What is the meaning of living with chronic temporomandibular disorder pain in Qatar?

A Qualitative Interpretive Phenomenological Exploration

by

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TABLE OF CONTENTS

ABSTRACT

Title: What is the meaning of living with chronic Temporomandibular Disorders pain in Qatar?

Sarra Gibreel

Background: To understand the effect of Temporomandibular Disorders (TMDs) on quality of life (QoL), researchers have focused on psychological, as well as direct and indirect factors. However, dentists have generally focused their TMD treatments on the oral symptoms and signs, ignoring the impact of pain on QoL; this compromises treatment success and patient satisfaction.

Aim: To understand the adaptation process of patients with chronic TMD pain in Qatar. This research is the first to explore the patient experience of chronic TMD pain in the city of Doha, Qatar. We used a qualitative research approach to explore patients' understanding of their experiences with chronic TMD pain, as well as changes in their function and how these changes have affected their lives.

Methods: This qualitative research study implemented an interpretive phenomenology method to explore TMD patients' experiences and adaptation processes. Twenty TMD patients were recruited from the outpatient clinic at the dental hospital in Doha, Qatar. Semi-structured and open-ended questions were used to guide the interviews that took between ¾ to 4 hours. Interviews were conducted in Arabic and English**,** and all data were coded.

Results: It was revealed that two significant factors shaped the patients' experiences and ability to adapt to their chronic TMD pain; these were family understanding of chronic TMD pain and the culture of the community. Finally, the strategies that patients used to cope with their pain included religion, meditation, work and volunteering activities.

Conclusions: The results of this research study will help in the management of chronic TMD pain in Qatar and elsewhere through possible newer and/or more targeted psychosocial strategies that could contribute to reducing the use of analgesics and the financial burden on patients and governments. It will also help health care practitioners to gain insight into their patients' experiences with chronic TMD pain. One immediate outcome of this work was that patients requested that their suggestions and comments be forwarded to the Chairman of the Dental Hospital. This was done, and the Chairman has now initiated changes based on their comments.

RÉSUMÉ

Titre: Quelle est la signification de vivre avec des douleurs chroniques de l’articulation temporo-mandibulaire au Qatar?

Sarra Gibreel

Contexte : Pour comprendre l’effet des troubles de l’articulation temporo-mandibulaire (ATM) sur la qualité de vie (Qv), les chercheurs se sont concentrés sur des facteurs psychologiques, ainsi que des facteurs directs et indirects. Toutefois, les dentistes ont généralement concentré leurs traitements des troubles d’ATM sur les signes et symptômes oraux, tout en ignorant l’impact de la douleur sur la Qv. Ceci compromet le succès du traitement et la satisfaction du patient.

Objectif : De comprendre le processus d’adaptation des patients qui sont atteints de douleurs d’ATM chroniques au Qatar. Cette recherche est la première à explorer l’expérience des patients atteints de douleurs d’ATM chroniques dans la ville de Doha, au Qatar. Nous avons utilisé une approche de recherche qualitative pour explorer la compréhension des patients concernant leurs expériences avec des douleurs d’ATM chroniques, ainsi que les changements de leur fonction et la façon dont ces changements ont affecté leur vie.

Méthodes : Cette étude qualitative a utilisé une méthode de phénoménologie interprétative pour explorer les expériences et les processus d’adaptation des patients atteints de troubles d’ATM. Vingt patients atteints de douleurs d’ATM ont été recrutés de la clinique externe de l’hôpital dentaire de Doha, au Qatar. Des questions semi-structurées et ouvertes ont été utilisées pour guider les entretiens qui ont durés entre 45 minutes et quatre heures. Les entretiens ont eu lieu en arabe et en anglais, et toutes les données ont été codées.

Résultats : Deux facteurs importants sont ressortis comme étant responsables de façonner les expériences des patients et leur capacité à s’adapter à leurs douleurs d’ATM chroniques; ceux-ci s’agissaient d’une compréhension familiale de la douleur d’ATM chronique et de la culture de la communauté. Finalement, les stratégies utilisées par les patients pour faire face à leurs douleurs incluaient la religion, la méditation, le travail et le bénévolat.

Conclusions : Les résultats de cette étude aideront à gérer les douleurs d’ATM chroniques au Qatar et ailleurs grâce à des stratégies psychosociales plus récentes et / ou plus ciblées qui pourraient contribuer à réduire l'utilisation des analgésiques et le fardeau financier pour les patients et les gouvernements. Ceci aidera également les professionnels de santé à se renseigner sur les expériences des patients ayant des douleurs d’ATM chroniques. Un résultat immédiat de ce travail était que les patients ont demandé que leurs suggestions et leurs commentaires soient envoyés au président de l’hôpital dentaire. Ceci a été fait, et le président a maintenant amorcé des changements en fonction de leurs commentaires.

DEDICATION

I dedicate this work to my precious parents; thank you for believing in me and for all of your support.

To my brothers, thank you for your endless support and love.

To my beloved country, Qatar.

To my sponsor, Hamad Medical Corporation, thank you for supporting my education and my dream.

To my dearest and beloved Mrs. Eileen, thank you for being you.

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“More than an umbrella, a person walking in the rain needs someone who would walk with him.
More than a handkerchief, a person in tears needs a chest he can cry on.
I was able to understand these after meeting you.”

Lee Jung Ha, 1962

I would like to express my deepest gratitude to each of the people and participants who allowed me to know them, share their secrets and be their deepest voices. Every research is a collection of people’s participation. I am proud to acknowledge all the participants who shared with me their lived experiences and thoughts.

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“Serendipity is a road to happiness.”

Thank you for all your prayers and great wishes.

PREFACE

I have been working in the dental clinic for ten years. During these years, I learned to interact with different types of patients and their family members. Patients and their families inspired me to conduct this study. The study explores the experiences of patients living with chronic TMDs pain and their strategy for adaptation.

My experiences in the dental clinic taught me to be observant, especially during my clinical work with the scheduled patients. Observing them helped me to improve my communication skills. My observation skills progressed qualitatively every time I treated a patient or attended a case, and that gave me a wider range of vision. It started with treating patients, easing their pain, and answering their questions. Later, I developed the habit of seeking to know the person or the human within these patients. Knowing the patient as a human being contributed to the success of my work. I became more confident in my work and the outcomes. The same single fixed treatment plan does not fit the clinical need of all patients. For example, I may have three patients diagnosed with gingivitis, but each one needed and accordingly received a treatment plan ideal for his or her individual physical and psychological status and eventually, the outcome has been successful.

During my work at the periodontology department, I experienced working with patients from different backgrounds, personalities, and co-morbidities. I learned to document their mental status to monitor my treatment plans and the outcomes. These observations and monitoring procedures taught me to be a researcher. With each case or patient, I would observe, monitor, and search for the best way to do my work and achieve a successful outcome.

At the Dental Hospital at Hamad Medical Corporation, where I worked, there was only time for clinical treatment. Most of the dentists were forced to singularly invest their time in clinical work. This singular focus on clinical work prevented the development of the hospital's dentists' contribution to dental research. For this reason, there is an apparent lack of database information and dental publications within the Dental Hospital at Hamad Medical Corporation.

This original qualitative research is the first to be conducted in the dental hospital at Hamad Medical Corporation. It is also part of my thesis, and my contribution to my patients, my community, and my country. I am extremely proud of all the participants who contributed to this research. It is not easy for people to open their hearts to someone they do not know. Certainly, in my community in the Middle East, it is a most difficult challenge to recruit subjects to participate in research. People are not accustomed to participating in research, especially interviews and one-to- one conversations for study purposes. It is not easy to have them talk about themselves, to share their secrets, and to admit their pain or weakness without reservation. Although I am from this community, I wanted to challenge this phenomenon. Thus, one of my aims in this study is to encourage and allow these patients to freely talk, express themselves, and share their experiences.

CONTRIBUTION OF AUTHORS

Sarra Gibreel, as master's degree candidate and the principal investigator for this study. I obtained ethics approval for this study from Hamad Medical Corporation, Doha, Qatar and McGill University, Montreal, Canada. I conducted interviews and wrote all sections of this thesis dissertation.

Jocelyne Feine, Professor, Faculty of Dentistry, Oral Health and Science, McGill University, Montreal, Canada: Co-supervisor and co-investigator.

Richard Hovey, Professor, Faculty of Dentistry, Oral Health and Science, McGill University, Montreal, Canada. Co-supervisor and co-investigator.

Having reviewed the literature, the candidate gathered the data, performed all data preparation, transcription and coding, and data analysis. Professor Feine and Professor Hovey were involved in all preparation and subsequent stages of the study, from the evaluation of the research proposal to the data analysis, editing, and final submission. Professor Angela Morck was involved in the editing process.

Any information used in the study based on the works of others has been cited and the sources of this information are provided in the "Bibliography."

I. INTRODUCTION

أنا أكره هذا الألم. أكره العيش مع هذا الألم كل يوم (غاضب). أنا لا أفهم عندما يقول الأطباء أنه لا يوجد مزيد من العلاج يمكن القيام به. كل مرض له علاج، لماذا لا يستطيعون علاج آلامي.

“I hate this pain; I hate living with this pain every day (angry). I do not understand when the physicians say no further treatment can be done. Every disease has a cure, why cannot they treat my pain” (Salwa). This is how Salwa felt towards the chronic TMD pain. She suffered a lot and looked for treatment in different hospitals and dental clinics. She strongly believes there is a treatment for all diseases and she refuses to live in unexplained pain.

يحدقون في وجهي (والديها)، ومن ثم يقولون "هذا يسمى الهروب من المسؤولية" نحن لم نربيك لتكون شخصا غير مسؤول.

“They stare at my face(her parents), and then they say “this is called running away from responsibility” we did not raise you to be an irresponsible person (waving her hands in surprise)” (Haya). Haya suffers more in trying to adapt her parents’ support and her surrounding environment to her pain. Her parents believe that she has become lazy and that she is trying to run away from responsibility, which has made them harsher and angrier with her. Her father will retire by the end of this year and all eyes are on her. Everyone in her family believes she is their only hope for financial support.

“I do not go out with my friends a lot like before. Once I was eating a burger with my friends, and I opened my mouth to take a bite but my jaw stopped, and I could not close my

mouth (showing her shock). I was very scared, and my friends were shocked, luckily I kept hitting my jaw with my hand, and it closed. I was very embarrassed and sad” (Maha). Maha is a university student who spends most of the day with her friends. She was a very active person; contributed in volunteering activities, helped in tutoring students, and participated in sports. After her TMD pain became severe, her life changed, she stayed home more and avoided people. She experienced sad and humiliating incidents with TMJ dislocation while she was eating out with her friends and this memory still embarrasses her when her friends mention it.

عندما يكون الألم شديدا، أظل في مكتبي، وإذا جاء أي موظف للتحدث إلى ، ا حرك بيدي ..لا. كلهم يعرفون الآن إن كنت أرفع يدي يعني أن لدي ألما ولا أستطيع أن أتحدث عن العمل وكل شيء معلق حتى أخرج من مكتبي

“When the pain is severe, I stay in my office, and if any employee comes to talk to me, I just wave my hand (he waved his hand above his head)...No. They all know now if I wave my hand it means I am in pain and cannot talk. As regards the work, everything is put on hold till I come out of my office.”(Ahmad) Ahmad is a business owner, and TMD pain was affecting his work performance. In severe pain, he would stop working and not allow anyone to talk to him. At home, when he is in severe pain, his wife knows; she takes the kids away, and everything becomes quiet until he opens the door to his room and starts talking with her again.

غيرت وظيفتي مرتين، وهذه هي المرة الثالثة التي اضطررت إلى المغادرة. ولا يقبل أي صاحب عمل إجازات مرضية كثيرة من الموظف. أخذت إجازات مرضية عندما الألم شديد؛ عملت كمتدرب لم أستطع التحدث طوال الوقت أو حتى تحريك رأسي.

“I changed my job twice, and this is the third time, I had to leave (sadly smiling). No employer will accept so many sick leaves from an employee. I took sick leaves when in severe

pain; I worked as a trainer and was unable to talk all the time or even move my head" (Mona). Mona tried a different type of strategy to control her pain. She believed that her job was the source of her pain. She changed her job twice. She worked as a trainer, then as a teacher, and then as a receptionist to avoid standing. She, however, could not avoid talking. Working as a receptionist was not a choice, as no other jobs were available at that time. She concluded her pain was caused by talking and standing all the time so, she kept switching jobs.

To live with chronic pain, people must adapt their lifestyles, work, finances, and social activities to their new reality. How does one cope with chronic pain? How can one adapt to his or her everyday lifestyle with chronic pain? The aim of this study is to understand the adaptation process of individuals with chronic TMD pain, as well as to explore the role of culture in shaping a person's adaptation strategies and the alterations in his or her lifestyle.

The positive side of pain is that it also works as a protective measure. Without pain, we could not sense a danger that might injure our bodies. I have always perceived pain in one way, the way the patients feel pain. That is because, as medical professionals, we are taught to be compassionate and sensitive toward our patients' pain and suffering, but with an emphasis on the meaning of duty in medicine. Personally, when I used to try visualizing a patient's pain, it was like a mirror without a reflection. I could never imagine about how it would feel if I had chronic pain. Recently, I experienced a joint pain in my right ankle, but I ignored it. I told myself that it was probably due to my heavy workload or may be because of my lack of regular exercise until one day my ankle swelled up and there was an excessive pain. I applied the usual pain ointment and a bandage, but I woke up the next morning with worsened swelling. At the hospital, the usual examination and blood tests were done. Finally, I was diagnosed with arthritis. The truth is, even though both of my parents had arthritis, I still thought I would never inherit it. Medication was ineffective for a long time and the pain would simply not go away. I had pain in my joints and I was limited from performing my work. While, on some days, the pain was mild, on other days, the pain would suddenly increase. In order to restore some of my activities of daily living and to relieve my pain and swelling, I had to undergo physiotherapy. The experience of undergoing physiotherapy changed my life. I do not mean a physical change, but a mental change. Although this may sound strange, I was excited to attend my appointments. I would never miss any of my appointments and was eager to sit between the patients in the waiting room. It was there that I met the most interesting people in my life; where I could listen to some of their stories and experiences of how they had lived for years and years with all kinds of chronic pain. I noted their courage and strength. In all honesty, they became the fuel to my soul and the educators that changed my concept and knowledge about living with chronic pain.

After an eye-opening experience with those chronic pain patients, I wanted to explore and reach out to the individuals with chronic pain in my own way. So, I decided to be their voice to the world, to give them a platform and convey how they feel, how they live through the chronic pain, and to share their hopes and dreams. I wanted to be their voice if they would allow it. The aim of my research is to help understand the adaptation process of patients with TMD pain. Also, I aim to explore the role that culture plays in shaping people’s coping and adapting strategies and the changes that pain imposes on their lifestyles.

1.1 Purpose of the Inquiry

Through the years, TMD studies have increased. However, very few studies have focused on sociocultural beliefs, the individual’s experiences, and coping strategies. Application of the phenomenology approach will offer an understanding of the adaptation process of people with chronic TMD pain. It is imperative to understand what role culture plays in shaping a person’s coping and adapting strategies, as well as the scope and experience of patients that will help in the plan to assist people in coping with their chronic TMD pain.

In general, quantitative methods have been used to measure the level of chronic TMD pain. They have been used to evaluate a patient's response to a specific therapy and to determine the success of a new or conventional technique used in treatment, such as the association between TMD and pregnancy in temporomandibular disorders and hormones in women (3,18). However, very few patient-oriented qualitative studies have been carried out to explore how people adapt to TMD pain. We thus have a limited understanding of people going through the transitional process from everyday activities to a new life with chronic pain. Although this study was conducted in Qatar, the literature review is based on international publications. Relevant publications conducted in Qatar and the surrounding regions were not found.

1.2 Introducing the Participants

This study consisted of 20 participants. All were recruited from the Dental Hospital at Hamad Medical Corporation, Qatar. They came from ten countries (Qatar, Egypt, Yemen, Syria, Sudan, India, Jordan, Pakistan, Philippine, Oman). Three participants were males, and seventeen were females, and they ranged in age from 23 to 60 years. The educational level varies from illiterate to a master's degree, as well as occupation from unemployed to full-time work.

Although nineteen of the participants admitted they suffered from depression, only two of them were referred to psychological or counseling treatments, and one asked her doctor to refer her to a psychiatrist. Even though sixteen of the participants found their work very stressful, only one took the initiative to change her job. This participant changed her work twice, and she stated, *"I felt a slight improvement when I changed the type of work I was doing."*

All of the educated participants in this study displayed the habit of searching for information through Google and other online engines. In particular, the online searches included questions to which the physicians sometimes do not give clear answers. As one of the participants stated, *“I usually ask each doctor I meet and, I met many physicians, “Please, do not give me the old talk, tell me something I do not know.”*

Many of the participants were overwhelmed by emotions and pain. Some were trying to face the challenges of chronic pain every day, while some were trying to deny it, and some avoided facing it. These challenges varied widely, depending on lifestyle and cultural challenges. The problem with these challenges is that, while some of them can be altered, the rest cannot be easily changed.

At the beginning of each interview, I made sure that I confirmed that the participants understood the important points. These points focused on their rights as participants and ensured their psychological and emotional wellbeing. By the end of each interview, I discussed with the participants the importance of psychotherapy and counseling. If a participant agreed to seek counsel, I referred him or her immediately to the psychiatric departments. The participants who refused, were given the option to think about it and return when they decided to seek counsel. I also explained to the participants that they needed to request the referral to the psychiatric department from their original doctor because I would be leaving for Canada to complete my thesis. I found that preparing them emotionally and psychologically helped a lot during the interviews. I talked with the patients regarding their feelings of shame, their fear of talking, their feelings of guilt, and their rights as human beings. All the participants names in this thesis are anonymous.

1.2.1. Participant # 1 (Haya)

Haya is a young female computer science graduate. She is motivated, creative, and very sensitive. Her parents planned her whole life; and though she did not have any objection for a long time, she wished that they would appreciate her efforts one day. Her parents have high expectations of her; their desire is for her to get a good job and help her father in supporting the family. Haya is the middle child. She feels it is not fair of her family to have her carry all the responsibility, especially as her father will retire by the end of the year. However, this did not change her parents' attitude towards her or her chronic pain. Haya explained, *"They (her parents) do not believe me (crying). I cannot do this (carrying the responsibility) anymore. It is very difficult with this pain; I am desperate for a solution. I do not think I can continue living like this any longer, no, no (shaking her head)."*

هم (والداها) لا يصدقونني (البكاء) لا أستطيع أن أفعل هذا (تحمل المسؤولية) بعد الآن. فمن الصعب جدا مع هذا الألم. أنا يائسة من أجل حل. أنا لا أعتقد أنني يمكن أن تستمر في العيش مثل هذا أطول، لا، لا (هز رأسها)

1.2.2. Participant # 2 (Sana)

Sana is female and a physician. She has a strong personality; she is independent, self-motivated, and always tries to stay positive. However, she describes herself as passive and weak when she is dealing with her family and her husband's family issues: *"I studied abroad, couldn't adapt to life easily. On top of that the stress was high and I could not make friends (looking sad). I could not adapt to life there (abroad)."*

أنا درست في الخارج، لا يمكن أن تتكيف مع الحياة بسهولة، وعلى رأس ذلك أن إجهاد الدراسة كان عال ولا يمكن لي تكوين صداقات. لم أستطع التكيف مع الحياة هناك (في الخارج)

1.2.3. Participant # 3 (Salwa)

Salwa is female and a teacher. She is over-confident and independent but is also often in denial when facing the challenges of her chronic pain. She tends to change her words a lot; sometimes she will deny she has any problem and sometimes she will tell me all her efforts on seeking different types of treatments in private and government hospitals. She was not keen on doing the interview. She started our interview by stating, *“I do not have any expectation (saying in disappointment), and I do not think I will learn anything new about my disease.”*

ليس لدي أي توقع، ولا أعتقد أنني سوف أتعلم أي شيء جديد عن مرضي

1.2.4. Participant # 4 (Mona)

Mona is female and works at the administration office. She has a complicated medical case and is weak physically and emotionally. *“I feel I lost peace in my life since this pain started. I spend my time looking for medications (eyes full of tears). I hate explaining about my disease to people. They do not understand.”*

أشعر أنني فقدت السلام في حياتي منذ أن بدأ هذا الألم أقضي وقتي في البحث عن الأدوية. أكره شرح مرضي للناس. إنهم لا يفهمون

1.2.5. Participant # 5 (Saja)

Saja is a widow, very strong, and un-educated. Her life revolves around her children. She lost her husband ten years ago from cancer. Later, one of her sons got into trouble and her life lost more balance and peace. *“I did not go to school, but I am strong (explaining proudly). I took care of my husband when he was sick and weak, but now I feel tired with this disease (saying sadly).”*

لم أذهب إلى المدرسة، ولكن أنا قوية. راعية زوجي عندما كان مريضا وضعيفا، ولكن الآن أشعر بالتعب مع هذا المرض

1.2.6. Participant # 6 (Bana)

Bana is a young female dental technician who is exhausted physically and emotionally. Her father's sudden death had a huge impact on her financially and emotionally. In addition, she takes care of her mother who was diagnosed with Alzheimer disease. *"What can I say, my life is complicated and hard (eyes full of tears). I love my family and my mother (stopped talking, overwhelmed by sadness, crying in silence) but I feel it is becoming difficult for me to stay strong."*

ماذا يمكنني أن أقول، حياتي معقدة وصعبة. أنا أحب عائلتي والدتي، ولكن أشعر أنه أصبح من الصعب بالنسبة لي البقاء قوية

1.2.7. Participant # 7 (Nora)

Nora is a housewife with five children. She has low self-esteem and lacks confidence. She has given up on any positive change in her life. She stated, *"Nobody cares about me if I am sick or well (looking down at the floor in sadness)."*

لا أحد يهتم لي إذا كنت مريضا أو جيدا

1.2.8. Participant # 8 (Brook)

Brook is female, speaks English, and is a nurse at the Heart Hospital. She has great courage, patience, and a beautiful smile. She described herself as a person with great faith and cheerfully said, *"I do not concentrate on my pain (looking confident). I keep talking to everyone all the time, this way I do not think about my pain."*

1.2.9. Participant # 9 (Ahmad)

Ahmad is a manager at a private business. He is a family man with two children, and is motivated and ambitious. He is addicted to mobile games. *“I play mobile games when I am stressed, or bored, but the headaches are severe. If I am driving, I park on the side of the road and I try to relax (explaining seriously).”*

ألعب ألعاب المحمول عندما أشعر بالقلق، أو بالملل، ولكن الصداع الشديد. إذا كنت أقود توقف على جانب الطريق، وأنا أحاول الاسترخاء.

1.2.10. Participant # 10 (Maha)

Maha is a young female college student and speaks English. She is motivated, ambitious, but is under great stress related to study and financial problems. She has taken a part time job to help her father. She says, *“I wish I could get a full-time job (looking sad), but it is hard, I did not graduate yet.”*

1.2.11. Participant # 11 (Faal)

Faal is a female physician and has low self-esteem and no confidence. She is looking for people’s acceptance and fears being alienated at work and even at home. She explains *“Who wants to hear about my troubles (saying in disappointment) It is not an important thing. Nobody cares (smiling).”*

لا تريد أن تسمع عن متاعب لي؛ فإنه ليس شيئا هاما. لا أحد يهتم (يبتسم)

1.2.12. Participant # 12 (Sawa)

Sawa is female, has a master’s degree in marketing, and works outside the home. She is confident, ambitious, and liberal. *“I am an open-minded person (saying confidently), but* *sometimes it is hard to cope with things, and this pain is not ending (staring at my eyes seriously).”*

أنا شخص منفتح، ولكن أحيانا من الصعب التعامل مع الأشياء، وهذا الألم لا تنتهي

1.2.13. Participant # 13 (Ria)

Ria is a female nurse, speaks English, and is strong and ambitious. She is an immigrant looking for a better life. She said, *“Looking at the situation in my country I do not think things will become better anytime soon (saying in disappointment). I think I will be an immigrant for a long time.”*

1.2.14. Participant # 14 (Sala)

Sala speaks English and is a female online business owner with two children. She showed a lack of self-esteem. Her husband makes all the decision at home and controls her business. She said, *“One day I will go away to a place nobody knows and forget about this life (staring at me in anger and trying to show how her thoughts are serious).”*

1.2.15. Participant # 15 (Jed)

Jed is male, speaks English, works as a private driver, and is an immigrant. He feels unappreciated, not respected, and seen only as a minority. He said, *with a slight raise in his voice while speaking and stressing on the feeling of pain, “They think I am not human (sadly expressing the feeling of being a minority), I feel pain, and I get sick”*

1.2.16. Participant # 16 (Fala)

Fala is a young, divorced woman. She speaks English and is an elder sister. She lacks a sense of freedom, and feels she is unheard and unappreciated. She stated there was a lack of communication between her and her family. She said, with disappointment and sadness, *“I feel invisible at home, no one listens to what I say, and my parents blame my pain and problems on the divorce (looking sad and more disappointed).”*

1.2.17. Participant # 17 (Zara)

Zara is a second wife, unappreciated, and shows a lack of confidence. Her husband is a different nationality. She said, *“He (her husband) comes and goes, we do not talk much (looking at the floor sadly), and he does not ask or care (saying in a blaming tone while showing her open hand). I spend my time taking care of my children. I think this is enough for me (feeling unappreciated).”*

هو (الزوج) يأتي ويذهب نحن لا نتحدث كثيرا، لا تسأل. أقضي وقتي في رعاية أطفالي. أعتقد أن هذا يكفي بالنسبة لي

1.2.18. Participant # 18 (Zawa)

Zawa is a young female computer science graduate, shy, sensitive, smart, and a recent immigrant. Her engagement was broken because of problems between her family and her fiancée’s family. She said, *“I am fine, really (looking sad). My engagement was broken before six months (saying in disappointment), and my younger sister got married after four months, I have to forget about it (smiling sadly).”*

أنا بخير، حقا. كان (حزينا) زواجي توقف قبل ستة أشهر، وأختي الصغرى، تزوجت بعد أربعة أشهر، لا بد لي من نسيانه. (يبتسم)

1.2.19. Participant # 19 (Fada)

Fada is male and unemployed. He showed a lack of confidence and feels unappreciated and not respected. Fada holds liberal beliefs that prevent him from easily communicating with his family and others. His family dynamic is complicated and resistant to change. He said, *in a* *lonely sad voice, "I feel I am not one of them. They do not try to understand me, and I am really tired of trying to communicate with them (his family) (in an angry tone)."*

أشعر أنني لست واحدا منهم، أنهم لا يحاولون فهمي، وأنا متعب حقا من محاولة التواصل معهم (عائلته)

1.2.20. Participant # 20 (Hanna)

Hanna is female and a teacher. She is a working mother who lacks self-esteem and confidence. She feels unappreciated, not respected, unheard and invisible, especially at work. When discussing her work environment, she said sadly, *"People are not considerate, if I ask for my colleague's cooperation, I hear them say, "If she cannot work she can stay at home." If I did not need this job, I would not have come (explaining in disappointment)."*

لا يأخذون الأفراد بالاعتبار، إذا طلبت من زملائي التعاون، أسمعهم إذا لم تستطع أن تعمل في البيت.

إذا لم أكن بحاجة إلى هذا العمل لم أكن قد تأتي

LITERATURE REVIEW

1.3 Timing

The literature review for this research study is divided into two parts. The first part of the general literature review was essential as it helped form my research questions and determined the best qualitative approach. The second part of the literature review helped me understand the extent to which the researchers explored the patients' tactics or strategies in adapting and coping with their chronic pain, especially in the Middle East and, specifically, in Qatar.

As human beings, we experience several types of pain throughout our lives; some pains are expected, and some are not, and the way we respond to pain is very subjective, shaped by our individual experiences and the surrounding environment. As defined by The International Association for the Study of Pain (IASP), "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described regarding such damage" (1). In human anatomy, pain thresholds vary amongst individuals. According to the IASP, "Pain threshold is the minimum intensity of a stimulus that is perceived as painful." Pain threshold is defined as the level at which 50% of the stimuli are reported to be painful (2). The definition of pain becomes more complicated when we try to apply it to patients with chronic pain. Chronic pain is an ongoing or recurrent pain that persists beyond the usual course of an acute illness or injury or more than 3 to 6 months; it adversely affects an individual's wellbeing (IASP 2004).

1.4 Types of Pain

- Acute Pain**:** Is an intense, recent onset, transient pain, which usually stems from an identifiable cause.
- Chronic Pain**:** Is an ongoing or recurrent pain that persists beyond the usual course of an acute illness or injury or more than 3 to 6 months, and adversely affects an individual’s well-being (IASP, 2004).

In order to live with chronic pain, these individuals must adapt their lifestyles, work, finances, and social activities to that of their chronic TMD pain. My research questions are thus: a) How does one cope with chronic pain? b) How does one adapt his/her everyday life to chronic pain?

Chronic pain

One of the most common chronic pain conditions involves the musculoskeletal system. Musculoskeletal disorders (MSD) are defined by the United States Bureau of Labor Statistics (BLS, 2010) as, “cases where the nature of the injury or illness is sprains, strains, tears; back pain, hurt back; soreness, pain, hurt, except the back; carpal tunnel syndrome; hernia; or musculoskeletal system and connective tissue diseases and disorders, when the event or exposure leading to the injury or illness is bodily reaction/bending, climbing, crawling, reaching, twisting; overexertion; or repetition.” It is also one of the most common occupational disorders worldwide and has been recognized as a medical condition since the 17th century (Ramazzini, 1964) (3).

Work-related upper limb musculoskeletal disorders (WRULD) involve the neck, upper limbs, shoulders, upper arms, elbows, forearms, wrists, and hands. These disorders can be divided into specific conditions with diagnostic criteria and pathological findings, such as tendon-related disorders (e.g. tendonitis) or non-specific conditions in which the primary complaint is pain or tenderness (4).

A recent Global Burden of Disease study shows that Musculoskeletal disorders constitutes over one-fifth 21.4% of all disabilities globally and is second only to mental health. This study included 8,559 participants identified from a random sample of 825 general practitioners. The study showed that musculoskeletal conditions represent the heaviest burden in general medical practices in France due to its high prevalence and largely negative impact on quality of life. This burden is expected to rise along with increases in the aging population. According to the World Health Organization, musculoskeletal conditions are major contributors to disability among elderly populations, specifically osteoarthritis, rheumatoid arthritis, osteoporosis, and back pain (4, 6). In Canada, no recent studies were found related to the prevalence of chronic TMD pain in Canada (16,17).

Musculoskeletal disorders have a major effect in the workplace. Musculoskeletal disorders workplace injuries disrupt and/or result in time away from work. These types of injuries affect the productivity of a business. Depending on the severity of these injuries, losses to businesses can be extremely high. It was reported that back injuries were nearly half of the Musculoskeletal disorders cases, requiring a median of seven days to return to work, but the greatest impact was found with shoulder Musculoskeletal disorders, with a median of 21 days away from work. However, they accounted for only 13.2% of all Musculoskeletal disorders cases in 2008 (5). Furthermore, the median number of days away from work for those with carpal tunnel syndrome (CTS) was more than three times higher than with any other Musculoskeletal disorders locations/sites. Musculoskeletal disorders was the leading cause of work disability and lost productivity (National Research Council and the Institute of Medicine, 2001) (6, 7, 12).

According to Tanaka et al. (2001), about 40% of all upper extremity Musculoskeletal disorders in the United States workforce were attributable to occupational exposures, representing over 500,000 affected workers every year (Dunning et al., 2010; Silverstein and Adams, 2007; American Academy of Orthopedic Surgery, 2008 (7,8,9,5).

In recent years, there has been an increase in the physical working load, such as heavy lifting, extreme bending or twisting of the neck or back, work with arms lifted or hands twisted, lifting or carrying loads, and pushing or pulling loads. Moreover, there has been an increase in working load caused by the market pressure, work demands and the growing economy, an increase which has lead to a corresponding increase in muscle activity and fatigue. Especially in cases of sitting for extended periods of time or sustaining awkward postures during work such as machine operators, product assemblers, food industry, construction industry, administrative staff, janitors, truck drivers, nurses and health professional staff (110). Absences due to sickness in work-related musculoskeletal disorders are a significant health problem resulting in temporary or permanent inability to work. Thus, most available research has focused on professionals in various jobs, including office clerks, dentists, nurses, farmers, and computers users. Studies have also shown that both physical and psychosocial factors are associated with Musculoskeletal disorders; these include heavy physical work, lifting, forceful movements, whole-body vibration, awkward postures, work demands, stress, and lack of job satisfaction (7, 8).

Economic-cost studies have been carried out to show the relationship between Musculoskeletal disorders and lost productivity in business. The (US) Bureau of Labor Statistics estimated the cost of Musculoskeletal disorders by using the cost-of-illness human capital method, which divides cost into direct and indirect categories. Their report shows the direct categories include medical expenses, medical administration expenses, and insurance administration expenses. Indirect categories include loss of earnings, loss of productivity in the home, loss of fringe benefits, disruption costs, and medical and indemnity administration costs (9). According to Peele et al. (2005), older workers with similar musculoskeletal injuries incurred significantly more lost workdays (wage compensation of $12,700 US per case) and higher wage replacement payments as compared to younger workers (wage compensation of $4,647 US per case). Occupational medical costs were $8,602 US for the older group and $5,601 US for the younger group of workers (10).

Chronic pain is well known as the leading cause of disability, changes in lifestyle, and work absence throughout most of the working fields around the world. Several associations have been found between female, older age groups, and body mass index (obesity and height), socio-economic, occupation, smoking behavior, physical fitness, and occupational factors (heavy work, lifting, bending, job dissatisfaction etc.), psychosocial status (anxiety, depression, emotional instability), pain behavior (e.g., exaggerated), comorbidities , postural stress, and education level and Musculoskeletal disorders (10,11). For example, low back pain (LBP) is known as one of the most common causes of chronic pain. The Global Burden of Disease 2010 study also showed that LBP was among the top ten highest burden diseases and injuries, with an average number of disability-adjusted lives. A national survey on the prevalence and social burden of active chronic low back pain was carried out on an adult Portuguese population; it showed that there is a relationship between increase in age and the prevalence of active chronic lower back pain (12). Research has also found that healthy lifestyle behaviors have a positive influence on the prognosis of occasional lower back pain. Healthy lifestyle factors include not smoking, performing the recommended level of leisure physical activity, minimal consumption of alcohol, and following a recommended diet with the consumption of fruit and vegetables (13, 14).

To our knowledge, no similar studies or publications relating to chronic TMD pain conducted within Qatar are available; this lack highlights the need for further studies. There is a need to not only form a database but also to expand the current knowledge base on different types of TMD cases in Qatar.

1.5 Chronic Temporomandibular Disorder Pain

Temporomandibular joint disorders (TMDs) are chronic pain disorders that affect the head and neck area. They are pathological conditions that affect the jaws and the surrounding musculature. TMDs include myofascial pain and internal damage in the joint and degenerative inflammatory joint disorders, such as arthritis (13, 15).

Patients with TMD usually complain of pain while chewing, and present with pain in the face and neck, clicking and locking of the jaw, muscle pain and stiffness in the face, muscles tenderness, and headaches. It is always a daunting task for a physician to correlate the medical history with clinical examination findings for patients with orofacial pain, especially if the pain is described as non-specified, diffused, and referred.

Pain in the head and neck includes the oral cavity, face, neck, and the cervical area. Many authors have suggested a variety of ways in assisting clinicians with diagnosis and management of orofacial pain. Some sign and symptoms are directly associated with orofacial pain and TMD, such as limitation of mouth opening, deviation of the mandible on opening, TMJ tenderness, TMJ crepitus, click and masticatory muscle, pain, tenderness, TMJ degenerative joint, clenching, and bruxism. Other symptoms appear to be more indirect, such as issues with the eyes, sinus cavities, ears, throat, lymph nodes, and salivary glands (15, 21).

Studies suggest that causes for the higher prevalence of pain in females are due to inherent gender differences in pain mechanisms and the craniofacial system. However, other factors may also play a role in TMD, such as psychosocial differences, hormonal, and environmental factors. TMD is also considered to be a localized form of fibromyalgia (18, 19). Korszun et al. (1998), found that 42% of a group of patients with chronic fatigue syndrome or fibromyalgia also reported symptoms of temporomandibular disorders (20).

To understand the effect of stress and depression on TMD patients, researchers have focused on psychological, as well as direct and indirect factors.

Since the main reason that forces patients to seek treatment is usually pain, physicians tend to focus on relieving the cause of pain. Therefore, most dentists design a treatment plan to deal with stress or dental pathologies. Dentists who follow dental etiology treat only the oral symptoms and signs. This raises the question as to what happens to the psychosocial part of the patients' treatment. Most of the time the physicians and dentists ignore it, which compromises the success of the treatment and patient satisfaction. Correspondingly, not enough attention is given to this part of the treatment. This inadvertent neglect raises another question: is the psychosocial part of the patients' treatment ignored because physicians and dentists do not believe it is important or because they do not know how to deal with it?

Dealing with the effect of chronic TMD pain on the psychosocial part of the patient's life is crucial. We need to explore the patient's experiences and strategies to cope with chronic pain. In (Figure 1), Fricton (2014) explains how the contributing factors interact with patients' lives, including the mind, body, emotions, spirituality, lifestyle, social relationships, as well as the physical aspects and the possibility of relapse (Figure 1) (21).

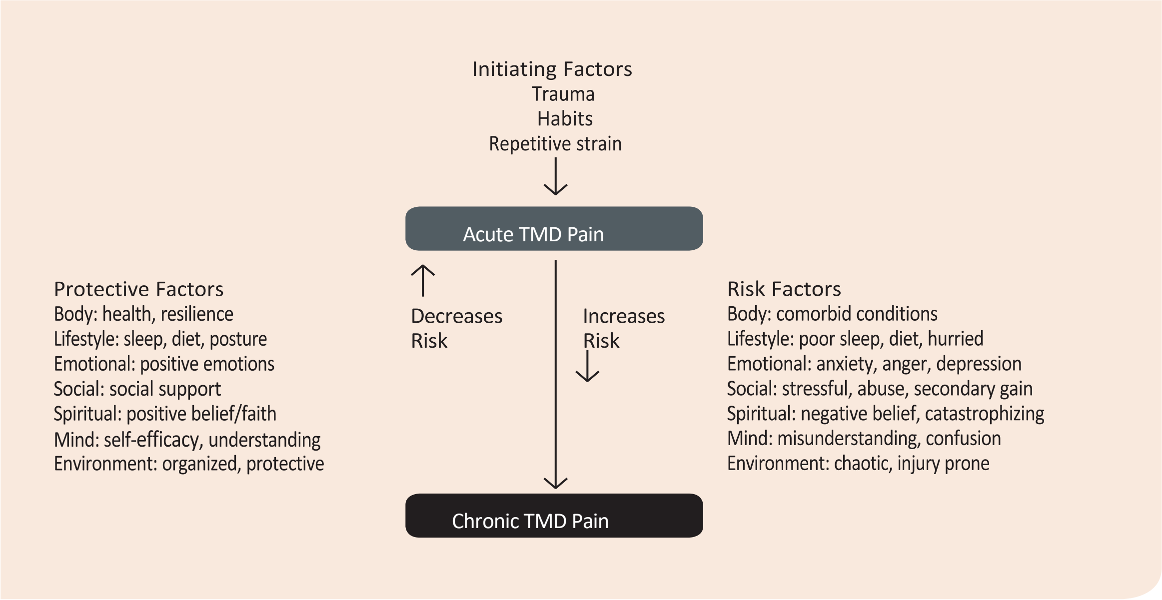

Figure 1. Multiple protective and risk factors play a role in the progression from acute to chronic TMD pain. (21).

Managing chronic TMD pain by applying this psychosocial strategy helps to reduce the use of analgesics and avoids the financial burdens on the patients and the government of Qatar. The aim of this study is to understand the adaptation process of patients in Qatar with chronic TMD pain and to explore the role culture plays in shaping their adaptation strategies and changes in their lifestyle.

1.6 Symptoms Related to Temporomandibular Disorder

1.6.1 Headache

The International Headache Society classifies TMDs as a subset of primary headache disorders (22). Findings from epidemiological and experimental intervention studies indicate that TMD is a chronic pain condition that can occur in association with some other common chronic pain conditions, such as headaches. A headache is regarded as the most common symptom in

22% of TMD patients, while 55% of chronic headaches patients that were referred to a neurologist had signs or symptoms of TMD (23-27).

Patients diagnosed with severe TMD often report having headaches. A study done by Akhter et al. (2013), on first year students at Okayama university in Japan showed a headache prevalence of 21.9% that was within the range of other studies that were conducted on Asian Chinese 24.2%, Japanese 22.8%, European 21.9% and Northern American 13-21% populations. They also found that headaches were associated with symptoms of TMD and that this relationship was found to remain significant after adjustments for age and sex (28).

Dahan, et. al. (2015) found a relationship between increasing number of comorbid conditions and a positive association with TMD pain duration and intensity. Also, the presence of some conditions, such as a migraine and chronic fatigue syndrome (CFS), are found to be associated with increased TMD intensity and duration. These findings could be clinically relevant, suggesting that in order to improve TMD symptoms other existing comorbidities need to be optimally assessed and addressed, probably in interdisciplinary clinics that host multiple health professions (29).

Anderson et al. (2010), suggested that TMD patients with increased frequency of a headache occurring in the temples show an increasing severity of TMD pain characteristics, such as the spread of pain, as well as increased sensitivity in trigeminal and non-trigeminal sites. Together, these findings suggest that these headaches may be TMD-related and that there is a relationship between both peripheral and central sensitization in TMD patients (30).

1.6.2 Sleep Bruxism

The prevalence of bruxism in the adult population is around 20% and is similar to that recorded in children. In a recent study conducted in Boston by Cheifetz et al. (2005), parents' interviews revealed that 38% of the children in a group of 854 with a mean age of 8.1 years presented with sleep bruxism. However, only 5% of the parents reported symptoms of TMD in their children (31).

Research studies have shown that the greatest incidence of bruxism is between 20 and 50 years of age, after which the rate progressively decreases. In addition, the intervention of occlusal interferences was initially hypothesized in relation to the etiology of bruxism. At present, emotional stress is considered to be the principal triggering factor. There are other triggering factors, such as central nervous system disorders, and a certain genetic and/or familial predisposition (32). In 2005, Magnusson et al. reported a longitudinal study in which they followed 420 individuals for 20 years. The study revealed a significant correlation amongst bruxism, TMD and dental crowding (33).

1.6.3 Tinnitus

Tinnitus is a heterogeneous condition, which presents the perception of sound in the absence of any external source of sound or apparent acoustic stimulus. The precise cause of tinnitus is unknown; it is not a disease-specific entity, but rather a symptom, with many potential causes. However, some evidence has indicated that it is the result of plastic changes in the auditory system. These changes cause the auditory neurons to become hyperactive and to shoot more synchronously. If the auditory system is injured, for example, the outer hair cells have been lost because of noise exposure or ototoxicity, then neurons that normally have low levels of activity begin to fire at a higher rate and more synchronously (34).

Patients describe hearing different sounds such as ringing, crickets, whooshing, pulsing, ocean waves, buzzing, and dial tones. Tinnitus can exist unilaterally, bilaterally, or centrally in the head, and the perceived sound can be tone-like or noise-like. Different etiological factors can cause tinnitus including presbycusis, which usually affects the elderly and it is also related to age-related hearing loss. In addition, it can be associated with much comorbidity, such as hyperacusis, insomnia, and anxiety or depression (35, 36).

Some recent research has found that tinnitus patients with TMD problems tend to be younger and female, compared to those with tinnitus but without TMD symptoms. They also seem to suffer from more muscle tenderness to palpation and higher stress levels (37). Correspondingly, it has been reported that an improvement of tinnitus symptoms can be achieved by a specific course of therapy for TMJ disorders (38).

In an attempt to understand tinnitus, many theories have been proposed. Costen et al. (1997) proposed the first theory, which believed that the loss of posterior teeth and vertical dimension of occlusion (VDO) could increase pressure on the ear structures and cause otologic symptoms. The second theory was suggested by Pinto et al. (1962) who proposed that the existence of a “tiny-ligament” could be responsible for the otologic symptoms in TMD patients. Myrhaug (1964) proposed a third theory that a muscular TMJ could cause a secondary hypertrophy of the tensor tympani and tensor veli palate muscles, generating aural symptoms. Presently, the most accepted theory is the sensory-motor theory, which suggests that tinnitus modulation can occur by muscular contractions (37-39).

There is a common perception that tinnitus is multimodal and may arise from complex interactions amongst different sensory and motor systems. For example, some patients can modulate its pitch, loudness, or both by forcefully contracting the muscles in the head, neck, or limbs, or by moving the eyes in the horizontal, vertical axis in addition to placing pressure on myofascial trigger points, moving the face and the mouth, or by applying pressure to the temporomandibular joint (38).

Another concept proposed that tinnitus is a somatosensory condition, identifying neuronal pathways mediating somatosensory input, including the fact that some patients can manipulate their tinnitus by jaw, neck, or head movements (38, 39). Alternatively, some studies suggested that there is a strong association between emotional factors and tinnitus. It is believed that other brain areas are activated by emotions and that the auditory and sensory motor systems have an influence on afferent activity. Moreover, similar to chronic pain, tinnitus has peripheral and central contributory factors. The association between tinnitus and chronic pain can be explained through the interaction of sensory-motor systems, illustrating the theory of tinnitus in patients with chronic TMD pain.

Unfortunately, physicians often tell patients with tinnitus to try to adapt and live with it. This can subsequently result in missing a potentially serious medical condition diagnosis and in dismissing the patient’s serious complaints. This results in the clinician failing to provide any hope of relief, as well as increasing the negative impact on the patient’s quality of life. (40) The disabling effects of tinnitus resemble those of chronic pain, such as: loss of sleep, interference with concentration, difficulties functioning at work, at home, and in social relationships, negative emotional reactions, including despair, frustration, depression, and suicidality. When a patient’s responses include both depression and anxiety, there can be a significant reduction in quality of life and impairment in coping capacities. Social withdrawal, feelings of helplessness, avoidance behaviors, and upset in interpersonal relationships are common signs that quality of life is compromised (40).

Correspondingly, dentists can treat tinnitus by treating the temporomandibular joints, the muscles of mastication, and the teeth. The prevalence of tinnitus in a Cleveland Clinic study of 109 patients with TMD was found to be 36% (40). The study also presented an association between cervical muscle disorders and masticatory muscle function. For example, patients who grind their teeth at night must contract the sternocleidomastoid muscles of the neck to stabilize their head during grinding. Consequently, correcting cervical posture, changing the sleep position, and controlling conscious parafunctional habits such as clenching the teeth and grinding the teeth together can decrease many of the TMD symptoms. Occlusal correction procedures (bite correction) can often provide long-term stability to the masticatory system.

Tinnitus can be treated by managing TMD through physical therapy. With the support of a therapist, patients can learn to recognize the daytime parafunctional habits and learn to decrease clenching and additional overloading of the masticatory system. A home exercise program may additionally help patients maintain their muscle strength and harmony (41). The use of physical therapy, including soft-tissue mobilization, deep heat, ultrasound, low-current electrical stimulation, myofascial trigger-point release techniques, and posture retraining alongside education on proper posture, ergonomics, and exercise techniques can also contribute advantageously. Subsequent therapy is designed to restore proper cervical and temporomandibular biomechanics. This includes identifying biomechanical problems of the head, neck, and jaw that can contribute to tinnitus treatment (42).

1.7 Comorbid Conditions and Chronic Temporomandibular Pain

1.7.1 Osteoarthritis (OA)

Temporomandibular joint osteoarthritis (TMJOA) is a subtype of TMD and is common in female patients with severe pain and dysfunction of the temporomandibular joint (TMJ). This may be due to an estrogen receptor alpha polymorphism. OA is characterized by radiographic signs of bone changes associated with TMJ arthritis including irregular, thickened cortical outlines (sclerosis), erosions, osteophyte formation, subchondral cysts, flattening and narrowing of the joint space, subchondral bone remodeling, progressive degradation of cartilage, synovitis, and chronic pain (43).

Osteoarthritis is divided into two groups:

a. Primary osteoarthritis: When there is no previous pathology, and the cause is unknown.

b. Secondary osteoarthritis: When it is secondary to some previous injury, stress, or pathology in the joint. The disease is defined as gradual loss of articular cartilage, which is primarily, associated with thickening of the subchondral bone. It undergoes a reactive hypertrophy forming peripheral osteophytes.

Although OA occurs most frequently in the joints of the hips, knees, and spine, which support more weight, it also affects the neck, hands, and the TMJ. In the TMJ, the most common signs and symptoms of OA include swelling and palpable tenderness of the joint, crepitation, and limited mandibular movement. The joint pain is usually mild in the morning and gets worse in the evening. The TMJ differs from other joints because of the covering fibrocartilage layer. The mandibular condyles are located beneath the fibrocartilage making it vulnerable to inflammatory damage and a good model for studying arthritic bony changes. The bones in the TMJ condyles are always under dynamic morphological transformations, which make it an essential part of the initiation, progression of arthritis, and cartilage degradation (43).

Some research has found protein level measurements to be higher in serum than in the synovial fluid, which indicates that arthritis is localized in small joints such as the TMJ. Nevertheless, this may not lead to changes in systemic levels of a protein that may lead to undiagnosed arthritis of other joints in the body. The diagnosis of TMJOA is based on medical history and clinical examination. There are no specific laboratory tests to make a definitive OA diagnosis. Laboratory tests such as rheumatoid factor (RF), erythrocyte sedimentation rate (ESR) and antinuclear antibody (ANA), are usually normal. For complete analyses, imaging examinations are required; correspondingly, panoramic and conventional radiographs may identify rough TMJ changes, but these methods are restricted in diagnosis, because of the anatomical superposition that prevents an accurate view of bone components. Therefore, computed tomography (CT) is useful and can assist in confirming the diagnosis of TMJOA and to grade its severity (44).

No radiographic criterion is a specific indication for rheumatoid diseases. In general, they show erosion, sclerosis, subchondral cysts, osteophytes, flattening, and a reduced joint space. However, reduced joint spaces, flattening of the condyles, and osteophytes have been reported to be more common in OA, whereas erosions in the condyles are frequently found in rheumatoid arthritis (RA).

1.7.2 Rheumatoid Arthritis (RA)

There is a major consequence of bone tissue destruction in an inflammatory rheumatoid arthritis disorder (RA). The involvement of the TMJ in RA often leads to changes in the jaw relationship, such as an anterior open bite and impaired chewing ability.

Although, the radiographic signs of involvement of the TMJ have been reported to occur in (45%) to (71%) of patients in the late phase of RA, very little is known about how early these changes appear and to what extent. In addition, the relationship between TMJ conditions and systemic inflammatory activity with bone resorption in the early phase of RA is not well known (45). Some studies have suggested that systemic inflammatory activity and the sex steroid hormones estradiol and testosterone might influence bone tissue resorption, as well as the RA and TMJ progression rate. In addition, the use of modern diagnostic criteria, such as the

Research Diagnostic Criteria for Temporomandibular Disorders (RDC/TMD) allows for multiple diagnoses and specific treatment, which can assist in the early diagnosis of joint and muscular pathology (45).

1.7.3 Fibromyalgia

The American College of Rheumatology (ACR) defines fibromyalgia syndrome (FMS) as a chronic musculoskeletal pain syndrome of unknown etiology. It is characterized by widespread pain for more than three months and it can affect at least three of the four quadrants (the left and right sides of the body, above and below the waist). Pain must be present in the axial skeleton (cervical spine, thoracic spine, lumbar spine, or anterior thoracic wall) to qualify as fibromyalgia. Also, it presents tenderness in at least 11 out of 18 tender point sites such as occipital bone insertion of the sub-occipital muscles, anterior cervical aspect of the intertransverse spaces at C5-C7, midpoint of the upper borders of the trapezius, origin of the supraspinatus, second costochondral junction, 2 cm distal to the epicondyle, upper outer quadrant of the buttock, posterior surface of the greater trochanter, and the medial knee fat pad (46,47). Patients with FMS display enhanced sensitivity to a wide range of stimuli, such as heat and cold, as well as mechanical and ischemic pressure. The syndrome appears to be linked to central neural mediation that alters sensory processing and pain perception. It is also more prevalent in females, which is corroborated by Balasubramaniam et al. (2007), who examined the TMJs of a group of women and men with fibromyalgia and found that 53% of the women met the criteria while 11% of the men met the diagnostic criteria for TMD. They suggested hormonal disturbances might explain why the difference was so great (47).

The relationship between fibromyalgia and myofascial pain is also associated with TMD. Temporomandibular disorders (TMDs) are chronic pain disorders that affect the head and neck area. They are pathological conditions that affect the jaws and the surrounding musculature. TMDs include myofascial pain and internal damage in the joint and degenerative inflammatory joint disorders, such as arthritis (13, 15). Fibromyalgia and craniomandibular disorders share etiological factors such as stress and sleep disorders. Craniomandibular disorders (CMD) refer to a group of musculoskeletal conditions occurring in the temporomandibular region. These conditions are characterized by pain in the mastication muscles and TMJ, or both (Okeson and de Leeuw, 2011) (111). Craniomandibular disorders are an increasing problem and its numerous etiological factors (stress, anxiety, trauma, and malocclusion) can contribute to their development.

In some cases, the involvement of the masticatory muscles aggravates the symptoms of FMS. Some patients diagnosed with fibromyalgia presented with a significantly higher prevalence of signs and symptoms of craniomandibular disorders, such as reduced jaw opening, greater pain, painful muscle palpation at certain points, painful joint palpation, and intraarticular noises (48).

Similarly, Leblebici et al. (2007) examined craniomandibular disorder prevalence in a group of women diagnosed with fibromyalgia and found that (80%) presented with TMDs, mainly affecting the muscles (49). Additionally, a study by Plesh et al. (1996) showed that, out of 60 patients diagnosed with fibromyalgia, (75%) met the classification criteria for craniomandibular disorders of a muscular nature and disc dislocation or arthralgia (50).

The fibromyalgia disorder appears to have a series of characteristics such as parafunction, muscle fatigue, functional overload, anxiety, and stress, sleep disorders, morning stiffness, allodynia, hyperalgesia, increased joint friction, and depression. All these constitute predisposing and triggering factors for TMD, and these factors could easily exceed the limit of functional adaptation to stress in the TMJ leading to its dysfunction (50).

Some studies suggested that diffuse pain originating from FMS is associated with sleep disorders. It may affect the performance of the masticatory muscles, leading to an imbalance in muscle function and impaired functioning of the stomatognathic system, which eventually results in facial pain. These centrally generated pain conditions may play a role in the onset and persistence of the clinically significant TMD (51). Previous studies have shown that FMS is highly co-morbid with primary headaches such as tension-type and migraine headaches and TMD. Identification and quantification of differences in trigger points (TrP) distribution and location of the referred pain between patients with TMD or FMS could be helpful for the clinical identification of pain patterns, despite the overlaps in symptomatology and clinical presentation of pain (52).

Recent studies have found that women with FMS exhibit a longer duration of this painful condition and higher levels of pain in the orofacial area than those with myofascial TMD. These findings reveal that the location of common pain symptoms in the orofacial region is similar among women with pure myofascial TMD and FMS, but the pain is more widespread in FMS, taking into consideration that FMS is a chronic condition that may not be diagnosed for an extended period (52). Therefore, it seems that trigger point (TrP) referred pain in FMS is mostly located in the neck region, whereas TrP referred pain in TMD is mostly located in the face area. One possible pathophysiological mechanism that explains differences in the location of the TrP referred pain could be related to a different clinical manifestation or degree of trigeminal brain stem sensory nuclear complex sensitization in relation to cervical/spinal sensitization. It is plausible that women with TMD would exhibit a greater sensitization of the trigeminal neurons than women with FMS, which would explain the TrP referred pain location in the face, rather than in the neck, for TrPs in the masticatory muscles (52).

Overall, FM and TMD symptoms lead to significant reduction in functional capacity and quality of life. Therefore, achieving an understanding of the interrelationships between TMJD, fibromyalgia, and widespread pain will lead to better management for these patients.

1.7.4 Chronic Fatigue Syndrome

McBeth et al. (2006), found a psychological relationship between chronic fatigue syndrome and chronic pain. They studied the presence of concurrent depression and anxiety between chronic pain and chronic fatigue. Factors examined included marital status, childhood psychological abuse, recent threatening experiences, and other somatic symptoms (53).

1.7.5 Juvenile Idiopathic Arthritis (JIA)

Juvenile idiopathic arthritis (JIA) is a chronic, inflammatory, systemic disease beginning before the age of 16 years and affecting one or more joints of the body. It is characterized mainly by idiopathic peripheral arthritis with an immunoinflammatory pathogenesis. Some of the manifestations include chronic synovitis, arthralgia, and impaired joint mobility. In addition, there are extra-articular manifestations of the disease such as fever, rheumatoid rash, cardiac disease and chronic uveitis. In the case of the TMJ, there is also involvement of the masticatory system (54).

Chronic inflammation in the TMJ results in degenerative alterations, the presence of signs and symptoms of dysfunction such as pain, TMJ noises, and limited movement. Changes in facial growth, such as micrognathia, retrognathia, facial asymmetry, and anterior open bite also occur due to condylar involvement. In addition, teeth and gingiva can be indirectly affected by

JIA due to physical limitations in the superior limbs of these patients, which leads to difficulty in performing adequate oral hygiene, thus increasing the incidence of dental and gingival pathology (54).

1.7.6 Burning Mouth Syndrome (BMS)

The main symptom of burning mouth syndrome (BMS) is a pain in the mouth characterized by burning, scalding, or tingling and, sometimes, a feeling of numbness. Other symptoms include dry mouth or an altered taste in the mouth. BMS is a painful condition in which the tongue is usually affected, but sometimes the lips, the roof of the mouth or all of the mouth are involved. The pain can last for months or years.

According to the protocol of the European Academy of Craniomandibular Disorders, about two-thirds of BMS patients showed initial signs and symptoms of TMD myofascial pain. Some studies suggest that a high percentage of TMD is found in BMS patients due to an overload of the masticatory system, anxiety, restlessness, and parafunctional habits (55).

1.8 Gender Differences in Temporomandibular Disorder Pain Threshold

There are differences in the pain perception and tolerance thresholds due to their association with factors such as ethnicity, genetics, and sex. However, because pain tolerance levels are a subjective individual experience, it is difficult to standardize or generalize it.

1.8.1 Psychological differences

Women appear to be strongly influenced by mental health and psychological factors associated with TMD.

Hessa explained her overwhelming emotion with sadness, *"I hide in my room. Sometimes I stay most of the day in the room. I hate interacting with people. I was not like this. Before I was* *very social and nice person, but now I have changed. People say I'm angry most of the time, but I'm not. I'm in pain."* This is how Hessa lives her life. Her pain changed the way she lives her life and the way she expresses herself. Ahmad on the other hand, runs away from his pain by playing mobile games, but it does not work all the time. He shared, *"I play with mobile games and if the pain increases I hide in my office."*

According to LeResche et al. (1997), TMD occurred in approximately (30%) of menopausal women on estrogen replacement medication, suggesting an association between sex hormones and TMD occurrence (56). Dao et al. (1998), also suggested that reproductive hormones may contribute to TMD pathophysiology based on the observation that there is a higher incidence in myofascial pain in women with childbirth experience (57).

In conclusion, while temporomandibular disorders are negatively associated with overall quality of life, comorbidities such as osteoarthritis and mental health issues strengthen this negative relationship. The association is found to be stronger in women, which may reflect susceptibility to chronic pain and mental health disorders (58,61,62). Further items that may be of interest include the association of quality of life with severity or prevalence period of TMD symptoms and gender analysis of the various pathological states that may accompany TMD (58-62).

1.9 Summary

According to the International Association for the Study of Pain (2004), chronic pain is an ongoing or recurrent pain that persists beyond the usual course of an acute illness or injury or more than 3 to 6 months, and it adversely affects an individual’s well-being. Temporomandibular disorders (TMD) are chronic pain disorders that affect the head and neck area. They are pathological conditions that affect the jaw and the surrounding musculature. Patients with TMD usually complain of pain while chewing, with pain in the face and neck, clicking and locking of the jaw, muscle pain, stiffness in the face, muscles tenderness, and headaches. Chronic TMD pain has a significant effect on patients’ psychological status and dealing with this effect is crucial. An interpretive phenomenological approach was used in this study to explore the patient’s experiences and strategies for coping with, and adapting to, chronic TMD pain. Learning about the factors that shaped the patients’ lifestyles and helped them cope with the pain is a part of the treatment for TMD pain. It assists in defining the main problem and forming the right treatment plan.

Some patients additionally must deal with co-morbid disease. These diseases can increase chronic TMD pain and make it unbearable. Previous studies have found a relationship between some co-morbidities and chronic TMD pain, such as OA, RA, Fibromyalgia, Chronic Fatigue Syndrome, JIA, and BMS. There are differences in pain perception and tolerance thresholds, associated with factors such as ethnicity, genetics, and sex. However, because pain tolerance level is a subjective individual experience, it is difficult to standardize or generalize it. Women appear to be strongly influenced by mental health and psychological factors associated with TMD (58,61,62). Some studies have suggested that reproductive hormones may contribute to

TMD pathophysiology based on the observation that myofascial pain is more prevalent in women with childbirth experience**.**

1.9.1 Prevalence of Temporomandibular Disorders in Qatar

Unfortunately, there are no data or publications related to chronic temporomandibular pain in Qatar, as well as the Gulf Cooperation Council (GCC) countries (United Arab Emirates, Bahrain, Saudi Arabia, Oman, Qatar and Kuwait). During my literature review search of the international publications, many studies were found related to TMD pain that used quantitative or mixed methods. However, limited numbers of qualitative studies have been published. We were unable to locate studies on chronic TMD pain in Qatar.

The keywords for the scientific review were: Temporomandibular Disorders, Chronic TMDs pain, Temporomandibular Joint, Comorbidities, Coping, Adapting, Experience, Qualitative studies systematic reviews, Mixed Methods. The search resulted in approximately 5,000 articles. The process of the literature review was comprised of search engines; these included MidLinePlus, PubMed, GoPubMed, Google Scholars, and Embase. All international publications were included in my review. No local or Qatari publications related to chronic TMDs pain, in Arabic or English, were identified. Unfortunately, it was therefore not possible to determine the prevalence of chronic TMD pain in Qatar or the surrounding countries of Saudi Arabia, Oman, Bahrain, Kuwait, and the United Arab Emirates.

In general, quantitative methods have been used to measure the level of TMD pain, to evaluate a patient’s response to a specific therapy, and to measure the success of new or conventional techniques used in treatment. Most of the quantitative studies reviewed were presented as case studies, such as the association between TMD and pregnancy (18, 19).

Very few patient-oriented studies have been carried out to explore how patients adapt to TMD, how they go through the transitional process from everyday activities to a new life with chronic TMD pain and chronic pain, in general. Particularly in the Middle East, this type of study is very rare. Most researchers in the Middle East and the GCC countries prefer research that is built on quantitative methods. This is especially the case in Qatar, where researchers believe quantitative research methods are less time consuming, as they entail less contact with patients (personal observations).

1.10 Research Objectives

The purpose of this phenomenological study is to understand the adaptation process of patients with chronic TMD pain and to explore the role of culture in shaping a patient's adaptation strategy. We also wished to explore the way TMD patients interact with their environment and how they make sense of their experiences, changes in their work, financial status, relationships, and lifestyle. A review of the literature found a gap in the understanding of the lived experiences of patients with chronic TMD pain in Qatar. Therefore, this study was designed to help fill that gap.

II. METHODOLOGY: INTERPRETIVE PHENOMENOLOGY

2.1 Interpretive Phenomenology Approach

This study focuses on the participant's perception of coping with chronic TMD pain, as well as, the change in their adaptation strategies along the years. I would like to extend our preliminary insights into the role cultural beliefs play on living with these conditions.

An interpretive phenomenological approach requires researchers to search in depth for their topic of exploration within the observed data and to then interpret the meaning back into the world. This demands that the researcher honors both the topic of interest and the experiences of the participants. It is a movement between the particularity of each participants experience and the collective experience that broadens our understanding of the topic. To practice this method of interpretation the researcher needs to be mindful of their connection to the topic of inquiry (the phenomena). As a researcher, I felt I could utilize an interpretive phenomenological approach for this research because most of my participants and I share the same culture. I understand their history and the way the Middle East culture has shaped their lives.

In Middle East culture, traditionally, people used to believe in talking about their problems to elderly members of the family or community. They believed all older adults hold a unique wisdom and knowledge from their experiences and what they have learned from their ancestors. Every house used to have an older adult, a grandfather or grandmother or both, and they used to call the house the family home. This concept or tradition has changed a lot under the influence of the urban and western lifestyle. The tradition of the family home has transformed and not every house has an elderly authoritative figure today. Instead, in most cases today the grandparents stay alone in the house, especially when their children marry and go away. Even the subsequent family visits by their children have become less and less frequent and are sometimes rare. Thus, the process of consulting or counseling that used to be in the home is now missing. Predisposed to this information about the culture background, I was inspired to apply an interpretive phenomenology approach to explore the present culture and its effects on persons with chronic TMD pain. This research approach is well suited to an exploration of people’s experiences of adaptation to chronic TMD pain.

2.2 City of Doha, Qatar

“Arabic: الدوحة, *ad-Dawḥa* or *ad-Dōḥa*; Arabic pronunciation: [addawħa] ***DAW**-ha*”(63).

Google Images (65)

This research was conducted in the city of Doha, and this is a general presentation of the city’s demography. This summary will represent the population demography in Qatar. Qatar Statistics Authority estimated the country's population at 2,637, 302 in November 2016. Projections released by Qatar Statistical Authority show that the total population of Qatar could reach 2.8 million by 2020 (65). The country has been divided into seven municipalities, and in 2010 Doha was the most populated municipality among them with a population of 796,947. Doha is located in the central east part of Qatar, bordered by the Persian Gulf on its coast. A significant part of Qatar's population lives within the confines of Doha and its metropolitan area.

The population density across the greater Doha region ranges from 20,000 people per km² to 25 people per km. (64,66).

2.3 Selecting Research Participants

Recruitment for healthcare research

Recruitment is one of the most challenging processes facing researchers. It is the process of enrolling the most eligible participants, with his or her free will and consent. Recruiting the suitable participant in healthcare research is very significant since it can affect the outcome of the research. Finding the right participant is a major challenge and a daunting process as is convincing them to participate in research, especially when the community lacks an understanding of the importance of health care research.

Google Images (65)

Agoritsas et al. (2015) showed that certain factors might affect the patients' willingness to participate including: patients' characteristics, hospital care experiences and lack of patient education. Also, improving the quality of care and doctor's availability may benefit the recruitment, as well as enforce trust and retention strategy (68).

One of the 20th century trends is the transformation of communities into multicultural societies. The main reason for this trend is the active movement of immigration and immigrants around the world. As the world changed, the city of Doha was also altered. Since 2006, the immigration movement to Qatar has seen a rapid increase. This rapid expansion transformed the community in Qatar dynamically (66). The change in the Qatari community continued, which transformed it into a multicultural community. Thus, a new direction should be considered for recruitment in the health care research to accommodate the cultural changes in the community (68,69,70,71). Some of the suggested changes in the recruitment in health care can be directed towards the availability of services in more languages, improving communication skills, engaging through the internet and social media, and introducing posters that represent a diverse community.

An economic change occurred parallel to the change in the community. There was an increase in the number of foundations, as well as the number of volunteering organizations both locally and internationally. Even though the number of volunteers has grown in different aspects of the Qatar community, the number of volunteers or participants in health care research is still low.

Factors affecting participation rates in healthcare research:

- Lack of community engagement in research.
- The need for new communication strategies.
- The need for an educational program.
- The level of education.
- Socio-cultural and religious factors.
- Lack of trust and fear of wrongdoing.

- The area of research (sensitivity and stress). Communication barriers and more commitments.
- Clinical factors.

Strategies to enhance community engagement:

- Identifying community collaborates (private sectors).
- Engaging the community through various ways such as cultural activities.
- Developing communication strategies (Flyers and posters).

2.4 Research Sampling

The sampling question always puzzled me; how do I know the correct sample size for an interpretive phenomenological study? My sample needs to provide sufficient data to produce answers to my research question. However, does that mean that my study sample needs to be large or from diverse research sites? In order to achieve the answers to my research questions, I learned that I needed to modify my search and look for more parallel cases to the ongoing analysis of data and try to look for the theme(s) and compare it with the theoretical development of my study. Sampling in qualitative research depends on the nature and design of the study. In interpretive phenomenology research, participant numbers cannot be measured or predicted by an equation. Therefore, there is no appropriate sample size calculation. The intent is to select sufficient participant numbers to provide the needed richness of data required for this particular topic at this level of study and analysis. For an interpretive inquiry, at a master level, twenty participants are more than substantive. Participant recruitment in interpretive work relies on purposive sampling in finding participants who can best inform the phenomena of interest. This may entail using a snowballing technique wherein one participant plays a role in the process of recruiting hard to reach groups, by informing their families, friends or other persons who may be interested in the research focus.

2.5 Participant Recruitment

Participants were recruited from the city of Doha in Qatar. All twenty participants were from the Prosthodontics Department and the Dental Diagnosis and Surgical Sciences Department outpatient clinics at the Dental Hospital, Hamad Medical Corporation, Doha, Qatar. They were either contacted by phone or contacted through their dentist directly. The participants I contacted via phone were chosen purposely from the dental clinic statistic list of patients. Sometimes I recruited the participants through their personal mobile phone and sometimes I approached them after they finished their dental appointment at the outpatient dental clinic.

Inclusion criteria

- 18 to 65 years old.
- Males and females from diverse cultures and backgrounds residing in Qatar.
- Diagnosed with chronic pain TMD for more than one year. The decision of a 1-year minimum was based on the criteria found in the description of chronic pain as an ongoing or recurrent pain that persists beyond the usual course of an acute illness or injury for more than 3 to 6 months. Thus, by the end of 1-year patients will be able to develop a strategy to cope with the pain and address the changes in their lifestyle.

Exclusion criteria

- Younger than 18 years or older than 65 years.
- Do not speak English or Arabic.

- No clinical signs and symptoms of TMD (such as no pain on palpation over the temporomandibular joint (TMJ) region, jaw, neck muscles, no pain or TMJ sounds during jaw opening and closing, and a normal mandibular mobility).

2.6 Written Consent

Signed consent forms were obtained from each qualifying participant as per the study criteria of chronic TMD pain. Each participant signed the consent form only after receiving a full and clear explanation about the study. Three copies were made of the signed consent form; one copy was handed to each participant, the other copy uploaded to all the patients’ electronic files, and a third copy was kept in a locked cabinet at the Dental Hospital that I solely had access to.

According to the guidelines and policy at Hamad Medical Corporation all researchers need to upload the participants’ consent forms in the patients’ electronic files for monitoring the medical research in Hamad Medical Hospital. I uploaded all the participants’ electronic files with the help of the Medical Record Office at Hamad Medical Corporation. All consent forms were translated into Arabic and English. All the content of the consent form was thoroughly explained in a simple and understandable language to the participants before the start of each interview. Some participants requested to take the forms home to discuss them with family members before agreeing to participate. I granted them their request.

2.7 Interviewing in Qualitative Research

The interview as a data collection tool is widely used in qualitative research. An interview can vary from structured, semi-structured to an unstructured or focused format. The structured interview is used primarily in surveys because of the need for structure and focused data. Alternatively, semi-structured and unstructured interview formats are used because of their ability to open up conversations about the topic or phenomena of interest (72).

Even though interviews have different structures they share some similarities or commonalities including face-to-face interactions between participants and the interviewer. Interviews also offer the benefits of introduction and exchange of knowledge between the interviewer and the participants. There is a shared knowledge of both the participants experience and understanding of the phenomena and the experience and understanding of the interviewer. The ability of the interviewer to open-up and foster a productive conversation about the topic with the participant is imperative to a successful interview (73,74).

The primary goal of the interview in an interpretive phenomenological approach is to give a voice to a topic that may have been unheard or silenced and to explore participants experiences. Participants and researchers carry with them their values, experiences, concepts, and ideas. Together, these inform the research interaction and in turn broaden our understanding of a topic.

2.7.1 Data Collection

The research interviews were conducted with 20 patients diagnosed with chronic TMD pain (Figure 2). All interviews were digitally recorded, some translated into English before the transcription but some transcribed in Arabic directly, then verbatim, and again compared with the recording for accuracy and analysis.

The initial plan was to space out each interview for around 45 minutes to 60 minutes. I was surprised that most of the interviews took one to four hours. Some participants even wanted to meet again. I met with these participants two to three times. I felt that they wanted to talk and I wanted to listen to them, in the hope that they can gain any comfort and relief. I wanted them to get something in return, as they came all the way to sit and talk with me about themselves and their experiences, and I was able to offer a listening ear with a sincere heart. It was my hope that the participants feel comfortable and supported through our conversations, which would help them in sharing their feelings and experiences, and this reflected by words said by the participants such as “Thank you, I feel better”, “I feel like I have been sitting with a counselor, I feel light and relaxed”, “Thank you, for listening to me” and “can I come again and see you?”

All interviews were semi-structured, with open-ended questions. I individually conducted all the interviews for this study; some were conducted in Arabic and some in English. The qualitative courses helped me in the process of interviewing and transcribing. Prof. Hovey taught me a lot about interviewing participants’ in interpretive phenomenology and qualitative research. He shared with me his experiences and his books, which in turn supported me in conducting the interviews in Qatar. I considered in the interview guide all the questions that could help me in answering the research question, as well as understanding the culture and background of the participants.

Qatar has a multicultural community, and the participants came from ten countries including Qatar. I needed to understand the interpretive interviews. Interpretive phenomenology is a type of phenomenology that engages the researcher in interpreting their research findings to understand a particular topic. This contrasts with descriptive phenomenology in which the intent is to provide a full description of the topic versus an interpretation. Collins described interpretive approaches as, “associated with the philosophical position of idealism, and is used to group together diverse approaches, including social constructionism, phenomenology, and hermeneutics; approaches that reject the objectivist view that meaning resides within the world independently of consciousness. (p.38) (75).

This research approach tries to understand the social phenomena of the participants and how they interpret their everyday lives. One of the related social phenomena in my culture is the fear of being interviewed. During this interpretive phenomenological research, I learned many things; one of which is the way people or participants behave when asked a question. I am not referring to the questions in the interview, but only to the questions I asked when introducing myself and approaching the participant to ask if they would allow me to take ten minutes of their time. I discovered that the number of people in my culture who have social phobia is greater than what I previously thought. Questions as simple as *“Would you allow me to take ten minutes of your time?”* or,*“Would you like to take part in this research?”* created a variety of facial expressions and hesitation from people in response. Some participants looked at me blankly, while some smiled and said they did not know. With women, especially, I had to ask their doctor to explain the study to them, and only if they acquiesced, would I explain more. Most of the participants were initially reluctant to participate in the research, either because they did not like the idea of audio recording or because they did not like the idea of being asked personal questions.

Although I explained to the participants that they had the right to not answer any question they did not like, the majority looked uncomfortable at the beginning of the interview. Every time before the start of the interview I would tell the participants we would just sit and chat. I purposely avoided the use of some of the words such as *“conducting an interview”* or *“ask you some questions.”* I ensured that the first page of my interview guide had short closed questions. I meant to design it in a way that the participants did not need more time to think. The idea was that they would feel the question to be short and thus would feel less burdened to answer. With questions requiring less thinking, they were given the feeling that the interview would be easy and fast paced. Later, as we progressed through the interview, I could see and feel the participants becoming comfortable and relaxed.

The dental clinic is not active in conducting qualitative research. The preference is for quantitative research. I believe this lack of precedent and experience made the participants uncomfortable in answering questions asked by a researcher. I asked the participants why they looked uncomfortable to sit for an interview. I was surprised to see that the participants, despite being patients in the hospital, were still uncomfortable with questions or interviews as it is typical in any dental clinic for patients to be asked a lot of questions, i.e., questions related to their pain, questions related to their habits or their medical history.

The fear of being asked a question is related to my culture and is a normal common behavior. I know people feel frightened if someone they do not know approaches them. However, in my situation the potential participants were already aware about the research from their physician. Sometimes, I wondered if it was the fear of talking face to face or the fear of being asked because some of the participants suggested being interviewed over the telephone. They were willing to do the interview over the phone, but not face-to-face. I even asked them, is it because your house is far or the time is not suitable? They said, *“No it is not like that,”* so I tried to ask them what the problem is and to tell them I could try to fix it. They responded, *“No, just we are not sure about the idea of sitting and being asked without being treated.”* I found that it was difficult for them, to answer questions without treatment. They felt it was not worth it,that it was a waste of their time talking but not getting treated. This behavior highlighted to me that a major issue with patient and family education programs in the hospital was that patients and their families do not understand the value of research in the dental hospital.

The strength of Qualitative Interviews:

- It gives a sense of the natural everyday human experience.
- It presents the participants’ experiences and concepts.
- It gives a voice for the unheard and unseen**.**

Challenges of Qualitative Interviews:

- The finding cannot be generalized to the population.
- It is very hard to replicate the qualitative interviews because each interview is different and each has its own unique emotional content from participant engagement and interaction with the researcher.

2.8 Interview site

All the interviews were conducted in the dental clinic. The site was approved by the IRB in Qatar. I tried to give attention to the interview site. I chose a clinic at the end of the dental clinic corridor to minimize the sounds and avoid distraction and interruption. This plan was not successful all the time, because of the renovation work at the dental hospital. In addition to the loud sounds and distractions, the availability of a clinic was another issue. This was particularly the case during the morning shift and sometimes during the evening shift. Despite these difficulties, I tried to stay motivated, looked and sounded cheerful for my participants, and talked louder to overcome some of the noises. It was a challenge to request for a clinic to conduct the interviews, as the priority is given to the treatment appointments.

The setting inside of the dental clinics was comfortable. The clinics were filled with sunlight and there were comfortable chairs. I was able to provide water and hot drinks to the participants. This was important as the weather was cold outside and the clinic itself is kept very cold because of the dental materials. These challenges caused delay in conducting the interviews, especially when participants requested morning appointments when the clinic was very cold.

I recruited and interviewed 20 participants. This process took approximately 5-6 months. I had hoped to recruit and conduct the research interviews in less time. This was particularly true as I had experienced a delay in receiving my IRB approval in Qatar related to a lack of staff in the Medical Research Center. According to the Office of the Medical Research Center, they tried to speed the process by sending the proposals nationally and internationally.

2.9 Recording the Interview

Living, or conducting, each interview was like living the creation of a painting. The participants' voices and emotions revealed a hidden picture or a portrait. Each participant's interview showed a beautiful painting by the end of our chat. Conducting 20 interviews felt like looking at 20 valuable paintings.

An interpretive phenomenology interview revolves around the participants' experiences, interpreting their expressions and movements. The balance between being with the participants and being at a far angle is simply trying to perceive the full picture. To achieve this, a careful selection of the environment that surrounds each participant is crucial. In this study, all the interviews were at a dental clinic; thus, it was an environment that is very familiar to all the participants and one that they can relate to.

All the interviews are audio recorded. Audio recording is very useful in interview and during the data analysis, as it also allows the researcher to focus more on listening, maintaining eye contact, probing, and following up with the participants. Audio recording can be a challenging process, especially in phenomenology research where the researcher may face difficult situations. Sometimes the participants may feel self-conscious and worry about having their personal life recorded. Therefore, the researcher faces refusal from some of the participants, which might force them to take notes during the interview. Taking notes can be distracting for the researcher and the participant. Some of the participants, Nora and Salwa, refused audio recording at the beginning of the interview, so I had to explain to them how important audio recording was in this study and its role in minimizing the error in transcription. This convinced them, so all the participants agreed to record the audio. Another benefit of recording an interview is the ability to listen to the participant's voice, metaphors, and emotions through their tone of voice especially after the interview is over. It helps the researcher to live the interview again and try to understand and interpret the participant's words with an accurate reference. It also allows the researcher to compare between the participants and assess the emerging themes.

2.10 Conversations with Participants

Paraphrasing: What Does It Mean in The Middle East Culture?

In the Middle East culture, paraphrasing has power, because of the diverse backgrounds and the different experiences that restructured and changed the local communities. Although the community in the city of Doha is a multicultural community, most of the population has migrated from Middle Eastern countries. Even though the Middle Eastern countries share history, backgrounds, geographical areas, language, and religion, some differences have a significant effect on communication. Herein comes the role of paraphrasing in communicating with the participants. The participants come from ten different countries, some from the Middle East and some from Asia.

The following is an example from my culture. A phrase widely used in my culture is in Arabic *"Ya Tek Al Afea -***يا تك العافية** *"* which in English means *"wish you good health."* However, in Morocco people become angry if you say this phrase, because in Morocco it means *"you will go to hell,"*, a very different meaning. I had to use paraphrasing a lot during my interviews, sometimes to clarify a question or to communicate with the participants. When paraphrasing, I could see the change in response in the participants' faces and action. When I conducted the first and second interviews, I realized that participants hesitated and refused if I used the word "interviewing", but they agreed if I said "invitation" or "chatting". In my culture, there is a hidden fear of being asked and especially interviewed. So, every time I talked with the participants I encouraged them to express their feeling sincerely. I used phrases such as, "*It is your right*" or "*It is okay to say*."

Part of me was happy to teach these participants how to express and how to talk about their thoughts. I felt able to release part of their voices, unspoken anger in some of the cases. It also gave them a feeling of appreciation, feeling important, and playing a significant part in the improvement of health care. Some of the participants were nurses, some were technicians and physicians; for them, the research was like a part of their everyday work. On the other hand, the participants external to the medical field described it as a good deed, as being useful, and left them feeling appreciated.

2.11 Data Analysis

"Phenomenology" means "αποφαινεσθαι τα φαινομενα -- to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (Heidegger, Being and Time, 1962, p.34) (109). This is the approach I used in my data analysis; I presented the data, the patients' emotions and their words, the way in which they expressed it. Heidegger (1962) explained the meaning of interpretive phenomenological research as showing the hidden meaning. This involves exploring and showing what is behind every thought and every word and unfolding the meaning behind patients' expressions and words. What their voices, the meaning of their words with regards to the topic. For example, when a participant stated, *"I hate this pain"* is he or she is complaining of unbearable pain, or they are desperate to get back to the time where there was no pain, and they were in peace? (107).

Analyzing or interpreting the data is influenced by the researcher's experience and background. For example, I could understand when patients expressed their fear of not going back to "normal" or the way they used to be before experiencing chronic pain. I lived this through stage or period; I lived in fear of not being able to practice my job as a dentist since I loved my job and still do. Every day I would monitor the extent of my pain and try to make sense of it. Trying harder to be positive and motivated, especially after my doctor told me I will not be able to practice dentistry more than 3-4 years. I planned my life around my dream and goal to be a dentist; I did not want to have to find a new plan and try to fit into it. My experience with chronic pain helped me to be closer to my participants and to relate to their pain. Personally, coming from the same background as some of the participants also helped me in interpreting many of their words and expressions. Some patients used words in Arabic slang language, words such as "لسعة" "sting", to describe their pain. Some patients also used "محطم" "destroyed" to describe their body condition after the pain is gone. I believe that as a dentist coming from the same background as these participants played a great role in communicating with them and understanding their words and meanings.

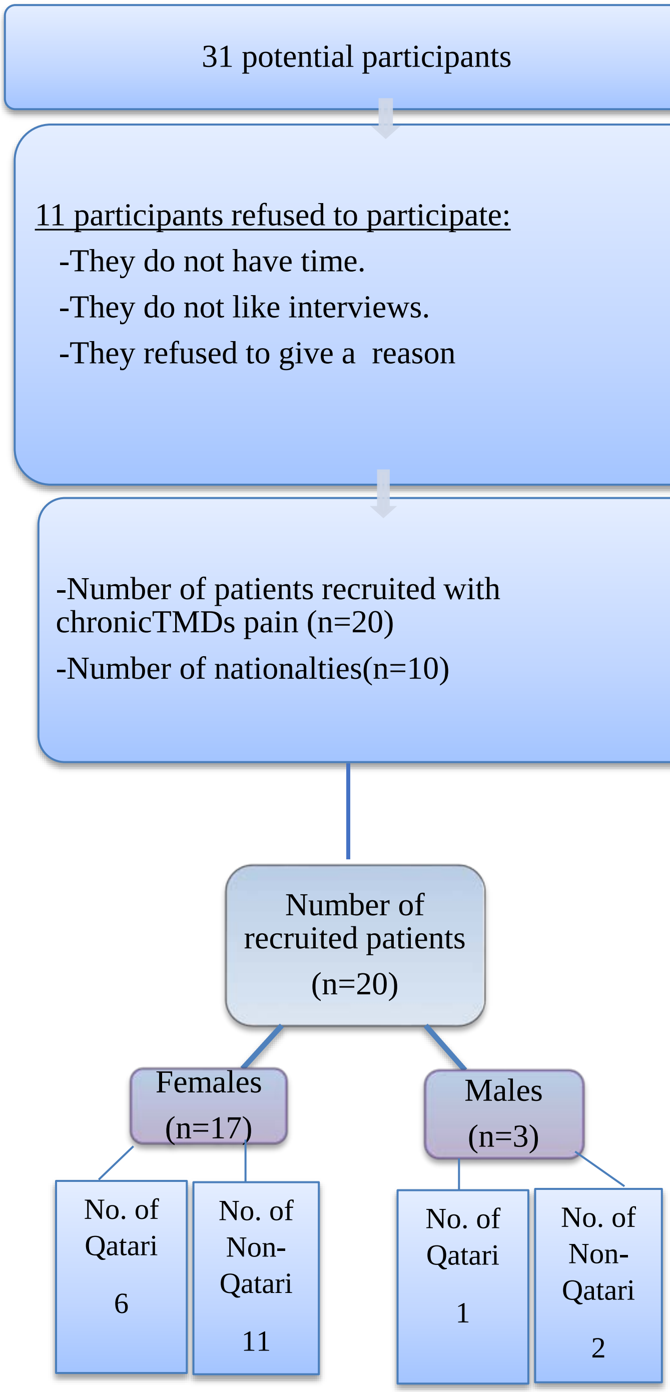

Figure 2. Flow diagram of participants' enrollment.

2.11.1 Interview Transcription

The process of transcription for all the interviews was challenging, especially as the participants came from diverse backgrounds. In this study, the participants belonged to ten nationalities. Most of the participants spoke in Arabic throughout the interview process, and some spoke English. Although most of the participants come from Arabic countries, they had different accents and pronunciations. Some of the participants were born in the city of Doha, while some had immigrated later. Whether or not the interviews were conducted in either English or Arabic the same questions were used. The interview guide and questions were approved beforehand by the IRB in Qatar hence I did not alter the questionnaire.

I was careful in translating each question in Arabic or English during the interviews. Some of the interviews were transcribed in Arabic and some in English. The Arabic and English quotes have been included in this thesis. Although my first language is Arabic, I found transcribing the Arabic interviews more challenging than the English interviews. In interpretive phenomenology, we try to preserve the participants' original words without applying any changes in the pronunciation or the sentences' structure because any applied changes may lead to changes in the meaning or the interpretation. Therefore, to preserve the wording of my participants in Arabic and then to translate it into English was not a straightforward process. Though the Arabic transcription was challenging it had its own beauty, the beauty that is felt by a researcher working on an interpretive phenomenological study. Listening to every participant's words and trying to interpret the meaning and the emotion that surrounded these interviews was beautiful. Every time I listened to these interviews I felt closer to them and I unwrapped a new understanding. In conclusion, transcription and interpretation in phenomenology is an ongoing process that extends our understanding time after time.

2.11.2 The Writing Processes

Writing the findings of qualitative research depends on the way the researcher reflects on the participants’ life and experiences. Similarly, in an interpretive phenomenological approach the researcher presents the participants’ narrations and his/her interpretation of them. This process also includes the researcher’s connection to the topic, which may be expressed as his/her self-reflection. Personally, the writing process helped me to reshape my thoughts and organize my ideas. Every time I rewrote I found a new link or relation between my participants, the topic, and myself. Sometimes, there were apparent similarities in our experiences, especially regarding the culture, and sometimes there were visible differences such as adaptation and knowledge.

2.12 Un-mask Patient’s Pain

After living for a period with chronic pain, patients tend to wear a mask consciously or unconsciously to hide their suffering. One of the underpinning reasons is their feeling of being ashamed, embarrassed, imperfect, and judged by others. Many women especially feel vulnerable towards their relationships and the environment. Often persons with chronic pain feel embarrassed to express their feelings and talk about their pain. How can people convey what they feel or think peacefully if they believe their physician is not interested in listening to their complaint unless it is a new symptom or unusual development?

Following an interpretive phenomenological approach, I tried to overcome this problem with the participants by listening to them carefully, interpreting their responses, and being honest and sincere. *“It is okay to complain”* is what I told the participants in this study. When you fall on the ground, you say, *“It hurts, I feel pain”* and now similarly with this chronic TMD pain they were encouraged to express their feelings freely. Some participants tried not to express their pain because they were shy or they thought that the physician is not interested in listening to their problem, so they refrained from saying everything. Thus, they only shared a part of the problem, and the physician subsequently treated them accordingly. Eventually, the pain stayed longer, and they became irritated and lost trust in their physicians. This is something I see as a continual problem with many persons with chronic pain.

Although many physicians do try to ask repeatedly about the type of pain or area of pain, patients may fail to respond. This communication problem is one of the biggest challenges that physicians must deal with in my culture. Some patients may be less cooperative, while others exaggerate in expressing their pain. This miscommunication has been longstanding between patients and physicians who work with or treat those with chronic pain. This can result in misdiagnosis and unsatisfied angry patients. Some patients complain, *“the physicians never said this outcome,”* or *“I never expected this result.”* Other common questions asked by the patients include*; “Why is this pain chronic? Why can’t you (physician) treat it? How long will it take to stop the pain?”*

There is also a difference in opinion and treatment plan between the physicians who treat chronic TMD pain. If the physician is a maxillofacial surgeon, they tend to have a more surgical approach to the problem. On the other hand, a specialized dentist in another department such as prosthodontics tends to be more conservative in their treatment plan by prescribing pain relievers, anti-inflammatories, muscle relaxants, mouth guards, physical therapy, as well as counseling and tricyclic antidepressants drugs if necessary. Of course, most patients prefer the conservative treatment plan and they only agree to the surgical approach when there are no other solutions or options left to deal with the pain.

2.13 Research Ethics Certifications

Since this research was conducted in Hamad Medical Corporation, Qatar, I followed the guidelines and policies as instituted by the Ministry of Public Health and Hamad Medical Corporation. All researchers, whether they are Principle investigator, co-investigator, or HMC employee need to be certified by the Collaborative Institutional Training Initiative Program (CITI program). In addition, all Hamad Medical Corporation employees are required to pass all of the modules and courses listed under the (iheed) application and Human Subjects Research Course (HSR). Although, the study is conducted in Qatar, as a master level student at McGill University I also followed the guidelines and policy of the University aligned with the Canadian National Research Ethics. Thus, I received a TCPS 2: CORE certification.

2.14 Research Ethics Considerations

This study required two different ethical approvals from two countries. The first ethical approval was granted from Qatar, where the study was conducted. It went through two research committees; 1 - Ethical Approval granted by Rumillah Hospital Research Committee (See Appendix C). 2 - Ethical Approval given by the Medical Research Center at Hamad Medical Corporation, Doha, Qatar. It was granted by the end of October 2016 (see Appendix D). The second ethical approval was granted from the McGill University’s Research Ethics Board Office, Montreal, Canada. It was granted on December 2016 (See Appendix E).

My plan was to recruit patients from two hospitals; Al Wakra Hospital, which is located in the city of Al Wakra, and the main Dental Hospital in Doha. Unfortunately, due to changes and re-structuring in the Hamad Medical Corporation, separate approvals became required for these hospitals. This meant I needed approval from each hospital’s ethical research committee, requiring more time. Eventually, I applied for the ethical approval at the dental hospital in Doha, because it had more patients, and decided to exclude Al Wakra Hospital.

Before starting the recruitment process, I met with the CEO and Dental Director of the Dental Hospital, Prof. Johann De Vries, to inform him about the study. Then, for all study purposes, I tried to meet with the heads of three dental departments, Dental Diagnosis and Surgical Sciences, Prosthodontics, and Maxillofacial department. I was successful in meeting two heads of departments (Dental Diagnosis and Surgical Sciences, Prosthodontics) but the third refused to meet or cooperate. This situation forced me to focus my recruitment on two departments only, which prolonged the recruitment process. I met with some of the dentists who worked under these two departments and explained to them what I needed and the criteria for recruitment. I also answered all questions related to redirecting the patients to my clinic. The recruitment process took different shapes; sometimes I spoke with the patients before their appointment with the dentists, at other times I had to speak with them in the dentist's clinic, and sometimes I waited for them to finish their appointments and then took them to the clinic. I recruited the patients over the telephone and also used face-to-face conversation.

This process took a long time but it was worth it. I succeeded in gaining the participants trust and listening to their voices, thoughts, and experiences. This overcame a great challenge in my culture. Some participants preferred to meet with me before the interview date, so they could understand what I wanted and if they could agree to it, whereas some took my number and said they would call when they decided to proceed with the interview.

Before each interview, I would hand out the consent form to the participants and then to parents or spouses, if they accompanied the participants. I would give them a pen and tell them to mark any point or paragraph they feel they did not understand or needed more information about, so that I could explain. Then I would go out of the clinic for 15 minutes to allow them to review the form in private; upon re-entering, I asked if they needed any help. Some participants had questions, and others did not.

Knowing that audio recording is a sensitive issue in my culture, especially with women, I had to carefully explain the need for recording and the ways for ensuring confidentiality. Only after the participants agreed, with joint consent of their parents or spouses if available, would I then take another permission from all involved to allow me to conduct the interview alone with the participants to ensure the privacy and confidentiality of the participant. I made sure I received approval from participants, parents, and spouses for all interviews.

All interviews had private and personal information; some involved family matters, culture, religion, or work. Each time a participant signed the informed consent, I would make sure to sign it in front of them and sign it in Arabic and English. This was especially important, as some of the participants did not know English and some were illiterate. For the illiterate participants, I informed them that they have the right to show the consent form to a third party or take it home and consult a relative, friend, or anyone they trusted. Only a few of the participants took the written consent form home for review.

I had a checklist for each participant, to make sure that I followed all the steps for the participants' privacy and confidentiality. Every step was transparent and clear in front of each participant. I felt that this was one of the main reasons that made some of the participants request a second or third meeting. During the follow-up meetings I re-emphasized some points, primarily their rights, privacy, and confidentiality. Pseudonyms were used with each participant in this research, including this dissertation and the transcripts that were shared with my supervisors to ensure the privacy and confidentiality of all participants.

Most of the participants had concerns and suggestions related to the system and guidelines of the hospital, and wanted me to forward them to the Chairman of the Dental Hospital. So, at the end of each interview, I requested permission to enclose these concerns and suggestions to the dental chairman. After I had finished all my interviews, I met with the Chairman of the Dental Hospital to present the concerns and suggestions of the participants. I discussed the points with the Chairman, and he requested me to meet with one of the physicians responsible for dealing with the issues. After my meeting with the physician, I had a meeting again with the Chairman for my feedback. No participants were identified or mentioned.

III. FINDING #1-FACTORS AFFECTING PATIENTS' EXPERIENCES

3.1 Cultures

All the participants in this study experienced a variety of cultural influences. The influence of culture was reflected in their homes, their work environment, and their relationships with friends. Although most of the participants came from different or diverse backgrounds, 15 out of 20 participants were born or raised in Qatar. The other five have been in the country for at least eight years. However, this did not prevent the participants from being affected or challenged by the culture and its people.

Home

"I feel like an alien," Participant Fada said, with reference to the major clashes he has with his family on cultural issues. He is unable accept the way roles were assigned in his family. His family was structured on the typical old traditional pattern prevalent in the Middle East. Everyone must listen to the elderly grandparent and the older son, even if his or her opinion was incorrect. Fada's father died a long time ago and this meant that the role of the father or the leader was automatically transferred to his older brother. He and his brother had different personalities. Fada said:

> *"Almost every time we (he and his older brother) talk we fight, we think differently, and we do not communicate well. No problem really, what I cannot understand is him being a bully and aggressive sometimes."*

Fada's brother and most of their family are very conservative, but Fada is very liberal. Fada's liberal believes extend to religion and this was considered unacceptable and lead to a major problem in their family. He said, *"Thank God I have my older sister, though she only listens."*

His older sister was a passive type, she would listen to him, but she did not support him in family discussion or arguments. One of Fada's painful memories, as he called it, was an incident that happened back when he used to spend time with his family. He has now stopped socializing or exchanging talks with his family. He said:

> *"Once I was sitting with my family, and the pain in my head and jaw was too much, I started hitting my jaw with my two fists. So, everyone asked me to stop; I explained to them that the pain was too much and I feel my head will explode. You know what happened? My older brother told me in front of everyone, "stop acting, be a man," I said angrily, "I am the one who's in pain," these simple words. You know what happened next? My older brother walked angrily towards me and hit me. I can never forget that incident. What does he know? I'm the one who lives with this pain every day." (Fada)*

Fada's tears were rolling down his face when he told me his story. He then apologized, *"Sorry, I do not know why I cried, but I am deeply hurt by the way everyone sees my pain."*

Participant Sala shared' *"Who cares, every time I say I am in pain my husband says he will marry another younger woman. He thinks I'm faking my pain because I'm bored."*

Sala was raised in a very conservative and traditional family. Her father was in the military, and that reflected on the way he treated everyone at home. Sala's mother is a weak person, uneducated, with low self-esteem. Sala is the middle of three daughters. She described herself when she was at her father's house:

> *"I am in the middle which means no one cares about me or listens to what I say. My father gave all the power to my older sister. Whatever she says happen, she even more powerful than my mother. I am the one who cleans, and takes care of my grandmother."(Sala)*

She felt unappreciated when she was at her father's house, and now she felt even her husband doesn't appreciate her.

> *"You know I get up early every day, prepare breakfast for my husband and two kids, I even prepare their lunch, because I want them to eat healthy. However, during this pain in my jaw and the headaches, I just can't work at all. I enter my room and lay down sometimes for hours." (Sala)*

Sala feels she is a devoted wife, but her husband does not appreciate her, and her father and mother do not care. She said, *"I used to hand make most of the things in my home, but since this pain started, I feel I have become a cripple."*

This chronic TMD pain made Sala question her value as a wife and mother. Her husband shut her off or threatened her with other *"ideal women"* as he described it to her every time she feels sick or complaints of pain. She said: *"Hearing him (husband) say stop faking, or I will get married to my ideal women, breaks my heart. It is more painful than the chronic pain that I live with."* She has been married to him for more than 25 years. She kept repeating *"One day I will not go back home and go to a place where no one knows me. I will live alone."*

Participant Nora shared; *"As much as I get up every day and the house work is done nobody cares."* Nora is a soft-spoken individual, who is overwhelmed by the housework and her ignorant husband. She has five children; the youngest is not in kindergarten yet. She said:

> *"I tried to tell my husband about my pain, but he thinks I am exaggerating. If I tell my mother and sisters, they say, "What can you do? Who will take care of your house and children, if the physicians cannot heal you try to live with it." (Nora)*

When she tried to explain to her family, they advised her to ignore the pain and not to think about it.

Work

The cultural effect within the work environment is complicated because it does not follow the standard work guidelines and policies. It is a mixture of work roles and cultural behaviors. Part of the effect of culture revolves around grouping and another part deals with the systems at work.

Participant Mona works in reception at one of the private hospitals; she stated' *"I love my work, really. If it were not for this pain, then I would happily achieve more."* The chronic TMD pain makes her feel angry, annoyed, and misunderstood by her colleagues. Her supervisor sometimes intimidates her. She shared, *"I tell myself I should not get irritated and I should be more patient with the visitors or patients. I understand that these patients are also in pain and seeking help."* The loud noises at the waiting area or at the reception increase her pain, especially when she has headaches. She said, *"Staring at the computer, answering impatient patients, and trying to avoid getting irritated is a huge thing."* Mona asked to be transferred to another department, but it was rejected because of a lack of receptionists in her department. She has refrained from resigning from this job because of a lack of other jobs.

Participant Zawa stated, *"This is not my specialty; every time I try to give a suggestion I get blocked. I'm new in this job, so no one looks at me or values my opinion."* Zawa is a graduate of computer science, and now after a long job search she works at the human resource department in one of the private companies. She shared about her work, *"Sometimes I try to be brave and voice my suggestion, but people ignore me, and I keep quiet because I do not want them to stop talking to me or talk about me behind my back."* She said that sometimes she bites her teeth so hard while working, that when someone asks her about something at work, she finds it hard to open her mouth or talk. She said, *"It is difficult to get along with everyone and I know I cannot leave this job. I cannot go back to my original country. The situation is really bad in my country, I'm sure you have seen in the news."* Zawa belongs to one of the unstable countries in the Middle East. Her country has faced many political conflicts leading to fundamental changes in their communities.

Participant Jed stated, *"How do people see me? I'm human, I feel pain also, and I get sick."* Jed is a private driver at one of the wealthy houses. Sometimes he works until a late hour and gets up very early the next day. His work as a driver varies from driving the employer's children to school, to buying goods for the house, to sometimes helping the maid in the house. He shared: *"I cannot sleep for days; my working hours keep changing according to my employer's wish or mood. If I do not answer my mobile, they keep calling and then they knock on my door."* Jed's work is negatively affecting his life. Problems such as lack of sleep, imbalanced diet and change in mealtimes had increased his headaches, gastritis, and lack of concentration, limited mouth opening, ear pain, and chronic pain in the TMJ area. He said: *"Sometimes I cannot talk because I cannot open my mouth, especially in the morning. Doctors give me medicine, but it does not work most of the time."* For Jed, taking sick leave is not an option because he lives in a room at his employer's house. In addition to that, he works almost all hours of the week and weekends. As an immigrant from an undeveloped country the idea of quitting and going back to his original country is unthinkable.

Participant Hanna stated, *"People have no respect for others' pain."* She works as a teacher at one of the private elementary schools. According to the school's policy, as a teacher she has limited days allowed for sick leave. Hanna's work in the classroom requires a variety of physical tasks; during the day she must talk continuously for long periods of time, while supervising her class she is constantly moving around and standing. She is also required to stand while teaching skills on the computer. Her work also requires emotional tasks such as controlling emotion, her voice, and her moods. In addition, she also has to take additional classes when one of the teachers is absent. She said:

> *"Teaching was always my dream, I love my work and my students. However, with this never-ending pain talking became a torture. I cannot stand noises, I people's voices and noises feel like needle pricks." (Hanna)*

Participant Haya says, *"I am a quiet person, I never used to complain about anything, even if it was unfair to me."* Haya was always an ambitious student who studied computer science and finished one year of her master's program. According to her, the TMJ pain became unbearable at the beginning of her second year. She explained:

> *"I really tried to ignore the pain and concentrate on my master, but it was very difficult. Some days the headaches are too much and I cannot see. Clearly, I even went and checked at the ophthalmologist clinic."*

Haya had a very sad experience with her supervisor after her pain started affecting her studies and work. She tried to explain her condition to her supervisor. She was hoping that her supervisor would be more understanding, but that did not happen. She said, *"I never used to complain to my professor, I used to help her with her projects and to supervise her students."* Haya explained that her supervisor's reaction was a great shock and disappointment:

> *"I never used to tell her (her supervisor) about my pain, but when my pain became unbearable, I had to tell her. Some days I could not open my mouth even to speak and sometimes my jaw would come out from its place, and this is the scariest thing for me. I*

> *would ask myself, what if my mouth will not close and stay open? What if it happens in front of the students?" (Haya)*

Haya decided to apply for a one-year leave from her master's degree program because she was scared she would not be able to do her work. However, her supervisor threatened to remove her and give the project to another student, which the supervisor eventually did. Haya said while crying,

> *"I do not know how to explain to you (researcher) the way I felt and the way I feel now. It really hurt a lot and still cannot understand why my life turned like this, do I really have to live with this pain all my life?" (Haya)*

When Haya requested for an appointment again with her supervisor to explain her situation, her supervisor refused to meet her. She shared, *"I was the perfect student. Last time I met my supervisor she told me that she is disappointed in me. I feel like I became useless to her."* When I asked Haya if her family accepted her decision to take a leave from her master's degree, she replied,

> *"Of course no, my parents got so angry and they told me, 'you could have waited till you finish your master.' I am a human also; I have been living with this pain for so long, with no complaint. However, now it has become very difficult for me to live with it, I lost my dream and my life because of it." (Haya)*

Friends

What makes a friend, a good friend, is it their support? Is it their understanding? Alternatively, is it their unconditioned love?

Some of my participants felt their pain had pushed away their friends. Maha said, *"I used to go out with my friends a lot, but now I go out less than before."* Another participant, Haya experienced breaking up with her friend:

> *"I used to tell my best friend everything, she is also a master's student in the same program. After I stopped my master's program, she started to avoid me and eventually she told me "I tried to understand your pain but what pain cannot be treated and stays for so long?"" (Haya)*

Bana shared: *"For me, not friends but my sister, who used to be my friend also, now tells me you complain of pain because you are fed up of taking care of our mother." (Bana)* Sana said, *"I do not tell my friend because I do not think they can do anything."* Several participants saw complaining about their pain as a sign of weakness. Fala stated, *"No, I did not tell any of my friends about my pain. I do not want them to think I am weak or needy."* Other participants believed friends are only for fun, not for sharing the pain and complaining. Ahmad shared, *"Why? Why would I tell my friend I have pain, it is not fun and complaining is boring?"* I wonder if maybe this is a masculine insecurity. In our culture men are not supposed to complain.

Alternately, for some of my participants, friendship meant endless support, unconditional love, unlimited power, and strength. This was especially the case regarding the participants who were immigrants. Friends were like a second family. Brook said: *"My friends' prayers gave me strength and hope. They even support my loved one." (Brook)* Sawa stated: *"I think I have the coolest friends in the world, I cannot imagine my life without them." (Sawa)*

Similarly, Ria shared: *"Sometimes my friends get me ointments or medicine if they heard it would work with my condition. They do not only listen but they take action sometimes." (Ria)*

3.2 Discussion

Culture vs. Religion vs. Tradition

Culture in sociology is defined as: "(noun) The ideas and self-concepts of a group or society (e.g., artifacts, attitudes, beliefs, customs, norms, symbols, and values) in a particular place and time, passing from one generation to the next" (77). The Merriam-Webster dictionary states culture is:

> The customary beliefs, social forms, and material traits of a racial, religious, or social group; also: the characteristic features of everyday existence (such as diversions or a way of life) shared by people in a place or time popular culture, Southern culture, etc. It is also the set of shared attitudes, values, goals, and practices that characterize an institution or organization a corporate culture focused on the bottom line (78).

Religion is defined as "the state of a religious a nun in her 20th year of religion (1): the service and worship of God or the supernatural (2): commitment or devotion to religious faith or observance" (79). Whereas tradition is defined as:

> An inherited, established, or customary pattern of thought, action, or behavior (such as a religious practice or a social custom) : a belief or story or a body of beliefs or stories relating to the past that are commonly accepted as historical though not verifiable; the handing down of information, beliefs, and customs by word of mouth or by example from one generation to another without written instruction; cultural continuity in social attitudes, customs, and institution (80).

Internationally all communities were formed from these three significant factors. Sometimes they interact and sometimes they work separately. Whether, the interaction is between religion and culture or religion and tradition or all, they significantly impact different communities. For example, in East and South Asia, these factors interact strongly. They are implemented in various parts of the community, such as business and health. In business, people seek guidance from temples before they start business trips or business projects. They also play a significant role in health, especially in healing and seeking treatments, or dealing with grief and pain.

In the Middle East, these three factors, especially religion, play an important role in shaping everyone's life. The societies or communities are structured around religion, and people's lives are formed according to the religion or are intrinsically related to it. This religiously influenced way of structuring life has been present for centuries. The majority of people are Muslims, who follow the Holy Book and the Prophet teachings and mostly speak Arabic. Despite this, there are differences in each country in the Middle East. Traditions and cultures have created these disparities. The truth is that these three factors interact strongly to the point that people have lost the ability to differentiate between what was originally a tradition or culture, and how these relate to religion.

The intersection between tradition, religion, and culture has built some of the communities in the Middle East to be more conservative and some more liberal. This intersection is a continuous process influenced by time, economy, and the surrounding environment. The participants in this study are the product of this intersection, which shaped them and their communities.

Perception of pain

In some countries, pain is perceived as a type of weakness and shame. The individual should not complain of the pain. Some communities do not even recognize depression and distress; not even grief is allowed in the case of death. In these types of communities, understanding pain can be very challenging, especially for the health care professional (81,82).

In 2015 Glaxo Smith Klein (GSK) conducted a study on global pain index considered attitudes towards body pain around the world. They studied 7,000 adults, across four continents and 14 countries. The findings showed significant variation in the perception of pain with a prevalence of (88%) of body pain around the global population. This increase in the prevalence of pain can have a significant impact on the lives of many peoples. It also showed that the way people respond to pain varies dramatically depending on where they live. The inclusion criterion for body pain included aches in muscles, tendons, ligaments, and joints (e.g. back pain, neck pain, shoulder pain or osteoarthritis; GSK, 2015) (84). During their study GSK conducted interviews to help understand patients' experiences with body pain. GSK asked key questions about how body pain is experienced across cultures, how body pain transcends cultural differences, how body pain impacts everyday life, and whether it impacts on quality of life. The interviews also included questions about who experiences body pain and how these people mitigate the effects of their body pain.

The pain index had three dimensions: a) Factual body pain indicators, b) Emotional elements, and c) Impact on daily life. Russia and Poland emerged as the countries which were most affected by body pain, followed by China, Japan, Brazil, and Sweden. Meanwhile, Germany and Saudi Arabia were the countries least affected by body pain.

According to the GSK pain index report, 8 in 10 people said that body pain negatively impacted their overall capacity, reducing their quality of life physically and emotionally: 78% of the participants felt that pain affected their professional life, 72% their social life, 64% their romantic and love life daily. Additionally, 94% of the participants across all 14 countries felt pain either in their back or lower back, which is crucial to movement. Also, 51% of the participants mentioned that body pain affected their ability to be happy, 35% said it affected their self-esteem, and 63% said it affected their ability to enjoy their day.

Although 71% of the participants needed treatment to feel in control of the pain, 69% of participants endured long-lasting pain, and 22% of pain sufferers reported severe body pain. Seventy-seven percent of the participants reported it in the neck, which limited their movement and physical abilities. Of this pain, 20% of sufferers reported it being due to arthritis, 58% of sufferers explained the pain as muscular, and 48% of sufferers related it to joint pain. 67% of people felt pain in the same area consistently, such as in the back which is a significant area for mobility (84).

In some countries such as China, Mexico, Brazil, and Italy, pain sufferers tended to be more vocal about their body pain in other countries such as Russia, Poland, Australia, and Germany pain sufferers were found to be quieter about it. Japan was found to be closer to the global average in how vocal people are about their body pain, although they are the most likely to ignore it. Australia followed close behind, with people in that country sharing the same sentiment as those in Japan. Cultures that label body pain as a sign of weakness tend to feel that body pain is taboo. This phenomenon was evident in China and Russia, two countries with a high number of pain sufferers who believe that pain is a sign of weakness and think pain is a taboo. Sixty-five percent of Chinese felt their pain to be a sign of weakness, while 23% felt it to be a taboo. (59%) of Russians perceived pain as a sign of weakness, with 37% thinking pain is a taboo (84).

Most sufferers felt they had difficulty doing household chores and keeping a clean home. In general, 60% of people believed that their pain worries their family and loved ones. Parents tend to feel a form of parental guilt, as 3 in 5 (60%) felt they are limited in their ability to play with their children, and more than 2 in 3 (67%) felt they would be a better parent if they did not have the body pain. Sufferers in relationships felt vulnerable, 49% felt less attractive, and 52% saw their sexual lives being affected. Fourth-six percent felt they could not pay attention to the needs of their partners and felt guilty. Social habits were also affected due to pain. 66% of sufferers noted an inability to go out dancing, and 57% of people felt they were unable to attend events. Furthermore, 44% of people felt this affected their ability to interact with others (84).

In workplaces, 66% of the professionals felt that because of their body pain their motivation was affected, 61% felt they had lost their ability to concentration, and 48% felt their performance was negatively affected. Two in 5 (39%) had to apply for sick leave, which directly impacted their productivity and performance that, consequences had a negitive impact on their incomes. In the case of students, 72% who suffered from body pain felt it impacted their ability to concentrate, 46% felt their performance was decreased and 66% felt less motivated. With 1 in 4 (26%) students missing class because of suffering from pain, the study showed how body pain’s impact extends beyond today’s economy and towards the future (84).

Sixty-four percent of sufferers said that pain compromised their participation in the physical activities and significantly impacted their mood. This research revealed a strong correlation between anxiety and body pain. Although body pain causes anxiety, anxiety further exacerbates the consequences of body pain by increasing the negative impacts felt by sufferers on their quality of life, as well as their daily routine and activities. The more anxious the sufferer is, the greater the physical and emotional consequences are (84).

Regarding medication and treatment 73% of sufferers felt in control of their pain. However, 71% of the sufferers felt that their control is reliant on medical treatment and combined treatments. With 12% of sufferers unaware of the cause of their body pain, there is a lack of knowledge and education around the science and reasons for pain. In fact, while 73% of people know inflammation is a leading cause of pain, almost every second person believed their pain could be treated with over the counter pain relievers. Thirty percent of sufferers were convinced that there is no best ingredient or were unfamiliar with the active ingredient found in their pain relievers, demonstrating a knowledge gap. 44% of people reported they were treating body pain by using rest as their primary treatment and 41% of individuals were using it as their secondary supporting treatment even though movement is sometimes essential for overcoming body pain (84).

Cultural Influences on Pain Perceptions and Behaviors

The GSK global report looked at the pain perception in different countries, but with the increase in global migration due to the economic and political factors, almost all the cultures and cities can be described as multicultural or cross-cultural. The studies showed that pain behaviors varied widely, were associated with culture, and are composed of physiological and psychological experiences of highly interactive emotional, cognitive, as well as sensory components. Some people cope by turning inward, describing the pain as a private and personal experience, while others are verbally expressive, sometimes expressing themselves by crying and screaming.

Khalaf and Callister (2003) suggested, “people in Eastern cultures have higher pain tolerance than those in the West…in the dominant cultures living in the United States” (85). Research by Nayak and Shiflett (2000) explained the willingness to verbalize that pain might “be due to the belief that pain is bad, need not be endured, and should be quickly eliminated” (p.146). This may not apply to other cultural groups (85). Pain is difficult to assess because it is subjective. Zborowski (1952) suggested that each culture has its own language of distress when experiencing pain (86). Gaston-Johannson (1990) noted there are similarities in word descriptors for pain in a variety of cultural groups, with the word “pain” characterizing the most intense discomfort, “hurt” characterizing less severe discomfort, and “ache” describing minimal pain (87).

Johnson-Umezulike (1999) found a correlation between self-reported pain intensity and ethnicity in a study of older African Americans and Caucasians, with African Americans reporting higher levels of pain intensity (88). Villaurruel (1995) conducted an ethnographic study of Mexican Americans who had had recent experiences with acute pain or who had family members with recent pain experience. Interesting themes were identified: (a) pain is an encompassing period of suffering, (b) pain is both expected and accepted as part of life, and (c) the primacy of caring in the face of pain and suffering is the essence of family (91).

On the other hand, Kodiath (1995) explained “that people in different cultures who find meaning in their pain show markedly less suffering than those who find pain to be meaningless.” (90). Women who were active in their religious faith seemed to accept pain as an inevitable and core part of life. These women believed in higher power to give them strength; and, thus, religious faith represented a powerful coping strategy engendering hope and a sense of wellbeing.

Culturally related pain behavior was also articulated by these participants, and varied greatly between endurance and patience to strong verbal and nonverbal expressions (91,92).

Most healthcare professional knowledge, which is sometimes devoid of the personal beliefs and perceptions, make objective assessment and treatment of patients' pain difficult and a significant challenge. Especially with the knowledge that in many cultures pain is an expected and accepted part of life. Rhiner, Dean, and Durcharmes (1996) suggested the use of different strategies to treat pain. Similarly, in many cultures it is more appropriate to use non-pharmacological measures to reduce pain (93).

In the Middle East some factors, such as culture, tradition, environment, religion, and gender, play a major role in shaping people's experience and perception of pain. However, there is variation around the world. In some countries, these factors are considered as the main pillars of the societies, while in other countries they are not of much relevance. In the Middle East these factors are considered part of the individual identity. It is where we come from and who we are as a group of countries that are similar in language, beliefs, and history. Identity can be considered as an important factor that translates and forms our experience and perception of pain. While it may not be the case in other countries, in the Middle East at least there is a strong relation between identity and pain perception. There are several clinical studies that found variations in pain intensity, attitudes, and behaviors among social groups with diverging cultures and racial characteristics (94).

A Swedish study by Dawson et al. (2009) comparing Middle Eastern and Non-Middle Eastern populations showed that Middle Easterners tended to be more sensitive to experimental pressure pain than Swedes. While Swedes had slightly higher mean pressure and thermal pain thresholds than Middle Easterners, the differences in pressure and thermal pain threshold levels

(PTLs) were significant (94). Regarding gender and cultural differences in pressure, electrical and thermal PTLs, Swedish men had significantly higher mean pressure, electrical and thermal PTLs than Middle Eastern men. Although pressure and electrical mean PTLs differed only slightly between Swedish and Middle Eastern women, Swedish women had significantly higher mean thermal PTLs than Middle Eastern women. Also, significant gender differences within the Swedish culture were found for pressure, electrical and thermal PTLs. While in the Middle Eastern culture, significant differences were only found for electrical PTL, thus suggesting that gender differences are more pronounced in the Swedish than the Middle Eastern culture (94).

Gender role socialization could also contribute to gender differences in experience of pain, since men and women have different learning experiences regarding pain behavior. There were no differences found in pain intensity or pain reaction between Middle Easterners and Swedes, which provided a new view of clinical reports that social groups with diverging cultures and/or racial characteristics were associated with significant variations in pain intensity, attitudes, and pain reactions. These differences were more clear among Middle Eastern and Swedish men than between Middle Eastern and Swedish women. In addition, gender differences in Swedish were more prevalent than in the Middle Eastern participants. These findings indicate that culture and gender have a great influence on pain experience (94).

In Qatar, no research was found regarding the perception of pain or the experience of pain and gender differences. Consideration must be given that Qatar is a multi-national culture and part of the Middle East countries, historically and geographically. It also shares the same cultural beliefs and traditions which may help in finding some similarities or relationships with the Middle East or the world. One of my objectives in this study wss to look into the information gap regarding pain perception and experience in patients with chronic TMD pain in Qatar.

IV. FINDING #2- COPING AND ADAPTING TO CHRONIC TMD PAIN

"People's lives are like the sea.

Some days are peaceful and beautiful, and some days are hard and challenging."

Traditional Idiom

4.1 How Do Participants Cope or Adapt to Chronic TMD Pain?

Most of my participants found it difficult to cope or adapt to chronic TMD pain. The majority believed it is difficult and they were not able to cope with it. Although they had been living with this pain for over three years they felt that most, if not all, of the treatments and strategies they used or were prescribed by their physicians were unsuccessful or entirely ineffective. For example, one participant, Mona, responded to a question about coping by stating, "*Coping! My doctor told me that there is nothing more he can do to stop the pain. I have to live with it."* Another participant, Salwa, who had seen most of the physicians in the country commented, *"I have told the last doctor I have seen, I can tell you about all treatments I used so far, and then you can tell me if you have something new."* Unfortunately, her physician did not have any additional treatment or more effective solutions to her chronic TMD pain.

According to the Oxford English Dictionary's definition "to cope" is to "deal effectively with something difficult." (95).

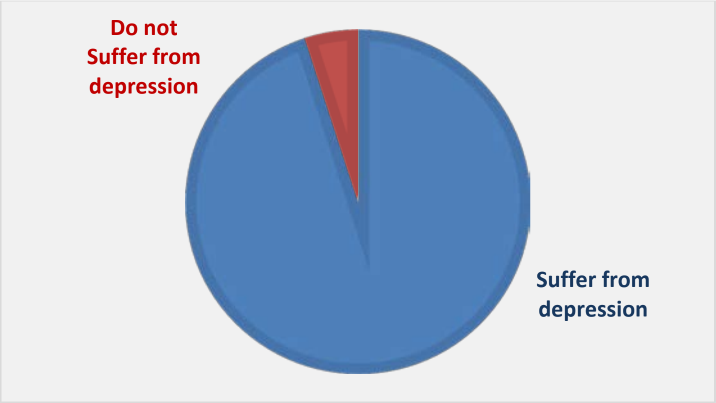

Figure 3. Patients who report that they suffer from depression

Almost all the participants in this study spent their journey with the chronic TMD pain rotating through a variety of physicians. They all requested a strong and short-term treatment, but the physicians could not satisfy all their expectations. Although nineteen of the participants admitted they suffered from depression and wish to get professional help, only three participants were able to visit a counselor or a psychologist (Figure 3). Meeting patients' expectations is one of the hardest goals that physicians try to achieve during treatment. It is almost impossible to reach satisfaction level with chronic pain patients (96). They usually have high expectations at the beginning of the disease, especially in the first few appointments. In fact, most of the physicians if not all, try to limit or control expectations in chronic pain patients. However, controlling their expectations is not successful most of the time, especially when the pain is of long duration (97).

All of my participants believed that every disease has a cure, and they disagreed with their physicians that some diseases are not curable. One participant, Zara, said, *"The doctor told me that there is no ending solution to this chronic pain. Why should I live with it? I am sure there is a cure somewhere."* This resulted in mistrust and doubt in the physician's knowledge and treatment plan.

After a few months comes the second period in the journey of living with chronic TMD pain. By this time many of the participants have experienced and gone through treatments, such as painkillers, appliances, steroid injections, physiotherapy and sometimes counseling. Then an equally important process called adaptation takes place**.**

Adaptation, is defined as the ability to "become adjusted to new conditions" (Oxford English Dictionary, 2017), in this case a chronic TMD pain. Participants tried to develop an adaptation strategy with the help of their physicians. Most of the physicians motivate or sometimes pressure the patients with chronic pain into finding or developing a strategy to help them adjust to this pain for a longer time. Physicians know that living with chronic TMD pain can be a challenging thing especially if the patient has no strategy (98).

One participant, Saja, asked, *"Does time really helps? Would the pain become better with time?"* Finding an answer to this question is challenging. Decreasing the pain is possible if a correct treatment plan is applied and the person develops a strategy to cope or adapt to the chronic TMD pain. Both a treatment plan and adaptation strategy are equally important for achieve some successful level of relief or less pain.

I asked the participants, *"How do you live day to day life?"* One participant, Ahmad, said, *"I pretend I am fine." Another participant, Haya, shared, "I avoid people, and I stay in my room most of the time."* Moreover, in the case of one of the participants, he shifted his lifestyle and activity to late hours. Fada explained:

> *"I live at night. I hibernate at the morning (laughing). I wait till I hear the last door close (at his house) that means everyone has gone to sleep. Then I go out of my room, eat, drink and watch TV. I wait till my mother finishes praying Al-Fajr (early morning*

prayer) then I kiss her head (a traditional sign of respect), and I enter my room again and hide."

Although all the participants stated that it was difficult to live with chronic TMD pain or that they have no adaptation strategy, I believe they are coping and adapting to chronic TMD pain unknowingly to some extent and with various levels. Some of the participants mentioned that they refuse to accept and continue living with chronic TMD pain all of their life. Refusing to accept the pain can be a problem. In fact, this may affect the outcome of their treatment and their psychological status (99). Personally, I believe giving their consent to interview, sit and chat about themselves and their experience with chronic TMD pain can be considered as a coping and adaptation mechanism. Every participant's effort to come to this interview and talk for a minimum of one hour is a big step. I asked all the participants to not shy away from experiencing a new strategy or contributing to educational groups, and they all agreed to participate in a future group discussion at the hospital.

4.2 Patients' Experiences with Counseling or Psychologist

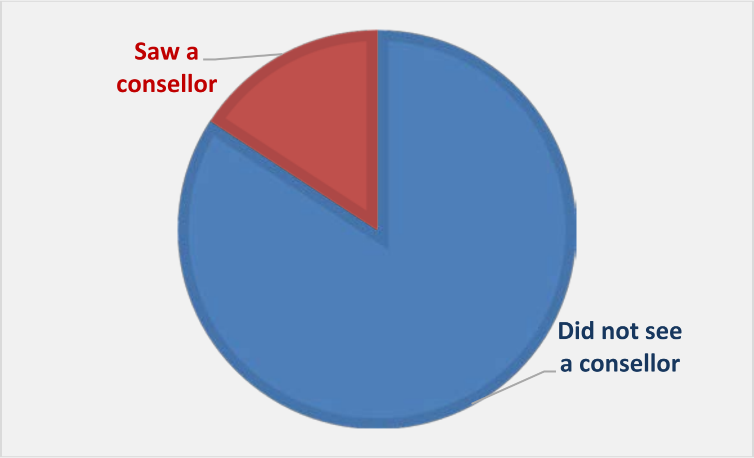

Figure 4. Patients' attitude towards counselors

Of the 20 participants in this study, only three had met with a counselor or psychologist (Figure 4). Counseling in the Middle East has a very negative image. Patients who seek treatment in the psychiatrist clinic or the counselor's office are seen as crazy and mentally challenged. They are stigmatized if ever their identity is known or exposed. They are also alienated and pushed aside by their friends and sometimes even their family members.

Middle Eastern countries have gone through significant financial, political and cultural challenges. These challenges have certainly impacted each individual living in Middle Eastern countries. Usually, the impact on the individual's emotion and wellbeing is great. Although the participants repeatedly mentioned that they suffer from depression and wish to get professional help, only three had the courage to visit a counselor or a psychologist. Perhaps, the courage to visit a counselor was because of their young age; all three of the participants are in their twenties. The recent generation in the Middle East is living through a groundbreaking movement. Being young and living in the Middle East can be a type of motivation to demand change. These younger generations tend to challenge and question their culture, tradition, and communities.

For the older individual in the Middle East it is harder to change or to seek help. Individuals, especially around 30 years old to above, are expected to be strong and to never complain. Complaining is viewed as shameful and weak. Additionally, there are different gender roles; males are not supposed to complain and are expected to be strong. Sometimes, even when they are young children, males are suppressed and not allowed to express their feelings. Females do not have it much better than males. Although females are permitted to complain or express their feelings of pain, their feelings are often ignored and unheard.

Haya lives under great pressure and pain. She said, *"I tried to explain to my parents my problem and my pain, but they think I am faking it."* Her physician referred her to a psychiatrist, whom she saw for only two months during her summer vacation in her original country. When she came back to Qatar she did not see any psychiatrists because she did not have a referral. Haya described her session with the psychiatrists:

> *"I liked seeing the psychologist; it was the only way I could take out my anger and express my feelings. Sometimes I feel the pressure is too much that I can die, I feel suffocated, and still, all that my parents care about is the money" (Haya)*

Haya's parents are under financial pressure, and they believed that Haya would be the one to get them out of their financial difficulties.

I asked her if she would like me to refer her to a psychiatrist and she agreed. I referred her to the psychiatric department. She continued, *"But I do not think my parents will care about why I need to see a psychiatrist again."* I explained to her that she cannot sit still and get more depressed, that she needs to do the things that made her feel better such as seeing a psychiatrist. I also emphasized how she needs to take care of herself and be self-motivated, and I gave her a choice to come and see me if she likes. She was happy and agreed to come again and chat. I saw her once again before I left Qatar.

Bana described herself as being under pressure and overwhelmed with pain and depression, *"Sometimes I scream at my children and at my sick mother, which makes me feel so sad and guilty."* Bana is taking care of her sick mother who has been diagnosed with Alzheimer disease. She explained what she does when she is sad and in pain, *"Sometimes I hit my head with both hands or I will cry for hours."* Bana shared, *"Sometimes I wonder what my children think of me, do they hate me. Sometimes I can see (her kids) sad. I used to love making them cakes, I was more fun and strong, but I have changed."* She started to cry. I stopped the interview for 30 minutes. When we began again Bana started apologizing to me by stating, *"I am sorry, see now I* *am crying at the interview, sorry for wasting your time."* I assured her that she is more important. I told her, *"This interview is about expressing yourself, taking out all your sadness. Cry when you feel like crying and take out you anger when you feel like it, I will never judge you."* Bana's guilty feelings towards her children, husband, and sick mother have increased with time. Her TMJ pain has weakened her, and with everything going on in her life she feels emotionally and physically drained. I asked her if she still visits her psychiatrist and she said not regularly. When asked why she does not attend regularly, she replied, *"I have to work two shifts, it is not possible for me to take appointment most of the time. The day is so short, I finish my shift, and I go back to take care of my family and sick mother."* She also explained about her mother's disease:

> *"My mother is diagnosed with Alzheimer disease, it is very difficult for me to take care of her. I watch her more than my children. Sometimes she will play with the electricity, and sometimes she insists on going into the kitchen. It is really difficult for me to deal with it (Alzheimer)." (Bana)*

I encouraged Bana to see the psychiatrist again. I told her she could come and see me any time she needs to talk or want someone to listen to her. I saw her once after her interview with me during her lunch break.

Unfortunately, Fada had an unpleasant experience with a psychiatric. He explained the difficulty he experienced during an attempt to visit a psychiatrist: *"You know how difficult it was for me to go out of the house and see a psychiatrist."* Fada had six appointments with three psychiatrists and he could only succeed in meeting the psychiatrist on the last attempt. Sometimes he would reach the clinic and run back home before meeting the psychiatrist. Sometimes he would run out of the patients' waiting room; and once the nurse called him and he refused to meet the psychiatrist and ran out of the clinic. Fada further explained, *"I cannot tell my problem to anyone (looking stressed). I feel shy, and I do not know what people will think of me. I have a problem, a true problem but I cannot, I just cannot say it."* I tried to explain that the psychiatrist would not judge him or criticize him if he told him his problem. He remained very worried and said:

> *"I do not know, I am not sure how I will have the courage to see a psychiatrist again. One day I told myself I have to go and see a psychiatrist, I really pushed myself hard, and I went alone. Setting the patients in waiting room, I wanted to just run, but I did not. I told myself in front of the doctor's room, "See you can do it." The session with the psychiatrist was for 30 minutes, he asked many questions, I felt intimidated, and I kept changing my answers. I wanted to feel relaxed and trust him but I could not, I stared at his face all the time and avoided answering all his questions. I felt I came with a specific issue but I still cannot talk about it and suddenly the doctor says, "You have 10 minutes left for this session." I was shocked and angry. I was trying to answer a question he asked, and before I finished my answer, he announced only 10 minutes left. I am really disappointed and sad. I have one specific problem, and I wanted the doctor to fix it so I can be happy."*

I explained to Fada that the psychiatrist had tried to keep track of time, he did not mean to shut him off. Fada was still disappointed and angry. Afterwards, Fada repeatedly mentioned that he will not try to go to a psychiatrist again. I wanted to help him, so I told him he could take an appointment with me in the dental clinic and talk about his problems. I would listen to him, and when he felt he was ready, he could go to see a psychiatrist . I also explained that everything would be confidential. He agreed to come again and chat. I saw him one more time after the interview, and during our last meeting he asked if I could also meet with his sister. I agreed to see his older sister, but she did not come. I explained to Fada, just as I explained to all my participants, that I would be going back to Canada but I would be happy to see them when I came back to Qatar.

Out of the 20 participants, only one said she was not depressed and not stressed. On the other hand, 17 of the participants stated that they wanted to talk to a psychiatrist or a counselor, but they did not want their families to feel ashamed or angry. I looked for a temporary solution to deal with the problem of consulting a psychiatrist. I felt I had a responsibility towards these participants because I motivated them to talk about their problems and pain. I could not cut them off and pretend that everything was fine. Personally, it felt like taking a thirsty person to the sea and bringing them back without a sip of water. When I was looking at the participants' eyes I could feel them holding tight to a new hope; they felt someone cared about and was listening to their problems and pain. Their trust and hope gave me a feeling of obligation towards these participants.

4.3 Discussion

Patients' Coping Strategies

Religion

As Saja is illiterate, she depended greatly on her husband, who was her friend and her strength. Losing him made her lonely and weak. Saja stated, *"Years back I used to ask God for fortune and good health, for my family and me. When my husband was diagnosed with cancer, I prayed even harder for him. Now, ten years since he died and I am praying for strength and health. Saying prayers make me feel happy (wiping her tears)."* Prayer is her hope and gives her strength to carry on. Hanna shared her own experience with religion*: "When I feel I am very angry or annoyed with my pain I listen to readings from the Holy book, and sometimes I read it softly in my heart. I feel I am healed even if it is a temporary feeling."* Hanna explained that when the pain is severe she hides in her room and refuses to talk to her husband and kids. When explaining her experience with religion Brook said, *"I joined a spiritual group in my church, we arrange events and teach classes. For me this is the time when I am most happy and relaxed."* Brook works as a nurse, she visits other patients in the hospital where she works, and gives them support and prays for them. Ria shared, *"I have a prayer corner in my house, whenever I feel the pain increasing I go and pray (smiling) then everything becomes better."* After a tiring day at the clinic, Ria feels the prayer corner in her house is the most comfortable get away place. For Mona: *"Only God can give me the strength to live with this pain if I did not have a strong faith in God I think I cannot live with this pain day and night."* Is it Mona' belief that only with strong faith can a person can survive this type of pain.

Meditation

Some of the participants tried the meditation technique. According to Sawa it is a perfect way to clear her thoughts and relax her body. Hanna joined a group of friends who like to meditate and says she feel better than before. Fala started meditation recently and likes it. According to her, meditation helps her to get away from her surroundings.

Work

Many participants believed that working or being busy was the best way to forget about the pain or pretend it was not there. Ahmad a business man, spends most of the day at his company, he says, *"I do not feel the time, and I do not have the time to think about the pain."* Ria and Brook are working as nurses and they love their jobs. They have been nurses for more than ten years. They walk through the hospital corridors with big smiles pretending that everything is fine. Sala, who works from home for an online company, said: *"Sometimes my kids come late from school, so I spend my time working on the computer otherwise I feel I will go crazy with this pain and alone at home."* Mona shared, *"I worked in administration for a long time and now I am the expert, so people need my help most of the time."* Salwa says, *" I am a teacher, and I love my students. With them, I feel important and happy."*

Volunteering activities

Saja is in her sixties but she is still active, she loves volunteering in everything. She said, *"Look at me I am old you will think that I cannot work, no I volunteer all the time and help others."* Maha, a student who volunteers at her college, said, *"I forget about my pain when I am working and learning things."*

4.4 Philosophy of Care

Philosophy of care is “The provision of what is necessary for the health, welfare, maintenance, and protection of someone or something.” (100) An ethics of care has a moral side to it in addition to the legal side. The phrase “care ethics” has its roots in feminist theory and was originally coined by psychologist Carol Gilligan. The phrase was created after a study was conducted on how little girls perceived ethics. Gilligan found in relation to boys, the moral development of girls tended to come from compassion instead of being justice-based (101). Gilligan (1982) proposed that ethics should be focused on relationships instead of emphasizing on autonomy and rules. Her theory focused more on our connections with each other and the situations being context dependent (108).

Another woman, philosopher Nel Noddings, further contributed to the theory in the 1984s (109). Noddings decided to focus the approach more on our intimate relationships. She felt that it was necessary to differentiate between “natural caring” or “wanting to care” and “ethical caring” and “needing to care” (Noddings, (1984), p.23-30). She explained the difference between caring because “I want” to care and caring because “I must”. When we care for someone because we want to care, when we help a friend who is in need or lend money to a loved one, this act of caring, according to Noddings, can be called a “natural care”. On the other hand, when we care for someone because we must care, when we lend someone a car because of an emergency, despite the desire to refuse, this is called, according to Noddings, an “ethical caring”. “Ethical caring” is Noddings’s term for when we are acting caringly out of a belief that caring is the appropriate way to act in this situation or to relate to people (102,109).

4.5 Patient Centered Care

For years, healthcare professionals thought their medical practice was all about the patients. Yet, the last few years have evidenced a lack of patient-centered care. Healthcare practitioners have focused their attention towards medical treatment rather than psychological treatment in most of the cases. This indicates a lack of communication between the health care professional and patients and their families. (103). On the other hand, most of the medical institutes are trying to teach their physicians the meaning of care in medicine. The Institute of Medicine defined patient-centered care as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” (104). In addition, care is also about empowering the patients by giving them the right to share their opinions about the healthcare system.

Designing a healthcare system that is built around patients’ needs is not a simple thing. With the complexity of the healthcare system, patient centered care may seem like a distant dream. Yet, a dream can come true. Some of the healthcare professionals feel that patient-centered care is an unrealistic thing because of the challenges that will come with it (105). Healthcare professionals were not trained to provide care that involves and encourages patients and their families to take part in the process. Personalizing care to patients’ normal routines was seen by the healthcare professional as unthinkable and impossible. Healthcare professionals have long been considered as the exclusive experts and care providers. Knowledge was not shared with patients and their families because they were considered to be seekers of help and advice; they were not invited to share an opinion or contribute to treatment (105, 106). Yet in recent years, a movement has started to emerge in favor of the patient’s perspective and need in the treatment plan. This change in the direction of providing treatment is used to evaluate the way healthcare professionals practice. Nowadays, healthcare programs are not only concerned with clinical capabilities, pharmaceutical issues, and improving technologies, but also with patients' experiences in the healthcare system (103, 104).

Healthcare programs are trying to evaluate and improve the way care is delivered in hospitals from the patients' perspective. However, to succeed in the mission of patient centered care, the staff experiences and ability should be included (105,106). Care for the patients will be compromised and ineffective if the staff themselves are unsatisfied and they feel that nobody cares about them. Patient-centered care does not compromise the medical care; rather, it complements and contributes to it. The first step before implementing patient centered care is the need to identify and understand what the patient's needs are. Moreover, identifying the obstacles and challenges that are preventing healthcare professionals from providing for their patients' needs must be identified.

Caring for patients or their families can start from a simple gesture of kindness or a smile. These small offers can reflect significantly on the patients and their families; it initiates trust, comfort, and content among the patients. Responding to letters or emails of complaint or suggestion can send a message to the patients and their families that their opinion is welcomed, considered, and appreciated. Such a small action can reduce the discontent of patients' and improve the relationship between patients and healthcare professionals. Although patient-centered care concentrates more on the human-to-human interaction, the use of technology can elevate the level of patient satisfaction (105). Services such as messages, online services for physicians' appointments, inquiries, and access to a medical library can give an impression of transparency and professional medical practice.

4.6 The Challenges and Barriers

Related to Patients

Some of my participants said that they would come for the interview in the morning shift because they have an appointment with another physician and it was easier for them and more convenient to do the interview after their appointment. However, the challenge with morning interview was the participants’ request for sick leave. Most of the working participants requested a sick leave note to present to their work. The problem here is that hospital policy does not allow for sick leave unless the patient has undergone a procedure such as surgery or abscess drainage. According to the participants, the interview may take more than one hour and by the time they reach their work more time will have been wasted. I understood the participants’ point of view and problems but according to the hospital’s policies, I could not give sick leave for conducting an interview for research.

The evening shift in the Dental Clinic started at 4 pm. Participants preferred to start the interview at 4 pm; all agreed to come for the interview if I could finish the interview before 6:30 pm. In the case of female participants, they explained they needed to go back home early to cook dinner and help their children with their homework. In case of the male participants, they said they needed to finish some family business. This limitation in time created a great challenge in the recruitment process. Most potential participants preferred to conduct the interview over the phone, which was not possible for this type of research. Additionally, I needed to record the interviews and observe the patient’s reaction toward my questions.

Another challenge I faced with the potential participants was the appointments. There was a long waiting list in the dental hospital, and most of them were frustrated with this. During the recruitment process, I would call the potential participant and explain to them that it was for recruitment into a medical research study. If they agreed, I gave them an appointment. On the day of the interview, I explained briefly what the study was about and why I wanted them to participate. To my surprise, they often asked for a treatment appointment even though I had stated over the telephone that this was a medical research and not an appointment for treatment. Some people became irritated, refused to do the interview, and left. I could not request for them to stay and I did not want to lie to them.

What does it mean having two souls in one body? This is how I felt during the interviews, where there was only the participant and me. It felt to me as though there were three people present at the interview. Mentally I saw two reflections of myself; Personally, I felt there were two forms of me, the researcher, who the participant saw, as well as another hidden version of myself, the observer, who was seated by my side. The observer was always interacting with the researcher homogeneously and actively during the interviews. The researcher would ask all the questions and try to be more objective, while the observer could immerse herself into each individual participant's experience and interact with the participant's emotions. It was a strange and surprising experience for me. I never thought I could have two active conversations at the same time; one conversation was physically between the researcher and the participant, and the other conversation was mentally between my two selves, the researcher and the observer. Thus, when my own problem with TMD started showing, and my biting changed due to stress, some of the participants noticed and asked if I have a problem with my joint. The observer self became my savior by helping the researcher self remain focused on the interview instead of being distracted. Therefore, I quickly explained to the participants my TMD problem and then redirected the interview back towards the participants. This phenomenon or personal experience was powerful for me, the feeling of being there with one body and two souls is hard to explain, but the role of the observer played in encouraging the researcher to stay strong and concentrate on the participant was very powerful.

Related to Healthcare Practitioners

The first time I encountered the differences in views and concepts between clinical practitioners and the medical researchers was when I began recruiting participants. I approached some of the physicians who treated TMD patients. Although those physicians expressed their full cooperation, when I went to confirm with them the appointment of some potential participants, they became over-protective and possessive. One of the physicians said to me, *"These are my patients, they are in my department."* I noticed that he talked as though he owned the patients. I tried to explain to the physicians the validity of the research using the official approval letter from the IRB committee that I presented to each one of them, which they read in front of me. I also realized that from the clinical practitioner's point of view all patients are their patients but, from the researcher's perspective, patients are people seeking treatment and are not owned by any doctor. As researchers, we try to emphasize the patients' rights as human beings rather than dehumanize the people as just faceless patients.

While interacting with the clinical practitioners I noticed that their knowledge is limited regarding the research policies and guidelines of the hospital. The problem with conducting interviews in the evenings was the availability of the dental assistants in case I needed help with the information system. The computerized information system was installed when I was at the university so I was not very familiar with it. Additionally, before calling the potential participants, I tried to sit down and discuss their cases with their physicians. However, during the discussion with the physicians, some tried to interfere with the methodology several times by enforcing their personal opinions. It would be all right if the physicians suggested some ideas, but problems arose when they got upset or became less flexible, thinking that I did not value their opinion because I did not make the changes they had suggested.

Related to Healthcare System

One of the greatest challenges I faced while recruiting participants was communicating with the departments. The participants came from three different departments. Although one of the department was cooperative, they did not have enough potential participants, and this was problematic. In the second department, only some of the dentists remembered to tell the patients about the study. The rest of the dentists felt the study was not a priority so they did not tell the patients or obtain their contact information for me. The third department was the most problematic because, while they had the largest number of TMD patients, particularly patients referred from primary health care, they refused to cooperate. In my mission to communicate with the Chairman of the third department, I requested to make an appointment with him many times, but he refused to set a day or time to meet. I also sent him the IRB approval letter and letter from the Dental Chairman but although he read the letters he refused to give any response. Lastly, I wrote an email explaining the situation, but still he failed to respond and comply with my request.

Another obstacle I faced was the referral system. Almost every participant I saw asked me if I would be their doctor or if I could change their present doctor. I explained that, in this study, I could not register them as my patients nor could I change their physician. My answer caused a great disappointment and irritation to them. Some refused to do the interview even though they came all the way to the dental clinic. I could not fix this problem with the system because my current status in the dental hospital is temporary. I wanted to help these patients, so I informed the consultant in charge but they did not offer any practical solution to the situation.

V. Summaries & Concluding Comments

"Experience is not what happens to a man; it is what a man does with what happens to him."

Aldous Huxley, 1932

Texts & Pretexts: An Anthology with Commentaries

5.1 My Participants

Twenty patients participated in this study. The study was conducted in the city of Doha, Qatar. The participants came from 10 countries; three were male and seventeen were female. Their ages ranged from 23 to 60 years old. Most of them were educated, with one being illiterate. Depending on the participant some of the interviews were conducted in Arabic and some in English. Some of the participants came in again after the interview to discuss and talk about themselves.

5.2 Finding #1: Factors Affecting Patients' Experiences

Culture played a very powerful role in this study. It magnified the feelings of pain and suffering in the participants. When a cultural conflict is combined with a lack of knowledge, the issue become expands. The study revealed a lack of awareness about chronic TMD pain not only amongst the participants in this study, but also in the culture and communities. The participants gained their knowledge about this disorder only after they had suffered for a long time and then decided to get treatment or stop the pain.

Patients' Opinion of Healthcare Professionals

Participants with TMD pain expressed feelings of distrust towards their care providers' competence and ability to manage their problem, which lead to mistrust of the received treatment. Such experiences may prolong the pain and are less likely to motivate the patient to adhere to the suggested treatment strategies. Some participants expressed feelings of distrust with their contacts within medical and dental healthcare. They expressed their mistrust of the care providers’ competence and ability to manage their problems. The consequence of not being believed severely damaged the trust between patient and caregiver.

5.3 Finding #2 Coping and Adapting to Chronic TMD Pain

Most of my participants found it difficult to cope or adapt to chronic TMD pain. Many of them believed it to be difficult, and they were not able to cope. Although they had been living with this pain for more than three years, they felt that most of, if not all, the treatments and strategies they were prescribed by their physicians were unsuccessful or entirely ineffective.

All my participants believed that every disease has a cure, and they disagreed with their physicians that some diseases are not curable. A participant, Zara, said, *“The doctor told me that there is no ending solution to this chronic pain. Why should I live with it? I am sure there is a cure somewhere.”* This resulted in mistrust and doubt of the physicians’ knowledge and treatment plan.

Patients’ Messages to The Dental Hospital

My participants in this study had some suggestions and recommendations for the Dental Hospital. I presented all the patients’ suggestions and recommendations to the Chairman of the Dental Hospital. In addition, I made a list of the solutions to address and resolve the problems. The Chairman accepted my solutions and encouraged all the ideas.

VI. APPENDICES

6.1 Appendix A: Sample Interview Guide

6.2 Appendix B: Research Consent Form, Hamad Medical Corporation, Qatar.

6.3 Appendix C: Ethics Approval, Rumillah Hospital, Hamad Medical Corporation, Qatar.

6.4 Appendix D: Ethics Approval, Medical Research Center, Hamad Medical Corporation, Qatar.

6.5 Appendix E: Ethical Approval, McGill University, Montreal, Canada.

VII. FIGURES

7.1 Figure 1. Multiple protective and risk factors play a role in the progression from acute to chronic TMD pain.

7.2 Figure 2. Flow diagram of participants' enrollment.

7.3 Figure 3. Patients who report that they suffer from depression.

7.4 Figure 4. Patients' attitude towards counselors.

VIII. PICTURES

8.1 City of Doha.

8.2 Diverse culture in Qatar.

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How does having TMD Affect Peoples' Lives?

InterviewGuide

***Demographic**

1-Nationality:

a. Qatari. b. Non-Qatari.

2-Age:
a.(20-30) years b.(30-40) years c.(40-50) years d.(50-60) years

3-Gender:
a. Male.b. Female.

4- Marital status:

a. Single. b. Married. c. Divorced. d. Widowed.

5-Education level:

a. Not educated. b. Elementary. c. Intermediate.

d. High school. e. Diploma. f. Bachelor.

g. Master. h. Doctoral. i. Others_________

6- Employment Status:

a . Full time. b. Part time. c. Unemployed.

d.Others______________

7- Religion:
a. Muslim. b. Christian. c. Jewish.

d. Hinduism. e. Buddhist.

f. Other____________________.

8-Residancy(Al Wakra, Al Khor, Doha city):

9-When did your TMD problems started?

10-What time of the day you feel most uncomfortable? (morning, afternoon, evening)

*Emotional/Psychological Scale

11-Do you suffer from depression?

a.No b.Yes

12-Are you under treatment for depression?

a.No b. Yes

13-Wereyou referred for any counseling treatment after youbeen diagnosed with TMD?

14-How do you describe your work:

a. Minimum stress. b. Medium stress. c. Very stressful.

*Adapting

15-What is the most important factor that helped you the most with coping with TMD pain?

16-How long it took you to adapt TMD pain?

17-Did you have to change any of yourhabits, if yes:

a. What?

b. Why?

***Coping**

18-How did you cope with TMD pain?

19-How much does your jaw problem affect your ability to carry out normal lifeactivities?

20-Did your condition affect your family?

***Patient's self-reflection**

21- Did you find difficulty in explaining your pain to your physician?

22-How do you describe yourself emotionally now/then?

23-How do you describe yourselfphysically now/then?

24-Is there anything you would wish people would know about your experience?

25- How do you describe your experience with TMD pain?

26-How do you feel about the disease? (a punishment, a test)

27-What would you like the world to know about (you as a patient/ about the disease)?

28- Have you been through any incident (good or bad) and you would like to share with the world?

29- Did you hear about TMD before you get it?

30- If yes, what was your personal opinion about the TMD disorder?

31-How did you feel about the patients that had the disease (before and now)?

32- If you have the power to change one thing, what would you choose?

33- Did you think about making a difference personally or in the society (such as educating others)?

34- Would youlike to see any changes? If yes, why and how?

35- What advice would you give a newly diagnosed patient?

***Others**

36-What would you prefer, filling a questionnaire or doing an interview?

37- Willyou agree to meet again?

Interviewer:Dr. SarraGibreel

October 2016

نموذج الموافقة على الاشتراك ببحث علمي
RESEARCH CONSENT FORM

مؤسسة حمد الطبية Hamad Medical Corporation HEALTH · EDUCATION · RESEARCH صحة · تعليم · بحوث	
1. Title of research	**1. عنوان البحث**
How does having Temporomandibular Disorders Affect Peoples' Lives?	كيف تأثر اضطرابات المفصل الصدغي الفكي على حياة المرضى؟
2. Principal Investigator	**2. الباحث الأساسي**
Dr. Sarra Gibreel Department of Dentistry Hamad Medical Corporation	د. سارة جبريل قسم الأسنان مؤسسة حمد الطبية
3. Why are we inviting you to join this research?	**3. لماذا ندعوك للمشاركة في هذا البحث؟**
The investigator and colleagues at Hamad Medical Corporation and McGill University are conducting this research. We are inviting you to join because we would like to understand the way patient cope with long lasting pain in the jaws, and how patient adapt to changes in everyday life. Our questions will help us to understand the effect of long lasting pain on patients' life. This study will be conducted by the researcher (Doctor. Sarra Gibreel) that was mentioned above.	يجري الباحث وزملاؤه بمؤسسة حمد الطبية وجامعة ماكجيل هذا البحث. ندعوك للمشاركة في البحث نظرًا لرغبتنا في فهم تحمل المرضى للألم المزمن في الفكين وكيفية تأقلم المرضى مع التغيرات الناجمة عن ذلك في حياتهم اليومية. وسوف تساعدنا الأسئلة المثارة على فهم تأثير الألم المزمن على حياة المرضى. سيجرى هذا البحث بواسطة الباحث (دكتور سارة جبريل) المذكور أعلاه.
4. What should you know about this research?	**4. ما هي المعلومات التي يجب أن تعرفها عن البحث؟**
• We will explain the research to you • Whether or not you join is your decision (you can accept or refuse no matter who is inviting you to participate) • Please feel free to ask questions or mention concerns before deciding, or during or after the research • You can say yes but change your mind later • We will not hold your decision against you	• سنشرح لك البحث شرحًا وافيًا • قرار مشاركتك في البحث أو عدم مشاركتك يرجع لك وحدك (يمكنك قبول الدعوة أو رفضها بغض النظر عن الجهة التي تدعوك للمشاركة). • لك مطلق الحرية في طرح أية استفسارات أو ذكر المخاوف قبل اتخاذ قرارك أو أثناء أو بعد المشاركة في البحث. • يمكنك قبول الدعوة ثم تغيير رأيك لاحقًا. • لن نستخدم قرارك ضدك.

5. Who can you talk to?	5. **ما هي الجهة التي يمكنك مراجعتها؟**
If you have questions or concerns, or if you think the research has hurt you, talk to the research team at: Dr. Sarra Gibreel Daytime working hours: 7:00am-3:00pm Tel: 55604455 If you have questions about your rights as a volunteer, or you want to talk to someone outside the research team, please contact: • HMC Medical Research Centre at irb@hamad.qa	إذا كان لديك أية استفسارات أو مخاوف أو إذا ارتأيت هذا البحث قد تسبب لك في أي إيذاء من أي نوع، يمكنك مراجعة فريق البحث على النحو التالي: د. سارة جبريل ساعات العمل اليومي: من الساعة 7:00 ص إلى الساعة 3:00 م رقم الهاتف: 55604455 وإذا كان لديك أية استفسارات عن حقوقك كمتطوع أو كانت لديك رغبة في محادثة شخص لا ينتمي لفريق البحث، يرجى مراجعة: • مركز البحوث الطبية بمؤسسة حمد الطبية على irb@hamad.qa
6. Why are we doing the research?	6. **ما هي الأسباب التي استدعت إجراء البحث؟**
To understand the adaptation process of patients with chronic Temporomandibular Disorders pain Our questions will help us to understand the effect of long lasting pain on patients' life. This study will be conducted by the researcher (Doctor. Sarra Gibreel) that was mentioned above. It will help in the management of chronic Temporomandibular Disorders pain by applying a psychosocial strategy will help to reduce the use of analgesics and reduce financial burdens on the patients and the government. It will also help the health care practitioners in gaining insight into patient's experience with chronic Temporomandibular Disorders pain.	فهم عملية تأقلم المرضى مع آلام اضطرابات المفصل الصدغي الفكي المزمنة. سوف تساعدنا الأسئلة المثارة على فهم تأثير الألم المزمن على حياة المرضى. سيجرى هذا البحث بواسطة الباحث (دكتور سارة جبريل) المذكور أعلاه. سوف يساعد البحث في إدارة آلام اضطرابات المفصل الصدغي الفكي المزمنة عن طريق تطبيق استراتيجية نفسية ستساعد على الحد من استخدام المسكنات وتخفيف العبء المادي الملقى على عاتق المرضى والحكومة. وعلاوة على ما سبق، سيساعد البحث ممارسي الرعاية الصحية في اكتساب رؤية ثاقبة ومعرفة دقيقة بخبرة مرضى آلام اضطرابات المفصل الصدغي الفكي المزمنة.
7. How long will the research take?	7. **ما هي المدة التي سيستغرقها البحث؟**
We think that you will be in the study during the process of data collection only. The duration of the interview will take 45-60 minutes, and the data collection will take approximately 3-6 month. We expect the research to last for 2 years	نعتقد أن مشاركتك في هذا البحث ستقتصر على مرحلة جمع البيانات فقط. وستستغرق المقابلة مدة تتراوح بين 45 – 60 دقيقة فقط، بينما سيستغرق جمع البيانات ما بين 3 إلى 6 أشهر تقريبًا. نتوقع أن يستمر هذا البحث لمدة عامين.
8. How many people will take part?	8. **كم عدد المشاركين في البحث؟**
Only 20 patients that diagnosed with Temporomandibular Disorders pain for a minimum of 1 year will be recruited.	سيلتحق بالبحث 20 مريضًا فقط ممن تم تشخيص مرضهم بأنه ألم اضطرابات المفصل الصدغي الفكي لمدة لا تقل عن سنة واحدة. وسيتم ضم المشاركين في المقابلات من العيادة الخارجية الخاصة بقسم

The participants for the interviews will be recruited from the outpatient clinic at the Department of Dentistry at Hamad Medical Corporation in Qatar. The recruiting process will be through a direct contact with the Department of Dentistry administration at Hamad Medical Corporation in Doha.	الأسنان بمؤسسة حمد الطبية بدولة قطر. وستتم عملية اختيار المشاركين من خلال الاتصال المباشر بإدارة قسم الأسنان بمؤسسة حمد الطبية بالدوحة.
9. What happens if you take part?	**9. ما هي الإجراءات التي ستترتب على مشاركتك في البحث؟**
If you agree to join, we will ask you to do the following: • An informed consent form will be presented to you prior the interview. • Semi-structured interviews will be used. • You will be asked open ended questions in the interviews. • You will tell the principal investigator about your experience with chronic pain. • The interviews will take around 45 minutes to 1 hour. • Your interview will be digitally recorded, transcribed verbatim and compared again with the tapes for accuracy. • Your interview will be conducted in a room/Dental clinic at the Department of Dentistry. • Your interview will be conducted by the principal investigator Dr. Sarra Gibreel. • You will do one interview. • If the principal investigator needs to re-confirm some of your answers, and you agree she will ask you for another interview. Only the interview questions will be asked to you, there will be no new questions asked out of the interview guide. • The principal investigator will have an access to your medical records.	في حالة موافقتك على المشاركة في البحث، سنطلب منك إجراء ما يلي: • سوف تعطى نموذج موافقة قبل المقابلة • سيتم استخدام مقابلات شبه مقننة. • ستوجه لك أسئلة مفتوحة ليس لها إجابات محددة في هذه المقابلات. • سوف تطلع الباحث الرئيسي على تجربتك مع الألم المزمن. • سوف تستغرق المقابلات حوالي مدة تتراوح بين 45 دقيقة وساعة. • سيتم تسجيل المقابلة معك رقميًا وتفريغها مكتوبة حرفيًا ومقارنتها بالشرائط مرة أخرى لتحري الدقة. • ستجرى المقابلة معك في غرفة / عيادة الأسنان في قسم الأسنان. • سيجري الباحث الأساسي دكتور سارة جبريل المقابلة. • ستخضع لمقابلة واحدة فقط. • في حالة رغبة الباحث الأساسي إعادة تأكيد بعض إجاباتك، وموافقتك على ذلك، سوف تطلب منك الباحثة إجراء مقابلة أخرى. لن توجه لك أية أسئلة أخرى سوى أسئلة المقابلة، ولن يكون هناك أسئلة جديدة من خارج دليل المقابلة. • سيكون من حق الباحث الأساسي النفاذ إلى سجلاتك الطبية.
10. Could the research be bad for you?	**10. هل يمكن أن يعرضك البحث لأي ضرر؟**

There is very little chance of discomfort or risk involved in this interview. However, the participants may choose to decline to answer any question. You have the right to withdraw from the study at any time, and this will not have any effect on him/her or their treatment. You will be assigned with a specific code and these codes will be deleted after the data rectification and analysis. The final results will not contain any identity to the subjects and all the data will be stored anonymous. This research will not lead to addition cost to you. This research will be funded by Hamad Medical Corporation. No financial compensation will be provided for the participating in this study. However, to help defraying some of your expenses in attending the interview session(s), you will receive a Hala telephone card equal to 50 Riyal Qatari.	إن فرصة الإحساس بالألم أو الخطر بسبب هذه المقابلة تكاد تكون لا تذكر. ومع ذلك، قد يختار المشاركون رفض الإجابة عن أي سؤال. ولديك الحق في الانسحاب من البحث في أي وقت، ولن يكون لذلك أي تأثير عليه أو على علاجه. سيتم تحديد هويتك برمز معين، وسيتم حذف هذه الرموز بعد تصحيح البيانات وتحليلها. لن تحتوي النتائج النهائية على أي هوية للحالات المشاركة وسيتم تخزين جميع البيانات وجعلها مجهولة المصدر. لن تفرض عليك أي تكاليف إضافية جراء هذا البحث الممول من مؤسسة حمد الطبية. ولن يتم منحك أي تعويض مالي نظير المشاركة في هذا البحث، إلا أنه للمساعدة في تحمل نفقات حضورك للمقابلات، سيتم منحك كارت هلا لتعبئة الرصيد قيمته 50 ريالًا قطريًا.
11. Could the research be good for you?	**11. هل يمكن أن تستفيد من هذا البحث؟**
There are no benefits to you from joining this research. However, possible benefits to others include helping in the management of chronic Temporomandibular Disorders pain by applying a psychosocial strategy that will help in reducing the use of analgesics and the financial burdens on the patients and the government. It will also help the health care practitioners in gaining insight into patient's experience with chronic Temporomandibular Disorders pain. There will not be direct benefit of this study.	لا توجد أي استفادة مباشرة لك من المشاركة في البحث. ومع ذلك، من المحتمل تحقيق فوائد للآخرين بما يشمل مساعدتنا في إدارة آلام اضطرابات المفصل الصدغي الفكي المزمنة عن طريق تطبيق استراتيجية نفسية ستساعد على الحد من استخدام المسكنات وتخفيف العبء المادي الملقى على عاتق المرضى والحكومة. وعلاوة على ما سبق، سيساعد البحث ممارسي الرعاية الصحية في اكتساب رؤية ثاقبة ومعرفة دقيقة بخبرة مرضى آلام اضطرابات المفصل الصدغي الفكي المزمنة. ليس هناك استفاد مباشرة من البحث.
12. What happens to information about you?	**12. ما هي أوجه استخدام المعلومات الخاصة بك؟**
We will make efforts to secure information about you. This includes using a code to identify you in our records instead of using your name. We will not identify you personally in any reports or publications about this research. The audio file as well as the written transcript will b stored in a password-protected personal computer The access for the personal computer will grant	سنبذل كافة الجهود لتأمين سرية بياناتك بما يتضمن استخدام رمز للتعرف على هويتك في سجلاتنا بدلًا من استخدام اسمك بشكل صريح ولن نذكر اسمك في أي تقارير أو منشورات تخص هذا البحث. سيتم الاحتفاظ بالملف الصوتي للمقابلة والتفريغ الكتابي في كمبيوتر شخصي محمي بكلمة سر.

only to the researcher. The information you provide will be disclosed in a way that eliminates any chances of associating it with yourself. Only the researchers will have access to any information that identifies you. All the interview material will be kept confidential through coding and storing. The information that you will provide will be coded and your identity will be password protected at all time. Each participant will be assigned with a specific code and these codes will be deleted after the data rectification and analysis. The final results will not contain any identity to the subjects and all the data will be stored anonymous. All the interview material will be kept confidential by coding and storing. The data will be stored for 5 years after that it will be destroyed. Audio recordings will be destroyed after transcription. The principle investigator Dr. Sarra Gibreel, Co-investigator Prof. Jocelyne Feine and Prof. Richard Hovey can access your coded information. We cannot guarantee complete secrecy, but we will limit access to information about you. Only people who have a need to review information will have access. These people might include: Members of the research team and McGill University representatives (Co-investigator Prof. Jocelyne Feine and Prof. Richard Hovey) whose work is related to the research or to protecting your rights and safety can access your coded information. • Representatives of the Ministry of Public Health and Hamad Medical Corporation who make sure the study is done properly and that your rights and safety are protected • Your doctors and nurses	سيقتصر حق النفاذ إلى الكمبيوتر الشخصي على الباحث دون سواه. وسيتم نشر البيانات التي توافينا بها بشكل يضمن استبعاد أي فرصة لربطها بشخصيتك الحقيقية. وستقتصر إمكانية النفاذ إلى المعلومات التي تحدد هويتك على الباحثين فقط. وسيتم الاحتفاظ بسرية جميع مواد المقابلة من خلال الترميز حيث سيتم ترميز كافة المعلومات التي توفرها ثم حماية هويتك بكلمة سر في جميع الأوقات. سيتم تخصيص رمز فريد لكل مشارك وسيتم حذف هذه الرموز بعد عملية تصحيح البيانات وتحليلها. ولن تحتوي النتائج النهائية على أي هوية للحالات المشاركة وسيتم تخزين جميع البيانات وجعلها مجهولة المصدر. وسيتم الاحتفاظ بسرية جميع مواد المقابلة من خلال الترميز حيث سيتم تخزين كافة البيانات لمدة خمس سنوات وتدميرها بعد انقضاء هذه المدة. وسيتم تدمير التسجيلات الصوتية بعد عملية التفريغ الكتابي. يستطيع الباحث الأساسي د. سارة جبريل والباحث المعاون بروفسيور جوكلين فين والبروفسيور ريتشارد هوفي النفاذ إلى معلومات المشفرة. لا يمكننا ضمان سرية البيانات بشكل مطلق، إلا أننا سنحدّ من إمكانية الوصول إلى بياناتك لتكون مقصورة على الأشخاص الذين يحتاجون إلى مراجعة المعلومات. وقد يشمل هؤلاء الأشخاص: • أعضاء فريق البحث وممثلو جامعة ماكجيل (بروفسيور جوكلين فين والبروفسيور ريتشارد هوفي) ممن يرتبط عملهم بالبحث أو بحماية حقوقك وسلامتك. • ممثلو وزارة الصحة العامة بدولة قطر ومؤسسة حمد الطبية المكلفون بالتأكد من إجراء البحث بالشكل الصحيح مع حماية حقوقك وسلامتك. • أطباؤك وطاقم التمريض
13. What if you don't want to join?	**13. ماذا لو كنت لا تريد المشاركة في البحث؟**
You can say no and we will not hold it against you.	يمكنك رفض المشاركة دون أن يستخدم ذلك ضدك.

14. What if you join but change your mind?	**14. ماذا لو شاركت في البحث ثم غيرت رأيك؟**
You can stop participating at any time and we will not hold it against you. If you stopped participating in the study your collected data will be deleted by the principal investigator immediately.	يمكنك التوقف عن المشاركة في هذا البحث في أي وقت من الأوقات ولن يستخدم ذلك ضدك. في حالة توقفك عن المشاركة في البحث سيقوم الباحث الأساسي تخصك على الفور بحذف ما تم جمعه من بيانات.
15. What else should you know?	**15. هل هناك معلومات أخرى يجب معرفتها؟**
This research will be funded by Hamad Medical Corporation. No financial compensation will be provided for the participating in this study. However, to help defraying some of your expenses in attending the interview session(s), you will receive a Hala telephone card equal to 50 QAR.	ستقوم مؤسسة حمد الطبية بتمويل هذا البحث. لن يتم منحك أي تعويض مالي نظير المشاركة في هذا البحث، إلا أنه للمساعدة في تحمل نفقات حضورك للمقابلات، سيتم منحك كارت هلا لتعبئة الرصيد قيمته 50 ريالًا قطريًا.
16. Additional Choices	**16. الاختيارات الإضافية**
__________I AGREE for Digitally recording. __________I DO NOT AGREE for Digitally recording.	________ أوافق على تسجيل المقابلة رقميًا ________ أرفض تسجيل المقابلة رقميًا

نموذج الموافقة على الاشتراك ببحث علمي
RESEARCH CONSENT FORM

Signature Page for Capable Adult	صفحة توقيع البالغ ذي الأهلية
Volunteer	**المتطوع**
I voluntarily agree to join the research described in this form. Printed Name of Volunteer Signature of Volunteer Date	أوافق على التطوع للمشاركة في البحث المذكور في هذا النموذج بمحض إرادتي. اسم المتطوع بالأحرف الواضحة توقيع المتطوع التاريخ
Person Obtaining Consent	**الشخص الحاصل على الموافقة**
I document that: • *I (or another member of the research team) have fully explained this research to the volunteer.* • *I have personally evaluated the volunteer's understanding of the research and obtained their voluntary agreement.* Printed Name of Person Obtaining Consent Signature of Person Obtaining Consent Date	أقر بما يلي: • لقد قمت (أنا أو عضو آخر من فريق البحث) بشرح هذا البحث للمتطوع شرحًا وافيًا. • لقد قمت شخصيًا بتقييم فهم المتطوع للبحث والحصول على موافقته طوعًا دون إكراه. اسم الحاصل على الموافقة بالأحرف الواضحة توقيع الحاصل على الموافقة التاريخ
Witness (if applicable)	**الشاهد (إن وجد)**
I document that the information in this form (and any other written information) was accurately explained to the volunteer, who appears to have understood and freely given Consent to join the research. Printed Name of Witness Signature of Witness Date	أشهد بأن المعلومات الواردة في هذا النموذج (وأية معلومات أخرى مكتوبة) قد شرحت بدقة للمتطوع الذي بدى عليه فهم البحث وقام بمنح موافقته للمشاركة في البحث بمحض إرادته. اسم الشاهد بالأحرف الواضحة توقيع الشاهد التاريخ

مستشفى الرميلة
Rumailah Hospital

عضو في مؤسسة حمد الطبية
A Member of Hamad Medical Corporation

Memo

ATTENTION	Dr Sarra Gibreel	**DATE**	20th March 2016
FROM	Rh-Research and Education Committee	**REFERENCE NO.**	RH-RC/26/16
SUBJECT	How Do Patients Cope with Temporomandibular Disorders	**FILE CODE**	
CC	Dr. A/Aziz Darwish		
☐ **URGENT**	☐ **CONFIDENTIAL**	☐ **PLEASE PROCESS**	☐ **FYI**

Dear Dr Sarra

Thank you for presenting your research proposal/project titled: How Do Patients Cope with Temporomandibular Disorders. Your proposal has been appraised by the committee and you may proceed by forwarding the documents to medical research Centre (MRC).

Should you need further information/assistance please don't hesitate to contact the RH-Research Committee

Thank you.

S. Ghuloum
Dr. Suhaila Ghuloum
Chairperson, RH Research & Education Committee

حمد
Hamad
مؤسسة حمد الطبية
Hamad Medical Corporation
HEALTH · EDUCATION · RESEARCH
صحة · تعليم · بحوث

مركز البحوث الطبية
Medical Research Center

Hamad Medical Corporation

Institutional Review Board

Email: irb@hamad.qa Tel: 00974-44390614
HMC-IRB Registration: SCH-HMC-020-2015
IRB-MoPH Assurance: MOPH-A-HMC-020

Approval Notice:

Protocol Title: How Do Patients Cope with Temporomandibular Disorders?
Study Number: 16086/16
Date of HMC-IRB Approval: 09 October 2016
Date of Letter Issued: 16 October 2016
HMC Principal Investigator: Sarra Hassan O M Gibreel
Review Type: Expedited
Decision: Approved
Approved HMC Enrollment: 20

The IRB has reviewed the submitted documents of the above titled research and approval to continue the study has been granted. List of the approved documents is attached.

IRB oversight expires 12 months from the date of approval indicated above.
It is the responsibility of the Investigator to ensure timely renewal of study oversight. Progress reports for continuing review must be approved prior to expiration date; therefore submissions must be received by the IRB 60 to 90 days prior to the expiration date.

As the Principal Investigator of this research project, you are ultimately responsible for:

- Protecting the rights, safety and welfare of research subjects
- Following the IRB-approved protocol (application and any materials submitted with it).
- Following the requirements of HMC policies, especially with regard to obtaining prior approval of changes to the research, reporting events or new information and final reports.
- The conduct of the study team with regards to all of the above.

Requested Resolutions: None

Any resolutions submitted must include a letter indicating that the submission is a follow up request by the IRB; this will ensure that resolutions are processed appropriately and in a timely manner.

If you have any questions or need additional information. Please contact IRB at the above mentioned email address or telephone number.

Sincerely,

Prof. David Barlow
Chairman Institutional Review Board
Hamad Medical Corporation

Cc: MRC Project File

مؤسسة حمد الطبية
Hamad Medical Corporation
HEALTH · EDUCATION · RESEARCH صحة · تعليم · بحوث
مركز البحوث الطبية
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List of Approved Documents:

1) 16086_InformedConsent_Eng-Ara_21Aug16_07Pages
2) 16086_IntialApplication_31Jan16_06Pages
3) 16086_Protocol_31Jan16_18Pages
4) 16086_SchemeofDelegation_02Pages
5) 16086_TMDInterview Guide_31Jan16_04Pages
6) 16086_UseOfDemographicData_06Jun16_02Pages

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February 24, 2017

Dr. Jocelyne Feine
Faculty of Dentistry
2001 McGill College Avenue – Suite 500
Montreal, Quebec H3A 1G1

RE: IRB Study Number A02-B14-17A
How do patients cope with temporomandibular disorders?

Dear Dr. Feine,

Thank you for submitting the above-referenced study for an ethics review on behalf of Dr. Sarra Gibreel.

As this study involves no more than minimal risk, and in accordance with Articles 2.9 and 6.12 of the 2nd Edition of the Canadian Tri-Council Policy Statement of Ethical Conduct for Research Involving Humans (TCPS 2) and U.S. Title 45 CFR 46, Section 110 (b), paragraph (1), we are pleased to inform you that approval for the study (August 21, 2016) is granted under the expedited/delegated review process on February 24, 2017, valid until **February 2018**. The study proposal will be presented for corroborative approval at the next meeting of the Committee and a certification document will be issued to you at that time.

A review of all research involving human subjects is required on an annual basis in accord with the date of initial approval. The annual review should be submitted at least one month before **February 2018**. Please inform the IRB promptly of any modifications that may occur to the study over the next twelve months.

Sincerely,

Roberta Palmour

Roberta Palmour, PhD
Chair
Institutional Review Board

cc: Dr. Sarra Gibreel
A02-B14-17B