Understanding the Influence of Changes to Diet on Individuals Living with Temporomandibular Disorder (TMD): An Interpretive Phenomenological Study

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Dedication

I proudly dedicate this work to

ALLAH,

Lord, Creator, and Sustainer of Heaven and Earth,

then to my greatest parents, Dr. Ibrahim Safour and Mrs. Fatima Al-Sharif,

my husband, Dr. Mohammed Amhmed,

and my children, Abdullah Elghaci Amhmed, Ali Elghaci Amhmed,

for their prayers, amazing support, and love.

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Abstract

The objective of this research was to better understand the experience of individuals who had to alter the types of food they were able to eat because of having a chronic temporomandibular disorder (TMD). An interpretive phenomenology research approach was chosen to achieve this purpose because of its utility to gain insight into complex human experiences. Interpretive phenomenology is a qualitative research approach that endeavours to understand the ways in which people make sense of their experiences. Phenomenology was used because the topic is exploratory in nature and enables rich, in-depth accounts of the phenomenon of TMDs as they relate to pain and food choice.

The two major findings from this study were first, the participants' concern for their diminishing health and second, the loss of trust in their dentist and healthcare. The first finding related to participants' health resulting from diet change due to their TMD conditions; these food choice changes resulted in gastric bloating and constipation, a dissatisfaction with not being able to chew previously enjoyed foods, changes in body weight, fatigue, and social connectedness. The second finding was the participants' diminished trust in the healthcare system, and their experience of poor communication about treatments and negative side-effects from prescribed medications.

In conclusion, the findings draw our attention to the general need for more effective treatment of people who live TMDs. Improved education about diagnosis and treatment from healthcare providers would enhance patient outcomes and improve their quality of life. The participants also spoke about the need for improved communication with healthcare providers to develop a therapeutic relationship, share knowledge about diet and nutritional practices, and to address the emotional aspects of living with chronic pain, including intervention strategies and programs designed specifically for people living with chronic TMD pain.

Résumé

L'objectif de cette recherche était de mieux comprendre l'expérience des personnes qui sont contraintes de modifier leur régime alimentaire en raison de troubles chroniques de l'articulation temporomandibulaire (TMDs). Au vu de son utilité pour mieux comprendre les expériences humaines complexes, l'approche de recherche en phénoménologie interprétative a été choisie pour atteindre cet objectif. La phénoménologie interprétative est une approche de recherche qualitative qui s'efforce de comprendre la manière dont les gens donnent un sens à leurs expériences. La phénoménologie a été aussi utilisée parce que le sujet est de nature exploratoire, et elle est riche des comptes-rendus approfondis du phénomène de la douleur et des choix alimentaires liés à la TMDs.

Les deux principaux résultats de cette étude sont les préoccupations des participants pour leur santé qui se détériore d'une part et la perte de confiance en services de santé en général et aux dentistes en particulier d'autre part. La santé des participants se détériore en effet à la suite du changement de régime en raison de leur état TMDs. Ce changement résulte en de ballonnements gastriques et de la constipation, et entraîne une insatisfaction de ne pas être en mesure de mâcher des aliments d'habitude appréciés. Il cause aussi des changements dans le poids corporel, la fatigue et l'isolement social. Quant à la perte de confiance dans le système de santé, elle est causée par la mauvaise communication sur les traitements et les effets secondaires néfastes des médicaments prescrits.

En conclusion, les résultats de cette étude attirent notre attention sur la nécessité d'un traitement plus efficace des TMDs en général grâce à une meilleure éducation sur le diagnostic et le traitement des prestataires de soins pour améliorer la santé des patients et augmenter la qualité de leur vie. Les participants ont également parlé de la nécessité d'améliorer la communication entre les patients et les professionnels de la santé pour développer une relation thérapeutique, partager les connaissances sur l'alimentation et les pratiques nutritionnelles et aborder les aspects émotionnels de la douleur chronique, notamment les stratégies d'intervention.

Preface & Contribution of Authors

The candidate, Wafaa Safour, wrote all chapters of this thesis under the supervision of Dr. Richard Hovey. Ethics approval for this study was obtained by my supervisor, Dr. Richard Hovey. He also created the research consent form. Data was collected between September and November 2017 by the candidate. All transcriptions, the data analysis, and the literature review were performed by the candidate, with Dr. Hovey's involvement throughout all the steps. All the citations provided in this thesis based upon the works of others. The sources of this information are provided in the Reference List.

Chapter 1: Introduction

This study explores the experience of patients who changed their usual eating habits as a result of having a temporomandibular joint disorder (TMD). As compassionate researchers of human experience, we are interested in learning from people who have had experiences that differ from our own. Appropriately researched, interpreted, and written research may provide valuable insight regarding the experience of change in dietary preferences due to TMD pain, enabling greater sensitivity of healthcare providers, clinicians, educators, and others for their patients.(1)

One of the main hurdles facing TMD patients is changing of the quality and quantity of food intake to minimize pain, which is one of the main symptoms characterizing TMDs.(2-4) Most TMD patients tend to choose softer foods that require less chewing to reduce pain intensity.(3, 5-8) Participants expressed a refocusing on the texture of their food rather than on its nutritional benefits, which leads to health issues such as weight gain, weight loss, loss of energy, and mental health issues.(3, 7-11)

Unfortunately, healthcare providers rarely devote time to understand the total suffering some of these patients experience. Providers mainly focus on the medical aspects of treatment while being unaware of the functional, emotional, and social issues that also may contribute to personal suffering.(7, 12) This research is intended to provide healthcare providers with insight into other aspects of the human experience of pain.

Researcher Reflexivity

My motivation for this research is twofold. First, my interest stems from the experience of being a general practice dentist who treats chronic pain patients. Second, I have had personal

experience of suffering chronic knee pain that began four years ago. Consequently, I am familiar with how chronic illness impacts the entire life of patients and the extent to which consequences of chronic conditions become more complicated. Therefore, it is imperative to make explicit the patients' experience through which healthcare providers are offered an expanded understanding and awareness of the healthcare requirements of TMD patients. TMDs affect patients in many ways, ranging from suffering physical pain and reduced productivity and work performance to having digestive dysfunctions that challenge patients' daily life and social experience. Additionally, patients may feel fear, frustration, and eagerness to find healthcare providers who truly understand their suffering and will take the extra time to assess and treat the whole person. I found that interpretive phenomenology was helpful in studying and exploring these patients' experiences, which profoundly motivated me to learn from people who themselves live with chronic TMD pain.

Chapter 2: Background

Orofacial pain (OFP) is defined as pain localized to the region in front of the ears, above the neck, below the orbitomeatal line, or in the oral cavity, and most commonly results from toothache and temporomandibular disorders (TMDs).(13) Toothache is defined as pain in the oral area, which may include pulpal pain, periodontal pain, or heterotopic pain.(14) Tooth pain or pulpal pain varies according to whether it is acute or chronic, but it is often difficult to localize. Periodontal pain or soft tissue pain may be acute or chronic, with a burning sensation of pain because of surface lesions and usually can be discretely localized.(14, 15) OFP (excluding toothache pain) accounts for 25% of the population, with up to 11% in chronic pain.(13)

Chronic orofacial pain (COFP) is often classified by symptoms and systems into four major types—vascular, musculoskeletal, neuropathic, and psychological/psychogenic pain—and/or pain with overlapping conditions. The influence of medications used to treat COFP may also influence nutrient absorption and diet.(3) These influences can affect patients' overall food intake, digestion, and absorption of macronutrients such as carbohydrates, proteins, and fats; and other prescribed medications can cause micronutrient depletion of minerals, vitamins, and organic acids either by preventing nutrient absorption (primary malabsorption), enhancing nutrient elimination, or both OFP symptoms can last for more than six months in some patients with consequences that impact various aspects of daily life, including loss of employment, sleep disturbance, fatigue, social withdrawal, difficulty chewing/eating, and anxiety about their oral and dental health.(16, 17) While specific causes of these conditions are frequently unknown, some factors such as neurophysiological, psychological, and mechanical factors play a role in

"perpetuating, predisposing, or initiating" painful facial conditions.(18 p 51a) People living with OFP seek out a variety of healthcare professionals, including dentists, headache specialists, otolaryngologists, maxillofacial surgeons, neurologists, chronic pain specialists, psychiatrists, physiotherapists, and psychologists.(19-21) OFP is associated with comorbidities with frequent healthcare utilization.(13)

The American Academy of Orofacial Pain defined TMD as a "collective term embracing a group of clinical problems that include the masticatory musculature or the temporomandibular joint (TMJ) and associated structures, or both."(3 p127-186, 22) The two most common types of painful TMDs are myogenous, or muscle-generated pain; and arthrogenous, or joint-generated pain.(23) TMDs are a group of clinical problems that include the masticatory muscles, TMJ, and the associated structures, such as capsule, articular disc, and retrodiscal tissue.(24-28) These conditions are characterized by chronic pain and dysfunction of the masticatory system or both.(2, 29) They also limit the movement of the lower jaw—locking, or stiffness of the jaw or both—and affect between 13.5% and 47% of the general population.(24, 29)

TMDs rank second among common chronic pain conditions with a prevalence of 5% to 12% in the general population; only musculoskeletal lower back pain has a greater prevalence.(2, 29-31) However, the etiology of TMD is still not well understood even though the annual cost for its treatment doubled, amounting to $4 billion dollars in the last decade.(2) The poorly understood causes of TMD add complexity to its treatments, which includes physical, pharmacological, cognitive-behavioral, and dietary therapies.(32) Approximately 50% of patients who suffer from TMD look for professional dental or psychotherapeutic care, and nearly 33% of them will continue to suffer from moderate to severe levels of pain, disability, and psychological distress independent of the treatment received.(33, 34)

TMDs commonly force changes in personal nutrition choices because of chronic jaw pain. Decreased oral functioning severely affects a person's capacity for masticating food and, consequently, alters their diet.(35) Mastication is important not only for food consumption but also for mental and physical functioning, and interferes with other systemic actions, including blood circulation, locomotion, excretion, endocrine function, and reproduction.(36) Multifactorial TMD conditions affect appetite and motor functions of the oral cavity, such as mouth opening, biting, and chewing, which are associated with pain and discomfort, (3) (3) (3) (3) (3) (3) (3) (3) (3) (3) (3) and painful TMD conditions may also negatively affect the sensory factors that involve drinking, eating, and swallowing, resulting in changed dietary intake and subsequent nutritional status.(3)

According to previous physiology studies, the masticatory process appears to be fundamental for gastrointestinal (GI) absorption for certain foods like meat, vegetables, and fruit.(37) The cornerstone of the masticatory process is the TMJ and surrounding structures, such as muscles of mastication, blood vessels, and nerves that occur in the oral phase.(38) In the oral phase, food is cut mechanically into smaller particles by chewing, mixes with saliva, which aids in taste, and then is transferred to the bolus for swallowing. In this phase, digestion of starch and lipids in the food is also initiated.(39) Saliva involves several factors that serve the nutritional canal mucosa against acidity.(40) Food mastication induces saliva production, which consequently increases its buffer capacity.(41) Any defect in the salivary function or defect in mixing food properly with saliva could lead to many systemic disorders and conditions, including malnutrition, eating disturbances, anorexia, and anemia.(39) This discussion confirms the relationship between adequate chewing and the integrity of the digestive system.

Nutrition is defined as the process by which a living organism takes in food and uses it for growth metabolism and tissue repair, while diet is more narrowly defined as a regimen of food intake planned to meet specific requirements of the person, including or excluding certain foods.(42) Both nutrition and diet have a significant influence on general health and are also considered as major considerations that contribute to improved health status. Consequently, oral health impacts on nutrition and diet by affecting a person's ability to eat.(3) Food quality and nutritional status are crucial for conserving and promoting health throughout our life span.(3)

Consequently, pain affecting the masticatory system will lead to the need to change previous diet and dietary preferences as well as avoid foods that are difficult to chew, causing pain or irritation.(3, 5, 6) These physical implications may subsequently lead to a possible avoidance of fruits, vegetables, nuts, and whole grains, which contribute to a healthy diet.(3, 5, 6) Additionally, 14% of TMD patients may also have symptoms of a psychiatric illness, such as sleep disturbance, energy loss, weight loss, concentration changes, and feelings of depression.(3, 7-11, 43, 44). All of these factors individually or in combination may have a profound effect on the person living with TMD thatover time may affect their overall health.

While alleviating personal suffering is essential in all aspects of medicine, chronic pain offers a unique challenge of learning how to manage pain while learning to live their lives with life-altering circumstances.(45) Unfortunately, healthcare providers who are concerned with alleviating pain take less time to help their patients cope with suffering that is lived outside of healthcare.(12, 46) In an acute care medical model providers are predominantly focused on identifying the biomedical needs to rid the person of their pain, while often ignoring the functional, emotional, and social issues that add to personal suffering.(12, 46) Therefore, understanding these aspects might help healthcare providers become more aware or empathetic

about their patients' experiences. In a discussion about whole person care, understanding the implications of having to choose softer foods that require less chewing can result in the unintended consequences such as weight loss or gain, loss of energy, digestive problems, and fatigue that follow from their choices.(3) There is a lack of literature of established guidelines for neuropathic or neurovascular disorders except for avoidance of specific trigger foods and validated standards to evaluate and manage diet and nutritional wellbeing in patients with TMDs. Therefore, specialists may not able to assess diet and nutritional status related to quality of life in these patients.(3)

In summary, understanding the influence of changes to diet and nutrition for individuals living with TMDs is the reason to engage in this research study. I hope to make a contribution to understanding the implications of OFP on the nutrition and diet of people living with chronic TMD pain. I hope to disseminate my research findings to medical and dental communities through such means as publications, creating educational programs, presentations at national and international scientific meetings, conferences, and seminar series.

Chapter 3: Aims and Objectives

Aims

The purpose of this study was to gain a deeper understanding of individuals living with temporomandibular disorder (TMD) who experience related changes in their nutrition and diet. I explored the health care experiences that TMD patients endured to become aware of this issue and understand obstacles that people living with chronic pain face. My literature review revealed a lack of research related directly to the understanding the influence of changes in nutrition and diet for individuals living with TMD in term of health. To gain insight into this topic, I wanted to explore research guided by the following questions: What are the experiences of people living with TMD and what are the consequences of changing their food choices on their physical, emotional, and social wellbeing.

Objectives

In this study, the following objectives were pursued:

- To explore the suffering of people living with TMD, the way they live, as well as the extent to which they describe their experience that may inform provision of healthcare.
- To contribute to the knowledge of the TMD experience and personal suffering to widen our understanding for other patients, researchers/clinical practitioners and educators.
- To inform healthcare practitioners about the lived experience of TMD conditions; to encourage effective communication between TMD patients and their healthcare professionals that provides patients with improved approaches on how to prepare healthy orofacial pain-friendly food. The intention of sharing this knowledge is to add a different dimension for healthcare providers to consider when supporting their TMD patients who

have chronic pain beyond only physical aspects of treatment.

To deepen our knowledge, we need to more closely understand the suffering of others. This process is not done as an objectification of others' suffering where one might feel sympathy because of their situation; but rather, we suffer along with the other within a compassionate-relational connection. We learn through and with the patients' direct experience that we share as a common topic and use to inform others.

Chapter 4: Literature Review

Chronic orofacial pain (COFP) is classified within musculoskeletal conditions such as temporomandibular disorder (TMD), vascular disorder, and neuropathic disorder.(3) Orofacial pain (OFP) affects the pleasure of eating and consequently quality of life and may also negatively affect general health.(3, 10, 47) The most common chronic orofacial conditions are TMDs.(48)

TMDs have a high prevalence, between 5% and 12% in the general population, ranking second behind chronic lower back pain as most common amongst musculoskeletal disorders.(2, 29-31, 36) The two most common types of painful musculoskeletal TMDs are arthralgia and myofascial pain (MP).(32, 49, 50) Arthralgia is localized to the temporomandibular joint (TMJ), including conditions that originate from and cause pain there.(49, 51) Typical jaw movements associated with chewing food may exacerbate TMD pain.(18, 52) MP is considered as a source of discomfort in individuals with regional pain symptomatology.(53, 54) The prevalence of MP is around 30% in patients with local pain complaints seen in primary care clinics and up to 85% in patients at specialized pain management centres.(55, 56) Patients with a severe intensity of myofascial pain syndrome (MFP) are likely to reduce their consumption of dietary fibre.(8, 53)

Most TMD patients struggle with food choices because pain forces them to change their dietary intake and thus influences their nutritional requirements.(2, 3, 32) People living with TMDs attempt to reduce pain intensity by choosing soft foods that require less chewing.(3, 5-8) A focus on the texture of their food rather than on its nutritional benefits may lead to other health

issues such as digestive problems, weight loss or gain, and loss of energy, with many such patients suffering psychological concerns.(3, 7-11)

Pain is the main concern in more than 97% of TMD cases.(57, 58) Increased pain leads to a decrease in one's capacity to chew food, which negatively affects patients by reducing their ability to eat the variety of foods previously enjoyed. Consequently, enjoyment of life is diminished when mood, social relationships, activities, sleep quality, and overall quality of life is affected.(2, 35) Deterioration of social life results from suffering theloss of or changes in social interactions, relationships, the ability to enjoy eating, employment, disengagement in social activities, lself-identity, and isolation.(59, 60) People living with TMDs feel that because their chronic pain is invisible, their families and the medical community may not fully acknowledge their situation. (60)

Unlike with terminal diseases with which sufferers "live in prognosis" organized by the stages of disease(61), the everyday experience of chronic pain gives no temporal context and no patterns on which to pin one's sense of a life process.(62) TMD patients are not at risk of becoming ill or having an unknown future, but they are at risk of fluctuating levels of pain than what they had previously experienced.(62)

Many OFP patients feel dissatisfied with the healthcare system that they journey through.(60) If the relationship between healthcare providers and OFP patients is ineffective and unsatisfactory in terms of management (63), the quality of this connection may further diminish.(64) The importance of this relationship reveals that a therapeutic alliance may either enhance the patient experience or diminish it by creating barriers perceived as negative by the person living with chronic pain.(63) "The subjective, quantifiable prevalence, frequency, and severity of symptoms placing a physiologic burden on patients and produce multiple negatives,

physical, and emotional patient responses."(65 p 693) Patients with chronic pain are constantly and understandably distressed, and many can become depressed. The empathic dentist understands and considers these feeling when designing an individualized treatment plan. Suffering an uncertain diagnosis generally causes complaints that impact negatively on daily life; if the diagnosis is uncertain, the focus should be chronic pain management and life skills.(66)

The data from other pain conditions suggest that an increased understanding of the role of nutrition in COFP might assist in an adjunctive capacity to improve the general outcomes of therapy.(3, 51) Improving the patient-doctor relationship could help enhance treatment.(12) The research findings of this study will help inform medical practitioners with more details on how COFP conditions affect their patients' lives, and therefore help them communicate more effectively with their patients by, for example, providing improved guidelines about how to prepare healthy, OFP-friendly meals or referral to another health care provider who specializes in these types of disorders.

I conducted my initial database search using the search terms TMD and diet/eating for qualitative research in Ovid Medline and Ovid Embase. This comprehensive search, accomplished with the help of a medical librarian, yielded few articles on this topic. However, this chapter is a brief account of the results from selected published studies that are relevant to this research. The literature reviewed will be discussed in terms of nutrition, central mechanisms of TMD pain, the relationship of chronic TMD pain and nutrition, TMD and suffering, and doctor-patient communication.

Nutrition

Nutrition is a scientific term that describes how diets meet energy output and balance the needs and demands of cellular activity, development, and tissue maintenance; consequently,

nutrition is fundamental for human growth and health, resisting infection, and disease prevention.(3) Furthermore, responses to medical therapies, especially treatment of physical and iatrogenic conditions, are primarily determined by one's nutritional status.(3) The relevance of nutrition for TMD patients who frequently have other comorbidities, such as headache, neck pain, back pain, fibromyalgia, and stomach pain is of interest to this study.(67)

Nutritional status is a measurement of the extent to which an individual's physiological need for nutrients is being met by his or her dietary patterns and choices.(68) Thus, measurements of nutritional status entail a review of dietary intake, biochemical markers of nutrient status, and anthropometric measures, as well as an assessment of clinical indices of health.(3, 69) Nutritional status is influenced by many common health conditions, including chronic pain conditions, frequent alcohol intake, suboptimal dietary consumption, changes in appetite due to aging, eating disorders, and food allergies or sensitivities to special diets; insufficient income for nonprocessed foods can also impact dietary choice and consumption.(70, 71) Moreover, many of these conditions may contribute to a deficient state of nutrition with a potential to change mental status.(70)

Malnutrition remains a serious international concern. Over the last decade, the estimated proportion of people who are undernourished has gradually decreased, but the absolute numbers still remain high.(72) The Centers for Disease Control and Prevention (CDC) have recognized four common causes of chronic diseases that include poor nutrition, lack of physical activity, excessive alcohol consumption, and tobacco use.(73) According to the World Health Organization's report of Global Burden of Disease assessment in 2000, the protein or/and calorie under-nutrition contributes to approximately 10% of the world's total burden of disabling illness and premature death.(72, 74)

Central Mechanism of TMD Pain

People living with TMDs that are musculoskeletal in origin may experience motor limitations that impede their ability to open and close their mouth, chew, and bite due to pain and discomfort. Illness or inflammation created by TMJ and related craniofacial tissues induce neural changes that increase excitability of the trigeminal nociceptive pathways in the brain.(3, 75) The nociceptive afferent nerve fibres which innervate the TMJ and other craniofacial tissues extend to the brainstem and can stimulate nociceptive neurons in the pain pathways.(75) The central substrates for TMJ pain are plastic, which means that they can be influenced by peripheral events and change in intrinsic modulatory systems. Furthermore, some of the central neurochemical mechanisms may be implicated in psychological change (e.g., related to anxiety, depression, stress, etc.) that may intensify the expression of pain, while others may contribute to the efficacy of some centrally acting drugs and other analgesic approaches used for pain relief.(75)

The Relationship Between Chronic TMD Pain and Nutrition

Diet, nutrition, and OFP are multifaceted and can work synergistically to influence the pain experience.(3, 76) The neuropathic, musculoskeletal, and vascular natures of OFP and its treatment can influence appetite and motor function, as well as sensory factors involved in drinking, eating, and swallowing.(3, 76) Chronic pain conditions have the potential to exert a long-term influence on dietary intake and, consequently, on nutritional status.(65, 77) Since TMD pain affects chewing and eating, disability of the jaw has negative effects on metabolic needs of the body and nutrition, and results in compromised nutrition if the jaw pain and oral disability seriously change the patients' diet.(35, 47)

The masticatory function is important not only for food consumption but also for the mental, systemic, and physical functions of the body.(3, 36, 47, 78) A high percentage of patients

who have eating disorders also suffer from moderate to severe facial pain; they might even have symptoms of psychiatric illness, feelings of depression, energy loss, weight loss, concentration changes, and sleep disturbance.(18) Patients with a severe intensity of MFP are likely to reduce their consumption of dietary fibre, possibly due to their attempt to decrease masticatory activity to avoid exacerbating facial pain.(8) TMD patients are limited in their ability to open their mouths, bite, and chew.(51, 79) These limitations can be mediated by a fear of pain caused by jaw movement, and the pain itself has a passive impact on oral functional abilities and diet selection.(51, 62) Painful TMDs may influence dietary intake and eating-related quality of life (ERQoL), thus negatively impacting nutritional status if the patient experiences pain due to TMDs over an extended period.(32, 51, 80, 81)

Along this line of thinking, patients who limit their food intake because of reduced masticatory function fall usually into the first two classes of protein-energy malnutrition.(82) In terms of excluding hard foods, older studies point out that apples, meat, and bread might frequently be banned from the OFP patients' diet.(51, 83) In addition, recent studies have recommended that meat and vegetables be prepared differently by using softer cooking methods.(51, 84) OFP patients choose to exclude foods that require more chewing, such as dietary fibre, whole grain foods, and vegetables that are rich in vitamins, antioxidants, and minerals but require more chewing.(4) Clinicians need guidelines to help TMD patients improve the quality of their diets and minimize or avoid eating-related pain, but promulgated dietary guidelines for patients with neurovascular or neuropathic disorders are lacking, except for excluding specific trigger foods.(4) Poor nutrition combined with other risk factors, such as physical inactivity or tobacco use, may amplify the prevalence of chronic illnesses, including

diabetes, obesity, cancers, osteoporosis, cardiovascular disease (CVD), and oral diseases.(3, 4) Conversely, oral health may influence dietary intake and nutritional status.(71)

In conclusion, we understand these points:

- The study by Brenseke et al.(78), Kafas and Leeson(47), and Nakata(36) demonstrated the importance of mastication for physical and mental health.
- Goldberg et al. study pointed out that there is a correlation between eating disorder and orofacial pain, and that patients who have these conditions could suffer from mental and physical illness.(18)
- Raphael et al. stated that a reduction in dietary consumption occurs because of myofascial pain.(8) Durham and Touger-Decker et al.(51) and Reiter et al.(79) emphasized this conclusion by Raphael et al. Irving et al.(84) and Nasri-Heir et al.(56) concur, and also found that painful TMDs negatively affect ERQoL.
- Schimmel et al. conclude that malnutrition could happen for those who have reduced masticatory function.(82)
- Durham and Touger-Decker et al., Greene et al., and Nasri-Heir et al. stated that most OFP patients exclude hard food from their menu, and that the quality of dietary intake and eating behaviours might be influenced by painful TMDs.(4, 51, 83) Moreover, the ability of TMD patients to eat and drink comfortably in social situations is still a significant concern for those with these conditions.

TMD patients often modify their eating habits due to pain, which compromises their diet.(3, 80) Both adaptive and maladaptive behaviours are common as patients with TMDs attempt to minimize the factors that initiate or increase pain.(80)

The Impact of Chronic TMDs on Quality of Life

An individuals' decreased ability to consume food is associated with a poor oral health-related quality of life and higher depression levels.(85) The enjoyment of life becomes diminished as a result of the decreased eating and chewing of previously enjoyed foods, which suggests that jaw disability not only influences one's metabolism resulting in fatigue, but also impacts life enjoyment for persons living with chronic pain.(47) Physiological and psychological influences of OFP may also change the enjoyment that individuals derive from eating, their food choices, the composition of their diet, and subsequently their quality of life.(51, 86-88) The ability to eat and drink comfortably in social situations concerns patients with OFP.(4, 51) COFP patients suffer a pervasive sense of hopelessness resulting in a lack of faith in their future with respect to all aspects of their life, socially, emotionally, and physically.(89, 90)

TMD Pain, Nutrition, and Mood

Mental health may be influenced by inherited genes and can also be altered by environmental influences and nutritional status.(70) Reduction in life enjoymentis strongly correlated with a negative effect on the mood of TMD patients, which may diminish a desire to attend social activities such as going out to restaurants and family dinners.(47)

Mental health and the individual's quality of life can be affected by a reduced capacity in food intake. Choi et al. demonstrated that as one's ability for food intake decreases, quality of life declines and depression increasesindependent of sociodemographic factors.(85) Brandini et al. in their study titled "Chewing in Temporomandibular Disorder Patients: An Exploratory Study of an Association With Some Psychological Variables" concluded that psychological factors, manifesting as stress and depression, could influence the association between pain and motor activity.(10)

Appleton and Roger showed that since ancient times the consumption of food and drink has been considered to have effects on mood, ranging from increased happiness, relaxation, alertness, contentment, energy, relief of sadness and anxiety, to feelings of guilt and failure.(91) Leyse-Wallace also mentioned that eating whole foods is preferable to capsules of nutrients, and that real food does are not amenable to double-blind experimental conditions because aroma, taste, and mouth sensations are giveaways.(70)

Side Effects of OFP Medications

Medications can influence appetite as well as GI function, resulting in alterations in food intake by having either a central or peripheral (localized) effect.(3) The medications prescribed for MP combined with low dietary fibre lead to an increased risk of constipation, and may also worsen comorbid medical conditions.(8) Analgesics and muscles relaxants are used for relieving TMDs pain; tranquilizers are used for anxiety, fear, and muscle tension; antidepressants are used for pain, depression, and enhancing sleep; and sedatives are used for improving sleep.(68)

COFP is commonly treated by using nonsteroidal anti-inflammatory drugs (NSAIDs). Serious adverse effects occur when these medications are used on a long-term basis as for many chronic pain conditions.(92) According to Ganzberg, using NSAIDs for a long time period to treat chronic diseases such as TMDs and MP requires laboratory monitoring for adverse renal effects, GI bleeding, and possible hepatic impact.(66) Randomized clinical experiments on anti-inflammatory medications NSAIDs, such as ibuprofen, for the management of myalgia recommend short-term use of these medicines for analgesic and/or anti-inflammatory effects.(92) MacDonald and Sheen supported this view based on their observation of a large number of studies that have endorsed this class of drug, finding adverse side effects on cardiovascular, renal, and GI systems ranging from minor dyspepsia to severe and life-threatening GI

hemorrhage and perforation.(92) While patients do not usually require hospitalization for minor side effects, they may still access healthcare resources for continued treatment. More severe adverse effects may require hospitalization, medical intervention, and additional healthcare resources.(92)

Many in class of pharmacological agents used to treat musculoskeletal spasticity cause a high degree of sedation.(66) Benzodiazepines, including diazepam and clonazepam, have been shown to be effective for muscle pain especially with stress and sleep disturbance.(93, 94) Cyclobenzaprine (Flexeril) has also been shown in clinical experiments for myalgia to be effective in reducing pain, improving sleep, and can be considered as an alternative if benzodiazepine is too sedating.(95) Potential side effects from the long-term use of skeletal muscle relaxants involve sedation, addictive potential, and hepatotoxicity; these side effects are more likely to occur in seniors.(66, 96-98) For example, the adverse effects of benzodiazepines such as diazepam include sedation, confusion, and anterograde amnesia, especially in higher doses.(97) Dizziness, fatigue, drowsiness, constipation, blurred vision, or headaches may also occur.(99) Furthermore, Additionally, mental/mood changes (e.g., memory problems, agitation, hallucinations), clumsiness, trouble walking, decreased/increased interest in sex, slurred speech, tremor, difficulty urinating, and/or sleep disturbances have been observed.(36)

Antidepressants are often prescribed to chronic pain patients due to an increased risk of depression from the burden of continuous daily pain.(66, 100, 101) Ganzberg observed a relationship between depression and chronic pain.(66) Additionally, antidepressants have an independent analgesic effect, but the adverse effects of these medications, including sedation, dry mouth, and orthostatic hypotension are likely to occur.(66)

Opioids could also be used for chronic pain management. However, if opioids are used for extended periods, dependence and tolerance can develop in patients who then may need to change the type of opioids periodically to maintain the benefit of the medication, but many patients can maintain a stable dose for an extended period.(66) The most common side effects of opioids are constipation and nausea, and with careful titration, respiratory depression and orthostatic hypotension are less common.(66)

Overall, the side effects of OFP medications intensify the decrease of dietary intake, which can have a devastating impact on patients' general health and quality of life.

TMD and Suffering

What is Suffering?

Suffering can be explained as a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. Hovey and Amir quote the Levinas definition of suffering as "not a private affair but solicit[s] the concern of the human community, calling for aid and compassion from physicians, parents, siblings, children, science, hospitals," and highlighting that our suffering takes on meaning through understanding the suffering of others—the "suffering for the other's suffering."(1 p161, 102) Suffering includes some symptoms or processes that threaten patients because of fear, concerns about the future, or the meaning of the symptom, which are a personal and unique experience for each patient.(45) Coping with constant pain is a continual source of concern and involves many life adjustments. Chronic pain such as that associated with TMD or illness introduces disorder to the temporality of lived experience.(62, 103-105)

Doctor-Patient Communication

The doctor-patient relationship can be understood as a significant therapeutic interaction between patients and their healthcare providers.(106, 107) This interaction promotes both a trusting relationship and improved communication where the healthcare provider and patient learn from each other.(106) Effective doctor-patient communication can be achieved by spending adequate time with patients to develop rapport while discussing the illness, treatment plan, and managing their condition.(106, 108-110)

Ha and Longnecker's literature review about doctor-patient communication stated that many patients seem to be dissatisfied with their doctor-patient relationship due to time restraints and lack of information provided about their condition.(12) This dissatisfaction was shown to be related to older practitioners who failed to focus on holistic patient care and the physical and emotional objectivity acquired during medical training, particularly in residency and internship, resulted in a lack of empathy and a lack of knowledge about how to enter into difficult emotional conversations.(12, 111)

Lack of trust can result from failure to respond to the specific needs of a patient.(112) In their study of patients whose dental needs were unmet Muirhead et al. found a lack of trust and confidence in their dentist were more likely associate with poorer scores on Oral Health-Related Quality of Life (OHRQoL).(112) Wolf found that COFP participants who expressed that their needs were taken care of, yet still conveyed limitations in their ability to cope with painful conditions, which highlights that a constructive approach in dentistry is necessary in caring for patients who have COFP.(89)

Conclusions

The current literature review extends our understanding of the complex effects of TMD for patients, which affects between 5% and 12% of the general population.(2) The suffering of

TMD pain and medication side effects for patients' nutrition and general health is exacerbated by misdiagnosis and poor communication with healthcare providers.

Although a number of quantitative studies have investigated the relationship between TMD and nutrition, with several qualitative studies regarding psychological effects of OFP on patients, currently no qualitative studies have investigatied the experience of TMD patients in terms of diet change on physical and social health. Few of the studies reviewed attempted to research in detail the extent to which changing diet affects patients' general health through insufficient oral functioning and a compromised quality of life, depression, and fatigue. Because knowledge on this topic is still limited, we lack a broader understanding of the perspective of TMD patients and the barriers they face regarding diet change diet.

In this project, I intend to better understand the TMD patient experience and inform healthcare providers and educators about ways to assist these people to learn to live better with such painful conditions. I hope that my findings can provide healthcare providers, dental education, and continuing professional dental education with clear details and transferable information about the barriers that TMD patients face as result of forced changes in food choice. This study hopefully will create effective communication between patients and healthcare providers, so they can provide patients with improved guidelines on how to prepare healthy food and learn to live better with TMD conditions.

Chapter 5: Methodology

Research Approach

Through this research, I intend to explore and understand the experience expressed by people living with orofacial pain (OFP) who must change their food choices to accommodate their pain. The research approach chosen was interpretive phenomenology because its foundational underpinnings are rooted in lived experience. Phenomenology, through its philosophical bases, views the world through a socially constructed, interpretivist lens in which people are always interpreting the world around them, reflectively.(113, 114) Interpretive phenomenology thus became a means of using interpretation and perspective to understand phenomena: events and experiences that happen to us.(114, 115)

Interpretive Phenomenology is a qualitative research approach in the human sciences that is deeply rooted in philosophical foundations.(116, 117) It involves an exploration of the lived experience of some phenomenon, or occurrence.(115) Phenomenological researchers endeavour to understand the ways in which individual participants, and participants as a collective, make sense of that experience.(116-118)

This study explored the lived experiences of participants who must consider adopting a new diet. A collection of individual perspectives provided the foundation on which the researcher came to an understanding of the experience of eating differently.(119) Interpretive phenomenology was used in this study because the topic is exploratory in nature, and sought

rich, in-depth accounts of the phenomenon of transitioning from one way of eating to another.(116)

Selection of Participants

When selecting participants for interpretive phenomenological research, researchers must ask themselves whether the participants have the experience they are looking for.(116) With this question in mind, my research task was to find and select participants who experience chronic temporomandibular disorder (TMD) pain that forced them to implement changes to their diet.

I sought out a sample size of approximately 6 to 8 participants, which is appropriate for graduate master's-level research.(116) The interpretive phenomenological approach in human science does not base its sample size on the number of participants but rather on the availability of suitable participants.(116, 120) The researcher's intention is to explore a phenomenon of interest, and is not dependent on the number of people recruited into the study.(116)

Given that I was seeking to speak with persons who were experiencing chronic TMD pain and have made changes to their diet, my inclusion and exclusion criteria were as follows:

Inclusion criteria:

English speaking

Experiencing TMD pain beyond 6 months

≥ 18 years old

Exclusion criteria:

Non-English speakers

TMD pain less than 6 months

Not younger than 18 years old

Recruitment of Participants

The participants were recruited between September and November 2017 from the McGill University student dental clinic, the Jewish General Hospital, and the Montreal General Hospital. Firstly, the supervisor of this study had contacted the dental departments at the Jewish General Hospital and the McGill Dental Clinic to allow the researcher to recruit and interview TMD patients. I met with the healthcare providers responsible for the examination and treatment of the TMD patients in all facilities and explained the aims of the study and provided Institutional Review Board (IRB) approval and consent forms (Appendix 1A and 1B). At the McGill Dental Clinic, the orofacial specialist, who also works at the Montreal General Hospital, asked to help contact patients who were eligible for the study to ask whether they were interested in participating. At the Jewish General Hospital, the professor responsible for the TMD studies in the dental department introduced me to graduate students who were working on TMD quantitative studies to select participants for the current study. If the patients agreed to take part in the study, then I could get access to patients' contact information and approach them to ask whether they would participate in the study. I approached prospective participants either by telephone, text message, or email using a contact script (Appendix 2) to briefly explain the intentions of the study, invite them to participate, confirm their agreement to participate in the study, and to schedule an interview.

Data Collection

I adopted two techniques for collecting data from my participants. The interviews were held face-to-face with the participants and audiorecorded account of the experience.(116, 121) I encouraged participants to express their experiences of living with TMD through a conversation rather than a formal interview, which provided me with rich and detailed information.(122) The open-ended questions for each semi-structured interview let participants explore their

perspectives and explain their experiences in depth and detail, enabling them to express additional issues that might not be covered specifically by the my interviewer questions.(123)

The interviews were conducted in English at the McGill University's Faculty of Dentistry. A quiet, private office was chosen to allow the participants to feel comfortable to talk and freely express their experiences. At the beginning of each interview, I thanked the patients for participating in the study and introduced myself (Appendix 3). This prelude that started the interview also hopefully provided a relaxed atmosphere. I then explained the aim of the research study, the interview process, and reviewed the participant consent form (Appendix 1B). During the interview, I followed the interview guide (Appendix 4) while allowing other questions or topics to arise.(123) The interviews ranged from 15 to 90 minutes in length. Each interview began with less sensitive topics by asking participants to speak a little bit about themselves, which was followed by questions about their general experience with TMD. The next questions were much more specific and focussed on the research topic.(123) Questions during the interview were flexible and changed to include the variety of issues presented by patients regarding their experience with TMD and nutrition.

In qualitative research, the use of an audio recorder is important to collect interview data for transcription and analysis at a later stage in the study.(124, 125) Recording the interview allows the interviewer to focus on the conversation rather than taking notes. Recordings also capture changes in speech, emotion, pauses, etc., that are vital components of the original conversation.(126, 127)

Data Analysis

This chapter describes phenomenological research as an"approach" that does not follow a prescribed or controlled process, but is based on and rooted in philosophy.(116,117,119,120,128)

Coherent application of the philosophy—using data collection methods and procedures consistent with phenomenological theory—is a crucial part of phenomenological data analysis.(116,117,129) Instead of strict procedures and rule, phenomenological data analysis flexibly responds to the research question.(130) Van Manen invites us to see phenomenology as a "way toward human understanding."(131) As such, there are multiple ways to approach data analysis in phenomenological research.(128)

Philosophy is the foundation for all steps of the research process, and makes phenomenology what it is: rich, nuanced, and adaptable. Numerous steps in the research process (interviewing, data transcription for analysis, writing nonverbal clues, e.g., sighing, smiling, and physical expression that are noted in the interviews in each transcript, listening to audio recordings, reading and re-reading the narrative data, comparing the transcript data to the audio recordings of the interviews, and then grouping similar interview excerpts) familiarized me with the data and facilitated the development and interpretation of "findings," the descriptions of the phenomenon in question.(113, 129, 132) To ensure that the findings were relevant and to gain credibility, data analysis was carried out by the researcher and the supervisor.

Ethical Considerations

Ethics approval was obtained in June 2017 from McGill University's Research Ethics Board Office. This approval was extended to allow interviews to take place until June 2018 (Appendix 1A). Psychological or physical harm is a minimal risk to the participants of this study.

At the beginning of each interview, the study purpose and process was explained to the participants and any questions were answered. This information was discussed face-to-face or provided to participants via handouts (Appendix 3). An informed consent form (Appendix 1B)

outlining potential risks and benefits was explained to each potential participant. Each participant then signed the consent form, and a copy was provided to them. I informed participants that they had the right to not answer any question that made them feel uncomfortable during the interviews. Also, the participants had the right to withdraw from the study at any time before the publication of the results without any explanation. During the process of gaining consent, the researcher explained to participants that all collected data would be stored confidentially, with their identity protected. Therefore, pseudonyms for participants' names were used with the study team (the student researcher and supervisor), any other person involved to identify participants, and any name mentioned by the participants.

Chapter 6: Findings

In this chapter, I briefly describe the participants. I share my findings, which are grouped into two major themes of 1) discontentment from a diminishing sense of health, and 2) loss of trust in dentists and healthcare.

Description of the Participants

The six individuals who agreed to participate in this study included four females and two males. Three participants, originally from India, Korea, and Iran, immigrated to Canada. Two participants were from Quebec. One participant was from Ontario. Participant demographic information about age, education, occupation, and residence location is shown in Table 1.

Table 1. Participant Demographics

Participant ID	Residence	Age (years)	Sex	Education	Occupation
Saddam	Montreal	51	Male	PhD	Student
Maryam	Montreal	22	Female	Undergraduate	Student
Jon	Montreal	29	Male	Masters	IT Advisor
Noor	Montreal	25	Female	Bachelor	Music Teacher
Monika	Montreal	64	Female	Masters	Retired
Shanna	Montreal	39	Female	Bachelor	Massage Therapist

Saddam

Sadam was a 51-year-old PhD student who, at the time of the interview, had been suffering from chronic pain for approximately ten years. According to him, the problem began with the mismanagement of his diagnosis. Consequently, the problem exacerbated into complex

health issues as a result of changing his diet. In general, he was agitated because of what happened to him regarding these conditions:

> *This is happening for the last ten years and because it was a mismanaged case, so because the teeth moved around, and I don't have the same contacts, and the prosthodontic cannot be done finally. I got into this temporomandibular joint pain and the experience of living with it. It's not fun because sometimes you start to have pains and creaks and you feel that the bite it's not in the right place, and it's just the thing that decreases the joys of life.*

Maryam

Maryam was a 22-year-old undergraduate student when she attended the interview. She was frustrated and anxious due to the effect of temporomandibular disorder (TMD) pain on her food choices and her health. Maryam expressed feeling miserable and that nothing helped to improve her TMD condition. She was slightly nervous at the beginning of the interview, but she felt more comfortable as the interview progressed:

> *It really started when I was in elementary school. I noticed that my jaw would click when I would eat, and it didn't bother me at the time. It was just like something that was like audible like my friends could hear it when I ate even. But then over time about a year ago it started to move when I would try to eat. And then you would have to push past that, and then when I would push past it, it was certain to hurt. And two months ago, it started where no matter what I ate and what I've been on too it would hurt so bad that I couldn't really eat properly. So, that's been going on for about two months now. And I got my wisdom teeth out two weeks ago. Just fly home, and I've been away for a bit, and even then, now I tried to eat again, and it still hurts. Nothing has really helped.*

Jon

Jon was a 29-year-old master's student who was generally calm during the interview. He suffered from TMD and faced health problems due to these conditions. He reported that the conditions had affected him recently and were seriously impacting his life. Additionally, he expressed that he had not received effective treatment for his TMD:

> *I would say I have started having this TMD quite recently, about maybe a year-and-a-half ago, and it's actually become really worse… I would like to say the pain is really bad. I've never had it before. And I didn't, you know, go with real treatment when I got dental appliance and so then I was biting a lot. So, I'm using that. That was helping me. But two or three weeks ago my condition started to deteriorate once again. So, I started to feel pain in my joint, and that is affecting a lot of aspects in my life…*

Monika

Monika was 64 years old and retired. Monika was very interested to do the interview and explain her 25-year story of living with pain. She tried to cope with her pain and be ready for any TMD pain attacks. She had faced many hurdles and suffered a great deal. She used the term "flared up" to describe her pain and to reflect on the extent of the pain that she had been living with. She mentioned that when she has TMD pain, she prepares smoothies, which become her main source of nutrition.:*It is not only pain in the jaw but in joint of the leg, the feet. I am suffering from arthritis. The pain is basically all over, so I manage the pain both by medication and exercise, that is the best solution to relieve the pain… When the flare is really bad, and I really have to eat, I will manage a make myself a good smoothie. It is home made, not factory-made… so I always have vegetables and fruits in the freezer…*

Noor

Noor was a 25-year-old teacher. She has had TMD for 3 years when the interview was held. Noor was also misdiagnosed in the beginning stages of experiencing TMD. She expressed that TMD implications affected her in almost all aspects of her life. She has had to stop work to find an effective treatment for her condition:

> *A doctor did not really know what it was. They thought it was a problem with my wisdom tooth, and they suggested like extraction of my wisdom teeth. But I wasn't too sure because I read about a few cases online about this jaw pain, and I learned that like it's not necessarily wisdom teeth. I met a few doctors in my home country and then they said like it's nothing to do with your teeth because they're like straight and fine, and one of the doctors said it was TMD. So, that's how we started… I would feel not really motivated, and I would feel a little drowsy and down.*

Shanna

Shanna was 35 years old. During the interview, she expressed being distraught and irritated regarding her TMD condition. She was very open to explaining her experience throughout the interview. TMD pain affected Shanna in every aspect of her life. She was upset by what happened to her, which made her cry when she told me her story:

> *I've had issues with my temporomandibular joint (TMJ) for a while. It's only become really apparent in the past maybe through three years where I actually have to massage and maybe stop eating or not eat certain foods or not kiss. Or at night I'll wake up, or I won't sleep on one side, you know. I won't sleep on my right side, which hurts more. And I find it affects my salivating, like sometimes I over-salivate because of the pain.*

Findings

To address my research question, *What are the experiences of people living with TMD and their changing food choices on their physical, emotional, and social wellbeing*, my findings are grouped into two major themes. The first theme explores the participants' displeasure from diminishing overall health through a number of subthemes. The second theme explores the participants' loss of trust in the healthcare system and their treatment team. These two themes assist in bringing forth an understanding of experience of the participants who were forced to change their diet due to painful orofacial pain. The implications of these changes affected multiple dimensions of the the physical (digestive system, musculature system) and mental health of the TMD participants. Additionally, the current study revealed the significance of the relationship between participants and their healthcare providers, most signifcantly the loss of trust in dentists' ability to specifically diagnose and effectively treat orofacial pain (OFP).

Theme # 1: Discontentment from a Diminishing Sense of Health

The research participants made changes to their diet and lifestyle that affected their physical and mental health. Consequently, their quality of life worsened over time. Diminishment of health is categorized into two subtheme concerns, namely diminishment of physical health and diminishment of mental health**.** The diminishment of physical health encompasses the participant's experiences in terms of physical body function deterioration as the result of loss and deprivation of eating hard or crunchy food due to TMD pain. The issue is not just the psychological effect, but also physiological impacts on bodily function that may also affect mental health.

Diminishment of Physical Health

Digestive Problems.

Digestive problems are categorized into three parts: 1) bloating and constipation, 2) loss of chewing activity, and 3) weight changes. Constipation is a private problem that many participants confronted during hospitalization but was rarely discussed with healthcare professionals.(133) Saddam said:

Constipation is a big problem for me; I don't go into the toilet.

In this quote, Saddam expresses concerns regarding his digestive problems. It was easy for Saddam to engage through the interview while he explained his experience in detail. His somewhat angry mood dominated the general atmosphere during the interview, especially when I asked him how TMD pain affected his general health. He replied by describing his situation characterized by an inability to preform a simple physiological function "defecation." For Saddam, constipation impaired this basic bodily function and he was also at risk for hemorrhages due to hemorrhoids. He attributed the root cause of this issue to be changes in food patterns. Due to his TMJ pain, he chose to eat soft food:

I suffer from constipation; it's because soft food has no fibre. That's what they (doctors) actually told me. And now I'm on the list for having a hemorrhoid operation. It's a big problem for me that I don't go into the toilet. Yes, my digestive system is affected definitely. I went and I did the colonoscopy, and doctors found just small polyps, but the hemorrhoid, it is something. I don't like it, I hate it.

Maryam and Jon also suffered from constipation. They did not know the cause of the digestive system defects and the mechanism that was behind it. They attributed their troubles with constipation to be from having only to eat certain kinds of the food because of their pain. They expressed their concerns about this issue that affected their daily lives:

Yeah maybe … but also because I haven't been drinking coffee so, that is too complex... I don't really know the precise cause of the constipation…

Jon was also frustrated by bloating. These issues made him go to a specialist where he had diagnostic tests, but he still does not know the exact cause of his symptoms:

Yes, I've started experiencing digestive problems. Starting this year, I have bloating and constipation. And I've never had this before, so I'm not sure if this is in relation to TMDs…it's frustrating. Yes, you know I've been seeing a doctor, and they've given me basically fibre supplements and FODMAP *diets to see why I'm getting bloated, why I get these kinds of symptoms. So, all I can say, you know, that treating this problem I am not sure that is related.*

Monika also had this bloating symptom, which she thought was because her diet contained gluten:

It is really like when I start to feel bloated, then bloated, so I cut the gluten, and it was a big difference. And they said to me, that it is regarding gluten.

Shanna was confused by her multiple health problems. As a result, she was angry and felt like losing her temper frequently because of her condition:

I don't know. I'm constantly in pain very frankly. It's not only the TMJ, it's my back, it's my knees, it's my digestive issues. There are a lot of things that come in line with that which probably studies have shown that if you have TMJ, then you probably have this. This problem is like everything is interconnected and the body kind of responds accordingly.

Participants explicitly expressed loss of chewing function due to TMD pain. Saddam shared his displeasure from losing chewing activity because he was forced to eat soft food

instead of hard food. Hard foods were his preference, and he would like to be able to add them back into his menu. Because of this, Saddam has lost the joy of eating:

> *I don't get the satisfaction of chewing because I eat softer things. I eat more bread, you know, and I have to put it in the sauce because it gets softer. There is a satisfaction when you chew things, it's satisfying. And I do not do that. I cannot eat apples unless I cut them. Like I remember my grandmother was cutting them because she had dentures, so she couldn't bite. I mean the same thing, the same problem which is ironic because I didn't understand her at the time and I was mocking her. But now I totally understand what's happening. Chewing is limited to just the premolars, and I cannot chew for long because then the pain starts to be worse. So, yes, I would like to get this crunchy food. Vegetables, like biting into an apple would be something that I would like to do.*

A similar feeling of frustration was expressed by Shanna and Jon as a consequence of loss of enjoyment eating crunchy food, which needs more chewing. This loss of enjoyment during chewing is one of the experiences shared by the participants as a consequence of their TMDs pain:

> *It's more about these, I love dry bread like rye bread that is a little harder with the rye or nuts. I don't eat as many nuts because it's a lot of crunching, which causes pain…. Now I can't open my mouth wide, so I take small bites. I don't take food that is chewy or very hard. So that I can macerate them instead of biting down.*

As far as Jon was concerned, his chewing difficulties caused him to take more time to eat meals:

> *When I eat I have to cut the food into small pieces, and I consume more time to chew.*

Maryam was emotional and negatively affected by her chronic pain. She was concerned regarding her struggles especially when she is "*still young*." She was annoyed because of her inability to chew food and her chewing function also made her so exhausted that she often needed to nap after her meal:

> *Well, in general, it takes a lot longer to eat and drink just because it does require a lot more effort to chew. I find it really exhausting to eat and sometimes by the time I get to the end I'm ready for a nap because it's just so tiring… I've kind of stopped eating a lot of them* [chewy food].

Most of the participants experienced changes in their body weight, either gain or loss, without knowing why. However, Saddam attributed his unexpected weight gain to the soft food. Moreover, he experienced other complications, such as fatigue and knee pain, which required him to use a crutch to walk:

> *I gained weight, which is something that I didn't expect because I expected I will lose weight because I have pain, but I gained weight… I feel tired or fatigued maybe because I'm overweight Also, I have pain in my knee because of the weight.*

Jon experienced weight loss when his pain was at its most intense. He attributed bloating as the cause of his loss of weight:

> *It was last year when it was really bad. There was a change. I was losing weight. You know because of digestive, a problem, the bloating you know was just constant.*

Shanna also experienced weight loss due to dietary changes and a decrease in the amount of food she ate because of jaw pain:

> *Because of the fact that I don't eat the same as much, I've lost weight. Because of the digestive issues that I had probably because of a lack of proper biting down on my food*

and because of my teeth. And because of the pain, there are certain foods I don't eat. There are certain foods that I don't chew properly. Hence, the digestive issues that affect eventually my digestive system going down.

Noor's case was more complex in comparison with other participants. She attributed her weight increase to several factors related to dietary changes, TMD medications, and stress. She felt sad regarding her weight gain. The pain caused stress, which led her to eat more. She also mentioned that because of her TMD medications she felt less energetic to move around:

I'm not as active as before, so I don't move as much. And yeah, I think I've gained more weight because of this... weight change… I definitely feel sad because I'm getting bigger and bigger.

Monika also experienced changes in her weight:

I have lost not weight but inches. I don't lose much weight, but was due to the gluten they said to me.

Limited Functioning and Energy Levels.

This subtheme recognizes participants' intense feelings of discontentedness about changes in their diet because of jaw pain. The implications of diet change could affect muscle activity due to lack of some nutritional elements.(134) Also, the side effects of medications used to treat TMDs can alter how the body functions, including food processing. These side effects decreased the participants' capability to fully participate in their daily activities, and in the end, they faced difficulty performing them.

Fatigue can be described as an unusual or intense sensation of tiredness that is not easily overcome by rest or by sleep and torments the whole human being.(135, 136)

Maryam struggled to sit through her exams. She attributed the underlying cause to be a deficiency in getting the right nutrients in the right amounts. She was frustrated by feeling fatigued most of the time:

> *I would say like I've just been so tired lately not getting the right nutrients that I should be, and I'm trying hard to make up for it. But again, that's exhausting too because your entire life just revolves around eating and it's not fun anymore.*

She also emphasized:

> *I can't study well... I am a student, and this needs more concentration…. I would say it is just frustrating… just because trying to go through midterms and assignments feeling like this has been really hard… Like, I haven't been able to study as much as I would like to because I've just been so tired all the time."*

Saddam also felt fatigued due to the lack of some essential nutritients. He was upset by this. Additionally, he suffered from headaches:

> *I feel tired and fatigued, and I think the lack of this kind of crunchy food and everything has a role to go into the fatigue causes… I have headaches and pain in the temporal area and shoulder while I do my work with the headache, which is not very good.*

Jon acknowledged that fatigue prevented him from performing his work, especially in the morning. The fatigue also made him less motivated:

> *So, I do under stress and tension, I feel that constant pain. So that just brings me down. You know that makes me feel very tired and even in the morning—the first thing in the morning—I feel I'm tired of this. It is affecting my work. Well, it has started to affect. I feel less productive…. Absolutely.*

He also experienced muscle fatigue that made him feel lethargic:

Well, I've started to notice that my body has become stiffer; I'm tensed all the time. So, I get shoulder pains, neck pains, and I feel nonproductive. I feel lethargic. I guess this is an important part of the body, like your face and the muscles over here.

Noor also said that she experienced profound fatigue. The fatigue affected her not only in her job as a teacher, which she had to stop temporarily, but also her entire life. This situation made her anxious, and she lost her self-confidence. Pain in her neck and shoulder area progressed into severe headaches that made her feel tired due side affects of medication:

I think my TMDs are in very strongly related to my neck and shoulder pain. And when I get the pain, it's not just my jaw, but then my neck and my shoulder are affected as well. It goes up all the way to my... I don't know where I cannot explain, but I do get a bad headache and, you know, tension in my jaw. So, it's like oh my god I don't know from my shoulder to my head. I always have tension and tiredness. So……. aaammm… Yes, so I get tired very easily, and that has affected me badly. Because of the pain, I'm taking a muscle relaxant. I'm under doctor's care from McGill Dental Clinic. I don't know that I'm just subject to that. So yeah…Not just my job but then because of that how my life changed. And just stress from that, you know… It's not like I completely dropped it [job], but I'm just taking a break to see how it goes. Yes, all these effects and tiredness leads to, you know, not really being productive. Yeah and there's feelings out about that. So, it's like a circle. I feel sad, and I get more depressed and more tired. … The dentist was giving me some muscle relaxants. Before that, I used to take just on my own like some kind of muscle relaxant and paracetamol as such every day. And then I would feel a little drowsy and down and that affects me.

Shanna was frustrated and suffered from energy loss due to the malnutrition, making her more anxious and agitated:

> *It's actually kind of really frustrating because it's not only the pain in the jaw. It kind of goes into the neck and affects my* sternocleidomastoid *muscles (*SCM) *and my upper traps and some of my scallions, my neck muscles. And I constantly have this tension and this pressure. So. I just deal with it wherever I can. Yeah, I don't know. Yeah. You know, I take a couple of Advil every once in a while…. Well, because I don't eat on a regular basis and because I don't eat certain foods I guess I don't have the same kind of energy as I used to… My body is weak because it's exhausted, and it went into a crash mode to save itself…. Imagine that pain on a constant basis. You're always hurting. You're always aware and conscious of the tension that you hold in your jaw.*

Another challenge participants spoke about was changes in how they were able to communicate. Speaking for long periods of time became difficult as a result of OFP from the surrounding muscles. This was also noted during interviews when participants had difficulty talking for long periods of time.

Monika, who taught swimming, was forced to ask for help from another instructor because she was unable to teach for long periods of time. This situation was frustrating for her because she was unable teach the way she wanted to:

> *When I teach, sometimes I tell the students that today it will be a quiet day because I can't speak when I teach. That is what prevents me from doing my job more when I speak up. I asked my co-teacher to help me. He tells the students what they need. I had to learn how to dispatch tasks. Also, I am the master in X where I live, so when I have to teach … it bothers me when I have to speak in public. That bothers me most when I teach*

swimming. That is really where it affects my freedom to speak… I have to be careful. I know that in case of emergency, probably adrenalin with the feeling that I would be able to scream, ahh.

Noor felt that her decreased ability to talk similarly affected her job. She was sad and frustrated:

Because I was a music teacher, I have to talk a lot. So, I'm taking a break because of what I have right now [TMD]. *So, yes, that changed my career as well. It's not like I completely dropped it, but I'm just taking a break to see how it goes*.

Maryam felt sad and that she had lost her identity. She found herself speaking less, which made her social life less active. She experienced face pain even when she smiled:

It's affected me because it does hurt to talk a lot for a long period of time. And smiling hurts too, which is really sad. So, it's hard to laugh, for which I was usually smiling and laughing.

Saddam loved to speak, but jaw pain prevented him from having long conversations with others. He tried to cope by learning a new skill that he called *brevity:*

Pain affected my talking because I'm not able to open my mouth in the right way. And that's one of the reasons I can't open my mouth wide. It's painful. And I talk a lot. So, I have to control that. I love to talk, which is the problem…. So, for example, if I have to talk a long time or anything I start to have pain. Also if I talk at a conference or five meetings, that's why I developed brevity as a skill. The brevity is a very short, concise explanation.

Jon described his speech as *wide speak* to describe how he takes time to say each word while trying not to move to reduce stress on his muscles while talking. He needed a long time to explain himself due to the pain in his jaw area:

> *You know even my speaking, it is wide speak because of it and you know I just want to rest my muscles. So, this is what's been going on lately."*

Shanna also expressed difficulty in expressing her thoughts and noticed how this has affected her socially:

> *The action of opening and closing the mouth through the articulation for even talking affects my wellbeing.Even like, I've actually noticed I talk a lot less because I don't explain my thoughts. I don't explain my actions. I don't have as much conversation with people because I just don't want to use the muscles.*

Mental Health Concerns.

This subtheme reflects the number of challenges the participants confronted while living with TMDs and how these affect their quality of life, which included concern for their declining physical health experienced due to changes in their diet and subsequent feelings of disappointment, upset, anger, and frustration. The implications of nutritional changes negatively affected their mental health in general.

Although Saddam loved food, he was angry because he lost his enjoyment of eating, personally and socially. He also showed his displeasure regarding the "fibre substitutes," which he reported did not work in his case. He described his situation as a "vicious circle":

> *If I go in social life to have a dinner or lunch or stuff with friends, and if I have pain, I can't eat what they eat. So, I have to ask like for softer things…. And sometimes I would like to eat. I like meat very much. But I can't eat it, so I need to eat minced, but minced*

meat it's good only with sauce… I liked very much to eat dried figs. Yes, and celery and celery buttons. But now I can't just because of this problem, and I had this (orthodontic brackets). I can't bite…. I am angry. I feel angry [because I can't eat meat], it's a vicious circle. I am angry, and I don't drink. I don't drink at all. I don't use drugs… I like food, and I crave food… I like eating… I like the taste... I like all the things… I think food it's a social equalizer no matter what country or this is something that we can all agree on. No matter from any a terrorist and nonterrorist will agree. They will agree on the food part. And I think having a lot of food places and food meetings will make a better world, actually, because that's something that we can really make.

In regard to the fibre substitute he was recommended to take, he said:

I don't think it's really working and it's awful.

Maryam explained in detail her feelings of loss in terms of enjoying her favorite foods, especially with her friends. She also expressed the need to have more to eat, which in turn increased her stress. She used the terms "bad, rough, and frustrating" to express her feelings related to pain:

I haven't been eating anything that's too crunchy. So, I like carrots and a lot of vegetables that are crunchy, I've had to take out of my diet or alter them, like cook them or something like that. No more pizza, which is the hardest part. Drinking hasn't changed all that much, although I was told not to drink coffee anymore because it's inflammatory. So, I have been suffering. Not drinking coffee, but eating-wise. It's mostly just the change of the diet and the duration of eating. That's been frustrating.

Maryam continued by stating that this has also affected her socially:

I feel kind of bad because I miss a lot of foods that I used to eat. And it's hard to like watching your friends eat pizza and other food so it really… I would say yes, a lot of effects socially ... sure. You can't really go out to eat anymore as often. And if you do, you're really restricted on what you eat…. I have been eating a lot softer food like you heard apple sauce, which I never really ate that much before. So, I guess it is kind of rough Yeah.

Shanna experienced similar issues of being deprived of her favorite foods:

It's more about these. I love dry bread because it's easy on my stomach to digest. But there is certain bread I don't eat anymore, like rye bread that is a little harder with the rye or nuts. I don't eat as much nuts because it's a lot of crunching I've had moments where I just don't eat just because I'm in pain. The pain grows even more, so I just skipped meals, which is not good. But I mean, you know… Oh yeah, I love nuts. Yes, and I love crab, and I won't have it. I love anything crunchy, and I a lot of crunchy things I won't have.

Jon and Noor were in the same situation with regards to feeling deprived of their favourite foods. Jon said:

I was fine, but now it's started again. So again I'm being forced to change it again to food that is soft. You know, no nuts, no steak meat... Yes, I have stopped eating meat. You know, like raw red meat. You know I eat like fish or ... really nicely cooked chicken in smaller pieces. So, no steaks, no burgers, not even pizza. Yeah, you know these are really good food you know tasty food. I would love to get those back into my diet.

Noor shared her sadness of missing certain foods:

So, I do get pain when I eat hard foods or just steak or very hard candies or chewing gum. [So, I don't like that hard food anyway….] So, yes, I have a problem. I kind of completely stopped eating steak. It's sad. I like to eat somethings like steak and hard food. Or something like a hot hard shell. I like taco shells, sometimes very hard. So, it's sad that I do not really have them anymore. I just mainly avoid steak. Otherwise, it's pretty much fried like chicken and fish I cut it into small pieces.

Monika became accustomed to soft foods such as smoothies as the best solution when she had pain. In sharing her story, she explained that she had to be ready for pain, it was inevitable, and she needed to be prepared. For her, it was learning to live with a chronic condition:

So, in case of emergency, I will mange to make myself a good smothi… I always have vegetables and fruits in the freezer

All the participants showed a strong desire to return to their favourite foods and shared that they considered missing these foods as more loss in their lives. To the question, "would you want to add this food back into your diet," participants replied:

Yeah. Yeah definitely … but I like to have it if I can. Yes. Oh yeah, I love crunchy food… Yes, definitely.

For many of the participants, negative feelings reflected a pessimistic view of their future, increased by the burden placed on them by their physical pain. Sadam described the repercussions of his experience on his psyche:

I am angry. I feel angry. So, the outlook for the future realistically it's not very bright, but hope it is a very good motivator.

Monika described her experiences, permeated with caution in its details, through feelings of sadness and brokenness as she handled many decisions needed to cope with the chronic pain:

It is more about the interpersonal relationships that it would entrench my freedom, like I have to be careful how I will speak up or when I teach. I have to learn to cope with it. That is really like when I have a flare I really have to say, okay if I have to teach that day, I have to manage to get my class differently and organized differently.

Monika wonders and worries about what will happen in her future:

I don't know. So far, now I can manage. I still give a class in the fitness gym, testing. I still swim and give swimming class, but for how long? I have a problem with my hands and to clean my teeth, but at least I take time to do it. But as soon as I can't be able to do this myself, who can do it for me?

Jon was forced to rearrange most things in his daily life, ranging from changing components of his meals to booking specific restaurants that could adapt to his dietary needs. He also showed his readiness to adopt any solution to relieve the pain caused by eating:

It is kind of frustrating. For sure, it is frustrating, but I accept the fact that I am in the problem that's started. I have to do whatever it takes so that I can get better because it's a constant pain and I don't, obviously, nobody likes to live with it. So, you know, I'm going to make whatever changes and do whatever it takes to kind of suppress it, manage it. So that's what I'm going through. So, maybe later I want to try and control…. I try to balance it other ways. You know, I try to eat food that is equally rich in protein…. and later on, socially if I'm meeting with some other people I have to go toward, you know, to have steak or something and I can't have that. I'm having a salad. So, yeah … I hope that I can manage it. You know I don't get it. Sometimes if people say that you want to go out maybe it's, you know, I have to accept that it may never go away, but I can learn to manage it. Like reduce or suppress it as much as I can. So that's what I feel…

Noor was upset and annoyed during the interview about the implications of TMD. She shared that she felt hopeless and had lost motivation in her life:

> *Health, if you're even talking about mental health, I would feel not really motivated, and always you know. Yeah, also because of the medicine I'm really just not motivated to do anything. I was a very active person, and now I just feel like relaxing. And then, so I'm not as active as before… I definitely feel sad. Also, I'm getting bigger and bigger and fatigued. Yes, its, yeah, my life has changed a lot. Well, the problem has changed in my life pretty much sad. But I'm still trying to work on it. And if there's any treatment or like you know just a new way of dealing with this TMD, I'm ready to try it.*

Shanna also was affected mentally, and she was not satisfied with her condition that irritated her. She stated that she had to think about everything constantly, which led to exhaustion and affected her personality:

> *You can't focus, you can't concentrate, and obviously my quality of life is affected …* [like] *my personal relationship with my boyfriend because I get irritated and he doesn't understand.… He wants to sit down and have a nice meal and I'm, like, but I'm not hungry because the pain is bothering me. You know I just don't feel like eating. The pain is sometimes unbearable…it's frustrating. It affects my hearing, the buzzing. It comes and affects all my scapular muscles, and you feel like the pain sometimes goes through in deep lines. Why?... I take care of myself, I eat well. I continue studying all the time, and I feel like I can't do anything. So, yeah, it's the lifestyle.*

She feels an overall decline:

> *In terms of mental power and energy, all this is declining… I would say is not as good, and general wellbeing mentally is not as good either because you're constantly thinking,*

I need it. Even when you're not thinking of it, subconsciously you're constantly taken aback because of this, so everything you want to do… some days you think there's nothing to be done and you just want to crawl into a ball and stay under your sheets, under dark sheets, not white sheets, dark, and just forget about the world, you know.

Shanna said that TMD pain has affected her thinking and has made her question how she views herself:

It has affected my wellbeing, my thought process, how I think I'm less of a person, which I'm not. I understand that. Yeah, I understand that, but when something is not working, when it only loses part of your health that you realize that it's that important. And this, unfortunately, affects me a lot on all kind of things that I do…. So, I'm not crazy because all these years I'm like, oh it's something else. It's just stress, it's just this, just that, and the grinding that probably doesn't help TMJ either. So, I don't know, everything is correlated to each other.

Maryam shared that she was scared of the prognosis of her disease and what will happen in the future, especially as she is young and lacks information about what will further exacerbate her jaw pain. This lack of information and uncertainty caused her mental health to suffer. When speaking about her future she said:

Right now, not so great…. I would say if anything …. it's frustrating, is the word I would use because I'm, like I'm only 22 years old and to be having this kind of pain. Eating is just kind of discouraging because I feel like as I get older, it's going to get worse. I just don't understand anything that's happening, and I don't know if it's going to get worse and how much worse. I don't know about these things personally. And you know things can be a little bit intimidating because everything always tells you have cancer.

Theme # 2: Loss of Trust in Dentists and Healthcare

This theme encapsulates the participants' reflections regarding healthcare providers, who they felt were not always helpful in assisting them to manage their chronic pain.

Saddam said:

They think they know before the patients say anything, they just look, they just mark the things that are required by the law, but they are missing a lot of information that will be helpful even in the treatment plan.

Saddam explained his experience with dentists, extendeding back more than ten years. According to Saddam, his medical-dental treatment was mostly ineffective. He believed that his TMD symptoms started because of dental care mismanagement:

This is happening for the last 10 years and because it was a mismanaged case, so because of that teeth moved around. I don't have the same contacts, and the prosthodontic cannot be done finally. I got into this temporomandibular joint pain and the experience of living with it…. the treatments are done by the specialist who is a dentist. The dentists don't care because they never went through it, and they are looking at the problems very localized by their training. Their training is very lacking. They don't have a new way to sense or mind the body thing. It's not necessarily a holistic view. They don't have an understanding of consequences that can be triggered by just apparently a minor thing because I think they don't understand the chain of reaction where it goes. It's a lack of knowledge, a massive lack of knowledge.

Noor, also upset with an exacerbation of her TMJ issues, questioned her dental care:

When I first tried to look into this problem and how can treat it, I had a huge issue for me here to find the right person for this jaw pain and …like 95% of dentists didn't know

what it was. So, they would like to suggest, you know, expensive treatments, hahaha, extra days with them too. And then, you know, I don't know grinding something. So, no I say just regular dentists they did not understand the pain at all. Like some of them. But maybe it also depends where I was. I was in [small town]. I went to like 10 different doctors. Only one knew what was going on and even he was, like he was educated abroad. You know, it will go away because it happens like once in a month because that happened to me and it started with like once a month, twice a month, click, click. And then, you know, it became it came a long way, and now it's kind of it's degrading my disc.

Shanna was generally angry at the method of treatment she received from healthcare. She described healthcare providers as money collectors who make patients sicker. She expressed frustration with her general practitioner, who she believed prescribed medication without analysis or tests:

The doctor doesn't do anything, just prescribes the pills. They just make the rich richer and you sicker. You know, not all medication, just a lot of medication that you really don't need. I went for the pain in my stomach, and my doctor prescribed me Pantoloc just without even doing any tests. He's like just take this every day, twice a day, and you'll get fine. Oh, screw you, man. I never took it. I never bought it because after looking it'll calm me down, but it doesn't answer the root of the problem. I'm not going to put some kind of chemical medication in my body just like plaster on my booboo to make sure that I don't see it, or I don't feel it. And all of a sudden it gets infected or it gets problematic or does something there.

Monika, as well, had a bad experience with the dentist whom she suspected jeopardized her health by prescribing the wrong medication. Upset and dissatisfied with her care, Monika took her time explaining the visit to her dentist. She, too, believed she was misdiagnosed:

> *It was Monday morning. I had a private dentist, and he didn't exactly understand what is going on, he couldn't understand the problem in diagnosis. First of all, l didn't see the TMJ could be affected by arthritis… I had to change dentists because I wasn't satisfied with my dentist, so that is why I came here to the dental clinic.… It is misdiagnosis.... so, I end up here. The dentist that I had gave me whole bunch of treatments... and I wasn't really sure that I need those treatments. I came here. And actually, none of them I need it. What you supposed to do, nothing has been done here. He wanted to take off all the golden filling, but I've been here since four years, these have been checking it and they said nothing wrong with those. Don't touch.*

Similarly, Shanna believed mismanagement of her orthodontic treatments led to her TMD jaw pain. She was also unsatisfied with her treatment, which she stopped after seven years, refusing to finish:

> *I was going to the orthodontist that I had, who was working a little too aggressively in my mouth, and my teeth were very cramped when he did the orthodontry. I don't think he did it right. And one of his colleagues told him this is too aggressive and, considering the way that her mouth is, it's not the right path to take. But the treating doctor didn't take that into account. So, after seven years and without having finished my treatment, I stopped it because not only was it too aggressive, but it also created more problems such as periodontitis.*

Saddam, who had studied dentistry, expressed the idiom:

It takes one to know one.

He admits he had not paid attention in learning to treat the whole patient experience, and just focused on local dental problems. After suffering with chronic pain, he experienced and understood what it means to live with chronic pain and how important it is to treat the whole patient, including the importance of understanding the suffering of people with TMDs to help them live more comfortability with their conditions. In reflecting on this position, Saddam shared:

> *I know more about this problem because I suffer from them. Before I had pain, I don't pay attention too much on the other body systems; maybe I gave attention more than others because I also did medical school. But even with that, I was not able to really see through longer in TMD patients.*

Saddam also commented on the guidelines given to him by his dentist, which appeared superficial and did not serve as a patients, but rather served the interests of dentists and healthcare. He also expressed dissatisfaction with the dental care he received, which he gave a low ranking:

> *Well, the advice they offer mostly it's kind of obvious and counterproductive. Doctors say well eat more vegetable and lose weight… And it is generic things I can find this on Google and it's an obvious thing anyway.*

Saddam offered this description of dentists:

> *They don't care. The only advice a dentist will give you is to eat more chocolate because they are capitalists. It's detrimental for them and their education in the sense of that oh you do these things you make money, and you're your own boss. It's against their education. So, yes, dentists will say oh brush your teeth and anything, but they don't*

really … they're not really pushing for it… I am not very happy. If I would put most from 1 to 10, 10 being the best. I would give it a 3 to 4, which means it exists, but it's not at the quality of understanding. It should be effective as a treatment.

Maryam also expressed her dissatisfaction with the advice from her dentist, which she believed did not help her deal with her pain:

I didn't really find that they gave me as many suggestions as they might have otherwise. They did tell me not to drink coffee, not to eat harder foods, but they didn't really give me any other suggestions.

She also felt the language the dentist used was too scientific, making it difficult to understand what her diagnosis was and the treatment plan, thus increasing her state of loss and fear:

I felt like again everything was so rushed.… They kind of just told me, oh it's osteoarthritis. And for my facial pain, use Naproxen. I was like what does that even mean? I didn't even know. Do I have arthritis everywhere, or is it just my jaw? How do you know it is in my jaw? I just felt like I didn't really get anything explained to me properly.

Noor was equally upset about the lack of advice she received from her dentist:

Because most of them, what they tell me is just go for physiotherapy.

Jon was also dissatisfied with the treatment he paid for. Additionally, he wondered if the treatment might be better elsewhere:

I guess they're doing the best that they can, but if I looked elsewhere maybe it is better. …. I get my treatment. I'm paying for it. It's great. You know, but it's the way I feel like is not good.

Saddam, who had been waiting two years for a hemorrhoid operation in Montreal, declined to where defecation caused him considerable difficulty. Additionally, Saddam criticized the nutritionist who used complex approaches that were difficult for him to apply:

> *I am waiting for two years which is increasing my anger degree because it's a long wait time and it's not solved. So, from a small thing, it compounds to actually a lot. And it makes you unhappy and depressed. It is a complex problem which started from a small problem… For me, I don't go into the toilet. It's a big problem. I was at the nutrition department … it's an approach based on basically they tell you tables from a book, and it's fairly difficult to do what they say.*

Jon was also sad because health insurance does not include treatment of TMD. TMDs generally do not seem to be considered a disease, while the specialist treatment he needs is expensive. For many persons, it is thus impossible to access some branches of dental care:

> *They do not consider this as a problem. So, this is very sad. So, whatever I have to do I have to pay for my own pocket. And, you know, sometimes I cannot because, for example, if I have to go see a specialist, it's not covered because it is TMJ. So, I tried, but my insurance refuses this claim because they don't consider this as a problem.*

Jon also mentioned what he believes to be superficial management of patients when he had an appointment with a healthcare specialist to treat his bloating. According to him, the doctors did not try to explain anything beyond this problem and its causes:

> *They just focus locally on the problem, it's not what's beyond that.*

Monika also expressed concern that health coverage does not include dental treatment. At times throughout the interview, she had many unanswered questions that made her anxious:

I was looking to my neighbor. She is 75 years old and suffering from Alzheimer's. She doesn't know how to clean her teeth; she completely forgets to clean her teeth. How do we do?... What are we going to do with arthritis? There is no program in dentistry for work with gerontology for older people … They [dentists] *don't care for that in hospital. They don't clean teeth; they don't brush teeth. That is gonna be a big problem. It is not just cleaning; there is nothing for prophylaxis in this process how to care for old people. If the mouth does not clean, the rest of food will taste bad, etc.*

Monika also was annoyed about what she stated was "no follow-up" in the healthcare system:

The problem I feel is following up. People go to an emergency room, they meet a doctor, they go home. But next time they will meet someone else [a different doctor]. *There is no follow-up. That is a big big problem.*

She continued to express dissatisfaction with the lack of follow-up in stating:

First of all, patients see a doctor, and they go back to emergency, and it is not the same doctor. Come out with a new diagnosis, get a new kind of medication, go to the pharmacy get a medication. That is worse than the disease itself.

Maryam also wished to receive more effective follow-up to help her deal with her pain:

Yeah, it would have been good to get like just have a little bit more time or have a follow-up on site when I thought of questions.

Summary

The findings in my study suggest that persons living with TMD who must make changes in their diet generally experience a decline in the efficiency of their digestive system. Beginning with less ability to chew food, bloating, and finally constipation occurs, with the added problem

of changes in body weight. They also experience changes in the musculature system with resultant fatigue due merely to eating. Mental health is also affected by TMD pain with the daily emotional challenges of frustration, low energy, and some hope for a cure. Additionally, many of the research participants spoke about their loss of trust in their healthcare providers and the healthcare system due to a lack of meaningful/helpful advice, lack of knowledge regarding TMD treatments, as well as what they believed to be a lack of interest or willingness to listen to their concerns. These interconnected findings all affected the participants' relationship with their illness state, their social connections, and their general wellbeing.

Chapter 7: Discussion

Through the findings, I explored my participants' experiences of how temporomandibular disorder (TMD) pain forced them to make changes to their diet with related life consequences. My findings were grouped into two main themes; the first one is related to the persons themselves, while the second acknowledges their relationship with healthcare providers and the healthcare system.

Discontentment from a Diminishing Sense of Health

Findings from this first theme, which revealed challenges the study participantsencountered, were divided into two subthemes representing physical aspects and mental health concerns affecting quality of life. These finding support previous studies that found physiological and psychological effects caused by dietary changes food on TMD patients.(3, 10, 47)

Diminishment of Physical Health

Digestive Problems. The dietary fibre in vegetables, fruits, and grains provide important nutrients that are considered to be a significant component of healthy food.(137) Eating high-fibre foods has important health benefits, such as lowering the risk of heart disease and diabetes, maintaining body weight, and maintaining stable and strong bowel function.(137) Irritable bowel syndrome (IBS), such as constipation and bloating, chewing difficulty, and weight change, are the most common digestive system problems the participants faced because of dietary changes. The change in diet disturbed the gastrointestinal (GI) system as well as many other systems in the human body. The change from hard food with more fibre from vegetables and fruits to soft

food with less fibre significantly affected the digestive system's ability to perform vital functions such as defecating. This is a real concern since constipation is a private issue rarely discussed between patients and their healthcare providers.(138) Another function affected is mastication or chewing of food, which leads to bloating and weight gain and its complications. Indeed, participants suffered from digestive system defects due to not consuming food containing sufficient levels of fibre.

Diet and food choice are fundamental issues that concern IBS patients.(139) According to the literature, the type of food has a substantial effect on the digestive system dysfunction. Also, the struggles faced by GI patients are correlated to the quality of their diet. Conclusions from Raphael et al. that clinicians should recommend optional dietary fibre sources for myofascial pain syndrome (MFP) patients indicates that TMD patients are at risk of reduced fibre intake in their food, which leads to the possibility of being affected by IBS.(8, 139) Furthermore, patients who had a high degree of food-related IBS symptoms were susceptible to increased anxiety and depression.(139-142) The participants in this study say that they did not receive useful food recommendation to help them cope with their complex conditions and optimal digestive system health.

Magnus Simrén et al. showed there were connections between the development of IBS symptoms and food ingestion.(140) Also, the majority of IBS patients recognized their symptoms to be related to meals which were rich in carbohydrates and fats. Nevertheless, most of them were normal weight or overweight.(139-141) Bohn found that GI symptoms in IBS are triggered by the type of food intake.(143, 144) Additional studies also reported that people with IBS often avoid various food items as a way of managing the disease, which can potentially lead to a lower intake of necessary nutrients.(139, 140, 145-148) Dietary fibre is most helpful for

persons with constipation(149); an increase in eating high-fibre food improves incomplete spontaneous bowel motion.(150) Constipated patients exhibit a higher prevalence of mood and anxiety disorders than in the general population.(151) However, few studies show there is a relationship between dietary fibre and bloating and diarrhea in IBS patients.(149) Studies by Chang et al. and Dapoigny et al. showed that 73–76% of IBS patients reported bloating as a troublesome symptom.(152-154) Indeed, IBS patients often rank bloating as the most troublesome symptom.(153-157) The findings from this current study support these results in terms of the relationship between softer foods with less fibre and IBS. The findings in Chapter 6 reported that participants in this study suffered from constipation and bloating, and some of them gained weight as a result of needing to ingest soft food.

Participants in a qualitative study by Fletcher and Schneider of women diagnosed with GI disorder, described their relationship with food as a dynamic learning process which they thought would be a lifelong struggle.(144) Another qualitative studyby Jamieson et al. concluded that women lacked information and assistance from healthcare providers related to mismanagement of IBS and Inflammatory Bowel Disease conditions with regards to the right choice of food and beverages.(146) Even though few studies have thoroughly investigated dietary intake in IBS patients, patients were often found to request nutritional recommendations about what they should eat.(139, 149) Munch et al., who studied the lived experience of constipation in older people before and during hospitalization, found a lack of information on how to manage constipation, including patients' struggle at the physical, psychological, and social levels, and that healthcare providers need to initiate conversations with patients regarding advising them on the management of constipation.(133)

Mastication is necessary for systemic and physical functions.(36) Also essential for psychological and cognitive functions, mastication is considered to reduce stress.(158-160) Frustration caused by the loss of masticatory function—fatigue in the muscles of mastication, and indigestion caused by inadequate chewing of mixing of food with saliva—were of the issues suffered by my participants that they claim led to loss of enjoyment of food, increased time needed to eat meals, and fear and uncertainty about the future progression of their symptoms. Consequently, their quality of life was affected. My findings support and are corroborated by the available literature regarding the physiology and psychology of mastication.

My findings regarding loss of the enjoyment of food, more time to eat, and fear of showing aging signs confirm Italia's earlier finding that pain and discomfort when chewing specific foods leads to a decline in engagement in socializing, social activities, and a change in patients' identity.(59) In addition to mastication as grinding food for swallowing and digestion, chewing also helps relieve stress and regulates cognitive function, especially by increasing attention.(138) For example, chewing gum while driving, for sleep prevention during work, and while learning tasks suggests a link between chewing and maintaining concentration. Several studies have demonstrated the positive attributes of eating on attention, especially on sustained attention. These results also underscore findings that improvement in stress relief and mood are influenced by the time of on-task performance.(138, 161, 162)

The dietary approach consisting of low-fat dairy products, vegetables, and fruits is correlated with weight loss.(163) Eating soft food resulted in weight gain for some of my participants and weight loss for others, but they lacked insight and knowledge about the cause of these changes. One participant reported suffering from a weight increase as a result of soft food

(less fibre), developed knee pain as a result of his increased weight, and now can walk only with the assistance of a crutch.

In addition to the pain itself, chronic TMD patients live discontentedly with the deterioration of their digestive system function as a result of adjusting their diet. By this reasoning, the effect of TMD pain on food intake seems to result in GI dysfunction, salivary gland dysfunction, and weight changes. While the participants in this study were aware that their GI problems were as a result of dietary changes, they did not have specific knowledge about what the exact causes of this deterioration were. Healthcare providers should be aware of these issues and address them with affected patients.

Limiting Functioning and Energy Levels. Despite attempts by the participants to overcome obstacles related to food deficits, they faced challenges related to living with fatigue. They seemed unaware that lethargy affects TMD patients or the cause of this lethargy. Many participants believed the medications used to treat TMD, deficient nutritional intake, or both could perhaps cause these symptoms. The participants suffered from a range of muscle fatigue, which lead to decreasing performance and production such as stopping work, taking a lot of breaks, or difficulty in school. Additionally, they spoke of being tired and in pain while eating, speaking, working, smiling, or laughing. The muscles of mastication and muscles of expression are also both adversely affected. These conditions ultimately changed participants' perceived identity and negatively affects their social connections and work situations.

Muscle fatigue is defined medically as an impairment of muscle force production or of shortening speed resulting from repeated and continued activity. The reasons vary considerably according to the nature and duration of the effort. The causes of fatigue are attributed to several factors, including emotional pain, distress, anemia, sleep disturbance, alterations in nutrition,

deconditioning, and comorbidities and nutritional interventions are recommended to advance functional capacity and activity tolerance.(164) The types of food eaten also have a significant effect on fatigue.(165, 166) [Additionally, as previously mentioned in my Chapter 4 literature review, the impact of TMD medications on patients include sedation, dizziness, fatigue, drowsiness, constipation, blurred vision, or headaches.(95, 99) Medications prescribed for myofascial pain in combination with low dietary fibre can also lead to an increased risk of constipation or worsen comorbid medical conditions. Based on this, TMD patients experience fatigue as a combined result of nutritional deficits and medications, and suffer from emotional pain regarding these TMD conditions. As a result, they may decrease their activity as a function of managing fatigue, which compounds itself. Healthcare providers need to be aware of these interrelated effects and assist TMD patients to manage their symptoms.

Mental Health Concerns

The mental health of the participants was affected by TMD pain due to changes in lifestyle, daily activities, diet, and hope for a cure. Oral health specialists use several indicators to identify difficulties with mouth opening, biting, and chewing in individuals with TMD, including the Manchester Disability Scale and Kurita's Score of Chewing Ability.(3, 167, 168) Durham et al. suggested the use of a TMD-specific Oral Health Impact Profile tool that contains questions on eating-related quality of life ERQoL.(80) However, there are no validated measures for clinicians to assess diet and nutritional status or eating-related quality of life in TMD patients; for example, no patient assessment tools exist to address the scope of eating and beverage consumption issues that patients with chronic orofacial pain disorders (COFP) face.(3)

The participants expressed feeling sad and pessimistic about being deprived of their favourite foods and needing to substitute these with less satifstying food. They spoke of craving

particular foods that they were no longer able to eat or, conversely, no longer wishing to eat. Furthermore, due to developing changes in chewing activity, digestion process, weight, and muscle fatigue resulted in decreased engagement in simple tasks like talking or smiling, which consequently negatively affected their social lives and wellbeing. Feelings of loss and depression were increased in the participants.

These findings lend support to the body of literature that currently exists wherein individuals' quality of life and mental health are affected by reduced food intake ability.(59, 60) Changes in participants' diet caused by TMD pain affected every aspect of their lives. As they rethink their entire life, while trying to cope with the pain on their own without sufficient professional support, they are not in a position to live their lives as they had previously. Pain and motor activity (mastication) are influenced by psychological factors and can manifest in stress and depression.(10)

Some of the participants in my study have come to accept their painful TMD conditions. This outcome reinforces the findings from Italia's work that showed that some participants reacted to their chronic pain condition by acceptance, while others ask why they must suffer such multifaceted pain.(59) However, some of my participants expressed being hopeful, which contradicts Italia's finding that participants in the same conditions lived without hope. Additionally, some participants live with an uncertain future, which generally affects their lives, which contradits Eaves et al.'s finding that TMD patients are at risk of a previously experienced level of pain, but they are not at risk of becoming too sick or having an unknown future.(62)

My findings have shown that TMD patients need to seek out programs to help address their mental health concerns before they become too distraught. Psychological or social interventions from specialists could assist them to improve their quality of life.

Loss of Trust in Dentists and Healthcare

All the participants in this study suffered from misdiagnosis and consequent mismanagement of their cases, especially from dentists. They attributed many of the causes of their TMD symptoms to ineffective dental care. Moreover, the participants reported not getting effective advice on how to deal with these conditions and how to effectively manage their pain. Additionally, the participants were dissatisfied with the overall healthcare system., expressing anger and disappointment with their healthcare providers. This finding supports previous findings that TMD patients are dissatisfied with the healthcare system.(60)

According to Israel, misdiagnosis and multiple failed treatments are common in TMD patient populations; consequently, these patients go through multiple stages of dental processes that fail to eliminate their symptoms, followed by referral to oral and maxillofacial surgeons for evaluation and treatment.(169) Some participants in my study reported suffering from misdiagnosis, including tooth extraction because the treating dentists mistakenly thought the orofacial pain (OFP) was tooth pain. Additionally, participants were seen by dentists who prescribed medications that resulted in other serious health problems. Some participants said their ongoing orthodontic treatments resulted in TMD and attributed the cause of their TMD conditions to mismanagement by the orthodontist. This finding confirms previous research findings that changes in the morphology of the temporomandibular joint (TMJ) could be the result of the constant force by fixed repositioning appliances used in orthodontic treatment.(170, 171)

Relationships with healthcare providers are critical for effective patient-centred care and safety.(172-175) High-quality relationships improve the outcome of care, which depends on providing specific treatments for specific complaints (64, 176-178), clinical outcomes of care

(64, 179, 180), malpractice claims (64, 181, 182), and switching physicians (64, 177, 183). The relationship between doctor and patient should be based on open, sustained, dialogue by sharing information and knowledge to build a high-quality, trusting doctor-patient relationship.(64) A high-quality doctor-patient relationship is considered as the heart of medical/dental care.(173, 184) Trust in this relationship is known as the patients' expectation toward the doctors' handling of their case.(173, 185) Unfortunately, quality of care has declined and patients' trust eroded, despite knowing that these relationships are part of the healing process and health outcomes.(64, 173, 186-189) Many factors, such as doctor shortages, wait lists, time pressure, and financial restraints account for this decline.(173, 188) Moreover, the state of the patients, such as chronic or acute illness conditions or both, impact the different expectations patients have toward the care they will receive.(173)

My current study confirms these findings regarding loss of trust of the participants in their healthcare providers. While neglect of healthcare providers could be attributed to time pressures to see more and more patients, one of the participants in my study believed that dentists seem to care more about collecting money and ignoring the consequences of TMDs for general patient wellbeing. Dentists' poor diagnostic and therapeutic knowledge and experience exacerbates suffering for TMD patients (45).

Furthermore, participants complained that dentists did not listen, nor did they give effective advice or efficient follow-up consultation. The language that the dentists used was felt by some participants to be scientifically complex and difficult to understand, which increased their state of loss and fear of those who already had a lack knowledge of their TMD condition. Also, oral healthcare professionals (OHCPs) may suggest a 'soft' diet to address TMD symptoms without any definition of what compromises a soft diet. While it is likely that the purpose of this

suggestion is a mechanically changed diet to minimize masticatory efforts, this information is not given to patients. For example, a doctor may suggest eating a "soft roll," which may still be considered too hard a food to eat for some patients as it requires masticatory effort to bite, chew, and swallow than that needed for popcorn kernels or a chopped tomato, both of which have more fibre.(3)

In terms of the healthcare system, one of the participants has been on the waiting list for two years for critical surgery, blaming healthcare system inadequacies for this wait. The same holds true for emergency room visits, where patients see different physicians each visit and may receive different and/or conflicting treatments or medications. Several of my participants blame these issues on the healthcare system. Also, some of my participants were burdened by costly treatment for TMD treatments not covered by health insurance.

Because full recovery for persons living with chronic illnesses might be limited or nonexistent, these illnesses must be managed rather than cured.(173) Based on this premise, persons who are diagnosed with chronic conditions need to contextually re-interpret and re-negotiate how healing occurs in their life.(173) According to Hovey and Massfeller, healing for chronic patients exists within the negotiation between doctor and patient to reduce stress and inspire a sense of a positive future.(119, 173) In addition, doctors who express empathy by "being with" a patient will assist the patient to heal by feeling connected to others and accepted in their unique personhood. Gadamer defined dialogue as a part of the treatment itself:

> In the realm of medicine, in any case, the dialogue between doctor and patient cannot be regarded as a preparation for or an introduction to the treatment proper. The dialogue between doctor and patient must rather be seen as part of the treatment itself.(190 p128).

Reasonable approaches for any healthcare provider observing a patient with a COFP (especially OHCPs), would be followed by asking open-ended questions about whether and how their condition has affected their ability to eat and drink at home or socially and then to investigate these difficulties and changes to their lives.

Guidance about diet modifications is crucial for the patient to reduce associated discomfort and pain and to enhance the eating experience.(3) Simply using moistened foods (via gravies or sauces) and cutting foods properly may be sufficient for some patients. In addition, peeling fruits and vegetables with thick skins and chopping whole foods to consistencies that patients can tolerate may allow them to consume their favoured foods and enjoy meal times at home or eating out. The national dysphagia diet may provide some useful programs for individual patients as well.

Participant Advocacy Suggestions

This section presents the particopants' comments regarding enhancing the quality of treatment that they hope to receive in the future.

Saddam referred to the importance of listening from dentists and expanding their field of learning beyond only treating the issue:

> *Doctors should listen, listen, listen more and more. They don't listen. They are missing a lot of information that will be helpful even in their treatment plan. They see the problem, but they don't really listen. Usually, that is done by an assistant. I think that, for example, after you learn about doing prosthetic work or doing fillings, the consequences of doing a bad filling not only in the word failure but kind of expand into it and what is evolved on it and long-term things and expand them more. And though they are mentioned in the books they are not really emphasized exactly. That's the message for the dentist. Listen more.*

Because if I told them "learn," the word they think they know, that's the problem because the way the dental education is done over the world is it's fairly isolated from the scrutiny of your peers. Like you are doing in medical school where there will always be a head of a department that will look over what we're doing for many years, and they will criticize, and then you have to present to your peers. And then you will get that as a dentist you're just alone, and you are honestly even if you want to do the best and you, and if you are making a mistake you don't know. And that's the fallacy because you don't know and nobody will tell you. You will just start to persist in what you're doing [wrong]*.... And because nobody will tell you that you were ever wrong you start to believe that you are really special as a person and you are way more educated as you know. All it needs to be known.... It's a bias, it's a bias that's present all over the place. But the environment is very conducive for this bias to appear very early and to expand. So, because dentists will not read more because of that, because they think they know enough, which is totally false. They could listen more and just by listening they will be able to find out lots of things like this*.

He suggested a solution to resolve the lack of knowledge problem:

So, I think making or introducing the sequences of TMD in the curriculum and also into the residency should be compulsory. This things and rotation seen in hospital at least in the digestive department. So were anything. Or just bring a different level of education and then a different layer of quality of the medical product. And sometimes having a better understanding of what's urgent to be done or what should not be done.

Noor emphasized her wish for more information:

I wish I had more information.... And in terms of that, doctors and students who are studying this should know not just telling people that there is a problem such as this and many people have a disease, but they don't realize it.

Maryam and Noor said that they preferred healthcare providers to give more time and awareness to the patients and schedule more follow-up consultations. They believed providing patients with practical guidelines may relieve them of their fears. These guidelines could be supplied to patients through booklets. Maryam shared:

Yeah, it would have been good to get like just have a little bit more time or have a follow-up on site thought of questions. So, I just wish that just in general like it would be nice to have more information about what jaw pain can make, how jaw pain can affect your life, and especially being as young as I, and what it might mean in the future. I was really upset about that. Also, what is the pain that's going on and how is it going to affect your life. It would be nice to have the booklet saying how you can alter your dietary needs and maybe just make suggestions on how to avoid making it worse.

Noor added that it is important to publish more articles in this field and raise people's awareness about this issue because a large number of people have a TMD but simply do not realize it because they lack knowledge about it. She hoped to see more advice about this. Otherwise the situation may worsen:

I think that the doctor should be aware of full information, a good-enough information about their patient's diet. For example, advertising this part of the study is too public because I read online that like many people these days, like 23% of the population have this problem because of stress or food or the style of diet, whatever. There are so many causes and many people how they like even my friends they have it, but they don't really

know about it. So, I mean this condition never going back, so I have to maintain this, don't go worse than this, I have to get some treatment done [surgery]. *So, I think people should be more aware of this. So, in the end, the doctor should be able to suggest an alternative and effective style of diet. … At times I get problems, and even like when I'm chewing soft food, I get a pain. So, I wish the doctors could tell me more about it. How my jaw operates when I chew something hard, a steak or something. It is like I want to know what's going on. If they could tell me, then I would be more careful, so I can have my favourite food without causing the pain.*

Monika's message was for healthcare providers and the healthcare system in general as she predicted large problems in the future and did not know what the solution will be:

People in residence if they can't clean their own teeth properly and take care from it. They will end up with abscesses, remove the little teeth they have, they will end up with a denture that is not properly adapted. People can't be eating probably etc ... How are they going to take care of people as they get older? That is a big problem... I see that is bigger problem in the years ahead and I really don't see what the solution is.

Shanna suggested a practical tool in the format of a TED Talk video to provide advice to assist TMD patients who change their diet:

I think something that might be good is maybe like a quick video. You know, you look at it on your off time. It takes five minutes maximum and all the information that will help a lot. So, this TED talk a little informative how you are curious things. Something like that for TMD would be great. Yes, I don't even know if it exists. It probably does because TED is just awesome. Yeah, but for our problems here, that might be an interesting solution for us.

Study Limitations

The findings regarding loss of trust in dentists' ability and dissatisfaction with the general healthcare service may not be generalizable to other societies with political, social, cultural, and healthcare systems different from the one in Quebec. Nevertheless, if there are similarities between the Quebec healthcare system and those of other countries or provinces, my findings may be transferable to their contexts. Additionally, I have only focussed on patients' perspectives and experiences; therefore, this study did not address healthcare providers' perceptions and opinions. Further research could explore the views of dentists and healthcare providers to gain their insights about this topic of concern.

Chapter 8: Implications and Conclusion

Learning from the Other occurs when the Other challenges

our knowledge, experiences, and preconceptions.(189)

My intention in this study was to understand the experience of patients who had to change their food preferences and eating habits because of chronic pain they experience due to TMD and the importance of the relationship and communication between them and their healthcare providers. According to the literature, low dietary fibre combined with the medications prescribed for myofascial pain syndrome (MFP) result in an increased risk for constipation and other comorbid medical conditions.(8) Consequently, I decided to pursue research that directly explores the experience of patients who have temporomandibular disorder (TMD) to better understand their suffering and the how TMDs affect their general health.

I conducted open-ended, semi-structured individual interviews with each participant who consented to participate in the study. I applied an interpretive phenomenological approach concerned with understanding the meaning of phenomena during analysis and interpretation of the data arising from these interviews. My research revealed two major findings: displeasure from the diminishment of patients' physical and mental health and loss of trust in dentists' ability, particularly a general dissatisfaction with healthcare.

These findings can be used to inform healthcare providers about the need for intervention programs to treat comorbid physiological and psychological concerns that can occur as a result from having a TMD diagnosis and enduring treatments. These comorbid conditions affect the gastrointestinal (GI) system, especially constipation, and the musculature system, thereby

diminishing mental health and overall quality of life.(66) This finding also emphasizes the importance of managing TMDs with a multidisciplinary approach, which means that dentists, psychiatrists/psychologists, physiotherapists, and nutritionists cooperate to design and apply a successful therapeutic strategy for these conditions.(191) This study additionally suggests that healthcare providers must acquire effective communication skills and expand their knowledge of TMDs to better support their patients. Improving the relationship between doctors and their TMD patients could result in positive health outcomes.

The uncertainty surrounding diagnoses negatively affected sufferers' daily lives. Therefore, TMD diagnoses need to be initiated at the first point of contact.(192) Furthermore, this study elucidates the need for healthcare providers to be attentive to the broad effect of TMD conditions on persons' lives and the need to initiate conversations with patients—and to listen to them. Appropriate and timely advice is also needed to assist patients in managing their chronic condition. Healthcare providers who have enhanced communication and interpersonal skills tend to discover problems earlier, prevent medical crises and expensive interventions, provide better assistance to patients, and refer them to the other necessary healthcare professionals, which is an approach that leads to lower care costs, higher patient understanding of health issues, better satisfaction, higher-quality outcomes, and better adherence to the treatment process and overall quality of life.(12, 111, 193)

Appendices:

Appendix 1A: Ethical Approval

McGill

Faculty of Medicine
3655 Promenade Sir William Osler #633
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June 13, 2017

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

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

Dear Dr. Hovey,

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

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

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

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

Regards,

Roberta Palmour, PhD
Chair
Institutional Review Board

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

McGill Faculty of Medicine

Institutional Review Board
- CONTINUING REVIEW FORM -

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

Principal Investigator	Richard B Hovey
Faculty and Department	Faculty of Dentistry Division of Oral Health and Society
Study Coordinator, if applicable	
Address:	2001 McGill College Avenue, suite 500. Montreal, QC, Canada H3A1G1
E-mail	richard.hovey@mcgill.ca
Telephone:	Tel: 514 398 7203, ext. 09
Study Title	Experience of living with chronic pain and patients' experiences of its treatment, future outcomes and social implications
Grant title, if different from study title.	
IRB Study Number	A06-B31-13A
Date of last approval	6/12/2016

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

If yes, please specify the changes/additions.

Status of the Protocol

- ☑ Active enrolment
- ☐ Recruitment complete
- ☐ Recruitment on hold
- ☑ Data analysis
- ☐ Secondary Analysis only
- ☐ Inactive/dormant**

When did this study begin?

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

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

Study sample size:	45
Total number enrolled in the study:	25

Number of participants that have completed this study:	25	Total number of participants withdrawn	0
Projected date of completion of study enrolment:	October 2017	Projected date of study completion:	June 2018

Please provide a brief description of what has occurred since the IRB's last ethics approval.

We have been actively recruiting participants and are close to completing this phase of the project.

Has the study revealed any new findings or knowledge relevant to the potential benefits and/or study risks that may influence participants' willingness to continue in the study?

◯ YES ◉ NO ◯ N/A

Has this new information been communicated to participants?

◯ YES ◯ NO ◯ N/A

If applicable, please describe the findings.

Has an amendment(s) to the protocol been submitted to the IRB in the past year?

◯ YES ◉ NO

What is the version date of the most recent IRB- approved protocol?

6/12/2016

Has the consent form(s) been revised in the past year?

◯ YES ◉ NO ◯ N/A

Have consent form modifications been reported to the IRB?

◯ YES ◯ NO ◉ N/A

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

6/12/2016

Have any adverse events occurred since the last approval?

◯ YES ◉ NO ◯ N/A

If yes, how many at McGill sites?

How many at all sites?

Have the adverse events been reported to the IRB? If no, submit all adverse events with this form.

◯ YES ◯ NO ◯ N/A

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

Have there been any publications?

◯ YES ◉ NO

If yes, append list:

SIGNATURES

Principal Investigator — Richard Hovey — Date: 4 11 2017

IRB Chair — Roberto Palomares — Date: June 12, 2017

Appendix 1B: Consent Form

Faculty of Dentistry	**Richard Hovey, PhD**	Faculté de médecine dentaire
McGill University	Tel: 514-398-7203, ext. 09056	Université McGill
2001 McGill College, suite. 537	Fax # (514) 398-7220	2001 McGill College, suite 537
Montreal, QC, CANADA H3A1G1	E-mail: richard.hovey@mcgill.ca	Montréal, QC, CANADA H3A1G1

Consent form for chronic pain research participants*: The Experience of living with chronic pain and patients' experiences of its treatment, future outcomes and social implications*

Research Project Leaders:

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

Dr. Richard Hovey, PhD.

Faculty of Dentistry

Division of Oral Health & Society

2001 McGill College Avenue, suite 537

Montreal, QC, Canada H3A1G1

Dr. Wafaa Safour, BDS.

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 influence changes to diet on individuals living with TMDs. Since food is so pervasive in our lives, we want to understand what the impactions of food change in your general health and your life are. The purpose of this study is to gain insight and understanding about the experiences confronted by people living with TMDs pain to create effective communication between patients and medical staff, such that healthcare staff provides patients with guidelines on how to prepare healthy food. The outcome of this study will be to improve patient health and medical care and increase collaboration among medical staff to relieve patient affliction.

In order to accomplish this, we plan to conduct 5-10 interviews from participants, who have been suffering from chronic TMDs 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. Wafaa Safour.

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 2: Contact

Phone Call and/or Text Message Script

Hello Mrs. Or Mr.,

It is Dr. Wafaa Safour. I am a master student and research assistant at McGill dental faculty. Also, I am a dentist since 2011.

As a part of McGill, we are conducting a study about TMDs problems or jaw pain like what you have, and it has effect on patients' lives as well as patients' health.

As you know, it is not easy to treat this problem and it usually stay for long time. This is why it is assumed that this kind of conditions may affect patients' lives as well as their health. For example, some patients are forced to change the kind of food they eat because of jaw pain. This change might cause weight loos or loss of energy.

So, my question is **Have you had to change your diet as a result of jaw pain?**

(* If yes, I continue by explaining the aim of study and structuring the interview.)

We do this study for understanding the suffering of patients' jaw pain to create effective communication between patients and healthcare staff that provides patients with improved guidelines on how to prepare healthy food.

We hope you will participate in this study through the interview that will take place at the McGill dental faculty, and which will last for about 30 min.

Everything is confidential.

In the text message I used this form:

Hello Mrs. or Mr.

It is Dr. Wafaa Safour who works with Dr. Zovi at the McGill dental clinic.

Thank you for your interest to participate in this study which is about living with the experience of jaw pain.

I would like to know what the best time to meet and talk more about your experience is.

Faculty of Dentistry

Division of Oral Health &

Society. 2001 McGill College Avenue, suite 537.

Montreal, QC, Canada H3A1G1

Hello Mrs. Or Mr.,

Appendix 3: Introduction of the Interview

Firstly, I would like to thank you for giving me this opportunity to speak with you. Thanks for your valuable time. I very much appreciate it.

I am Wafaa Safour, a graduate student at the Faculty of Dentistry, McGill University. I will be asking you questions about your experience with jaw pain and its effects on your food.

For the interview to be formal, I would like to give you two documents which are the consent form, that needs your signature if you agree, and the interview questions document, which contains interview questions that we are going to discuss after your consent. Please read them before we start, and if you have any questions feel free to ask me

If you agree to take part in this study, could you please sign the consent form?

*Before I start the interview, I will explain the two documents to the participant.

The interview questions document includes a number of questions. Your participation will be confidential, and secret as appears on the consent form.

Please do not hesitate to let me know if you have any questions related to this interview or if you need any explanation or clarification of my questions. Also, please let me know if you ever want to take a break from the questions.

Before we start the discussion, do you have any specific questions?

Appendix 4: Interview Guide

Research Questions

1 - Tell me about your experience living with TMDs (jaw pain), and what that does it mean for you?

2 - Have you had to change your diet as a result of this condition?
could you explain how you have changed your eating and drinking practices and the duration of these changes?

3 - Have you stopped eating any foods because of your pain?

- If yes, which foods? And how do you feel regarding this change?
- If you could, would you want to add these foods back into your diet?

4 - How has your pain affected your general health?

5 - Have you noticed a change in your body weight? Please explain

6 - Do you feel tired or fatigue? Please explain

7 - Are there any digestive problems? Please explain

8 - How do you feel regarding these problems (weight change, fatigue, digestive problem)?

9 - Has your pain affected other aspects of your life?

10 - Have you received any treatment for (weight change, fatigue, digestive problem)?

11 - Were your doctors understanding about your suffering? What advice did they offer?

12 - How do you feel about the quality of treatment you received from healthcare?

13 - What are your suggestions to get effective communication between doctor and patient to alleviate patient suffering regarding the change their diet?

14 - How is your outlook for your future?

15 - Is there anything else you would like to add on this topic?

By the end I would like to ask you some background information about you. Please be ensured that the answers you give will be saved confidential. If there are some questions make you uncomfortable, you have the right not to respond.

Demographic Questions:

. Where are you from?

. Where do you live?

. What is your age?

. Are you male/Female?

. What is the highest level of education that you have completed?

. What is your occupation?

Appendix 5: List of Abbreviations

COFP - Chronic orofacial pain

ERQoL - Eating-related quality of life

GI - Gastrointestinal

IBS - Irritable Bowel syndrome

SCM - Sternocleidomastoid muscles

MFP - Myofascial pain syndrome

MP - Myofascial pain

NSAIDs - Nonsteroidal anti-inflammatory drugs

OHCPs - Oral healthcare professionals

OHRQoL - Oral health-related quality of life

OFP - Orofacial pain

TMDs - Temporomandibular disorders

TMJ - Temporomandibular joint

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