sententious approach; the selective or highlighting approach; and the detailed or line-by-line approach [79]. Each of these processes is designed to filter the description into the essence of the phenomenon by finding the unities among the texts [79]. According to the sententious approach, I read each transcription as a whole and wrote a summary paragraph about each text, which I then attempted to narrow down to a single phrase or sentence. Using the selective approach, I read each text multiple times highlighting sections that seemed particularly revealing or significant about the phenomenon. I then listened to each participant's interview. Immersing myself into the account, I asked which ones most revealed the phenomenon in question. I reviewed each transcript multiple times, pulling out all relevant findings that related to the experiences of living with chronic pain. I color coded each statement for the ease of identifying and tracking the statements for each participant. Finally, in the detailed approach, I studied every single sentence in the transcript to understand what this specific line was revealing about the participant's experience. Avoiding the usage of coding software, I read each transcript numerous times, making notes of my interpretations and philosophical points. Throughout my reading I also highlighted quotations relevant to the research questions which were unique, particularly interesting or key to the participant's experience. Also highlighted were excerpts that suggested a common finding among the participants. Finally, I compiled quotations, notes, excerpts, and interpretations into findings.

Phenomenological reflecting, writing, and re-writing

As a research approach as well as a philosophy, phenomenology requires thoughtful reflection to gain a better understanding of the phenomenon [79]. Phenomenology practices a certain manner of reflection through the act of writing. It is a dialectic process of constructing a text, born of the essential relationship between research and writing. Human science research is a linguistic approach that strives to make the life experience reflectively understandable. As Van Manen said (p. 127), *"Writing separates us from what we know* *and yet it unites us more closely with what we know "*. It is through language, our words, that we are able to make the invisible become visible [79].

A solicitous and careful selection of words facilitated organizing my thoughts and expressing reflections on the interpretation I had made of the participants' accounts. I addition, writing a variety of texts further organized my thoughts. Working through the phenomenological reading approaches, I took time to reflect on developing an image of my participants' chronic pain experience. I imagined myself experiencing what participants had, and then reflected further on what I heard. I addition, I considered different titles for my findings.

Reflexivity

What differentiates reflection from reflexivity, is the earnest attempts of reflection to achieve accuracy when reporting participant accounts. In other words, reflection can be considered as a discrete set of tasks involving process and verification for the purposes of ensuring quality. Conversely, reflexivity is an honest evaluation of the self. The etymological roots of the word "re-flexivity" include looking again or turning one's gaze to one self. Thus, reflexivity is the reflection of one's thoughts back to oneself [80]. Reflexivity has been defined in many ways and its implications vary depending on the philosophical approach adopted by the researcher [81]. While the descriptive phenomenology described by Husserl claims that reflexivity requires the researcher to recognize her or his biases, knowledge, and assumptions and aside or "bracket" them, interpretive phenomenology embraces the knowledge, experiences, assumptions, and biases of the researcher and considers them as essential and critical components of her or his ability to understand the experiences of others [77].

It has been discussed that reflexivity enables a holistic approach to qualitative research. By making ourselves aware of our own feelings and expectations about the research, we can begin to fully understand the nature of the investigation and the experiences of participants [80]. A co-constitution of knowledge and a fresh understanding of a phenomenon is achieved through the researcher's awareness of the ways in which her or his identity, beliefs, experiences, and knowledge interact with the participants' accounts [80]. In other words, reflexivity involves the writer's constant consideration of the ways in which her or his contribution to the research process affects all phases of the research [80, 75].

Throughout the research process, I spent ample time reflecting on my own pre-existing beliefs, experiences, and feelings as a general dental practitioner working with chronic pain patients on a regular basis. I tried to relate to my participants' feelings and experiences and to exhibit a non-judgmental attitude towards them. In fact, I recall a particular conversation with a co-worker while I was working at a summer dental clinic and writing my thesis. My co-worker told me about a patient who would constantly seek care due to pain. Since no diagnosis could be confirmed, my co-worker suspected the patient was a "pain drug seeker". In other words, the patient was claiming to suffer from pain in order to be prescribed strong painkillers. Before starting this project, I probably would have agreed with my co-worker. However, because I had been researching chronic pain patients confronting disbelief, I immediately felt obliged to defend this patient. My reaction confirmed to me that I was non-judgmental towards my participants' experiences, a stance which was beneficial to the reflexivity of the project.

Generalizability and Transferability

Generalizability is practiced by researchers in an academic setting and can be defined as an act of analysis that draws general conclusions from particular observations in a study. Generalizability is commonly recognized as a quality standard in quantitative research. On the other hand, in most qualitative research, the research goal is not to generalize but rather to provide an in-depth and rich understanding of some aspects of human experience [82]. In the present study, the common elements and experiences of those living with chronic orofacial pain were explained. By doing so, I was hoping to select a representative structure for the phenomenon in question.

Via transferability, readers of research apply what they have read from one context to another as a means of expanding understanding. Unlike generalizability, transferability does offer general statements, but invites readers of research to make a connection between the elements of a study and their own experience or research findings [83]. The researcher's task is to provide readers with rich descriptions that promote such interconnections [82]. It is hoped that the present study will benefit other sufferers who are learning to live with chronic pain or other chronic health conditions. When reading the present study, one is invited to reflect on the participants' experiences of living with chronic pain, as well as one's own suffering transferability. However, it should be noted that I did not ask my own participants to confirm if the findings were consistent with their accounts. This is not required in phenomenological research if the researcher holds that the accounts are rich enough in description to confirm the credibility of the data [70]. I believe that my personal commitment, involvement, and reflection during the present study and the interpretive nature of this study did not require confirmation. Furthermore, based on Heidegger's philosophy, since I did not bracket my biases, there was no need for the participants to verify the study's findings [70].

Positioning myself

A significant role in the context of the current study was my general dentistry experience with chronic pain patients on a regular basis. In addition to the insight I have gained through my profession, I have come to know the suffering from long term chronic pain from close family members. I have witnessed how pain affects one's entire life. Some relatives had to quit work, change the way they perform most tasks, and discontinue doing others. I have observed their frustration, fear, and eagerness to find a non-judgmental practitioner who truly understands their plight and will take the extra time to fully assess and treat them. I have often heard about their desire to find a practitioner who would be sympathetic and attentive and not simply prescribe a pill and then become exasperated when the medication has no effect. With this professional and personal exposure to chronic pain, I embarked on my journey to discover what can be learned from those with the attempt to gain understanding from suffering and to gain an insightful perspective of their unique experiences. This study represents a central part of my life for the last year and I hope to pursue research on chronic pain in the future. Working my way through course work, conducting research, and writing this thesis have all sprung from a motivation and perseverance to shed light on and promote understanding of chronic pain sufferers.

Ethical Considerations

Ethics approval was obtained in June 2015 by McGill University's Research Ethics Board Office and this was extended to allow interviews to take place until June 2017 (see Appendix C). There was a minimal risk of psychological or physical harm to the participants in the study. Prior to interviews, the purpose of the present study and its process were discussed with all participants in detail. An informed consent form (see Appendix A) outlining all potential risks and benefits was fully explained to each potential participant and signed by before the interview. I carefully pointed out that participants could choose not to answer any question and could withdraw from the study without any explanation and at any time prior to the publication of the results. I also described the measures taken to assure confidentiality and identity protection. So as to maintain confidentiality, all work shared with others, including this dissertation, pseudonyms were used to identify participants and anyone whom they mentioned.

FINDING # 1 – SUFFERING FROM LOSS

The findings of the current research study suggest that sufferers of chronic pain experience various forms of loss due to their condition. There are adverse effects on their relationships, employment, social activities, and even the ability to eat the food previously enjoyed. These all culminate in a loss of self-identity. For these study subjects, chronic pain dominates every aspect of their lives, not only physically but also psychosocially. According to the participants, distress and other psychological symptoms following chronic pain are more difficult to understand and manage than the physical pain itself. Although the physical pain may be overwhelming for the participants, its psychosocial effects, such as distress, shifting identities, poor sleep quality, isolation, and low quality of life, were their chief complaints. These findings are in line with previous studies conducted on chronic pain [16-22]. Some participants even attempted suicide to escape their miserable condition. Pain also causes shifts in personal identity. Life with pain necessitates sufferers to redefine or negotiate their identities in order to continue to cope with chronic pain.

Participants experienced significant losses in their lives: *"I lost everything in life except my family of course and my wife."* One patient could not choose career that she was passionate about: *"The pain meant that I picked the field that I'm in because it's a field where most of the time you don't have to be there as long as you get the work done; you can get it done on your own schedule. Which is unfortunate because I love what I'm doing but I picked it not because I'm passionate about it. There were things that I was passionate about that I couldn't do because I know that I know that I can't show up…. I mean, I maybe will be able to show up at that time but I can't promise that I will be there."* Another patient lost the ability to eat the food that she once enjoyed: *"I have to be careful when I eat and I have to avoid some stuff…you know…nuts…I love raw vegetables…carrots, I can't eat that anymore."* Some experienced changes in physical capacity: *"I used to exercise a lot before but when the pain started I couldn't go to the gym anymore or other sports and that was so frustrating."* As a result of chronic pain, some experienced the loss of engaging in social activities: "*It's an everyday fight… if I would be at home right now… what time is it… I would need to go to lay down…at least to relax… a bit… but it's not because I'm really tired but the pain is tiring".* Another patient commented: *"I don't have the energy to socialize with friends and family. I prefer to stay at home and rest. Sometimes I don't even have the energy to play with my daughter."* Others had experienced some financial loss because of losing employment: *"I enjoyed working but it was too physically demanding for me and I couldn't handle it anymore."* Some participants spent money on alternative treatments but were not able to continue with these treatments due to financial difficulties: *"I was sent to an osteopath who worked on it and it really helped but you know 60 bucks for twenty minutes when it's not covered by insurance is not a long term solution…I mean I could go less often but it wouldn't help enough. It only helps if you do it often so like once a month or a week…I don't think it's a really good investment."* Another patient said: *"Acupuncture was too expensive for me, specially since I was unemployed."*

Isolation

One of my main findings revealed that chronic pain can be isolating for the participants, as a result of not engaging in social activities and losing relationships. When the pain never stops, it is difficult to feel connected with once familiar surroundings. Unpredictable symptoms affect relationships and friendships and sometimes the sufferers feel lonely in spite of being surrounded by people. Instead of reaching out to others for support, some choose to withdraw from the world and so isolate themselves: *"You know I don't plan things anymore, you know because I'm afraid to have pain, and if I have pain I won't sleep. If I don't sleep, I won't be able to think. Sometimes I have to cancel on my friends last minute and that makes me look unreliable so I have stopped planning."* This is an example of how social isolation creeps into a chronic pain sufferer's life. This particular participant fears unpredictable flare-ups and feels guilty from letting her friends down. Because of her constant pain, she is unable to live the life she once knew and loved.

One study conducted on chronic pain patients found that a strong sense of emotional distress, social isolation, and loneliness developed because it is difficult to make sense of their condition [84]. In line with this research, several of the current study's participants reported a combination of guilt, anxiety, and fear. Although appearing to make an effort to socialize with family and friends, these subjects really preferred to be home and alone; for them the the loneliness of the pain experience was felt even in the company of others. Due to constant apprehension about accepting social invitations, their pain meant that they missed out on family and friend gatherings and so also struggled with guilt: *"When friends or family invite me I force myself to go cuz I don't want to end up alone. But the only thing that I keep thinking about is when I can go home and lay in my bed and rest."*

Another participant, who had developed chronic abdominal pain at the age of eleven and chronic jaw a few years later, explained how pain gradually started taking over her life. In attempts to manage the pain, she even had to drop out school and isolate herself at home. This subject felt that she had missed out on teenage life and was simply an observer of her own life. At the time of our interview, she was turning 26 and fortunately able to return to school: *"I had to drop out of the CEGEP one semester because of the pain. Well, I mean it makes it hard to concentrate when your whole face hurts. I stopped studying a couple of times because of the pain."*

Loss of self-identity

"I am a nice person, but the pain takes over and I become so mean…but it's not me...it's the pain…and my family keep telling me I'm not the same person I used to be."

Because she no longer could recognize herself as "who" she was before, the above participant was devastated. She identified herself as a nice person and claimed that the pain taking over her life was transforming her into someone that she did not want to be. The experience of living with chronic pain not only induced her to herself differently, but also allowed her to perceive that others were seeing her differently. Pain changes people in ways that are unpredictable, thus adding complexity to the pain experience.

Another participant was a former fireman who had tried to return to work after diagnosis. His co-workers could no longer identify him in his role as a fireman: *"I went back to work for a while…but people at the fire station told me that I wasn't the same man."* At the time we conversed this subject was no longer working and had lost contact with former colleagues. His self-identity as a skilled fireman and provider for his family was challenged: *"You might think I'm not normal. I've got papers proving that I'm not crazy and I have passed 10 years with that support group, without being able to go back to work of course. I had to declare personal bankruptcy. I lost everything in life except my family of course and my wife."*

From an etymology dictionary, the origins of the word identity are defined as "sameness, oneness, state of being the same," [2]. We are identified as persons living in a world with families, relationships, occupations, beliefs, and day-to-day activities. In other words, as we evolve in our lives, our identity becomes how we understand ourselves and the ways others perceive us [85]. A diagnosis of long-term illness can dramatically change the way self-identity is experienced, with the chronic pain sufferer going through a transformative process of becoming someone other than who she or he was before pain. As observers, we only have a shallow view of someone else's suffering. What we often do not see is the struggle that follows after a life-altering diagnosis and the shattered identity that needs to be pieced together towards healing.

My findings suggest a shifting of identity among participants. As they coped with a changing body, capabilities, and shifts in health and well-being, many tasks they had performed before chronic pain, presented themselves as new and challenging. Some subjects felt that their familiar body had become unreliable and that they were facing the reality that their familiar life had changed. Others felt disconnected from society and were drifting into isolation. Some participants felt left behind because they could no longer participate in social activities, while others were hurt by careless comments by friends and family members: *"I used to become irritated when I was in pain and my family didn't talk to me when I was too irritated. They didn't understand my pain. It was a very difficult time and well I guess if you are not in pain it's hard to understand. We stopped talking a few times but now it's much better."* Such experiences all affect the ongoing transformative process of self-identity. Some participants were exhibiting changing moods and became easily angry or irritated: *"When I'm in pain I get so irritated. I can't talk to people. I can't* *even handle my daughter. When my family sees that I'm angry because of the pain they stop talking to me."* Another participant commented: *"The hardest part is that I get easily irritated and sometimes I get mean. I didn't use to be like this."*

Poor sleep quality

"So I didn't sleep, I really--I didn't sleep--during one week sometimes I slept two hours. It was a very difficult period, we tried everything but the pain wouldn't disappear."

Poor sleep quality is among the most common complaints reported by chronic pain patients [86-87]. Similarly, the participants of the current study reported suffering from disturbed sleep due to chronic pain. *"I experience pain 24 hours a day. It depends…it's worse when I get up.... it's about two weeks now…the pain is waking me up. I've got medication also…to help me sleep and everything."* Others said: *"You know if I'm in a lot of pain it's harder to fall asleep" "And--uh--I sleep with that, perhaps half an hour and I get up and I--uh--put up some heat. Usually I don't sleep when I have a flare. It's too--uh--too painful."* This lack of sleep adversely affected their daily functioning and impaired physical, emotional, occupational, and social functioning. *"I didn't sleep a lot the last two nights so I have problems with my concentration." "I'm afraid to plan things because I'm afraid to have pain and if I have pain I won't sleep. If I don't sleep, I won't be able to function."*

Discussion

The participants of the present study experienced a multitude of chronic-pain related losses which individually and overall contributed to their suffering. Their condition is not only caused by chronic pain, but also by an entire life affected in every aspect by pain -

personal, social, familial, emotional, and recreational.

The experience of loss is common to human life and during one's lifetime, different types of losses are experienced. Loss is an individual experience that may differ from person to another [88]. Likewise, loss is common among those with a chronic illness. Some patients are able to restore themselves and eventually find acceptance through life course changes, while others can not. These losses are both similar in an absolute sense to but also different from other types of loss in life, for example the loss associated to the death of a loved one [89].

Suffering is the way one senses life. It can help to grasp and interpret what is experienced. Suffering involves a person's entire existence: how one acts in the world, connects with others, and understands priorities and ambitions [90]. Suffering has previously been researched through multiple methods. However, it is not possible to apply one particular methodology since every suffering is unique. While efforts have been taken to quantify the experience of suffering, researchers have failed to gain a deep understanding of this matter. From the perspective of caring sciences, research in understanding human suffering is mostly qualitative [91]. Qualitative methods for researching human suffering, including interviews, advocate that sufferers articulate and otherwise convey their own understanding of them [92]. While it has been previously discussed that the research of suffering should be avoided because it could "awaken" the interviewee's suffering, Arman et al argue that talking about one's own experience of suffering is an important step towards the alleviation of suffering. Their findings show that people suffer the most when not given the opportunity to share their pain with others [92]. As occurs when experiences of suffering and its effects are shared with researchers. In endeavoring to understand these experiences and share findings with other researchers, students, health care providers, as well as other sufferers, researchers promote recovery and understanding of pain [91]. Researching a traumatic experience, such as chronic illness, means that the researcher provides a phenomenological narrated account of the events as they occur [91]. Suffering is an individual experience and those undergoing the same experience express it differently. It is impossible to objectify or colonize the experience of suffering, since it is lived through individual contexts and meanings [91]. Hence, in order to understand their suffering, it is essential to find its unique meaning to each person who suffers. Our work as researchers is to listen to sufferers who are willing to share their experiences with us, suffer together with them, and share their experiences to reach understanding [91].

FINDING # 2 – DISBELIEF

The participants often felt judged and stigmatized by the people they engaged with in their surroundings, including health care professionals, friends and family members. Those who did not suffer from chronic pain expressed disbelief of the participants' pain. As a result, the participants sensed a lack of adequate validation and understanding by others. For some, the lack of objective findings and pathologies caused deep suffering. The inability of health care professionals to provide a diagnosis led these pain suffering to feel discounted and powerless to deal constructively with their condition. These findings are in line with previous qualitative research conducted among patients suffering from orofacial pain [50, 52, 60].

The Invisibility of Pain

The disbelief experienced by the participants sprung from the fact that they exhibited no visible signs of chronic pain, save for their expression of pain, limp or words to describe their suffering. Participants expressed their frustration of being misunderstood, often because others had not experienced similar chronic pain: *"My son can't do anything for me…well I mean if you don't have the experience of chronic pain it's hard to understand someone who is in pain."* The invisibility of their pain also added to the disbelief and misunderstanding they encountered. Furthermore, the participants sensed that health care professionals found it difficult to believe their complaints of pain for which there was no clear physiological reason: *"Well I had to change dentists a few times before someone said ok you are actually having pain and that I wasn't pretending. And of course I probably wouldn't have got the referral here for the jaw pain because jaw pain doesn't seem to be* *taken that seriously I have noticed but I got the referral for the abdominal pain and as soon as I was here the main doctor that I am seeing said we will take care of that too."* This patient suffered from additional distress and anxiety because some health care professionals rejected her symptoms by claiming the pain was imaginary. Similar results were found in a qualitative study of patients suffering from orofacial pain; these findings suggested that patients experienced distrust and rejection at consultations for orofacial pain [50]. Another patient recounted: *"We have been running many many tests and finding nothing unusual so my doctor gave me a prescription of antidepressants and referred me to a psychologist. Do I look sick to you? Even my family thinks it's all in my head."* This patient had been suffering from chronic pain for over 20 years. Due to the absence of physical pathology, her illness had been discredited and the source of pain had been deemed psychological. The lack of evidence validating the existence of her pain had led doctors and family members to question her credibility, a stance which the participant viewed as very damaging to her integrity.

Searching for an explanation

The participants of the present study experienced a lack of clear explanations and a definitive diagnosis. According to findings, participants sought to legitimize their pain. They desperately needed to have someone believe their pain and to give them an appropriate diagnosis or explanation: *"Well parts of it also was you know when you are eleven years old you are not being taken seriously and even when you are 15 and even when you are in your 20s but you look like you are 15 they just think she is sensitive…well maybe I am…but when it is stopping you from doing anything…even if you are sensitive it's* *a problem…and yea…so these are diagnosis but it's a diagnosis you get when you can't find anything else. We might find something someday. It's frustrating but that's it."* This particular participant had developed chronic pain at the age of 11, and at the age of 25, she was finally diagnosed. Despite this, she still felt frustrated, as she mentioned, *it's a diagnosis you get when you can't find anything else* and she was still hoping to find the explanation she had been seeking for many years. Similar findings were suggested by Durham et al [52] who explored the experiences of those living with temporomandibular disorders, in which a lack of diagnosis negatively impacted these sufferers.

Since no pathology was identified, for some participants, their pain was not understood by health care professionals. These participants also realized that health care professionals are too busy and not willing to provide any assistance or referrals to specialists: *"Finally how did it happen… It was after forcing and forcing… and breaking down the doors and everything… [laughter] I got to come and see a specialist in here…a dentist…after nine months…like I said making phone calls and having…almost begging please take me please take me…"* Some participants saw that nobody took responsibility for their treatment nor had time to listen to them. When health care was sought, symptomatic treatment, such as medication, was prescribed, from which there are many negative side effects: *"My dentist was going on vacation and didn't have time to help me. He gave me painkillers but they made me so tired and I had difficulties sleeping so I stopped taking them."* Allsop et al (55) suggested similar findings in their qualitative study of patients suffering from trigeminus neuralgia. Delays in diagnosis and persistent side effects from medication were reported. Likewise, Bonathan et al [60], who conducted pre-consultation and post-consultation interviews with orofacial pain patients, suggested that patient fears and beliefs about chronic orofacial pain are dominated by worry and a search for meaning before consultation.

Discussion

To summarize, the participants of the current work were not believed by people they encountered, which, in turn, provoked distress and anxiety. The participants' main concerns were the lack of explanation about their pain and the absence of physical signs to support or validate their pain narratives. For some patients, the need to have their chronic pain acknowledged and to receive a diagnosis resulted in repeated consultations with health care providers. Some participants were referred to psychologists as their primary health care providers considered their pain as signs of mental or emotional problems, due to its invisibility and lack of physical signs.

"I also don't complain a lot…I mention it to the dentist. I say I'm getting this very bad jaw pain and what can we do about it? But I guess I was never…eh… I find it if you cry they could take you more seriously sometimes with pain and I guess I seemed maybe too calm. That makes me very angry."

The quote above is by one of the study's participants who observed that the pain experience is taken more seriously if one cries. Pain, in spite of its subjective nature, has often been associated to physiologic signs, such as increased pulse, the inability to sleep, high blood pressure, or groaning and crying. However, some patients may be in pain and not demonstrate any of these symptoms. This results in the underestimation of pain by health care professionals who might feel that the patient is not in pain as there are no demonstrations of expected pain behavior [9].

Chronic pain is an individual and personal experience and cannot be measured as many other conditions are in medicine, by an x-ray or a blood test. Unfortunately, for chronic pain sufferers, there are no medical tests to measure pain levels. The lack of physical findings or objective evidence is daunting for the patient. Many chronic pain sufferers go from one health care provider to the next in search of an explanation, which can lead to redundant assessments and treatments or conflicting opinions. It is reasonable to suggest that a majority of people, at one point in their lives, have experienced some level of acute pain. Thus, pain can be considered as a universal human experience; thus, despite the subjective nature of acute pain, people are able to empathize with sufferers based on their own similar experiences [93]. Furthermore, most acute pain demonstrates physical signs to confirm its existence and validate patient reports, such as cuts, bruises, swellings, and deformities. A patient complaining of leg pain with signs of inflammation is more likely to receive empathy than one complaining of the same condition but whose leg appears healthy. Thus, visible physical signs are critical to gain others' understanding and recognition of the pain experience [93].

In the existing literature on chronic pain, it is often indicated that these patients confront disbelief by their health care professionals. The use of patient narratives can assist health care professionals to gain a deeper understanding of the chronic pain experience [93, 94]

Margo McCaffery (1968) (p. 17) defined pain as "whatever the experiencing person says it is, existing whenever he says it does" [10]. According to this definition of pain, health care practitioners should accept the patient’s subjective pain accounts as they are. Failure to do so further contributes to the patient’s suffering.

Finding # 3 – DISSATISFACTION WITH HEALTH CARE

The research participants in this study initially sought help from their primary care practitioners before receiving secondary care referrals. In their journey through the health care system, they experienced dissatisfaction with wide range of issues, from practitioners failing to take their concerns seriously by listening and attempting to understand to clinical aspects, such as of lack of or delays in diagnosis and struggles in gaining access to care.

Experiences of primary care

Participants of the present study experienced inadequate management of their pain by primary care, which then resulted in frustration. Some experienced disinterest by health care providers: *"The other doctor that I had before did not want to work or take care of my sickness. She said you've got specialist for this. But I said you know damn well we got to work as a team…but she didn't want to. She didn't want to. She never wanted me to have any exam concerning my shaking. accepted that I took the blame…that we don't fit together anymore. I divorced from her [Laughter] And ever since then I feel better."* Participants also observed attempts by dentists to treat a complaint, which failed because discussion, explanation, information, or support were limited: *"The dentist just kept drilling my teeth. I went there a few times for the same complaint and he would drill my teeth every time but it didn't help and finally I stopped going there because I wasn't getting any help and I didn't even know why I was in pain."* Patients felt their pain was a frustrating and even an annoying problem for their dentist to deal with and so were left feeling unsupported and even abandoned by health care services: *"I barely got any help…he started to--you know—polish my teeth, and give me--he was going on vacation, and give me some pills. I don't* *remember what it was. But--uh--I feel very sleepy. And it didn't help me so I stop taking that."* Participants also recalled the wait after referral to a specialist in secondary care. During this wait, their ongoing symptoms impacted every aspect of daily life: *"It has been one year and nothing has changed…I'm still in pain and they were not able to help me. I think I'm still angry. I don't want to be like that but you know a lot of people can open their mouths and they don't have any problems. But I'm angry. Yeah [laughter] And the fact that I was angry, even if the dentist was very nice, I was not able to return there so I had to wait to be seen by a specialist and it took almost a year." Among* other concerns expressed by participants were the ongoing search for a diagnosis, mainly in primary care, and being ill-informed about the cause of pain. Some participants were told that the pain might be considered psychosomatic and were referred to a psychologist or psychiatrist. *"She got me to see a psychiatrist and they said you suffer from major depression, and I'm like come on what's that? Not again." "They offered me to see a psychologist. I said ok I'm going to try it maybe he is going to give me new tricks…it's always the same thing…it's always the same thing…".* Some patients reported relief after being referred to secondary care, hoping to finally receive an explanation for their pain.

Experiences of secondary care

Overall, the participants of the present study reported having a better experience of secondary care compared to primary care. Yet, some were left dissatisfied. The chief complaint was the long wait to be seen by a specialist. During this time, the participants felt abandoned by clinicians, all the while experiencing symptoms which negatively affected their lives. The patients' main desire during this wait was to receive a diagnosis and explanation for their complaint once accessing secondary care. One participant attempted suicide multiple times during his journey through secondary care. In an interview, he mentioned seeing a specialist who said there was no cure for his condition: *"Dr. X is not very good and I would repeat it in front of him….in diplomacy…ok? He came in front of me about six inches from my face and said Mr. B there is no cure for your sickness. The day after I never came to the hospital… I tried to kill myself. But they can't help me…In psychology they can't help me in the hospital…forget it…there is not room for me… inside the hospital for patients like me…"* It is clear that pain drove this to desperation and suicide. It is also evident that the doctor's blunt and insensitive announcement of "no cure" devastated the patient. During the interview, the participant fortunately exhibited his will to fight: *".... but there was not a cure… but I'm still hoping… this is why I'm fighting… believe me I'm fighting because to prove that maybe…[laughter]. I want to…I want to be able to be the first man in the world saying I fought and I beat it, the burning mouth syndrome!"* This participant could recall numerous visits to various specialists and hospitals and was still hoping to find a cure for his condition.

Discussion

Overall, participants expressed a dissatisfaction with consultations in primary and secondary health care. The findings of my research study paralleled other findings from previous studies conducted on those living with orofacial pain [50,56, 58, 61,63].

In his book The Enigma of Health (1996), the German philosopher Hans-George Gadamer discusses health care issues by exploring ethical and human issues raised by the scientific successes of modern clinical practice. Gadamer argues that we should acknowledge the restrictions of a purely technical approach to medical treatment, as well as the significance of a qualitative and patient-centered approach to healing [95]. The philosophy of person-centered healthcare is contradicted by the need for healthcare practitioners to assess and treat patients as quickly and efficiently as possible. With its objectification approach, dominance of quantitative research in the practice of medicine, also plays a role in this contradiction [96]. In his book, Gadamer further argues that the goal of modern science is to "measure" everything through quantitative methods. He mentions that *"instead of learning to look for illness in the eyes of the patient or to listen for it in the patient's voice, we try to read it off the data provided by technologically sophisticated measuring instruments."* (p. 98) [95].

The following comment is by one of the research participants at the end of an interview:

"Now I will be sad for a while…because I have been talking about my pain but it doesn't matter. It's the first time since many many years that somebody let me talk."

This subject had been living with chronic pain for 20 years and was still hoping to find a cure. While we were talking, he started to cry because he was reminded of his years of suffering. However, he was happy that he could share his experiences with someone because, as he mentioned, his health care providers were not interested in listening to him at all.

In *The Enigma of Health,* Gadamer further explores the two concepts of treatment and dialogue. He explains that the term "consulting hours" suggests that the dialogue between the doctor and patient belongs to the process of treatment and can help to break down the distance which lies between them. Gadamer also discusses the meaning of the word "treatment" in contexts other than health care: *"We say, for example, that we must treat someone with care, that we must be careful what we do or say to them."* (p. 127). He holds that this also applies to all patients, who must always be treated with care because of their need and great vulnerability. Gadamer further emphasizes the importance of the patient-doctor dialogue [96].

In the health care system, sometimes superficial encounters between a doctor and a patient are sufficient to provide a straightforward and satisfactory conversation about one's life, health and outlook. Other encounters, however, are more emotional and complex, such as with a person who is suffering; in these cases, a more genuine and developed conversation is required in order to obtain facts as well as to begin the healing process [95-97]. The dialogue between doctor and patient not only serves as a way to record the patient's history, but also to improve the patient-doctor relationship and build a mutual understanding [95-96].

SUMMERIES & CONCLUDING COMMENTS

The purpose of the present research study was to explore the experiences of living with orofacial pain via individual face-to-face interviews with the participants. The research study utilized an interpretive phenomenological methodology supported by Martin Heidegger's philosophy for a competent insight to the understanding of chronic pain. This served as a guide and outline for this study as I sought to understand the meaning of living with chronic pain. The participants' views of their own experiences were crucial part in perceiving the experience of chronic pain. Through my own experience as a dental practitioner, I had learned that each patient manages pain in a very individual and unique way depending on personal experience. I chose to use interpretive phenomenology to interpret the data as language is the best approach for exploring the participants' experiences. Interpretive phenomenology provides a method of analysis in which the patient's perceptions of her or his individual experience of chronic pain can be understood. Throughout the interpretation work, the interpretive phenomenological approach offered an ongoing process to deepen insight and understanding. Additionally, the contribution of phenomenology to this study guaranteed that the rich and in-depth data provided by the patients would be investigated and studied in such a way that each individual experience would deepen the understanding of what it meant to live with chronic pain. As a researcher, I was able to individualize and reveal hidden meanings through a broad and in-depth interpretation of the data obtained. Heidegger's interpretive phenomenology approach allowed me to explore the experiences of my participants' by engaging with them and not bracketing or setting aside any of my pre-existing beliefs and thoughts. In comparison, Husserl’s descriptive phenomenology would not have advocated this approach since it demands that researchers bracket themselves from the participants’ individual accounts.

The literature review suggested that the experience of living with orofacial pain had not been fully explored and that there was a lack of qualitative studies in this domain. While quantitative research and reporting is vitally important in scientific medicine, qualitative analysis increases understanding and the possibilities of supporting and treating patients in a more individualized way. Each methodology provides unique and valuable insight into the complete experience of living with chronic pain.

In the data analysis, three essential findings emerged: 1) suffering from loss, 2) disbelief, and 3) dissatisfaction with health care.

The first finding, suffering from loss, indicated that chronic pain affects every aspect of the participants’ lives. This results in various forms of loss, such as the loss of relationships, employment, the ability to eat the previously enjoyed food, and engagement in social activities, all of which can lead to isolation and a shattered self-identity. The second finding, disbelief, suggested that the pain sufferers participating in this study experience disbelief from families and the medical community because of the invisibility of their chronic pain. The last finding, dissatisfaction with health care, revealed the participants’ dissatisfaction with the care received on their health care journey. The review of literature suggested that these findings are not only unique to my participants, but also to others in previous qualitative studies on orofacial pain.

Participants of the present study and in the literature place grate emphasis on their health care providers' disbelief of their subjective pain experience. For the participants, living with chronic pain was made even more agonizing because of this disbelief and their need to feel validated. They were unable to prove the existence of their pain without signs of physical injury or illness. Some lacked a diagnosis or name for their condition. Others were even told that their pain was imaginary. One of chronic pain's main issues is its invisibility since it cannot be visualized due to its nature nor be detected by any device. The experience and sensation of pain is always individual and there is no criterion by which the experience of pain can be refuted. Thus, denial of another's pain is comparable to the denial of another's experiences. Therefore, believing patients and recognizing their pain is a fundamental step in the therapist-patient relationship, which can be built upon their constructive dialogue. Findings also suggest that the participants suffered from not receiving an early diagnosis in primary care and the long wait to see a doctor in secondary care. Perhaps further research can address the reasons for delay in diagnosis. The stigma when one's pain is not believed derives from different sources, including health care professionals and family members. This is an issue that health care providers need to be aware of when dealing with conditions in which there is no clear underlying pathology. A search of literature identified studies that considered disbelief to be an issue among chronic pain sufferers. The lack of support by health care professionals, as reported by the present study, further aggravated the chronic pain experience as a whole. The ensuring despair even led one of the participants to attempt to end his life.

Because of the impact that health care providers have on sufferers of chronic pain, I believe that the findings of the current study contribute much to the approach taken with such patients. For instance, since the current study reports that disbelief of the patient's pain is devastating for the sufferer we can improve the bedside manner and approaches to treatment to ensure that patients feel believed. Achieving this can be as simple as being a good listener and providing attentive support as health care providers. Patients do not want to feel judged, depreciated, or treated as "timewasters" rather, patients deserve to be treated with empathy, earnestness and kindness. Such practice will build a more therapeutic relationship between health care providers and patients. Patients can then channel their energies into coping with pain and maintaining a better quality of life instead of trying to salvage their credibility with their health care providers. Thus, patients will be relieved of the destructive negativity associated with this complex pain phenomenon. Health care professionals must validate the patients' accounts of subjective pain in order to allow them to accept chronic pain and live with it. From the present research, we understand that a lack of clear explanations and a definitive diagnosis is extremely frustrating and stressful for the patient. As qualitative researchers, the accounts of pain sufferers should be made available to a variety of audiences as a means of promoting education about the suffering of others. In this way, interaction with these patients and treatment can change. Through such accounts, we can enlighten and educate those who have not experienced chronic pain, as well as those who have. When sharing these accounts with the latter, we validate their experience of suffering and assure them that they are not alone in dealing with this often times debilitating condition. For the sufferer of chronic pain, this realization may be enough to begin the healing process. In this research study, by listening carefully to the accounts of my participants and retelling these in my thesis, I hope to offer much needed insight into the experience of chronic pain suffering.

A truly holistic approach to pain assessment begins with listening and believing; then, an appropriate treatment plan for managing the pain can be developed. It is critical that health care providers and patients enter into a therapeutic relationship, in which the provider actively involves the patient in choosing an individualized treatment plan that is the most appropriate for that particular patient. A patient-health care provider relationship based on compassion and empathy includes listening actively, accepting the pain experience as told by the patient, and presenting a non-judgmental attitude towards the patient. In this manner, health care providers can support chronic pain patients as they manage pain more efficiently and so maintain a high quality of life. Findings have further suggested the need to develop closer liaisons between various health care providers in efforts to insure successful multidisciplinary care based on effective communication with patients and among those providing treatment. Conducting a dialogue with patients about their accounts of pain and validating these stories through attentive listening is crucial in having these sufferers accept their pain and improve their quality of life despite the pain. A wide range of psychological approaches can assist patients, including acknowledging the reality of pain, listening to patient experiences, and addressing distress.

In conclusion, chronic pain requires a multidisciplinary approach since it is experienced as a multifaceted illness. In order to improve the sufferers' quality of life, focus must be given to the most damaging psychosocial symptoms, such as disbelief, distress, isolation, and hopelessness. Understanding the phenomenon of chronic pain and its outcomes demands a multidisciplinary collaboration in research. Hence both qualitative and quantitative research methods are vital, as well as the application of research findings to clinical practice. By involving subjectivity and revealing the individual meaning of pain, the current research study shows that phenomenology offers new insight into to the present picture of chronic pain. Pain has a multifaceted nature which incorporates emotional, psychological, and physical factors. In order to reveal the true nature of the life experience of chronic pain, it is essential to explore all of these elements together rather than independently. Despite studies that have explored specific elements of the chronic pain phenomenon, and so contributed to better understanding chronic pain sufferers, there is still a lack of exploration of this phenomenon in its entirety. For instance, a meta analysis of all existing phenomenological studies can be beneficial. More phenomenological research is needed to increase knowledge about the holistic world of pain sufferers. Other areas in which future research can promote deeper understanding of the life experience of chronic orofacial pain are:

- TMD and nutrition: How does a TMD diet affect the sufferer's life?
- Treating patients with orofacial pain from the perspective of the health care providers
- Living with a family member who is experiencing chronic orofacial pain
- Patients' experiences of disbelief and the health care professionals' decision of whom to believe

APPENDICES

Appendix A: Informed Consent Form

McGill

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Consent form for chronic pain research participants

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

Research Project Leaders:

(McGill Study # 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

Dr. Mahta Hosseinkhani Hazaveh
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 experience of people living with chronic pain. The purpose of this study is to gain insight and understanding about the experiences confronted by people living with chronic pain to enhance the interactions and reduce barriers between the patients and clinicians.

In order to accomplish this we plan to conduct 10 to 15 interviews from participants, who have been suffering from chronic pain. Each interview may last approximately 30 to 60 minutes. Participation is completely voluntary and you may stop the interview at any time during the interview process. The type of questions you will be asked will relate to your chronic pain experience in the past days/months/years.

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

Possible Risk and Discomfort:

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

Potential Benefits:

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

Cost and Reimbursement:

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

Confidentiality:

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

Voluntary Participation and / or Withdrawal:

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

Questions and Contact Information:

This research has been reviewed and approved by the McGill University Institutional Review Board. If you have any questions about your rights as a research participant, please contact Ilde Lepore, Senior ethics Administrator of the Institutional Review Board at 514-398-8302.

If you have a question about the research itself or wish to report any adverse event, you may contact Dr. Richard Hovey or Dr. Mahta Hosseinkhani Hazaveh.

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 GUIDE

Background information:

- Thank interviewees for their participation in the study
- Go through consent form and obtain written consent
- Explain the study and how it will help others suffering from chronic pain.
- Explain how that participants' confidentiality and anonymity will be protected

Questions:

1- What does it mean for you to live with chronic pain?

2- How long have you been living with chronic pain?

3- Please tell me about when and what caused the pain?

4- Can you describe the kind of pain you have?

5- Where do you feel the pain most?

6- What have you learned or been told about your pain?

7- How does a typical day look like for you?

8- Does your pain interfere with your day-to-day activities?

9- How is life with chronic pain different from before? In what ways?

10- Have you received any form of treatment for your chronic pain? Why? Why not?

11- What was your experience of seeking help like? Doctor? Hospital? Dentist? Chiropractor?

12- How did they respond to you?

13- Did you ever feel that you did not receive the treatment you needed?

14- What makes the pain better or worse?

15- Do you take any painkillers or medication for your pain?

16- Apart from all those treatments you have received, what helps you to cope with or manage your pain?

17- Do you talk to anyone about your pain?

18- Do you know anyone else who lives with chronic pain as well?

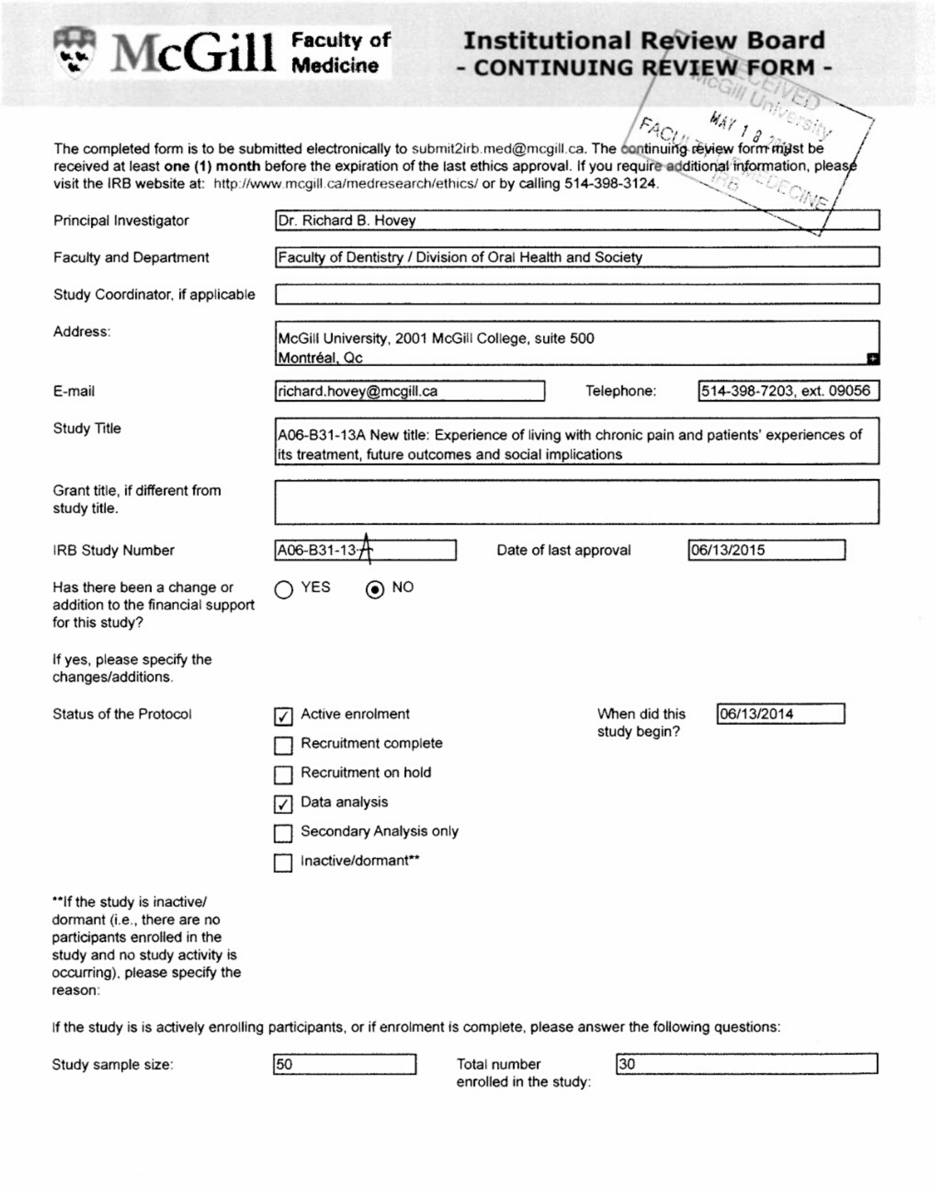
19- What does it feel to live in a body that is in pain all of the time?

20- Do you feel like your experiences with chronic pain have changed you?

21- How do you see your future?

22- Is there anything else you would like to talk about?

Appendix C: Ethics Approval



McGill Faculty of Medicine

Institutional Review Board
- CONTINUING REVIEW FORM -

RECEIVED
McGill University
MAY 1 8 [illegible]
FACUL[illegible] MEDECINE
IRB

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: Dr. Richard B. Hovey

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

Study Coordinator, if applicable:

Address:
McGill University, 2001 McGill College, suite 500
Montréal, Qc

E-mail: richard.hovey@mcgill.ca
Telephone: 514-398-7203, ext. 09056

Study Title: A06-B31-13A New 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: 06/13/2015

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? 06/13/2014

**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: 50
Total number enrolled in the study: 30

Number of participants that have completed this study:	30	Total number of participants withdrawn	0
Projected date of completion of study enrolment:	06/15/2017	Projected date of study completion:	06/15/2018
Please provide a brief description of what has occurred since the IRB's last ethics approval.			
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?	06/15/2015
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):			
Have any adverse events occurred since the last approval?	○ YES ● NO ○ N/A	If yes, how many at McGill sites?	1
		How many at all sites?	1
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:	

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