There is More: An Exploration of Adolescent Girls Living with Chronic Pain

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Abstract

Introduction: Adolescents living with chronic pain are vulnerable to negative outcomes such as disability and an impaired quality of life; they often miss school, are unable to maintain social contacts, experience sleep disturbances, and suffer from anxiety and depression. This often leads to negative avoidance coping behaviours, resulting in physical deconditioning, adoption of sick role behaviour, as well as catastrophic beliefs about their bodies and individualism.

Objective: This study uses an interpretative phenomenological approach to explore the meaning and context of pain from the perspectives of adolescent girls who have experienced them. The ultimate goal is to liaise with physicians, allied health practitioners, researchers, and policy makers to modify, adapt, and improve current adolescent chronic pain services. This way, we can help patients foster skills that will allow them to adapt positively, regain a balanced social life, and live successfully despite their pain.

Results / Findings: Central to all accounts is a sense of interrupted life—phrases with negative connotations such as "couldn't do" and "had to stop" are repeatedly used to express feelings of loss of control. To regain control over their situation, participants create within themselves a positive internal dialogue: they reconstruct the meaning of normalcy, practice acceptance, make downward social comparisons, and engage in daily positive affirmations. While chronic pain disrupts their career trajectories, the experience of living with pain has instilled in them the pursuit of metamorphosis. This need to *morph* seems to be propelled by the imagery of a full life ahead—the idea that *there is more* to life than their current state. Ironically, some participants are seen to be grateful for their pain. Living with pain has gifted them with intuitive empathy for the suffering of others, as well as the emotional credibility to help.

Résumé

Introduction: Les adolescents qui vivent avec des douleurs chroniques sont vulnérables aux issues négatives tel que l'invalidité et la qualité de vie altérée; ils sont souvent absents à l'école, incapables de maintenir des relations sociales, ont des perturbations de sommeil, et souffrent d'anxiété et de dépression. La continuité de l'évitement de comportement d'adaptation au-delà du temps de la guérison normale a aussi été démontrée qu'il résulte des conséquences négatives tel que le syndrome Disuse-un état associé au déconditionnement physique, comportement maladif, retrait psycho-social, ainsi que les croyances négatives et catastrophiques.

Objectif: Cette étude utilise une approche phénoménologique interprétative afin d'explorer La signification qualitative et le contexte de la douleur de la perspective d'adolescentes qui les ont vecus. C'est pour minimiser l'impact de la douleur et ses conséquences. L'objectif ultime est de se lier avec d'autres médecins, des chercheurs alliés, et les décideurs politiques pour modifier, adapter et améliorer les services actuels des douleurs chroniques destinés aux adolescents. De cette façon, nous pouvons aider les patients à acquérir des compétences leur permettant de s'adapter de manière positive, de retrouver une vie sociale équilibrée et vivre avec succès malgré leurs douleurs.

Résultats: Au cœur de tous les récits se trouve le sentiment d'une vie interrompue - des phrases avec des connotations négatives tel que "ne pas pouvoir faire" et "falloir arrêter" sont respectivement utilisés a exprimer des sentiments de perte de contrôle. Afin de reprendre le contrôle par dessus leur situation, les participants créent avec eux-mêmes un dialogue interne positif : ils reconstruisent le sens de la normalité, pratique de l'acceptation, faire descendre les comparaisons sociales, et engager dans des affirmations quotidiennes positives. Tandis que les douleurs chroniques disputent les trajectoires de leurs carrière, l'expérience de vivre avec la douleur a inculqué en eux la poursuite de l'importance. Cette poursuite est propulsée par l'imagerie d'une vie entière et parait d'être particulier dans cette tranche d'âge. Ironiquement, quelques participants sont vus reconnaissants envers leur douleur. Vivre avec la douleur leur a offert avec une empathie intuitive pour la souffrance des autres, tout comme la crédibilité émotionnelle pour l'aide

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Contribution of Authors

This dissertation in its entirety was written by myself, Manuella Widjaja, under the guidance of my graduate supervisor, Dr. Richard Hovey. Dr. Marc. O. Martel and Dr. Christopher Bedos both acted as committee members and helped track my academic progress throughout the duration of my graduate studies.

Ethics approval for this study was finalized on January 22 of 2019. Interviews commenced the week after. Participant interviews were done by both myself and Rachel Swzimer, a fellow master student researcher exploring friendships and loneliness in adolescent chronic pain sufferers. As outlined in the consent form, all voice recordings and transcriptions were kept in a password locked computer device and only privately shared between Dr. Richard Hovey, me, and Rachel Szwimer. Transcription work was equally divided between Rachel Swzimer and me. Translation from French to English, if necessary, was done by Rachel Swzimer, a native Montreal resident. This was the case for 2 of our participants, who used both English and French during their interviews. Transcription analysis were done together with Rachel Swzimer and Dr. Richard Hovey. All references, including the ethics approval and consent form can be found in the bibliography section.

Introduction: Thesis Objectives

Chronic pain is personal and subjective, while its origin may be physical in nature, its consequences extend further— affecting the individual’s emotional, psychological, and social life. Despite its heavy toll, chronic pain is still mainly recognized as an adult and geriatric problem. As such, research is still heavily focused on this demographic. Adolescence is a critical period in which individuals develop their personal and social identity. The intent of this research study is to explore adolescent girls’ experiences of chronic pain—the ways in which they navigate their lives, all while simultaneously undertaking adolescent developmental tasks. The meaning and context of pain for the sufferer is important because only then can we better develop services for adolescents and their families struggling to cope with pain. The hope is that it will lead to the development of services that will allow them to adapt positively, regain a balanced social life, and live successfully despite their pain.

This study will be guided by this central research question:

What is the meaning and lived experience of adolescent girls living with chronic pain?

I did not seek to define, theorize, or measure the character and nature of chronic pain nor to define the developmental mileposts they experienced as adolescent girls. This question was generated through my interest in adolescents and chronic pain and driven by a substantiated need for research informing our understandings of this experience. Through interpretative phenomenology, I endeavored to transform my participants’ lived experiences into textual expressions— paying special attention to how they lived their lives alongside chronic pain.

My biggest hope for you as a reader, is that you appreciate and acknowledge the bravery behind the smiles that they tirelessly harness every day. In reading their accounts, you will soon realize the weight that chronic pain has—and continue to place on these adolescents; in their case, plans are interrupted, and goals are dismissed, no matter how important. They need an advocate—a cheerleader if you will— and I want to be that person for them.

Preface

I like leaving clippings of mantras and motivational quotes in the nooks and crannies of my apartment—on my desk, by my bedside table, on my walls, even on my fridge. Everyone who has paid a visit knows this because they usually spend the first 10 minutes wandering around amused. This trait started in middle school because I was nervous over a math test; too nervous for my own good, I scribbled a simple "you can do it" on my workbook. Over the years, the quotes become more meaningful, more elaborate, more heartfelt. Here is one of my favourites, something I found 3 years ago as I was about to start my last year of undergraduate studies.

Dream Freely
Envision Excellence
Cherish your creations
Exude enthusiasm
Be inspired
Inspire others
Take pride in you
Recognize inner beauty
Draw on inner strength
Look inside your soul
Create peace
Seek truth
Spread joy
Embark on adventure
Launch new ideas
Think big
Invoke positives
Live fully
Reach out
Aim high
Find happiness
Expect the best
Be the best

I bring this one up specifically because these affirmations are what I think of when I listen to the interview recordings of my research participants; in each one of them, I see every single line of this mantra. Living with pain, it seems, have given them a unique sense of intuitive empathy, one so organic and pure that they inspire others. Just as I was worried about finishing my undergraduate studies and starting a new journey, my participants too, are on the edge of two horizons—except for them, what lies ahead is more turbulent, and more daunting. On their left is a world that they had once knew, pain free and dependable. On the right, is a world they will have to accept, one that might be discouraging and unpredictable, but manageable with the help of others. So, what would you do if your future is dictated by something you are not in control of? In the case of my participants, they had to draw on inner strength and undergo a difficult process of *reconciliation* and *metamorphosis*. Despite the physical pain, emotional burden, dismissive attitudes, and stigma surrounding chronic pain, my participants still manage to maintain a positive well-being and functioning. As beautifully summarized by Dr. Brene *Brown: "Owning our story and loving ourselves through that process is the bravest thing that we will ever do"* (140). And that, that they did.

Chapter One: Review of the Literature

Background to Pain

The complexity of chronic pain makes it difficult to define as it is a personal and subjective experience that is affected by various physical, emotional, social, and cultural factors (1). Traditionally, pain is regarded as an adaptive biological tool, one that warns humans of the potential disequilibrium or danger in his or her body (1). From this physiological standpoint, pain has a protective purpose because it lets us know that a restorative plan is required (1). This idea was cemented as early as the 17th century, when French philosopher and mathematician René Descartes discussed the Specificity Theory of Pain in his manuscript the *Treatise of Man* (2). He described how each somatosensory modality has its own specific receptor and sensory fiber, and how it is sensitive to only one specific stimulus. Pain, he deemed, is a purely physical phenomenon—that the amount of tissue damage is related linearly to the amount of pain experienced (2). This notion was later challenged, especially after differences in pain experience (intensity, duration, quality) was observed between patients with similar levels of tissue damage. Pain science was as such, redefined and reframed. In an attempt to explain this phenomenon, J.P. Nafe suggested the *pattern theory (2)*. There is to be no linear relationship between stimulus and pain, because pain signals were hypothesized to be sent to the brain only after summing together to produce a pattern (2). In 1965, Melzack and Wall added to this theory when they brought into light the potential role of the central nervous system in pain perception (2,3). According to the Gate Control Theory, pain signals generated from injured tissues do not simultaneously travel to the brain; in essence, there are 'neurological gates' at the spinal cord level that determine whether or not these signals will ever reach the brain. Pain is therefore only perceived when the gates open and allow these signals—all, or in some cases only in parts—to pass and reach the brain (2,3). While this theory is oversimplified and not a full representation of the complex nature of pain and the central nervous system, it was a captivating theory in its time, adding new perspective to pain literature and created the spark for more research in the field of pain. In the 1970's with the emergence of the biopsychosocial model of pain, pain was no longer viewed as a purely physical phenomenon, instead, it was seen as the result of interaction between biological, social, and psychological factors—what it is commonly seen today (4). In 1986, the International Association for the Study of Pain formalized this notion when it described pain as "an unpleasant sensory and emotional experience that is associated with actual or potential tissue damage" (5,6).

Each person learns to associate pain through their own individual experiences, such as past experiences with injury in early life, or fear and the perception of incoming danger. In the past 50 years, this has been the accepted model and as such, has been the model used to guide pain research, assessment, and treatment. Considering the vast research on pain that has been conducted, the next few sections are meant to be narrative and illustrative, not exhaustive.

Biological Factors of Pain

While pain is a subjective sensation, it is first a physical sensation that can be confirmed through electrophysiological methods (7). Before we realize that something hurts, there are a number of physiological processes that occur in our body (7). Pain can be generated with and without receptors, and from both the peripheral and central nervous system (7). If the pain stems from a pain receptor, then it is known as nociceptive and physiological (7). In such cases, free nerve endings, also known as nociceptors, respond to biological, electrical, thermal, mechanical, and chemical stimuli (e.g., pain from muscle tear, electrical injury, heat damage, incorrect bending/ lifting motion, acid spill), transmitting it to the cerebral cortex in brain, where pain perception interpreted (7). Nociceptive stimuli are transmitted through large, myelinated Aδ fibres, producing a fast, sharp, and well-defined pain. Because of the fast, almost simultaneous pain sensation at the point of injury, it allows the individual to elicit an “escape” response (7). This is the reason why pain is regarded as an adaptive biological tool, because its purpose is to warn the individual of the injury in the body. Once this “escape” response is elicited, a “second pain” wave, transmitted by a smaller, unmyelinated C fibers will reach the brain. This signal is usually manifested physically in the form of a dull, aching, or pulsing sensation (7). Again, this acts as a safety net—a reminder to the individual that protective action is required. At the actual site of injury, there will be chemical substances—histamine, bradykinin, acetycholine, and prostaglandins—to a name a few, that will synergistically act to alter capillary permeability (8). This allows for white blood cells to tend the injury, which can be observed as symptoms of inflammation, such as redness, swelling, itching, and presence of warmth (8).

Nociceptive pain usually arises from irritation in the receptors of the integuments, muscles, and joints, which, on average, can last from six to twelve weeks (7, 9). While it is most commonly associated with sports related injuries, it can also develop from overuse—an example would be rotator cuff injuries in carpenters and butchers (7,10). If the stimulus associated are continually repeated, then it can lead to adaptive changes in the central nervous system, which in time, can preserve, encourage or even cause, further pain (7). At this point, the pain felt can be generated without association with any receptors (7,11). When pain stems from non-receptor pain, then it is known as pathological (7). In this case, the pain felt is not a manifestation of any nerve or tissue damage; it has no protective function and is not a symptom of any other disease—in fact, in cases as such, the pain itself is considered a disease (7). Common examples would include fibromyalgia and irritable bowel syndrome (7). This type of pain is what is usually associated with chronic pain, which I will discuss in a later section. Because of the ambiguous nature of non-receptor pain, physicians would include an additional evaluation of psychological, social, environmental, and lifestyle factors—on top of the routine physiological exams. An example of a lifestyle factor that affects the pain experience is sleep deprivation (12). While its influence cannot be labelled as causal, the predominant view is that sleep and pain are reciprocally related; the less sleep, the more pain is felt (12). A longitudinal study done on Norwegian women found that women who suffer from insomnia were significantly more likely to develop fibromyalgia 10 years later (13). Additionally, a headache-free British sample were seen to significantly be more likely to suffer from new incidents of headaches after a one-year follow up with insomnia symptoms at baseline (12). Clinical features of pain include factors such as location, intensity, duration, quality, and suffering—the last of which, is mainly subjective with psychological factors at play (7).

Psychological Factors of Pain

The phenomenon of pain perception is dynamic and personal, varying not only from person to person, but from time to time in the same individual. This is in part due to the psychological factors that are intertwined into the experience of pain. In fact, there is growing evidence that the meaning of pain—and not pain itself, is what predicts how individuals react and cope. (7) Using health care samples of patients with recurring musculoskeletal pain, Denison et al showed how disability, as measured by the Pain Disability Index, was better predicted by self-efficacy and fear-avoidance beliefs then pain intensity and pain duration in primary care patients with musculoskeletal pain (14). Similarly, Foster et al found how pain self-efficacy was a more important obstacle to recovery than in patients with chronic lower back pain, pain self-efficacy was shown to be a significant mediator in the relationship between pain intensity and disability. In an attempt to explain these factors, social scientists have outlined models that would help patients—and society as a whole, understand the emotional and behavioural response that stems from pain (14,15). In this section, I will discuss an influential model known in pain literature as the fear-avoidance model. As mentioned previously, nociceptors respond to pain stimulus by transmitting it to the cerebral cortex, where pain perception is interpreted (7,16). This step is known as cognitive processing, which is what leads people to act—or not act—on their pain (7). For example, an athlete in the midst of finishing a marathon might choose to stop her race upon feeling a pulsing sensation on her knee—or she might not. On the other hand, if a person is to be walking alone at night and fear that someone is behind following, he or she might choose to run, even if he or she has an occurring injury that prevents that level of fitness. Similarly, when pain is not perceived as dangerous, people living with chronic pain are usually able to continue their daily activities, thereby promoting functional recovery (16). This reactive response is initiated by an initial assessment. At this first level of assessment, the individual will subjectively evaluate the pain level as well as the environment that he or she is in. If the pain or the environment is perceived as a threat, then the individual will be motivated to react, finding ways to cope; if not, then the pain will fade to the background, and the individual will continue with the activity at hand, without interruption (16). This is the reason why an injury might be perceived as intense and unbearable by one individual, but minor and insignificant by another.

The Fear-Avoidance Model

The majority of persons who are injured will realize a full recovery, yet, a subset suffers from continuous pain, leading to disability (7). While there are many factor as to why this might be the case, this can in part be explained by the fear-avoidance model, which posits how catastrophic appraisals—the dysfunctional belief that physical activity will exacerbate pain or lead to injury—had been seen to promote a self-perpetuating cycle of avoidance, hypervigilance, depression, and kinesophobia (fear of movement), leading to physical deconditioning (17-22). The perception that the pain will last long into the future not only lead to fear of rehabilitative activities, but also extends to everyday activities (17-22). This model had been verified quantitatively as well. With 147 sub-acute whiplash patients as participants, Nieto et al performed two regression analyses, with kinesophobia and catastrophizing as the independent variables, and disability and depression as the dependent variables (23). Even after controlling for descriptive variables, such as pain duration and intensity, catastrophizing and kinesophobia were still found to be in significant positive correlation with disability and depression. In agreement with the fear-avoidance model, catastrophizing and fear of movement were found to be legitimate predictors of disability and depression (23). Similarly, a questionnaire-based survey conducted in 122 patients with chronic low back pain showed how hypervigilance to pain is associated with heightened pain severity, underlining the importance of psychological factors in guiding pain management. In the absence of fear-avoidance beliefs, individuals are more likely to be motivated in confronting their pain, and stay consistently engaged in their rehabilitation process, resulting in improved daily function (26). This positive mental state is described in medical literature as self-efficacy (23-25). If an individual is to adopt this mindset, then the individual has the personal belief that he or she can successfully cope with the difficult situation presented to them (17-25). By this definition then, pain self-efficacy denotes the degree of confidence that a pain sufferer has in engaging—and progressively increasing the volume, intensity, frequency, or time—of their activities and tasks, whether it be their rehabilitative exercises, or household chores (17-24). In patients with low chronic back pain, a sense of high self-efficacy despite the pain is seen to be a significant predictor of recovery; on the other hand, weak self-efficacy is seen to predict long-term disability (26). If one is to practice self-efficacy, then they become associated with a state of acceptance and commitment—where one chooses to focus on living life to the fullest, participate in valued activities, and pursuing personal goals (24-26).

Acute Pain

Acute pain is most commonly associated with a specific disease or injury and therefore, the activation of the sympathetic nervous system. Common factors that lead to the onset of acute pain include trauma, medical procedures, physical labor, and diseases. Medically, acute pain would be considered as pain that stems from receptor pain, or nociceptive pain; as mentioned previously, this serves as a survival function and alerts the individual of the presence of injury, or potential tissue damage (7, 27). The sensation associated with acute pain is single and sharp, specific to one anatomical region, and will disappear without a trace when the damage has healed. On the other hand, it can lose this adaptive function, persists beyond normal tissue healing time, and turn pathologic—severely impacting a person’s quality of life (7, 27). At this point, pain occurs in the absence of tissue damage, with no distinguishable end point (7, 27). Nociceptive pain is predicted to last between six to twelve weeks. When pain extends beyond this period, pain is no longer defined as acute, it is defined as chronic (7,27).

Chronic Pain

The distinguishing factor that defines pain as acute or chronic pain is typically the duration of the symptoms. When pain lasts for a period longer than 3 months, it is classified as chronic pain (7,27,28). Chronic pain differs from acute pain in that it persists beyond the normal tissue healing time, even after the underlying cause of the pain is no longer present (27, 28). As such, chronic pain serves no biological purpose (7,27,28). This can stem from changes in the property of the peripheral nerve cells, which can occur either through (a) repeated use of the injured tissue resulting in damage to the nerve fibres; (b) spontaneous firing or alterations in sympathetic neurotransmitter properties (7,27,28). Chronic pain is diverse in nature and varies from person to person, differing in many of its elements, such as etiology, intensity, frequency, and duration. chronic pain can be classified by anatomic location such as the head/face/neck region, the back, upper extremities, lower extremities, or by the different organ system, such as the nervous system or musculoskeletal system. (7, 27,28). It is also ambiguous in that it can stem from many different causes (7, 27,28). For example, while chronic pain is most often associated with an initial injury, it can also stem from disease treatments itself, such as surgery and chemotherapy (7, 27,28). By this definition, chronic pain is what we would refer to as pain that stems from non-receptor pain, otherwise known as pathological pain (7, 27,28).

The Burden of Chronic Pain

Those affected by chronic pain not only suffer from physical ailments such as muscle atrophy, immobility, and increased susceptibility to disease, but also from psychosocial and emotional ones, including dependence on medication and caregivers, anxiety, social isolation, and fear (29). A common finding is that psychosocial factors contribute to disability above and beyond pain intensity. As such, chronic pain has become the second major cause of suicide, second only to bipolar disorder (29).

On a day to day basis, individuals suffering from chronic pain can experience any of the following, usually simultaneously (12,29,30):

- Poor quality sleep and immune system, delaying potential recovery and prolonging pain.
- Functional limitations and reduced mobility due to guarding and compensation.
- Decreased pain and activities tolerance resulting in social isolation.
- Catastrophic thoughts about the affected area or body succumbed to pain.
- Increased perception of other pain resulting in poor concentration and the inability to relax.
- Feelings of helplessness resulting in anxiety, depression, and in some cases, suicidal ideation.

As discussed, chronic pain does not only result in physiological changes, it also results in negative psychological and social changes (29). Because of the intensity of their pain, individuals suffering from chronic pain have difficulty finding a comfortable sleeping position—which, in conjunction with the interruption of sleep by pain attacks, result in a depressed immune system (12). The physical and mental fatigue that stem from this process led to decreased tolerance in previously enjoyable hobbies, resulting in social isolation (12). This state of insufficient activity is known as Disuse Syndrome (30). As time passes, this physical immobility result in a depressed mood, propelling obesity, anxiety, irritability, and in some cases, suicidal ideation. This sense of helplessness stemmed from the lack of control they feel from not being able to find the causes and ways to relief their pain (30). A common trajectory for chronic pain patients is job loss. A European survey of 4839 chronic pain patients indicated how 61% of their participants were not able to work from outside their home, with 13% losing their employment and another 13% changing their employment (31). With job loss comes loss of income, decreased self-esteem, and relationship problems. It does not help that chronic pain is heavily stigmatized—so much so that in 2016, pain-related stigma has been identified as a public health priority by the National Pain Strategy (32). The ambiguity of chronic pain leads to difficulty in diagnosis and usually results in medical providers themselves to doubt the pain accounts of their patients, interpreting the symptoms as invalid (33). The lack of observable symptoms or causes in medical imaging and blood tests meant that the pain is undermined and invalidated, being referred to instead, as “only psychological.” (33) One’s sense of self is made up the sum of the societal reactions (34). As such, some chronic pain patients resorted to avoid the shame associated, leading to concealment of the actual pain during social interactions and medical appointments. Not only does it lead to a delayed diagnosis, it also leads to treatment bias, impairing treatment recovery (35). As captured by Maria Hudspith, executive director of Pain BC: “when we think about medicine, we think about it being scientific and measurable. With a broken body part, we can see it. But for pain, when it becomes chronic, it’s not that way.” From a patient’s perspectives, we can take into consideration the account of Meldrum—a car accident survivor and chronic pain sufferer, who said: “You start to question your own sanity… the most important you can hear is that someone believes you.” (35) This is because negative stigma can be internalized, resulting the individual to adopt the negative societal stereotypes, resulting in self-blame and hindering recovery (33,34,35).

Gender Differences and Chronic Pain

While studies have reported the prevalence of chronic pain to being female-predominant, (36-38, 40), it is important to understand that there are underlying mechanisms that might play a role in the gender disparities seen in chronic pain. Taking musculoskeletal pain as an example, here are the three main explanations currently used: (a) women, as outlined by the exposure model are more exposed to risk factors for musculoskeletal pain; (b) women are physiologically at a higher vulnerability than men in developing musculoskeletal pain.; and (c) women are more willing to report musculoskeletal pain. (36-38). Research done in Australia with 737 government employees showed how sex-segregation of women into sedentary and repetitive domestic work exposed women to more risk factors, which supported the exposure model (39). Point B and C are in contrast to the phenomenon seen in the male population, who because of the enculturation of masculinity in our society are reluctant or unable to seek help (41). Stereotypes of masculinity include being stoic, independent, and emotionless, and it is because of this that men remain silent and unwilling to show the people around them their trivial symptoms (41). For most men, this means seeking help only when they show visible, physical symptoms (41). It can be understood from this that the stigmatizing impact of chronic pain affects women and men differently. Sex differences in response to pain have also been shown experimentally. In a study done by Levine and De Simone, males were seen to report significantly less experimentally induced pain (cold pressor task) in the presence of a female experimenter than when interacting with a male experimenter (42). In another study by Weisenberg et al., it was reported how when told to immerse one's arm in a container of ice water, women reported higher levels of anxiety than men and obtained lower scores on a measure of perceived ability to cope with pain (43). In a sample of Albertans, Schopflocher et al. performed a study analyzing the prevalence and descriptive epidemiology of chronic pain, looking specifically at age-sex relationships (44). When compared with males, women older than 18 years of age are seen to have higher chances of suffering from chronic pain—the prevalence increasing with age—from <6% at age 18, to 18% at age 65 in males and 24% in females (44).

Chronic Pain Care

In Canada, one in five people are approximated to be living with chronic pain (45). Despite its prevalence, a substantial gap remains between chronic pain and its care process. As a result, chronic pain still remains under-recognized and under-managed in the clinical setting. Among the barriers to successful CP outcome is the organization and administration of chronic pain care itself, which is largely based around the traditional model of acute care (45,46). Under this model, chronic pain is classified as a symptom, not a disease (46). This model of care promotes a "wait and see" approach, which prolongs the time between the initial diagnosis and treatment initiation specifically for chronic pain (45,46). Instead of actively preventing further pain, treatments are reactionary and are only initiated when the patient complains about the intensity of pain (46,47). As one can imagine, this does not align with the needs of chronic pain patients, who, for treatments to be successful, need continuous care, as well as a referral to a specialist within the first few weeks of the onset of acute pain continuing past three months and beyond (46). Unfortunately, the average wait time for chronic pain care in Canada can take up to a year; during this time, conditions can worsen, resulting in the diminished ability to return to a fully-functioning capacity (45,46). Another barrier is the lack of inter-level communication. Chronic pain care often involves the collective effort of a multidisciplinary team, yet test results and treatment summaries are not well communicated among health care professionals in charge (48). This lack of access to information, along with time constraints, reimbursement policies for physicians, and minimal training in medical schools all lead to services that are fragmented, inefficient, and difficult to access. As such, as pain transitions from acute to chronic, chronic pain patients are left to seek help on their own (49). A popular choice amongst chronic pain patients is the incorporation of complementary and alternative medicine (CAM), which involves non-pharmacological approaches such as acupuncture, chiropractic care, physical therapies, mindfulness, and overall lifestyle changes (50). This approach is highly valued because it is accessible and gives patients the opportunity to play a more active role in the management of their condition (50). Despite popular beliefs, chronic pain is not exclusive to the adult population—it affects all ages, including adolescents. Population-based cohort studies have shown that 25% to 37.3% of adolescents report chronic pain (51).

Adolescence

In the 1930s, the term adolescence was more a status symbol than a term used in medical literature—during this time of economic depression, the term was used to describe the high school- aged kids who “packed up and took off” riding the rails and hitchhiking in hopes of finding fortune (52). This term was mostly associated with kids from poorer districts, who had to start work early to help out with their family’s finances (52). Over the years, this term was redefined and reframed: in the period between the 1940s and 1960s in the post-war times of mass education, economic prosperity, and the emergency of youth culture, teenagers were seen to be the generation that rebelled without a cause—young adults who were energetic and not restrained in creating their own image (53,54). Today, the “teenage years” is more commonly referred to as adolescence, a word used to describe the life of a young adult from the age of 12 to 18 (55, 56)—a stage that is distinct from childhood but cannot yet be classified as fully adult in status. In this sense, it is not the developmental stage that has changed, but the social context in which the term is associated with. This term is not to be confused with the restricted period of puberty. Although the timing of these periods overlap, puberty solely refers to the acquisition of sexual maturation (57, 58). In contrast, adolescence describes the period following this onset, during which one undergoes rapid physical, social, and psychological maturation, as well as heightened vulnerability and experimentation with identity (56,59). The noticeable difference between today’s society and decades past is the structured educational environment, along with globalization and social media, where the end goal is to train to adolescent for the distant future (60). As such, this period involves developing priorities related to career, identity, friends, romantic partners, family, community, and religions/ philosophical beliefs (60). This differs from pre-industrial societies, where adolescents apprentice and learn utilitarian skills through social gatherings (60). Today's landscape has therefore changed the way the speed at which social norms are affected, with both risks and opportunities (60).

Given that adolescence is a natural time of learning and adjustment in long-term goals and personal aspirations, this period is often regarded as a period of rapid self- development in one's intellectual, occupational, and psychosocial areas (53-60). However, the greater freedom of choice available to today's adolescents can also be viewed as "double jeopardy" (53). Double jeopardy leads people to believe that problems are mainly individually based versus socially constructed, which results in increased pressure on one's self, which can lead to low self- esteem and self- compassion (53). These problems come in the form of many—with the most common ones being barriers such as lower socio-economic status, chronic diseases, disability, and being labelled as part of a minority. In the context of my research study, this barrier is chronic pain. Unlike their peers, adolescents who suffer from chronic pain have relatively higher guardian protectiveness, leading to fewer peer socialization, which can lead to feelings of loneliness and other depressive symptoms (61,62). Parents whose child suffers from chronic pain have described treating their adolescents as a dependent preteenager, instead of the young adult that they once were. (63) These social and personal barriers are intertwined with feelings of (a) the way they see themselves, and (b) the relative priority of their goals. The lack of motivation that can stem from these barriers can act to decrease the adolescent's desire to persevere through difficulties (63).

Transitioning to Adulthood: Positive Youth Development

There has been an increase in attention on the promotion of self- esteem—the idea being that it will help these young people in becoming more optimistic, confident, and achievement driven (64). Self-respect is an intrinsic human need and as such, it is important for adolescents to learn to feel good about themselves (65). In research, self-esteem can be moderated by self-compassion—the act recognizing and accepting the imperfect human condition (such as suffering and failing), and reacting with warmth as to care for one's self and connect with others, instead of feeling behind, or separated or isolated from others (65). In adolescent literature, self-compassion has been recognized as a "buffer" against low self-esteem and the various range of negative psychological and physical health outcomes (66). Adolescents who are taught self-compassion skills in interventional programmes, are seen to have reduced rumination, depressive symptoms, as well as increased positive affect and life satisfaction (66). This understanding led to research on adolescent identity development, a process that in Western culture, emphasizes individualism (the self) over interdependence (65,66). From the perspective of a growing adolescent, adulthood is felt to be reached when they have developed the ability to make independent decisions, such as accepting the responsibility for their social actions and making financial decisions (67,68).

The burden of chronic pain severely impacts the accomplishment of financial and decision-making independence—the traits that adolescents associate with success and adulthood (69).The transition to adulthood is therefore used to evaluate adolescents' progress—both in research and in the clinic, as it sheds light into the well-being of the adolescent, providing the care provider with knowledge to provide quality intervention and psychosocial care. (67, 68, 70). With the understanding that humans have basic psychological needs, the Self-Determination Theory (SDT) highlights three needs: autonomy, competence, and relatedness (71). SDT explained how the need for competence is fulfilled by the experience that one can effectively bring about desired effects and outcomes, that the need for autonomy involves perceiving that one's activities are endorsed by or congruent with the self, and that relatedness pertains to feeling that one is close and connected to significant others." (71, 72). Because adults regulate their behaviour and self-perception on the basis of internal values, the process of internalization is a critical aspect of children's development and growth. As such, interventions usually emphasize the need to address the relations between adolescents and their settings (73). In Western societies, these internal values are based off of the accepted social role markers for transition into adulthood is most commonly recognized as completing an education, gaining full-time employment, moving out of the family home, and reaching parenthood (74). These markers contrast that with the sets of role markers in non-industrialized societies, where adulthood is most commonly denoted by marriage (74). As such, adolescence is seen as a dynamic and interdependent process—the accumulative product of social expectations that are associated with the normative structure of a given culture. (53,73). PYD supports the notion that the development and nurturing of relationships experienced in the adolescent's context helps them mediate the developmental task of belonging and connectivity to others and construct a confident and secure identity, which helps ease the transition to adulthood (75,76). Of particular importance are peer-directed social interactions; during an average week, adolescents have been reported to spend close to one-third of normal waking hours talking with peers (77). This developmental task of connectivity is at risk when peer interaction is limited, such as often happens to adolescents with chronic pain (77). However, while peers can provide positive experiences such as accompaniment and a sense of support, peers can also facilitate conformity to antisocial behaviours such as cheating, stealing, trespassing, disordered eating, and substance use (78,79). Because of the heavy number of transitions and responsibilities, adolescents are viewed to be in a chronic state of threatened homeostasis (79,80). Suffering from chronic pain represents a major source of unpredictability and can therefore further disrupt an already threatened state of homeostasis. Given the sensitivity associated with adolescence, it is therefore important to explore the range of challenges that adolescents may face as a result of their pain and how they navigate it while simultaneously undertaking the task of identity development (73-77).

Adolescent Identity Development

Central to this period is the emergence of autonomy and empowerment; however, while it is often described as a period of independence, it is more appropriate to describe it as a period of change in the balance of dependence—manifested most commonly through the increase of dependence on their peers, and independence from their guardians (81-83). As such, adolescents can be described as a time in which one is free to explore psychological characteristics of the self—who they really are—outside of guardian influence. One of the first to outline adolescent development is Erik Erikson with his “Stages of Psychosocial Development” model—a progressive set of eight stages in human development from birth until death (67, 84). He discussed developmental challenges as binary crises—two forces that the individual must negotiate before being able to move to the next stage (84). The developmental task he assigned to adolescents is labelled as identity formation versus identity confusion; if the adolescents do not successfully form an identity, then he or she may become confused individuals—individuals who are not sure of who they are and what they like (84). As a result, they were hypothesized to drift from one career or relationship to another, living a life without a sense of personal cohesiveness (84). If adolescents are successful in reaching an individual sense of self, then the adolescent will be able to define themselves—along all dimensions, including academics, athletics, appearance, social relations, and moral conduct—in their own terms, with their own personal beliefs and standards (84,85). Currently, adolescents seem to work through issues regarding body acceptance; forming mature peer relationships with both sexes; achieving a sex role; emotional independence and autonomy from parents and other adults; preparation for joining the workforce; preparation for marriage and family life; as well as achieving socially desired behavior (67,85, 86). This stage is important as poor self-esteem had been seen to correlated with negative behaviours that often associated with this age group, such as poor school performance, substance abuse, cheating, stealing, trespassing, disordered eating, and substance use (85). As a result, adolescence is often associated with increased risk-taking behaviours and emotional reactivity (82, 85). However, it is important to understand that these behaviours are transitory in nature, with most growing up to be responsible, employed, and law-abiding adults (85).

Chronic Pain and Adolescence

Contrary to popular belief, chronic pain is not exclusive to the adult population. Approximately 14% of adult sufferers revealed that their current pain is a consequence of untreated chronic pain during their adolescence (87). Unlike pain experienced in the adult population, pain in the adolescent population cannot be attributed to the wear and tear associated with aging. The underlying pathophysiology is often pain arising from (a) idiopathic activation of peripheral nerve endings, or (b) neuropathic pain resulting from past diseases, epigenetics, repeated injury, or medical error (87-89). Common symptoms include headaches, abdominal pain, as well as musculoskeletal and joint pain. While pain may be local to a specific region (e.g., abdominal pain), it more commonly affects the entire nervous system, leading to *central sensitization* and therefore, the development and maintenance of a new, localized chronic pain (51, 90). Although most adolescents with chronic pain can effectively manage their condition, an unfortunate minority become severely disabled (51,87). Because of the ambiguity of chronic pain, these adolescents are relayed from specialist to specialist—all in the hope that one medical evaluation, or one diagnostic testing will reveal a physical cause (88). However, as with most cases of chronic pain, no sound diagnosis can be agreed upon and no treatment course is planned; for these adolescents, life revolves around the four walls of a hospital consultation room. It is during this time, known as the *diagnostic vacuum*, that the adolescent realizes the severity of his or her condition (88). Over time, the weight of this experience may lead the sufferer to develop symptoms of chronic disability, sleep disturbances, and social withdrawal. (51, 91-96). As such, greater anxiety is a common feature that accompanies chronic pain presentation (91-96).

Taking this into consideration, it can be understood why adolescents with chronic pain are seen to suffer from the psychological stress and isolation when compared with their healthy peers (91-96). The fear avoidance model of pain applies to adolescents as well. Catastrophizing—referred to in adolescent chronic pain care as "awfulizing" resulting in the amplification of the significance of pain, feelings of helplessness, as well as rumination, otherwise known as the anxious preoccupation with pain (90). This, coupled with the normative challenges of identity formation associated with adolescents prove to be a burden, leading to externalizing behaviours such as aggression, delinquency, and other maladaptive coping mechanisms such as drug and substance abuse (91-96). While it is true that higher pain duration and intensity is associated with poorer functioning, it does not necessarily determine the level of disability associated with pain (91-96). A range of other factors affect disability, including the adolescent's adaptation to chronic pain, their affective state, and specific beliefs about pain (91-96). As with adults, there are also gender differences in pain perception in the adolescent age group (97). In-depth interviews performed by Williams et al. in 2000 showed how adolescents suffering from chronic diseases, such as type 1 diabetes and asthma, projected different gendered identities. While most girls adjusted to their chronic illness by integrating it into their personal and social identities, the majority of boys separated themselves from the illness, finding ways to resist it instead. These observations are in accordance with the stigmatizing impact of masculinity mentioned earlier (97).

Although current literature provides a base understanding of the impact of chronic pain, the majority was done quantitatively, where impact is measured through questionnaires and then coded into statistical data. Moreover, the topics explored would be epidemiological or economic in nature, such as the national cost burdens of chronic pain, pain prevalence in certain ethic groups, pain prevalence in relation to demographics, etc. Given the aforementioned psychosocial burden of chronic pain and its negative affect on the positive transition to adulthood, it is important that we explore the qualitative meaning and context of pain for the person living with chronic pain. As mentioned previously, the prevalence of chronic pain had been reported to being female-predominant. Little is currently known of how adolescent girls cope with chronic pain and the kinds of support preferred. The objective, therefore, is to understand the complexities of chronic pain through the lens and lived experiences of chronic pain these girls themselves- because only then, can we begin to understand the pain-related beliefs, attitudes that affect their lives. There are also currently no specific programs to support adolescents suffering from chronic pain. The knowledge gained from this study can then be used to create social activities that adolescent girls prefer, feel comfortable attending, and participate in. We purpose to achieve this through research using open-ended and semi-structured interviews- the process of which is outlined in the next chapter.

Chapter Two: The Research Process

Interpretive Phenomenology

While it is true that human science and lived experiences can be studied through statistics and quantitative assumptions, we should also acknowledge its complexity: every lived experience is unique and as a result, cannot be captured through a number on a scale, or a series of yes or no binary questions (98). Phenomenology as a qualitative research approach was articulated for that very reason—so that researchers can detach themselves from controlled experimentation protocols and embrace the *possibility of anything* (99). In essence, phenomenology as a research approach aims to explore lived experiences from the perspectives of those who have experienced them (100). In the most basic division, phenomenology can be branched into two categories: descriptive phenomenology and interpretive phenomenology (99-102). Simply put, descriptive phenomenology intends to describe a phenomenon as they appear to the consciousness: the objective is to describe a phenomenon's general characteristics, not the individual's experiences. Having introduced it in the early 20th century, phenomenologist Husserl believed that it is important to set aside everyday assumptions so that the phenomenon can be described in its purest form, as it occurred (99). In descriptive phenomenology, objectivity is crucial, and the researcher is required to restrain, or *bracket out* previous understandings and biases (99-103). In its early conception, however, questions were raised as to how researchers can truly distance, or *bracket out* their attitudes, prejudices, and beliefs from their findings (103). As such, a concrete definition of *bracketing out* was tabled (103). Bracketing out does not mean reporting blindly, it means being cognizant of the biases that might compete with their findings and shifting them to the background as to suspend, or reduce as much as possible, their influence over the findings, so that the findings can be described in its purest form (103).

In interpretative phenomenology, we forego this process of bracketing out and add a layer of intricacy: our own interpretation. As McConnell-Henry explained, the researcher is not an isolated entity, but a part of the research itself (99). A core aspect of interpretive phenomenology is *co-constitutionality*— the concept that meanings are the result of both the participant's and the researchers' interpretation (99). Interpretative phenomenology is not a rule-bound process, but the free act of *seeing* meaning (99). This free act means that analysis can come from any sources that act to shed light on the individuals' perception of reality and phenomena—it can be presented through language in the traditional form—such as poetry, letters, conversations—or, through visual mediums such as photography and painting. The only criteria being that it conveys emotions and speaks to a lived experience (99,100). As the approach gained popularity, Hans-Georg Gadamer, a contemporary of Heidegger, added scholarship to the approach, outlining the significance of *language* in uncovering the notion of experience and existence (100). According to Gadamer, "a dialogue seeks resolution in a fusion of horizons" (101, 104-106). Here, horizons are used as a metaphor to represent the dynamic and fluid views and beliefs inherent in all actors present in the dialogue—the fusion of which, therefore, represent the different perspectives meeting and forming a new and integrated picture (104). In the process of acquiring this new horizon, both the researcher and the participant learn to look beyond what is close at hand—this does not mean that we look away or dismiss the old horizon, we just learn to see it better (104-106). As Heidegger offered, there is nothing rich or deep about lived experiences until we as researchers put on our interpretative lens and ask: What is the person trying to tell me? Am I noticing something that the participants are unaware of? What do their words tell me about their mental and emotional state? The researcher then, is an instrument that must achieve "a honed dexterity with language and relationship, tact, discretion, courage, and timing—enough so that every condition is set for the arrival of good data" (106). To produce this rich data, one must find a balance between (a) allowing the person to finish and (b) bringing attention to what seems as the most meaningful, avoiding invitations to counsel or teach and recognizing critical junctures and curiosity as a means to remain engaged" (106). The guiding principle of this methodology is, hence, the researcher's interest in learning about the participant's perspective of their world, as well as his or her desire and endeavor in understanding the complexity and personal implications behind its meanings (107). It is through this same lens that I will explore the experiences of adolescent girls as they navigate their journey with chronic pain. The findings in this study are therefore a result of my own interpretation: they are influenced by my own sensitivity to language and reflect my own perspective of the dialogue.

Why Interpretive Phenomenology

The purpose of utilizing interpretive phenomenology as a research methodology is to bring into light and put into textual expressions, the lived experiences of adolescent girls suffering from chronic pain. Interpretive Phenomenology is used as it allows the researcher to explore the meaning of a lived experience as it is presented by his or her participants, rather than one that is pre-prescribed by existing theoretical conceptions—beneficial especially for an emotionally heavy topic such as chronic pain. Through interpretive phenomenology, participants can converse with the knowledge that there simply is, no right or wrong answers. Questions are open-ended/ semi-structured and sessions are more a conversation than a structured interview. This puts the participant in a position of control as it allows them the freedom to guide the conversation in a direction that they perceive best reflects their lived experience, allowing the researcher with the opportunity to go beyond surface-level description of findings. After all, they are both the perceiver and spectator of the experiences that I am trying to study (106). The relatively small and homogenous sample inherent in interpretive phenomenology also allows the researcher to capture in-depth and concentrated details from a specific subset of individuals (in this case adolescent girls suffering from chronic pain), therefore ensuring that the findings are as insightful as can be. In essence, Interpretive Phenomenology returns this experience back to the participants, with emphasis on the subjective and experiential of the phenomena in study. It is important that the meaning and context of pain is based off the lens of the sufferer because only then can we better the development of services for adolescents and their families struggling to cope with pain. The long-term goal is to liaise with physicians, healthcare providers, allied researchers, and policy makers to modify, adapt, and improve current adolescent chronic pain services. This intention makes the narrative and subjective nature of lived experience all the more important, as it addresses the topic from the perspective of the beneficiaries of the modified pain services.

Participant Selection and Recruitment

This project does not focus on the underlying pathological cause of pain. Therefore, chronic pain will be regarded as an umbrella term and refers to any persistent pain that lasted for a period of longer than 3 months, as defined by the International Association for the Study of Pain (IASP) (6). Previous studies had noted that females are not only more likely to report chronic pain, but they are also more likely to demonstrate the highest level of somatization and depression (36-40, 108-109). This research finding is reflective of what is seen in the patient roster at the Montreal Children’s Pain clinic, where 75% of the patients are female. Because mild associations have been noted between gender and disfunction in chronic pain patients, it was agreed upon that only female adolescents would be interviewed. This way, we were able to eliminate gender from becoming a confounding factor. As such, our inclusion criteria were as follows:

- Female and between 14 to 17 years of age
- Registered patients of the Montreal Children's Hospital Chronic Pain Management Clinic
- Living with chronic pain for a duration of longer than 3 months, as defined by IASP.
- Comfortable communicating in French or English

The practice of Interpretive Phenomenology relies not on the quantity, but rather on the quality and dept of meaning and complexity of the interview data. As such, it is not possible to predict the number of participants needed. Because of the qualitative nature of this study, quantitative measures such as statistical "power" and representative sampling were not used. Our participants were recruited to harvest experience, not to collect data for the purpose of re-producing knowledge, verifying existing literature, gather enough information to reduce or simplify a topic into themes, or making general claims for a larger population (106, 111). A more appropriate guideline for qualitative research participant sampling is that the number of participants should reflect the point at which the researcher reaches data saturation. Saturation is defined as the point in which adding more participants to the study does not add perspective nor information (112). By this definition, it can be argued how one participant in a study would be just as justified—provided of course—that the individual can generate a rich and compelling account (112). After 8 participants, it was agreed upon that there was sufficient data to generate the interpretations needed to expand my understanding of the research topic. Recruited from the MCH CPMC, their pain condition(s) included fibromyalgia, arthritis, back pain, widespread pain, related disorders, and/or orofacial pain conditions. These participants are all female, ranging between 14 to 17 years old.

Interpretive phenomenological studies explore a topic or phenomena of interest by engaging in conversation with participants who can best "speak to" and enhance the knowledge of the phenomena (106). My intent was to explore and extend our understanding of their experiences as adolescents girls living with chronic pain. In this inquiry we chose, through purposive sampling, adolescent girls who could speak to their experiences of living with chronic pain. This type of inquiry cannot be measured or predicted by a number and there is therefore no appropriate sample size calculation. Originally, my supervisor and I estimated that 6 to 10 participants would need to be interviewed to provide the needed richness of data required for this particular topic at this level of master's study and analysis. As mentioned, after the completion of 8 interviews, we felt confident in the richness and depth of our data to cease participant recruitment.

In the early stages of our project, my colleague Rachel (master's student) and I would attend rounds to get a better sense of the patient roster at the Montreal Children's Chronic Pain Services. Dr. Pablo Ingelmo, pediatric anesthesiologist and director of the Chronic Pain Services, along with his research assistant Nada Mohamed, identified participants fitting the inclusion criteria and introduced the study and asked if they would be willing to hear more about the study from the research team (myself, fellow master's student, and / or my supervisor). We were then introduced to the potential participants, carefully explained the reasons behind the study, and asked if they would like to participate. If they were willing to participate, we set up an interview appointment at their convenience.

Data Generation

The semi-structured research interviews occurred one-on-one with individual participants (and / or their mothers) and myself and fellow master's student in a mutually agreed upon time and location. The interviews averaged between 30 minutes to an hour in a quiet location at the Montreal Children's Hospital which allowed for time to establish an environment conducive to the sharing of their experiences. A list of guiding questions was generated from my own curiosity regarding the topic, as well as, those from the study supervisor and fellow master student (Rachel Swzimer). However, the wording and sequence of questions were not fixed and was different for each interviewee to cater towards their personal experiences. It may be noted that many of the questions in our guide were written as close ended in the consent guide (see Appendix A, project proposal). However, in the actual interviews themselves, these questions shifted to more exploratory and open- ended questions that allowed the participants the space to answer and share their understandings. The questions were open-ended specifically so that my participants felt a sense of freedom when answering questions, because only then will they be their authentic self and be comfortable in sharing the raw, sometimes delicate lived experience that they had for so long, kept to themselves. Probing and clarifying questions were only followed if it was understood between Rachel and I that the action will result in a more in-dept account. Even then, the participant is still given full control in how they choose to answer the question. The study was conducted in such a manner because as Gadamer asserted, it is by means of a conversation that we can open and maintain the space for a phenomenon to be engaged (106,113). The back and forth action of questioning and inquiring allows both the researcher and the participant to be transformed into a conversation, learning from each other instead of the researcher merely putting him or herself forward and asserting their individual point of view. (106, 113).

Interviews were conducted mainly in English. In the case that French was used (*Julie & Samantha), translation was conducted by my colleague Rachel Swzimer, a native Montreal resident. Interviews took place between January and April of 2019. The interviews were audio-recorded and then transcribed verbatim into written text. The written text allowed for a revisit of the interviews on repeated occasions. I wrote field notes after each interview to capture contextual details and beginning interpretations. These then accompanied the transcribed interviews as beginning interpretations. The interviews were audio recorded, transcribed verbatim, and later, reviewed concurrently with my colleague (Rachel Swzimer) and my supervisor.

Data Analysis

Data analysis in an interpretive phenomenology inquiry begins at the time of the research interview (106). This process continues through the transcription process, reading and re-reading of the transcripts, reflection on the interviews, writing and review of field notes and interpretive memos, generation of interpretations, and interpretive writing. This also included meetings to discuss the findings with my supervisor and fellow master's student where we discussed our individual perception of findings. Interpretive phenomenology does not prescribe a strict procedure in performing data analysis and as such, the process of going from a transcribed interview to an interpretation of value and resonance that describes and expands our understanding of a phenomena depends on the interpretation by the researcher—which in turn is affected by how it relates to the surrounding culture, and what it means to the researcher. An interpretation done by a school teacher will be different from those performed by a physician, and different from those performed by a social worker. Data analysis in a qualitative study, especially interpretative phenomenology, differs from other approaches mainly because it is divergent in nature, not convergent (106). Rather than focusing on a single theme, theory, or explanation—as in the likes of searching for protein X that causes condition Y, or the precise side effects of drug Z—it is about opening up associations that strengthen the understanding of the topic. This process is what we previously described as the fusion of horizons; in this study specifically, both the researcher and the participant enter the conversation with their own horizon, and out of this, both will leave with their own new expanded horizon of understanding. However, we are not dismissing the old horizons; this interaction (fusion) is meant to constitute a new conversation, in which the participant's voice is replaced by text and then brought back into the world through an interpretation (104,106,113). This process is centered around an "openness to meaning" which allows me as a researcher to move from an all-too-familiar (pre-understanding, prejudices, and fore-conceptions), to allow for what is different. It is important to understand then, that the findings reported in this study will never be a finitude—or what in quantitative studies would be referred to as a scientific reproducible truth; they are always provisional and open to alternate interpretations (113).

As previously mentioned, the analysis requires us to ask interpretive questions such as: What is the person trying to tell me? Am I noticing something that the participants are unaware of? With every question and every interpretation, what once was unfamiliar, strange, or anomalous, can be better understood—neither remains unaffected, and both are transformed, fusing the two horizons together (113). An analogy to represent this analysis process is the peeling of an orange—the act of which lets us discover the interior patterns or delicate structure that is previously hidden. Because of the exploratory nature of this study, no rigorous measurement tools or method—such as category coding, or line-by-line coding—is used. In identifying the "significance," I depended on teamwork and collaboration—this supplies rigor as it tests out the worth of my interpretation in dialogue with others (supervisor and fellow master student). Based on Gadamer's fusion of horizon (1957), my supervisor with 20 plus-years of study and research in phenomenology and hermeneutics, conceptualized and separated the process into 3 steps: *deconstruction, interpretation, and reconstruction.* He finds this process useful for his own thinking and research but also to assist graduate students such as myself to step into the previously unknown and vast world of interpretive scholarship.

1) The *deconstruction* process refers to the act of reading and re-reading interviews, both independently and together.
2) In interpreting our transcript, passages of text linked by a common theme were identified and grouped into categories that were deemed appropriate in framing patients' perspectives around chronic pain. As previously mentioned, we put on our interpretative lens and ask: What is the person trying to tell me? Am I noticing something that the participants are unaware of? What do their words tell me about their mental and emotional state? We make comments on the use of language, of pauses, and of the explicit expression of emotions (e.g., tears, laughter). We also note patterns and words used repeatedly throughout the interviews, as well as contradictions between what participants said in the beginning and at the end of interview.
3) The last step is the act of *reconstructing*. Here, quotes are presented in a way that shows the relationships and insights collected from the interpretation phase. As discussed in the results section, I have categorized the results obtained into 3 main themes: "I am Who I am", "But What if my Pain is Invisible?", and "Metamorphosis as an Act of Normalization: There is More."

As findings were deconstructed and reconstructed, thorough readings and re-readings of the transcripts were repeated to ensure that our interpretation remains in context with our research topic. The constant repetition and review ensured that the data was read thoroughly, which allowed us to consider different avenues that might have been initially missed and enhance our understanding of the topic. Literature review from multiple disciplines outside of chronic pain —such as philosophy and narrative medical journalism were examined to find meaning in the history, context, and language of the topic. This method of analysis does not claim to be a source of validation, nor does it serve to confirm that the interpretations presented in the next chapter is *the* right one. As such, the findings in the next chapter should not be seen as a conclusion—but rather, as the recognition of voice and experience, and of human life in the midst of suffering.

Trustworthiness of the Research

Madison articulated that the rigour of interpretive research be judged on its coherence, comprehensiveness, appropriateness, and potential (115); or as explained by Moules, its credibility and trustworthiness should be judged upon its ability to present a topic in a way where the researched human experience be understood “from the inside out and the outside in” (106). This study was intended to be explorative and as such, was performed while embracing the *possibility of anything.* As described by Madison, “when we opt for a given interpretive work, we do not do so because we know it to be true… but because we believe it to be the best…” (106, 115). By this perspective, we are then true to our work if, “in our rewriting and retellings, we are able to preserve and take up, in a more meaning-giving way, the greater subtlety of the “*truth of our past*” – which, in this case, are the data that we collected and use as base for our interpretation. Taking up the principles established by Madison (1998), my supervisor and I centered the veracity of this study around contextuality—making sure that the recognition of themes and discussions were not written and read in a way outside of the context from which it emerged from (115). Another is penetration—which refers to the capacity of the work to make an impact. When presented to the adolescent pain clinic at Montreal Children’s, it was decided that our findings and patient accounts (which will continue to remain anonymous) will be reworked and included as part of the continuing medical education credits for physicians. Another tenet we relied on was comprehensiveness—the understanding that we need to speak to the topic and dig deeply enough as to expand our understanding of the topic. The comprehensiveness of my work was thoughtful and extensive, as detailed through repeated audit trails, journaling, and interpretive notes. In addition to this, my supervisor, who is well versed and experienced in the topic of chronic pain and interpretative phenomenology reviewed my work on a weekly basis. This ensured that I had the appropriate feedback I need regarding the quality of my work and its appropriateness in relation to the research topic.

Ethical Considerations

This research project was submitted to the McGill Research Ethics Board and the Montreal Children’s Hospital Review Board for approval. Principles of ethical research were addressed through an ethics review board examination of informed consent of participants, privacy and confidentiality, conflict of interest, and inclusion in research. The consent form

(Appendix C) and consent process included an overview of the inquiry, a statement of commitment to participate in a research interview, an explanation of the voluntary nature of participation and ability to withdraw consent at any time, and a description of how confidentiality was addressed throughout the research process.

Per Quebec law, any person below the age of 15 has to obtain the permission of a caregiver before participating in any research studies. To respect this, the consent form has a separate line for a caregiver's signature. The participant provided both an oral and written consent before participating in the interviews. Two girls (*Myriam & Samantha) arrived with their mothers for the interview and wished them to be included. This request was honoured, and both the daughters and mothers signed consent forms.

Consent and Confidentiality

At the time of meeting with potential participants, informed consent was obtained. This included consent for audiotaping the interviews, as well as for publication and presentation of the research findings (Appendix C). Transcription work was equally divided between Rachel Swzimer and I. Translation from French to English, if necessary, was done by Rachel Swzimer, a native Montreal resident. This was the case for two of our participants (*Julie & Samantha), who used both English and French during their interviews. Transcription analysis were done together with Rachel Swzimer and Dr. Richard Hovey. Consent forms were kept in a locked drawer in my supervisor's office, and were the only items containing participant names or study ID numbers. Transcripts, documentation, and field notes related to the research were kept in a locked filing cabinet. All electronic versions of data were maintained on a password-protected computer. The audio-recordings were destroyed after being transcribed. The research transcriptions will be destroyed 7 years after the completion of this research project.

Participants' names were replaced with aliases in the transcripts. These aliases will also be used in any future writing or publications. Any direct quotes from transcripts used for publication will be further screened to limit identifying information that could lend to the participants' identification. It is however possible that despite every effort, the participants and others may recognize the participant's story if they are to read it. Participants were made aware of this risk.

Should a participant decide to withdraw from the study during the interview, it was agreed upon that the interview would be stopped, and the recording deleted immediately. This did not happen, and all participant interviews were utilized in our analysis and interpretations.

Potential Harm

While no harm was expected from this research study, measures were taken to prepare for its possibility should it arise. Should a potential for harm to self or others be revealed, the participants were informed in the consent form, that the appropriate medical staff be informed. In our context, we had an on-call psychologist who specializes in adolescent chronic pain, who was available for consult immediately, if needed. If during or following the interviews, a participant indicated they were in need of further counseling support, they would have been referred to this said individual. This was important to plan, especially since participants were entering into conversations that might be overwhelming or distressing. Recollecting these experiences might have brought forward uncomfortable emotions, and as such it was necessary for us to be cognizant of this potential risk. None of the participants indicated, during or following the interviews, that they were distressed. As such, no further follow-up counseling support was required. Several participants specified that the opportunity to share their experiences was helpful in reviewing their values and beliefs regarding their lived experience as a chronic pain sufferer. Prior research had also noted this, revealing how the opportunity to discuss these experiences, particularly related to loss and grief, beneficial, helpful, and even cathartic in dealing with the emotional sequelae (141).

Chapter Three: Introduction of the Participants

Eight adolescent girls living with chronic pain agreed to participate in this research study, met the inclusion criteria, and were interviewed. To ensure that their confidentiality is respected, only relevant data pertaining to their pain description is offered. No medical records were reviewed and as such, the accuracy of the medical diagnoses mentioned or discussed in this section cannot be commented upon. The pain intensity, duration, and consequences are subjective as they are self-reported by the participants interviewed for this study. In addition, participants were diagnosed, and or, misdiagnosed multiple times before being admitted to the Montreal Children's Hospital, adding further complexity to the estimation of said pain intensity and duration. Based on their accounts however, it can be said that the average duration of pain is 4.5 years, with the most common symptoms being pain in the upper and mid extremity of the body such as the head, the stomach, and the back. Written in this section are brief introductions of my participants, something I find necessary to include as it provides the reader with a context to base the quotes (results) around and understand why I interpret the quotes (results) the way I did. As this is an interpretative study, the reader can also—if he or she desires—reflect on and interpret the quotes through their own lens. The upcoming descriptions will provide the materials for the reader to do so. To protect the privacy of my participants, they are listed under the aliases of Katie, Amy, Melissa, Myriam, Julie, Helena, Cassey, and Samantha.

Katie

Like most dancers, Katie had suffered from multiple injuries. She was used to the sensation of minor aches from twisting her ankles and wrist but was by no means prepared for the pain that she experienced with her knees. At one point she had to rely on a walker. Up until then, Katie was an accomplished dancer performing competitively with a team. She returned to dancing after a year of rehabilitation; however, she found that the pain persisted even without any injuries. She realized then that she was no longer going to be able to perform at the level she once did and stopped dancing altogether. She had since turned to music and painting, both of which she referred to as her "bubble of creativity." She credited her optimistic mindset, which she had finessed ironically through her experience with chronic pain. Despite the pain, she expressed her gratefulness and described herself lucky for the support she found in her family and understanding group of friends. Katie was tearful towards the end of the interview when she realized that she had just relived the early days of her diagnosis.

Amy

Amy was born into a life of adventure. Her father is a documentary filmmaker, so she travels and spends her time abroad several months at a time. She contracted Giardia, a stomach parasite, while on a canoeing trip. She went to her family physician, only to be sent home without any diagnostic testing or prescription. When she was finally correctly diagnosed, she was prescribed two rounds of antibiotics, both of which failed to properly eradicate the infection. Her late diagnosis, as well as her weakened immune system lead her to contract 2 more parasitic infections, which eventually lead to a condition known as small intestinal bacterial overgrowth. The constant trauma left her with abdominal sensitivity and chronic pain, which gets triggered even with the lightest touch; at her worst, a soft touch was enough to cause her to jerk away. Amy’s physiotherapist had to gently rub her abdominal area with different textures and fabrics to re-train her tactility. She is now in a place where she can enjoy her favourite physical activities with minimal discomfort. Amy is an optimistic individual and as such, is described by the chronic pain team as the ideal chronic pain patient.

Melissa

Melissa is a soccer player who, before her chronic pain, was playing at the highest level for her age group. Her dream was to play for the Quebec provincial team. At age 11, she woke up paralyzed. The physicians at the hospital could not explain her condition—she was told that she suffered from a lumbar sprain and was sent home. She had trouble walking and for a whole year, went through rehabilitation to improve her gait. After one year of rehabilitation, she continued to pursue soccer and tried out for the provincial team Les Jeux de Quebec. She was on the final roster before being cut due to her sudden onset of chronic pain, which impaired her ability to run. Melissa also suffers from migraines, which causes her to miss many school days. Before her migraines, she was an avid saxophone and piano player, often trusted with solos and featurettes. Melissa was visibly trying to hold her emotions in, trying hard not to appear tearful. Her mother was present during the interview and spoke up on behalf of her daughter when she saw that Melissa was too emotional to speak.

Myriam

Myriam was diagnosed with spondylitis, a hairline fracture on her L4. She suffered from multiple misdiagnoses, which eventually worsened her condition. She is now on “phase two” of spondylitis and is unsure of how to help her condition. Her pain is constant and stops her from participating in sports. Before her pain, Myriam was an active individual, participating in volleyball and basketball. She had to wear a full body brace for 7 weeks, which affected her confidence. She admitted that it is harder for her to engage with her friends since they can no longer participate in volleyball together. She is aware of the many precautions she has to take just to engage in everyday activities and wishes that she does not have to. She has since started singing and painting, something that was encouraged by her parents to fill the void left from no longer being able to participate in physical activities. Her mother was in the room and repeatedly applauded her for her bravery and perseverance.

Julie

Julie is an athletic adolescent, participating in many sports such as hockey, flag football, running, and yoga. She had complained of pain on her feet and knees for a while, which caught the attention of her physician. They suspected that it to be juvenile arthritis, but no testing was conclusive. This past year in November, the pain spread to her arms and hands, locking them in a fist position. Despite this, she continues to play hockey. Her coach is very understanding and helps fit her into her gear. She is maintaining her activities as best as she can, although she worries that it will be “impossible to play,” since her pain continues to persist despite medical efforts. She chooses to remain optimistic and credits this mindset from years of playing hockey. She says that when she is in a good mental state, she plays better. She takes this mindset and translate it to her everyday life. She is, however, disappointed that she is not able to get a definitive diagnosis with a management plan. She is very appreciative of her mom, who keeps her company even when she is at her worst. She wants to let other fellow chronic pain sufferers know that pain should not stop them from living their best lives.

Helena

Helena is 17 years old and has been suffering from chronic pain for the past 7 years. Her pain started after fracturing her ankle. The fracture healed but the pain persisted, gradually moving up to her knees and wrist. Her musculoskeletal pain is now manageable, but she suffers from intense migraines and requires a nerve block intervention every few months. Before her pain, Helena was active in soccer and rugby. She was disappointed when she realized that she would no longer be able to play rugby. Helena's dream was to play for the Women's Irish, which she qualified for at the age of 16 because of her strength and naturally larger stature. During the interview, her and her mom repeatedly expressed their frustration over the lack of empathy from the medical community and her school. Each time she visits the emergency department, she is told that there is nothing to be done and that she should seek the care of her family physician. In school, her teachers continue to question the legitimacy of her pain. While she is upset over the pain that has taken over her body, she said that the experience helped her build a stronger character. She now stands up for other bullied kids; her dream is to one day be a special education teacher.

Cassey

Cassey has been dealt a hard card in life. She does not have the best relationship with her parents and has been living on her own since the age of 14. She was also raped at age 12, which not only scarred her emotionally, but also left her with chronic pelvic pain. Her pain is concentrated in the pelvic region but would spread towards her lower back when she sits or stand for long periods of time. She has also been diagnosed with borderline personality disorder. Before getting nerve block treatments at the pain clinic, she was not able to attend school or work on a regular basis. Her co-workers and classmates question her absences and label her as a "troubled kid." Cassey admits that she has lost hope in ever being pain-free, but she makes the constant effort to live each day with a positive mindset. She motivates herself to do her rehabilitation exercises and practices breathing techniques on a regular basis. She does not yet have a definitive diagnosis but is grateful of all the treatments that have given her a better quality of life. She is worried, however, about her upcoming birthday. Being 18 means that she will no longer qualify for the services that are available at the Montreal Children's Hospital.

Samantha

Samantha has been suffering from chronic pain for the past 4 years. She was active in gymnastics before her pain. She concentrates her efforts in her education but is frustrated as she has to miss several days at a time because of her chronic pain. Her and her mother are frustrated over the lack of empathy from her school administration, who does not seem to acknowledge her pain. She is aware that she has matured quicker because of her pain and shares that she does not relate to other girls her age. Her sole focus right now is building a positive attitude, getting better, and being happy. She had recently met with a surgeon who gave her a definitive diagnosis—one that surgery can potentially fix. As such, she is more motivated than ever to get better. Samantha was tearful throughout her interview. She understands the sacrifices that her single mother has made for her and is appreciative of everything that her mother has done for her. Samantha's mother was present during the interview and repeatedly expressed how proud she is of her 15-year old daughter's perseverance.

Chapter Four: Findings

I Am who I Say I Am

Individuals living with chronic pain are aware of the limitations inherent in their prescribed treatments (51, 92-94). Even if they are to receive the best care, their pain cannot be eliminated—only subtly minimized; as it turns out, our current medical literature is simply not equipped to provide them with the relief that they seek (79). Attention in chronic pain management therefore revolves around the psychological and emotional state of the suffering individual: the greater the optimism, the better the livelihood. Indeed, chronic pain has a psychological element— dependence on medications and caregivers, anxiety, as well as social isolation all act in synergy to rob the sufferer of their individuality (92-94). This sense of interrupted life was well reflected in our interviews; for instance, all of the participants repeatedly used phrases with negative connotations such as "*couldn't do*" and "*had to stop*" to voice their loss of autonomy and pessimism.

> *Well honestly after my chronic pain started, I just didn't have the motivation to do anything, my pain got so, so, so bad. I couldn't work, I couldn't go see my friends, I couldn't do anything. There are things you just can't do. The pain makes me very tired." (Cassey)*

Interestingly, instead of describing the personal and unique attributes that made them, them, the participants centered their self-introduction around their pain. While the hospital setting and the nature of the interviews might prompt them to react in such a manner, their closed posture, tearful eyes, as well as their overall feeble demeanor suggest otherwise. They would start with a brief description of simple demographic factors such as their age and their grade at school, before giving us a detailed history and trajectory of their pain.

> *I got my ankle twisted twice, my wrist got twisted, I got my knee problem back because I was walking with the walker and this went on and on for a year. And then after, when everything was fine, I started doing sports again and I realized that I was still in pain even though I was okay… She first thought it was arthritis so we went to see a*

> *rheumatologist and then she said that it was not that so she referred us here. So that's when I got my diagnosis of yeah… this is me basically. (Katie)*

One participant even started her introduction with this declarative sentence: *"I was diagnosed with spondylitis."* Another participant did not remember life outside the confines of her pain. For her, life seems to be a constant cycle of school, medical appointments, and emergency room visits.

> *I study in college, I study specialized education… I've been coming to this department of chronic pain for 1.5 years. My pain pretty much started when I was like 12. I don't really know what else to say. (Cassey)*

It was only when the participants were prompted with keywords such as hobbies or free time, that they began to give us glimpses of their unique attributes. Even then, the focus was always on the dichotomy of life before chronic pain, and life after. When pain reached its peak, some goals became unattainable; as a result, plans were interrupted and goals were dismissed, no matter how important. For our more athletic participants, the failure to engage competitively in their sports has detrimental effects—because they no longer meet the athletic standards that they had previously impose on themselves, they view themselves as less valid, and ultimately, as flawed and inferior. As a result, they separate themselves into two entities—their *actual* self and their *ideal* self.

> *Soccer was like my life. I was doing it every day. And when I stopped, I kind of felt empty. I was in the soccer team going to regionals and I had to stop, and I was this far from being in Les Jeux de Quebec. I was this close to being in the selection and then I just couldn't run anymore so I was cut. (Melissa)*

The dichotomy between life before chronic pain and life after was further stressed through the context in which they use the word normal. When asked how life will change if chronic pain were to completely disappear, participants replied with the following accounts:

> *Basically, you know, if I want to go out with my friends, I don't need to worry about the fact that am I going to be able to. And, the little stuff like that. Like being a normal teenager… I've never really been a normal teenager. (Cassey)*

> *Just living like a normal life, like to be able to go out with my friends, to be able to work (Samantha).*

This sentiment was also echoed by our participants' parents. When one participant was asked of the things she have had to give up because of her pain, her mother instantaneously said: "everything," mentioning how her daughter can no longer run or jump *"like a normal person."* As seen, these abilities are not exclusive to athletic or musical talents; in fact, they refer to basic activities of daily living that *"people don't really think about"* such as *"doing up [one's] jacket or taking notes in class." (Julie)* What was once taken-for -granted now become a bullet point on a list of abilities to re-learn.

> *I cannot really write, so I have a computer. And even for my exams it's just really difficult cause I can just have a pen in my hand and it's uncomfortable and so writing is really difficult. And like I said, stupid stuff that people don't really think about like washing your hair, going up and down the stairs, just having to bring some stuff with you at school like your binders and stuff, I have a backpack because I cannot bring them with my hands. (Katie)*

It is explicit through their accounts that the participants experience pain through the absence of autonomy. This occurrence is also observed by Hans-Georg Gadamer. In his book *The Enigma of Health*, he wrote of how in Germany, doctors will begin a medical consult by asking "Na, wo fehlt's denn?", or "What are you lacking?" Similarly, when one is unwell, one will say "Es fehlt mir etwas"- literally, "I am lacking in something" (116). For our participants, the uncertainty surrounding their pain serves as a constant reminder of their current condition, which in turn leads to insecurity (116). Phenomenologist Havi Carel refers to this phase of one's pain experience as the stage of "*bodily doubt*", when one starts to mistrust one's own bodily capacities and capabilities (117, 118). As a result, anxiety and a sense of doom become frequent visitors in the participants' emotional life. One participant highlights the nature of this psychological distress when she differentiates her pain into two categories: physical and psychological. This participant has pain so unbearable that she cannot sit down for long periods of time, yet she attests to how the physical pain is only secondary to the psychological burden that chronic pain has imposed on her. With a sincere face, she said:

> *The pain is really unbearable but the psychological pain I get from it is … it's crazy. Sometimes it gets so bad that I would rather die than deal with that. (Cassey)*

Another participant said:

> *Well, you know, I am focused on what I'm doing but there's still this little voice in the back of my head. You know, I have a lot of difficulties shutting down my brain. I simply cannot. And, ya, so, I am in my own bubble I'm focused but like I said there's always going to be this little voice in the back of my head… and like saying "be careful", "don't do it too much, cause you're going to be in pain" and I'm like "no, I'm fine, see? I'm doing it? There's no pain" like "no, be careful, stop it!" You know, so yea. (Katie)*

As I heard, my participants live a life of constant fear and worry: their minds scramble, and they scramble loudly. A figurative analogy would be the inner gears of manufacturing machines—constantly grinding to fit together. Their worrying serves as fuel that makes the gears grind even louder and faster, creating a positive feedback loop that restricts them from adopting a positive mindset. As suggested by Bury in 1982, chronic pain should not be seen as a mere assault to the physical body, but as a *disruptive event* that leads to social disadvantage and oppression (119). Chronic pain not only disrupts the structures of everyday living, it also breaches what he refers to as the *common sense boundaries* (119). These boundaries are what protects taken-for-granted every day activities such as walking with ease and dressing one's self; the inability to perform these routinized activities are what leads one to feel *disabled*—or as our participants call themselves, "*not normal.*"

Husserl described this phenomenon as the loss of *practical* confidence (118). For context, let us take into consideration our participant Melissa. In the light of her diagnosis, she starts to feel deficient. Negative thoughts occupy her mind and she feels as if she will never be able to play soccer to the level that she was once able to. As a result, the soccer field feels different—if before it was homelike and dependable, now it is daunting and unpredictable. As a result, her actions become less spontaneous and her words less fluid and feebler. We can thus observe why my participants stress their dialogue around the dichotomy of life *before* chronic pain and life *after*; their sense of being "at home" in the world, is now lost. In the words of disability scholar Liz Crow, "a person's functional limitations are the root *cause* of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure" (120). However, as we have learned, pain that is chronic in nature cannot necessarily be cured, it can only be managed. It is exactly for this reason that chronic pain leads to feelings of exclusion, frustration, and grief. As seen, my participants expressed a sense of interrupted life and repeatedly use phrases such as "*couldn't do*" and "*had to stop*" to voice their loss of autonomy, which in turn leads to feelings of helplessness.

As explained by Brown and Harris, this emotion occurs *at the juncture of plans and purposes,* during which the chances of a likely outcome of an event occurring—in this case their ambitions, become profoundly changed (118). Suddenly, previous ambitions become unattainable; as a result, plans are interrupted and goals are dismissed, no matter how important they are to the individual. Through this, my participants were forced to reflect on their transition from a functional, pain-free body—i.e., a body which *passes them by in silence,* to one that is in a state of unexplainable disequilibrium (121,122). It is through this act of hard reflection, as we will later see, that my participants are able to shift their narrative away from *foreclosure*—the idea that one's life has effectively ended, to that of *reconciliation*, *normalization*, *metamorphosis*, and new beginnings.

But What If my Pain is Invisible?

The mental switch from foreclosure to normalization occurs during their time of self-reflection; during this time, our participants reconcile with their condition, adjust to life with pain and search for new meaning in life. It is also during this time that our participants realized the need to reach out to family and friends for social support—but what happens when the individual's own environment does not support their recovery? The community in which one situates themselves in is important as it can either act as a) a system of support, or b) a place of negative judgement and labelling. Unfortunately, there seems to be an impression within the general public that pain needs to be visibly demonstrated before it is acknowledged. In the absence of material culture such as a cast, or crutches, pain does not seem to be taken seriously. As a matter of fact, many of our participants recall being referred to as *"lazy"* by their peers.

> *When you look at my physically you can't tell that I have issues like I don't have a cast on, I don't have a concussion that I know about, so they kind of like ohhh… she is one of those girls who is trying to avoid activity with like saying she is on her menstruation cycle or she has a headache or something like that ummmm… and I try to explain to them no, I have chronic pain but it's kind of like a really long explanation they don't really understand what is happening. (Amy)*

On the other hand, her friend who embodies the physical representation of what it means to be ill, receives better understanding from her peers.

> *One of my best friends Maggie, she tore her ACL and so it was a major operation to get it all back together it was a torn meniscus and torn ACL. So she is gone through like a lot so she can't participate in gym either unless she like wears a great big brace which she sometimes does, so they are all very understanding and very knowledgeable. (Amy)*

This attitude is unfortunately also carried by school professionals. One participant mentioned how her teachers had accused her of faking her pain in order to skip a class. It was not until the teacher saw the participant's hand swell up before her very eyes that she finally believed her.

> *They don't see the physical, if they don't see it, there is no pain, so the one day, she kept telling them, my wrist is really sore but they wouldn't let her leave her, and then one day, the teacher came and her arm and wrist were swollen and she dropped her bag and she was like oooh you are really right eh… unless they see the physical, the don't believe it…her teacher is telling her well we know you are doing it cause she doesn't like shop so no I am doing it a because I don't want to be here yes and because I am in pain. (Helena)*

It does not help that they are the subject of other's gaze and conversation. Often times, participants would hear questions such as *"what is that"*, *"why are you like that"*, or *"why aren't you in a hospital,"* and *"why are you here,"* and even piercing orders such as *"go home."*

> *Yea but people don't understand. Now I can go up the stairs but limping, I go slowly. Sometimes people ask me what I am doing and I just say oh I hurt my foot. (Samantha)*

She even mentioned how she is grateful to be enrolled in a small school.

> *Everyone knows each other- I think it's better because there are fewer people, fewer people that I need to explain myself to. If I was in a regular school with 1000 people, it would be harder…more people looking and asking questions. (Samantha)*

School, a place intended to shape its students' characters and instill positive values such as curiosity, achievement, benevolence, and citizenship, ends up being a place of judgement and labelling.

> *All the time, they were always asking for notes, they were always wondering why I was skipping school. They thought that I was just like a troubled kid and didn't want to go to school, but it's just that honestly when my pain got so bad I was going in and out of emergency, I had appointments here, I was missing school like 3-4 times a week, I would literally go one time a week. It was really hard because NO ONE understood. Even when I tried to sit down and explain it, no one understand. Well not that no one really cared but that no one really understood. (Cassey)*

One participant was even called in to the Principal's office for questioning despite handing him a doctor's note at the beginning of the year.

> *He is like I heard that you have been skipping class I am like what and he is like you have been skipping class like no I haven't, yea you have to go down to the guidance counsellor. I am like no that's because of my pain. And he is like ok you are going to need a doctor's note and I was like you already have a doctor's note but I will go get you another one specifically saying like every once in a while I will have to skip 15 minutes. So I mean it's not as obvious as like broken foot where like of course you can leave 5 minutes before class to get to your next class so you don't to have to hustle of the hallways. (Amy)*

Heartbroken and tearful, one participant told us of the message she wishes to convey to her school board:

> *Take psychological effect seriously because one day…people habituate to living with chronic pain like anything else, like now I am habituated to living with a 9/10. So I can seem fine but don't think that if this happens during an exam that I don't feel good that you should not believe me and that I just don't want to write the test. (Julie)*

This is why it is important to acknowledge the environment that our participants are in. Relationships of any kind—even short-lived, every day interactions—can serve to mold one's experience and attitudes (37). Unfortunately, this lack of empathy is also present within the medical community. Below is an account of a participant who was told that her pain was *"just a concussion."* Her voice was neglected, and concussion became an easy response by her medical professional—a default diagnosis.

> *They thought it was a concussion because I had a little shot from a snowball to my head and they said – this is it, it's that. But it lasted 3 months so for a snowball…like all the doctors kept saying it must be a concussion, but it was a snowball, there was no ice in it. It was just snow on my head and I didn't feel any pain, but it started only a half hour after it, the same day so they said this is it. And then they stopped – I felt like they stopped – looking for other things. (Melissa)*

> *Like the emergency as soon as we say that we deal with chronic pain, they stop treating us, they tell us to go home, go talk to your family doctor that was it that was all same thing, you have chronic pain, deal with them don't deal with us, we cannot do anything for you. (Helena)*

Unfortunately, this negligence is helping perpetuate the already dangerous opioid epidemic currently sweeping the nation.

> *You know her doctor tried to put her on Amorcet, which could have killed her. As soon as I brought it to Jean Coutou [pharmacy] they were like yea we are not going to give her any of that that's very dangerous of her. They give her morphine and then the chronic pain doctors were like no never always see us before you try any new medication because we are the ones that have to help. (Helena's mother)*

The negligence associated with the adult side of chronic pain care is well acknowledged amongst our participants. In fact, a pressing concern across our participants is having to leave behind the multidisciplinary care they are currently receiving at the Montreal Children's Hospital when they finally turn 18 years of age.

> *It's kind of scary because I've been coming here my whole life pretty much and all of sudden they find my pain, they find what the problem is, they treat me, they help me, and now it's going to completely go away, and it's going to go to the adult side. And that really freaks me out because I don't know if they are going to understand me the way that Dr. Ingelmo did. (Cassey)*

As previously discussed, the barriers to successful chronic pain outcome is the organization and administration of chronic pain care itself, which is largely based around the traditional model of acute care (45,46). A 2011 report on personalized pain therapy reported that only 32.5% of Canadian medical students receive an average of only 16 hours of formal instruction on chronic pain; up to this day, minimal to no changes have been made to better cater the chronic pain in Canada (123). A 2017 report looking at content analysis of chronic pain content in across 3 medical schools in Ontario reported how one school's medical curricula tend to include pain as a symptom of other diseases and therefore spread pain content across the curriculum in general required courses such as pharmacology, neuroanatomy, and neurophysiology, resulting in an inefficient education of the content, such that pain content has no "home" (123). All three curricula were found to contain negative pain beliefs that characterize pain patients as difficult, overwhelming, and unrewarding to work with (123). In fact, two of the three medical schools studied here do not have a pain curriculum (123). A recent article addressing the chronic pain crisis in Canada mentioned how veterinary schools in Canada provided six times the number of hours of pain-management training than in medical and nursing schools (123). Unfortunately, this negligence may be contributing to the opioid epidemic (124,125). Every day in Canada, 11 people die of an opioid overdose, most of which are a result of the increasing misuse of opioid prescription (126). Indeed, our health care system here in Canada is not designed to treat chronicity; it is specialty driven, meant to manage crises such as organ transplants and motor vehicle traumas, leaving millions living with complex chronic pain illnesses and multiple comorbidities to suffer in silence (127,128). What remains invisible to others continue to overwhelm, eventually leading to feelings of helplessness. chronic pain as such can be regarded as a critical situation—a form of body alienation or betrayal, requiring the individual to rethink their own biography (129). Accordingly, if we are to peek into the minds of an individual suffering from chronic pain, we would see a disrupted explanatory framework, with questions such as "why me?" or "why now" repeated over and through—questions of which, have no sound explanation, especially given the uncertainty and ambiguous nature of chronic pain. The combination of diagnostic vacuum and everyday reminder of their deteriorating body eventually forces the individual to accept their condition and learn how to tolerate and put up with the effects of chronic pain. The next chapter will explore this process of normalizing—or as I view it the act of metamorphosis.

Normalizing as an Act of Metamorphosis: There is More

Contrary to current developmental literature, the transition into adulthood in adolescents living with chronic pain is not delayed, it is streamlined and enhanced (92). This is in part due to the fortitude they gained as an outcome of their adaptation efforts. As mentioned, the current healthcare system is not yet able to rightfully serve our participants; for the most part, our participants are left to take on their own burden of care (127,128). In doing this, our participants have to engage in a steep learning curve. While their peers are "*learning how to deal with emotions and relationships and this and that,*" *(Myriam)* they had to learned how to communicate with health care professionals, find coping mechanisms to manage unexplainable pain flare ups, and fight for equality and proper accommodations at school. The pressure they put on themselves to achieve recovery milestones and perform tasks eventually lead to pressure and a sense of urgency. Frantically Myriam recalled:

> *[I am] trying to figure out what I have exactly. Because it was kind of stressful. You know, you're in pain and you're like can I do things? Can I not do things? What can I do? Is there something? (Myriam)*

Because of this sense of urgency, my participants view other activities associated with adolescence as "*superficial*," referring to makeup as "*stupid things*."

> *Well I just skipped that whole superficial phase where I am material and wear a lot of makeup. All my friends are kind of going through it and I'm not just – like those are not necessary. You know? You do not need them to survive. Foster personal growth faster. And so I think that I am more mature and that I got mature way faster because of that and it's kind of said because it's not like I had the choice. It's not like I was like "I want to be an adult" it's like – there, and just be an adult, and just be more mature. (Katie)*

This enhanced maturity is also acknowledged by several mothers:

> *Listen she is brave, umm, she has got a strong character I means she has been through thick and thin misdiagnosed with something else at another hospital that's why we are not there anymore… and there were big repercussions to that you know and she came through and she was like going on and on you know and she still you know… she is a strong character thankfully because umm …you know and dealing on a daily basis with all the issues at school… you know wearing that brace like you said, it takes a toll on your confidence … you know and your emotional… you know. (Myriam's mother)*
>
> *I think it's more an example of the person she is at 15 years old. I'm so proud because [emotional and crying] a lot of teenagers who have chronic pain that we cannot see or talk about, they don't cope with it well. And yes, we are going to cry like this about it but I am so proud that she is doing good in school, she has friends, but she copes with that pain for 4 years… And sometimes I feel like I cannot help her, I'm doing my best, and that's it. But I'm proud. We can say I have a teenager here that copes with a lot - for 4 years - with the pain that she is still going through and she doesn't have dark thoughts that you can see from other people, she doesn't do drugs… (Samantha's mother)*

Unfortunately, this can lead to a sense of entitlement—while my participants do not mean to dismiss the pain of others, living with chronic pain has led some to be more intolerant towards other's behaviours. Katie mentioned how it *"bothers"* her that her friends find satisfaction in taking *"selfies,"* emphasizing several times over the course of the interview that it is *"not an important thing"* in life. In short, others' interests—and even problems, are seen to be less pressing and unworthy of attention. Below is an account of a Samantha who uses the word *"complainer"* to separate herself from her peers.

> *…more mature than other people my age… like if they have a hurt arm because of a bruise they are always complaining. I am not complaining about my feet because I'm not a complainer. But others do. (Samantha)*

Similarly, Cassey shared that she views her peers as immature:

> *Like I feel, honestly like when I look at other high school kids like especially back then I feel like they are immature 5-year old and I felt like I have the mindset of a 40-year old with like 3 kids. (Cassey)*

However, despite this perceived sense of entitlement, our participants seem to show no signs of attention seeking behaviour. One participant encapsulated it best when she said: *"I am here trying to figure out how to help myself."* In essence, they have "*no choice"* but to build a new ideal self and *morph* into it. This was evident throughout the interviews during which I saw—live, the concept of *normalizing* in action. As defined in health literature, normalizing is the ability to integrate something into one's daily lives, making that one entity a new part of themselves. The act of normalizing is well acknowledged by philosopher Georg Friedrich Hegel, who describes it as the natural human desire to be at home with themselves—free of anxiety and secure from threats of danger (116). In my participant's case, normalizing and accepting their condition is an act of breaking open from what is oppressive and constricting. This need to *morph* seems to be propelled by the imagery of a full life ahead—the idea that *there is more* to life than their current state. One participant was even seen to be aggressive with herself, presenting her choices as an ultimatum:

> *Well it was basically like, that's how things are, there's nothing you can do about it. So what you can control, try to control it the best way you can and how you want to control it. You know? Because my pain – I cannot control my pain. I control what I do and how I deal with it. (Julie)*

For my participants, it is the prospect of an unfulfilled life—and not their pain, that poses the most difficult challenge.

> *Yea I mean I kind of just have to move on with my pain, like I am not going to mope about it, it is what it is, I am going to try and get better, I want to get better there is stuff I want to do, things I want to see. (Amy)*

> *There is a lot of things that I like I plan my future you know*, like I have to start college soon like right after so like it's harder to think like what could I do and what do I want to do and like I don't know like obviously career wise like a big thing do I want to stay here do I want to move out, it's a big thing cause that limits a bit because I want to explore more like I want to figure out the future more and like figure more of the world to know what I want to do. (Myriam)

> *I am like panicking about my future I am like OMG cause since it's like pelvic pain, I am telling myself maybe I won't have kids you know like it just, it just brought my mindset to a very dark place. (Cassey)*

In realizing this, my participants seem to adopt a strategy known in psychology as stress inoculation, in which individuals deliberately take on increasingly difficult challenges so that they can gradually learn to handle higher levels of stress—even if it means having to find comfort in the discomfort (130). As explained by German philosopher Friedrich Nietzsche, "He who has a *why* to live for can bear almost any *how*" (131). For our participants, stress inoculation seems to be synonymous with exploring the limits of their *new* body, which they seem to seamlessly integrate into their everyday lives. For example, instead of passively walking her dog, one participant made it into an exercise that would promote active recovery. While there is no guarantee for complete recovery, our participant is able to feel more confident in her ability to manage her pain, which results in a new more positive mindset.

> *I am running but maybe it's for 9-12 seconds and then I stop but like congratulate my dog and then its break and then we will do it again so like I am doing things that will*

> *hopefully accustom my stomach so it's been getting better and I have more tolerance I can do more stuff I have had less bad days. (Amy)*

This new positive mindset presents my participants with a new sense of hope and is well reflected through their healthy lifestyle—which excludes smoking and the recreational use of dangerous substances. One participant confirmed this principle when she said: *"I know that I was obligated to have a better life, so I started sleeping good, drinking more water, doing exercise"* (Samantha). One parent mentioned just how proud she is of her daughter for not engaging in drug use, even when she is surrounded by influence.

> *Do you know how many people I know tell her to smoke a joint like migraines will go away my brother too my brother is straight up let her smoke a joint…like I brag because she is a good kid. (Helena's mother)*

Another component of *metamorphosis* is finding replacement activities to fill the void left by earlier activities. Most rely on art as a form of cathartic relief (132,133). Through singing, photography, and painting, our participants are able to transport themselves to their own "*bubble*"—a safe refuge where they can organically express their emotions and channel their *ideal self*. Here the *ideal self* is given a new definition: it is no longer about achieving prestige in their chosen field, it is about being at peace with their limitations and marching on.

> *When I listen to music I get into my own bubble and I just go with the music. I sing the lyrics and I move my body to the music and it just helps me to get my mind off the pain. And same with painting. I get into my own bubble of creativity and I just go. (Katie)*

If in the beginning of the interview my participants struggled to describe what is normal and what is not. For many however as they spoke they seemed to move into language that revealed an active process of reconciling with their situation.

> *I was playing to go really high in soccer and to go farther. I wanted to do that with my life… so at first, it was really hard—that's for sure—but right now it's kind of okay. I got used to it. (Melissa)*

> *…it would be really cool if I could start dancing again, but I don't need it.* (Katie)

However, while the phrases "*but right now it's kind of okay*" and "*I don't need it*" indicate that they are in the ongoing process of practicing acceptance, this process is not without its own set of struggles. No matter their effort, troubled thoughts seem to repeatedly surface. In talking about the functionality of her hands, Julie mentioned:

> *Sometimes it works, sometimes not… but it's certain that if I'm like this then it's impossible to play [sport]. (Julie)*

Many of my participants are constantly reminded of their limitations, both at their chosen sports:

> *I'm definitely disappointed because it's sad because it's our game and I'm the goalie. I'll still stay there and practice with my team but I'll be disappointed. But I know that being negative will just make it worse so I try to be the most positive I can be. (Julie)*

As well as during activities meant for relaxation, resulting in the constant interrogation of self:

> *Even if I take baths, it relaxes not my hands but the rest of my body. (Julie)*

As a result, they are in a constant state of flux: their hopes sit side by side with their disappointment and frustration. While Melissa mentioned being okay and getting used to her condition, she admitted how playing soccer professionally is still in the back of her mind.

> *I told myself that if maybe I get better maybe I can get back and continue and still follow my dreams. (Melissa)*

What is distressing to see is how this participant chooses to cope with her situation during this state of despair. While most people make excuses to get out of doing things they do *not* want to do, Melissa makes excuses to get out of doing things she *wants* to do, proclaiming that her dreams are no longer valid, since *"all the [soccer] teams of Quebec are already formed."*

One of the ways in which adolescents counter this flux is by practicing downward social comparison—a process in which one compares their own situation to a worse outcome, therefore perceiving themselves as having better off circumstances.

> *When I couldn't walk, I was thinking well some people have cancer. I'm not about to die. I have nothing to complain about. (Samantha)*

One participant shared how she repeats mantras such as *"I am blessed to have a house, a loving mom, clothes"* repeating throughout the interview, *"I am not good but I'm better than some people."* Effort is therefore concentrated on staying positive and fighting the urge to "*get all sad*"

> *Well I tell myself if I – well not depression – but if I let myself get all sad and just go to the negative side, I think it will just be worse. So, I don't think it's easy every day but I'll try to see the positive side and just smile… it's better for me because in anything I do, the mental state is very important. (Samantha)*

We can read Samantha's struggle in choosing the right word to describe her mental state: it is explicit that she had meant to use the word depression, but chooses to pause, and then restructure her sentence to exclude the word. From this, we can understand how those with chronic pain are not faking being sick—they are faking being well. One participant mentioned how she does not necessarily show it when she is *"out and about"* but cries behind closed doors. This sense of helplessness is also shown by a mother, who expressed the heartache she has over seeing her daughter crying, saying how "*[she] can't handle it no more.*" (Samantha's mother)

> *For sure I sometimes have pain at 9-9.5 but I don't have a face that says that it's 9-9.5. Sometimes I'm scared the doctors will doubt what I say but that's not my goal – my goal*

> *is just to be honest so we get to the right diagnosis. I don't want to lie so that they realize how badly I feel so that they give me medications. (Samantha)*

> *I really lash out I get intense anxiety cause I am always saying to myself like OMG I am going to come to the emergency it's going to get worst, like omg its full like anxiety, and I lash out at him, I lash out at everyday cause I really don't know what to do you know, he is trying to help me, but I like I just him to leave me alone because I am like panicking, I am like screaming at him at the same time trying to manage my pain. I honestly lash out and anxiety is like the number one thing that I feel in those moments. (Cassey)*

While negative emotions are natural in the face of adversity, my participants are aware of the consequences dwelling on the past can have on their lives. This can be reflected in how they feel about their support group. Instead of helping them move forward, it served to reaffirm their struggle.

> *The only thing they do is they describe your past, talk about your emotions, how to survive them. But that won't help because they only talk about the negative side. (Samantha)*

This seems to be noticed by several mothers as well, who mentioned:

> *This is why she left the other group, because they are like when you are in pain does it want to make you hurt yourself to stop the pain and she is like no cause then I am going to have more pain. (Samantha's mother)*

> *I know right that's why she stopped the other one, now she is like seeing her 1 on 1 so it's not so depressing on her. like one time they asked her, like are you depressed, and she is like what does that mean, she is 17 years old, she doesn't know what it is to be a depressed kid. (Cassey's mother)*

While there are many negatives associated with chronic pain, there seems to also be positives. One participant even credited her pain experience in helping her *"build"* for life that *"isn't always easy." (Samantha).* Once they are able to move past the grief of living with chronic pain, our participants are seen to shift their attention towards a greater good. Although they are not yet experts in the management of their own pain, they are aware that their lived experience can help others in ways that health professionals might not be able to. The reality that they have experienced pain themselves gave them an intuitive empathy for the suffering of others, as well as the emotional credibility to help. This concept was acknowledged by Hans-Georg Gadamer. In his book *The Enigma of Health*, he argued how it would be an act of misinterpretation to look at the concept of illness solely through the standpoint of scientific medicine—instead, we should include within our rhetoric the patient's own self- understanding (116).

> *It's like for someone who never plays hockey and then me who is a goalie, there will be that difference… and that difference in understanding so for sure it would help make friends, help us discuss. We're not specialists but we're almost like psychologists in what we live so it could be good. (Julie)*

Their pain it seems, has called them to move from a life of pity and doubt to a life of advocacy and activism. At a broader level, what chronic pain established in them was the pursuit of significance. It is no longer about sharing chronic pain health facts, it is about adolescents making a commitment to stand together and take charge of their health, as well as the health of those in similar circumstances. It is interesting that helping others have long been recognized for its therapeutic benefits. By helping others, they are replacing negative emotional states with the positive state, also known as the "Helper's High" (134,134). This sentiment relates to the Self-Determination Theory, which mentions the intrinsic need for competence and relatedness, both of which can be actualized through sharing and helping others (136).

> *So this changed my perspective in a way where I know that everyone that they are living their own things and if anyone is asking for help in any way, if I can help them, I am going to. Because I know that if I ask someone for help I would LOVE for them to help me. (Katie)*

As may have been realized, this positive attitude is in far contrast from the attitude shown at the beginning of the interviews. I previously highlighted the *narrative foreclosure* that is inherent in our participants' dialogue; dependency on caretakers and the abrupt change in their career trajectory seems to be the source of anxiety (137). This took over their thought process, resulting in further doubts surrounding their future. However, it was also through this reflection that my participants were prompted to change their attitude, re-interpret their condition, and morph into a new self. To understand this, we can look at the Self-Discrepancy Theory. The Self-Discrepancy Theory explains that the self is made of three parts: the actual self, as defined by our self-concept; our ideal self, the person we would like to be, and our ought self, what others think we should be (71,72,138). The less gap there are between the three selves, the higher the individual's self-esteem. In the case of my participants, the act of normalizing serves as a way to re-establishing a sense of connection between these three selves (71,72,138). Closing this gap leads our participants to have a sense of *homecoming*, which as Hegel described, is a state of mind where the individual is free of anxiety and secure from perceived threats of danger (116). My participants achieve this by shifting their locus of control—if in the beginning they had an *external* locus of control, where they feel as if the outcome of their lives was beyond their control, now, they possess an *internal* locus of control where they believe that they have the power to control their own fate (139). As previously discussed, my participants did this by normalizing rehab exercises and integrating them into their daily lives—making it a part of their lives, and therefore, slowly integrating their three selves together. This fusion of selves lead to what Husserl defines as "*open uncertainty*" (118) In this mindset, the individual will earnestly package an outcome in positive circumstances (118). For example, when predicting an event, one will declare "xyz *can* happen," or "xyz *will* happen". This was why it is important for our participants to create their own "bubble"— fundamentally, it is in this safe space that they are able to adopt this same sense of open uncertainty. Here, my participants are able to *bracket off* the impact of illness, so that its effects remain relatively slight (116). This is in contrary to "*problematic uncertainty*." As the name suggest, in this mindset events and outcomes are packaged in negative circumstances (118); when predicting an event, the said individual will instead say: "xyz might *not* occur," or that "xyz will *never* occur" (118).

As seen my participants still shuffle between these two mindsets. While some might perceive this as an act of catastrophizing or blame it on the lack of fortitude, Husserl contended otherwise. He argued how as humans, we cannot—and do not have the ability to separate the present from the past. This is because the actual experience of a moment is a combination of "*retention*"— the *retained*, present experiences that has *just* passed, and "*protention*"—an anticipated future event that flowed out of said previous event (118). They act in synergy and are therefore not mutually exclusive. Take for example, the act of listening to a melody. The present note is simply inseparable from the previous note; the previous note readies listeners to the next note and the next note originates from the first (118). Acknowledging this, it becomes understandable then how my participants are in always in a constant state of flux. They are always in the state of searching and acknowledge there is more to their lives than their diagnosis of chronic pain. There is more than their current experience of pain.

Chapter Five: Concluding Thoughts

Considerations

The primary focus of this study is to explore the meaning and lived experiences of adolescent girls living with chronic pain. As such, the results of this study depend not on Likert scales or darkened circles from yes or no binary questionnaires, but on the *voluntary* insight given to me by real adolescent chronic pain sufferers. By default, my participants are those who have had the time to reflect on their condition and are comfortable enough to talk about their pain. They are in essence, what we can refer to as *stable* patients. While still in constant pain, my participants are able to attend school, socialize, attend to their hobbies, and participate in light to moderate physical activities; their pain is—at least for now, manageable. My participants are also a distinct cohort because of all the services available to them at the multidisciplinary Pain Clinic at the Montreal Children's Hospital. By being a patient registered under the Pain Clinic, they have access to psychology sessions, physiotherapy, analgesic nerve blocks, and meticulous consultations that together span hours. While these services are necessary, they are also privileges not commonly available to others also suffering from chronic pain. The coping mechanisms and thought processes highlighted in this study are therefore by no means a reflection of *all* adolescents suffering from chronic pain. Another factor to consider is gender. Mild associations have been noted between gender and disfunction in chronic pain patients; the enculturation of masculinity had been noted previously to result in boys and men alike to be reluctant in seek medical services and engage in negative coping mechanisms (41). The results may therefore be vastly different if we are to include males into the study. What we can appreciate however, is the raw and unfiltered insight into the lived experiences that adolescents in our pain community attach to their illness.

Findings Summary

The Findings obtained from this study can be identified as 3 themes: "I am who I say I am", "But What If my Pain is Invisible?" and "Normalizing as an Act of Metamorphosis: There is More". As seen in the narratives presented, my participants are at the junction of two worlds; if before they are *in* control of their environment, now, they are *under* control. The trajectory of their days and lives, at least through their eyes, are dictated by the pain that has infiltrated their bodies. A sense of interrupted life is inherent in their dialogue; they feel disabled, *not able*, *not normal*, and *not at home*. In this phase of "bodily doubt", my participants start to mistrust their own bodily capacities and capabilities; as such, their internal narrative become hostile and damaging (116,118,139). In their eyes, their life has ended and in essence, is under *foreclosure*. But their strength proved to be formidable as it was in the midst of their mental chaos that they were able to find the strength to *morph*.

This metamorphosis was propelled by the imagery of a full life ahead and the great potential that is inherent in each of them. During this time, our participants reconcile with their condition, adjust to life with pain and search for new meaning in life. This new positive mindset is well reflected in their lifestyle; with a new sense of hope, our participants seamlessly integrate active recovery into their everyday lives, shy away from dangerous substances, actively manage their mental health and emotions, and engage in positive cathartic relief. In the process, they were able to create their own *bubble*, a safe refuge where they can organically express their emotions and channel their *ideal* self.

Knowledge Translation Plan

While chronic pain had brought anguish and despair, it was also their pain experience that propelled our participants into a life of advocacy and activism. Living with pain it seems, has gifted them with intuitive empathy for the suffering of others, as well as the emotional credibility to help. The next step then is to work *bottom-up*, alongside our participants to improve and build safe and evidence-based services. Taking into consideration our participant's insight, I have laid out two practical proposals: a) the addition of a word-bank in the pre-appointment questionnaires to bridge patient-physician vocabulary gap and b) the development of a community *bubble*—a safe space for themselves and others to share their unique experiences, become less isolated and experience true belonging.

As seen, the current landscape of Canadian Chronic Pain care is at best fragmented and inefficient. Care is still grounded on negative stigma, with physicians questioning their patient's pain claims. Our participants are made to feel flawed and inadequate, which eventually made them doubt their *own* pain. This, alongside with their inability to accurately describe their pain acts as a double edge sword—resulting in superficial attention and care. Unintentionally, both parties encourage the "wait and see" approach, which further prolongs the time between the initial diagnosis and treatment initiation. I propose that we consider the current pre-appointment questionnaires in clinics as an area in need of improvement. Currently, most pre-appointment questionnaires depend on quantitative measures such as the Likert scale and reductionist yes or no, binary questions. In the case of chronic pain where disease etiology is uncertain, the more accurate the description, the better. Incorporating a word bank will allow our participants to better describe their pain and allow for greater recognition by the medical community—because in truth, there are tremendous differences between a 7/10 pain that is dull and constant, and a 7/10 pain that is searing, but intermittent. From the physician's perspective, it will help them research their patient's condition and facilitate conversations between themselves, before the actual appointment. In essence, this gives them the ability to compare similar cases, estimate disease trajectory, focus on specific symptoms, and approach the problem in the best way they know how to. From the patient's perspectives, being exposed to these vocabularies will give them a mental vocabulary bank that they can use in unexpected cases of pain flare ups, which will hopefully lead to better care and attention in emergency departments and walk-in clinics.

Another area of concern is the current support group model of talk, which evidently does not resonate strongly with our participants. In the words of one my participant's:

> *The other people it was their first time seeing a psychologist, but not me - it's been 3 years that I've been though that so I am better. And they are not good. And me, I think if I had this in the beginning it may have helped but now I am better. People are like why is she here, she is positive. They say "say an emotion" and I say "happy" because I will think positive. And they are like "no, no, think another emotion, not happy" and I'm like why? People were just telling bad stories and I'm like WHY am I here. (Samantha)*

The primary intention of a support group is exactly as the name implies: *support*. However, if the discussion centers around the negatives and life *before* chronic pain—something they themselves are trying to shift away from, then instead of connecting and regaining a balanced social and personal life like it is intended to, the support group may actually serve to reaffirm their struggle. One way to overcome this is by creating programs that gives the ability to "talk-sideways", or "horizontally," as if on a soccer field, or a dance team where camaraderie is needed. We can achieve this by letting them engage in a secondary activity during their support meetings. These activities do not have to be educational in nature; an emerging area of interest amongst chronic pain patients is complementary and alternative medicine (CAM), which involves non-pharmacological approaches such as cathartic narrative through art and music, mindfulness, and overall lifestyle changes (50). Engaging in a secondary activity will let them a) focus at the task at hand, therefore minimizing the mental capacity for rumination and b) the time, space, and opportunity to share narratives, coping mechanisms, and collaborative problem-solving skills—just as they would in a support group. In essence, it mimics the effects of a community *bubble*—a safe space for themselves and others to become less isolated, experience true belonging and finally, feel at *home*.

References

1) Raffaeli, W., & Arnaudo, E. (2017). Pain as a disease: an overview. *Journal of pain research*, *10*, 2003–2008.
2) Massieh M., & Karen D. D. (2012). Theories of pain: from specificity to gate control. *J Neurophysiol* 109: 5–12, 2013.
3) Mendell L. M. (2014). Constructing and deconstructing the gate theory of pain. *Pain*, *155*(2): 210–216.
4) Gatchel R.J., Peng Y.B., Peters M.L., Fuchs P.N., Turk D.C. The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychol Bull.* 133(4):581-624.
5) Large R.G. (1996) Psychological Aspects of Pain *Annals of the Rheumatic Diseases* 55: 340-345
6) International Association for the Study of Pain (2018) *IASP Terminology.* Retrieved from: https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698
7) Swieboda P., Filip R., Prystupa A., Drozd M. (2013) Assessment of pain: types, mechanism and treatment. *Ann Agric Environ Med* 1:2-7.
8) Chen, L., Deng, H., Cui, H., Fang, J., Zuo, Z., Deng, J., … Zhao, L. (2017). Inflammatory responses and inflammation-associated diseases in organs. *Oncotarget*, *9*(6), 7204–7218.
9) Igolnikov I., Gallagher R.M., Hainline B. (2018) Sport-related injury and pain classification Handbook of Clinical Neurology 158:423-430.
10) Hainline B, Derman W, Vernec A. (2017) International Olympic Committee consensus statement on pain management in elite athletes *British Journal of Sports Medicine 51*:1245-1258
11) Hansen, M. C., Aagaard, T., Christensen, H. W., & Hartvigsen, J. (2018). Work-related acute physical injuries, chronic overuse complaints, and the psychosocial work environment in Danish primary care chiropractic practice - a cross-sectional study. *Chiropractic & manual therapies*, *26*, 4.
12) Finan, P. H., Goodin, B. R., & Smith, M. T. (2013). The association of sleep and pain: an update and a path forward. *The journal of pain : official journal of the American Pain Society*, *14*(12), 1539–1552.
13) Mork PJ, Nilsen TI. Sleep problems and risk of fibromyalgia: Longitudinal data on an adult female population in Norway. Arthritis Rheum. 2012;64:281–4
14) Baird, A., & Sheffield, D. (2016). The Relationship between Pain Beliefs and Physical and Mental Health Outcome Measures in Chronic Low Back Pain: Direct and Indirect Effects. *Healthcare (Basel, Switzerland)*, *4*(3), 58.
15) Foster NE, Thomas E, Bishop A, Dunn KM, Main *CJ Pain. 2010 Mar; 148(3):398-406.*
16) Herrero A. M., Carmen R.M., González V. (2008) Personality, Cognitive Appraisal and Adjustment in Chronic Pain Patients 11(2): 531-541
17) H. Wideman [a], Heather Adams [b], Michael J.L. Sullivan (2009) A prospective sequential analysis of the fear-avoidance model of pain 145:45-41

18) Buitenhuis J., De Jong P. J.(2011) Fear avoidance and illness beliefs in post-traumatic neck pain. *Spine* 1;36
19) Denison E., Asenlof P., Lindberg P. (2004) Self-efficacy, fear avoidance, and pain intensity as predictors of disability in subacute and chronic musculoskeletal pain patients in primary health care. *Pain* 111(3):245-52.
20) Nadine E. Foster□, Elaine Thomas, Annette Bishop, Kate M. Dunn, Chris J. Main (2010) Distinctiveness of psychological obstacles to recovery in low back pain patients in primary care Pain. 2010:148(3): 398–406.
21) Ferrari S., Chiarotto A., Pellizzer M., Vanti Carla., Monticone M. (2016) Pain Self-Efficacy and Fear of Movement are Similarly Associated with Pain Intensity and Disability in Italian Patients with Chronic Low Back Pain Pain Practice 16 (8): 1040-1047
22) Johan W.S. V., Steven J. L. (2012) Fear-avoidance model of chronic musculoskeletal pain: 12 years on. Pain 153: 1144–1147
23) Nieto. R., Jordi M., Huguet.A. (2009) The fear-avoidance model in whiplash injuries *European Journal of Pain* 13 518–523
24) Luciola D. C. M, Christopher G. M., James H. M , Mark J. H. , Rob J.E.M. (2011) Self-efficacy is more important than fear of movement in mediating the relationship between pain and disability in chronic low back pain *European Journal of Pain* 15: 213–219
25) Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977;84:191–215.
26) Goubert L., Crombez G., Van Damme S. (2004) The role of neuroticism, pain catastrophizing and pain-related fear in vigilance to pain: a structural equations approach. *Pain* 107(3):234-41.
27) Grichnick, K.P., & Ferrante, F, M. (1991). The difference between Acute and Chronic Pain. *Mount Sinai Journal of Medicine*, 58(3), 217-20
28) Treede, R.-D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., Wang, S.J. (2015). A classification of chronic pain for *ICD-11*. *Pain*, *156*(6), 1003–1007.
29) Henry, J. L. (2008). The need for knowledge translation in chronic pain. *Pain Research & Management : The Journal of the Canadian Pain Society*, *13*(6), 465–476.
30) Simons L. E. (2016). Fear of pain in children and adolescents with neuropathic pain and complex regional pain syndrome. *Pain*, *157 Suppl 1*(0 1), 90–97.
31) Lynch,M.E., The Need for a Canadian Pain Strategy. Pain Research and Strategy, 16(2), 77-8
32) Wakefield, E. O., Zempsky, W. T., Puhl, R. M., & Litt, M. D. (2018). Conceptualizing pain-related stigma in adolescent chronic pain: a literature review and preliminary focus group findings. *Pain reports*, *3*(Suppl 1), e679.
33) Lumley, M. A., Cohen, J. L., Borszcz, G. S., Cano, A., Radcliffe, A. M., Porter, L. S., … Keefe, F. J. (2011). Pain and emotion: a biopsychosocial review of recent research. *Journal of clinical psychology*, *67*(9), 942–968.
34) Green, S., Davis, C., Karshmer, E., Marsh, P., Straight, B. (2005) Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families *Sociological Inquiry* 75 (2): 197-215

35) Pain BC (2018) *"Complainers, malingerers and drug-seekers" — the stigma of living with chronic pain* retrieved from: https://www.painbc.ca/blog/complainers-malingerers-and-drug-seekers-stigma-living-chronic-pain
36) Leveille, S. G., Zhang, Y., McMullen, W., Kelly-Hayes, M., & Felson, D. T. (2005). Sex differences in musculoskeletal pain in older adults. *Pain*, *116*(3), 332–338.
37) Wijnhoven, H.A.H., De Vet. H. C.W., Picavet H.S. J. (2006) Explaining Sex Differences in Chronic Musculoskeletal Pain in General Population rivm retrieved: https://rivm.openrepository.com/bitstream/handle/10029/5533/wijnhoven.pdf?sequence=1
38) Nordander, C., Ohlsson, K., Balogh, I., Hansson G.A., Axmon A., Persson R., Skerfying S. (2008) Gender differences in workers with identical repetitive industrial tasks: exposure and musculoskeletal disorders. *Int Arch Occup Environ Health*. 81(8):939-47.
39) Strazdins L., Bammer G. (2004) Women, work and musculoskeletal health. *Soc Sci Med* 58(6):997-1005.
40) Wise, E. A., Price, D. D., Myers, C. D., Heft, M. W., & Robinson, M. E. (2002). Gender role expectations of pain: relationship to experimental pain perception. *Pain*, *96*(3), 335–342.
41) Moynihan, C. (1998). Theories of Masculinity. *BMJ : British Medical Journal*, *317*(7165), 1072–1075.
42) Levine, F.M., De Simone, L.L. (1991) The effects of experimenter gender on pain report in male and female subjects. *Pain* 44(1):69-72.
43) Sullivan M. J. L., Tripp. D. A., Santor. D. (2000) Gender Differences in Pain and Pain Behavior: The Role of Catastrophizing. *Cognitive Therapy and Research*, 24(1): 121-134
44) Schopflocher, D., Taenzer, P., & Jovey, R. (2011). The prevalence of chronic pain in Canada. *Pain research & management*, *16*(6), 445–450.
45) Henry, J. L. (2008). The need for knowledge translation in chronic pain. *Pain Research & Management : The Journal of the Canadian Pain Society*, *13*(6), 465–476.
46) Boult, C., Karm, L., & Groves, C. (2008). Improving Chronic Care: The "Guided Care" Model. *The Permanente Journal*, *12*(1), 50–54.
47) Lynch,M.E., The Need for a Canadian Pain Strategy. Pain Research and Strategy, 16(2), 77-8
48) Lynch,M.E., The Need for a Canadian Pain Strategy. Pain Research and Strategy, 16(2), 77-8
49) Groven, K.S., Galdas, P.,& Solbraekke, K.N. (2015) Becoming a normal guy: Me making sense of long-term bodily changes following bariatric surgery. International Journal of Qualitative Studies on Health and Well-being 10(1), 10:29923
50) Metcalfe, A., Williams, J., McHesney, J., Patten, S.B., & Jetté, N. (2010). Use of Complementary and Alternative Medicine by those with Chronic Disease and the General Population. *BMC Complementary and Alternative Medicine*, 10(1)
51) Becker, A. J., Heathcote, L. C., Timmers, I., & Simons, L. E. (2018). Precipitating events in child and adolescent chronic musculoskeletal pain. *Pain reports*, *3*(Suppl 1), e665
52) William H. Young, John J. Butt, Nancy K.Young (2002) *The 1930's*. Westport, Connecticut: Greenwood Press.
53) Cote, J. E., & Allahar, A. L. (2006). *Critical youth studies: A Canadian focus.* Toronto, ON, Canada: Pearson Education Canada.

54) James Gilbert, A Cycle of Outrage: America’s Reaction to the Juvenile Delinquent in the 1950s (New York: Oxford University Press, 1986)
55) Jaworska, N., & MacQueen, G. (2015). Adolescence as a unique developmental period. *Journal of psychiatry & neuroscience : JPN*, *40*(5), 291–293
56) Christie, D., & Viner, R. (2005). Adolescent development. *BMJ (Clinical research ed.)*, *330*(7486), 301–304.
57) Abreu, A. P., & Kaiser, U. B. (2016). Pubertal development and regulation. *The lancet. Diabetes & endocrinology*, *4*(3), 254–264.
58) Chulani, V, L., Gordon, L, P. (2014). Adolescent growth and development. *Primary Care: Clinics in Office Practice*, 41(3), 465-487.
59) National Research Council (US) and Institute of Medicine (US) Forum on Adolescence; Kipke MD, editor. Risks and Opportunities: Synthesis of Studies on Adolescence. Washington (DC): National Academies Press (US); 1999. 2, Adolescence: A Time of Opportunity and Risk.
60) Sawyer, S., Afifi, R., Bearinger, L., Blakemore, S. J., Dick, B., Ezeh, A., & Patton, G. (2012). Adolescence: A foundation for future health. *The Lancet, 379*(9826)
61) Nangle D, Erdley CA, Newman JE, Mason CA, Carpenter EM. Popularity, friendship quantity, and friendship quality: Interactive influences on children’s loneliness and depression. J Clin Child Adolesc Psychol 2003;52:546-55.
62) Forgeron PA, King S, Stinson J, McGrath PJ, MacDonald AJ, Chamber CT. Social functioning and peer relationships in children and adolescents with chronic pain: A systematic review. Pain Res Manag 2010;15:27-41.
63) Crone,E. A., Dahl, R.E. (2012) Understanding adolescence as a period of social-affective engagement and goal flexibility. *Nat. Neurosci. Nature* 13(9):636-50
64) Scales, P. C., Benson, P. L., & Roehlkepartian, E. C. (2011). Adolescent thriving: The role of sparks, relationships, and empowerment. *Journal of Youth and Adolescence, 40*(3), 263- 277
65) Gilbert, P. (2009). *The compassionate mind.* Oakland, CA: New Harbinger Publications.
66) Marsh, I .C., Chan, S. W. Y., MacBeth, A. (2017) Self-compassion and Psychological Distress in Adolescents—a Meta-analysis Mindfulness 9(4): 1011–1027
67) Dolgin, K. G. (2011). *The adolescent: Developmental tasks, relationships, and culture.* Boston, MA: Allyn & Bacon.
68) Barker, E. T., & Galambos, N. L. (2005). Adolescents’ implicit theories of maturity: Ages of adulthood, freedom, and fun. *Journal of Adolescent Research, 20*(5), 557-576.
69) Taylor, R. M., Gibson, F., & Franck, L. (2008). The experience of living with a chronic illness during adolescence: A critical review of the literature. *Journal of Clinical Nursing, 17*(23), 3083-3091.
70) Arnett, J. J. (2001). Conceptions of the transition to adulthood: Perspectives from adolescence to midlife. *Journal of Adolescent Development, 8*(2), 133-143.
71) Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68-78.
72) Reis, H. T., Sheldon, K. M., Gable, S. L., Roscoe, J., & Ryan, R. M. (2000). Daily well-being: The role of autonomy, competence, and relatedness. Personality and social psychology bulletin, 26(4), 419-435.

73) Tyyska, V. (2009). *Youth and society: The long and winding road* (2nd ed.) Toronto, ON, Canada: Canadian Scholars' Press.

74) Arnett, J. J. (2007). *Adolescence and emerging adulthood: A cultural approach* (3rd ed.). Upper Saddle River, NJ: Pearson.

75) Collins, W. A., & Steinburg, L. (2006). *Adolescent development in interpersonal context.* In N. Eisenberg (Vol. Ed.), W. Damon & R. M. Lerner (Series Eds.), *Handbook of child psychology* (6th ed., Vol. 3)*: Social, emotional, and personality development* (pp. 1033-1068). New York, NY: Wiley.

76) Scales, P. C., Benson, P. L., & Roehlkepartian, E. C. (2011). Adolescent thriving: The role of sparks, relationships, and empowerment. *Journal of Youth and Adolescence, 40*(3), 263- 277.

77) Friedman, H.L. (1989). The Health of Adolescents: Beliefs and behavior. Social Science and Medicine 29(3), 309-315

78) National Research Council (US) and Institute of Medicine (US) Forum on Adolescence; Kipke MD, editor. Risks and Opportunities: Synthesis of Studies on Adolescence. Washington (DC): National Academies Press (US); 1999. 2, Adolescence: A Time of Opportunity and Risk.

79) Johnson, S. B., & Jones, V. C. (2010). Adolescent development and risk of injury: using developmental science to improve interventions. *Injury prevention : journal of the International Society for Child and Adolescent Injury Prevention*, *17*(1), 50–54.

80) Yeager, D. S., Lee, H. Y., & Jamieson, J. P. (2016). How to Improve Adolescent Stress Responses: Insights From Integrating Implicit Theories of Personality and Biopsychosocial Models. *Psychological science*, *27*(8), 1078–1091.

81) Jaworska, N., & MacQueen, G. (2015). Adolescence as a unique developmental period. *Journal of psychiatry & neuroscience : JPN*, *40*(5), 291–293

82) Friedman, H.L. (1989). The Health of Adolescents: Beliefs and behavior. Social Science and Medicine 29(3), 309-315

83) Christie, D., & Viner, R. (2005). Adolescent development. *BMJ (Clinical research ed.)*, *330*(7486), 301–304.

84) Erikson, E. H. (1950). *Childhood and society.* New York, NY: Norton.

85) Roisman, G. I., Masten, A., S., Coatsworth, J. D., & Tellegen, A. (2004). Salient and emerging developmental tasks in the transition to adulthood. *Child Development, 75*(1), 123-133.

86) D'Agostino, N. M., Penney, A. M., & Zebrack, B. (2011). Providing developmentally appropriate psychological care to adolescent and young adult cancer survivors. *Cancer, 117*(10), 2329-2334

87) Fisher, E., & Palermo, T. M. (2016). Goal Pursuit in Youth with Chronic Pain. *Children (Basel, Switzerland)*, *3*(4), 36.

88) Eccleston, C., & Malleson, P. (2003). Managing chronic pain in children and adolescents. We need to address the embarrassing lack of data for this common problem. *BMJ (Clinical research ed.)*, *326*(7404), 1408–1409.

89) Simons L. E. (2016). Fear of pain in children and adolescents with neuropathic pain and complex regional pain syndrome. *Pain*, *157 Suppl 1*(0 1), 90–97.

90) Friedrichsdorf, S. J., Giordano, J., Desai Dakoji, K., Warmuth, A., Daughtry, C., & Schulz, C. A. (2016). Chronic Pain in Children and Adolescents: Diagnosis and

Treatment of Primary Pain Disorders in Head, Abdomen, Muscles and Joints. *Children (Basel, Switzerland)*, *3*(4), 42.

91) Simons L. E. (2016). Fear of pain in children and adolescents with neuropathic pain and complex regional pain syndrome. *Pain*, *157 Suppl 1*(0 1), 90–97.

92) Jordan, A., Noel, M., Caes, L., Connell, H., & (2018). A developmental arrest? Interruption and identity in adolescent chronic pain. *Pain reports*, *3*(Suppl 1), e678.

93) Eccleston, C., Wastell, S., Crombez, G., Jordan, A. (2008) Adolescent social development and chronic pain. *European Journal of Pain*.12(6):765-74.

94) Eccleston, C., & Clinch, J. (2007). Adolescent chronic pain and disability: A review of the current evidence in assessment and treatment. *Paediatrics & child health*, *12*(2), 117–120.

95) Palermo, T. M. (2000). Impact of Recurrent and Chronic Pain on Child and Family Daily Functioning: A Critical Review of the Literature *Journal of Developmental & Behavioral Pediatrics*. 21(1),58–69

96) Gauntlett-Gilbert, J., J.Eccleston, C., (2007). Disability in adolescents with chronic pain: Patterns and predictors across different domains of functioning. *Pain*.131(1-2),132-41.

97) Vlassoff C. (2007). Gender differences in determinants and consequences of health and illness. *Journal of health, population, and nutrition*, *25*(1), 47–61.

98) Chessick, R, D. (1990) Hermeneutics for psychotherapists. *American Journal of Psychotherapy*. 44(2), 256-73.

99) Tuohy, D., Cooney, A., Dowling, M., Murphy, K., Sixsmith, J. (2013) An overview of interpretive phenomenology as a research methodology. *Nurse Research*. 20(6),17-20.

100) Sloan, A. & Bowe, Brian (2014). Phenomenology and Hermeneutic Phenomenology: the philosophy, the methodologies and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity*.48(3) , 1291-130

101) Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British journal of pain*, *9*(1), 41–42.

102) Burch, R. (1990). Phenomenology, Lived Experience: Taking a Measure of the Topic. Phenomenology + Pedagogy, 8, 130-160.

103) Wiklund, L., Lindholm, L., Lindström. (2002) Hermeneutics and narration: a way to deal with qualitative data. *Nursing Inquiries*. 9(2),114-25.

104) David Vessey (2009) Gadamer and the Fusion of Horizons, International Journal of Philosophical Studies, 17:4, 531-542

105) Gadamer, H-G. (2007). *The Gadamer reader: A bouquet of later writings.* R.E. Palmer (Ed.). Evanston, IL: Northwest University Press.

106) Moules, N. J., McCaffrey, G., Field, J. C., & Laing, C. M. (2015). *Conducting hermeneutic research: From philosophy to practice.* New York, NY: Peter Lang.

107) Smith, J. A. (2015). Qualitative psychology: A practical guide to research methods. Los Angeles: SAGE.

108) Meana, M., Cho, R., & DesMeules, M. (2004). Chronic Pain: The Extra Burden on Canadian Women. *BMC women's health*, *4 Suppl 1*(Suppl 1), S17

109) Barsky, A. J., Peekna, H. M., & Borus, J. F. (2001). Somatic symptom reporting in

110) women and men. *Journal of general internal medicine*, *16*(4), 266–275

111) Englander, M., The Interview: Data collection in descriptive phenomenological human scientific research. Journal of Phenomenological Psychology, 2012. 43(1): p. 13-35.

112) Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., … Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & quantity*, *52*(4), 1893–1907.

113) Gadamer, H-G. (1960/2004). *Truth and method* (2nd rev. ed.; J. Weinsheimer & D. G. Marshal, Trans.). New York, NY: Continuum.

114) McCaffrey, G., Raffin Bouchal, S., & Moules, N.J. (2012). Hermeunitics as a research approach: A reappraisal. International Journal of Qualitative Methods, 11(3), 213-229.

115) Madison, G. (1988). *The hermeneutics of postmodernity: Figures and themes*. Bloomington, IN: Indiana University Press.

116) Gadamer, H, G. (1996) *The Enigma of Health*. Stanford, California: Stanford University Press

117) Carel H. (2013). Bodily doubt. *J. Conscious. Stud.* 20, 178–197.

118) Ratcliffe, M., Ruddell, M., & Smith, B. (2014). What is a "sense of foreshortened future?" A phenomenological study of trauma, trust, and time. *Frontiers in psychology*, *5*, 1026.

119) Bury, M. (1982). Chronic Illness as Biographical Disruption. *Sociology Health Journal.* 4(2),167-82.

120) Goering S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current reviews in musculoskeletal medicine*, *8*(2), 134–138.

121) Yeager, D. S., Lee, H. Y., & Jamieson, J. P. (2016). How to Improve Adolescent Stress Responses: Insights From Integrating Implicit Theories of Personality and Biopsychosocial Models. *Psychological science*, *27*(8), 1078–1091.

122) Johnson, S. B., & Jones, V. C. (2010). Adolescent development and risk of injury: using developmental science to improve interventions. *Injury prevention : journal of the International Society for Child and Adolescent Injury Prevention*, *17*(1), 50–54.

123) Comer, L. (2017). Content Analysis of Chronic Pain content at three Undergraduate Medical schools in Ontario. Canadian Journal of Pain, 1(1), 75-83

124) Gallagher R. (2018). New category of opioid-related death. *Canadian family physician Medecin de famille canadien*, *64*(2), 95–96.

125) Kim, B., Nolan, S., & Ti, L. (2017). Addressing the prescription opioid crisis: Potential for hospital-based interventions? *Drug and alcohol review*, *36*(2), 149–152.

126) Governent of Canada (2018). Retrieved from https://www.canada.ca/en/health-canada/services/video/opioid-awareness- campaign.html

127) Martin, D., Pollack, K., & Woollard, R. F. (2014). What would an Ian McWhinney health care system look like?. *Canadian family physician Medecin de famille canadien*, *60*(1), 17–19.

128) Martin, D. (2015) Delivering on the promise of Medicare. Canadian family physician Medecin de famille canadien, 61(2) 111-5, 120-5

129) Soklaridis, S., Cartmill, C., Cassidy, D. (2011) Biographical disruption of injured workers in chronic pain. *Disabil Rehabil* 33(23-24):2372-80.

130) Puder, R. S. (1988). Age analysis of cognitive-behavioral group therapy for chronic pain outpatients. *Psychology and Aging, 3*(2), 204-207

131) *Nietzsche, Friedrich Wilhelm, 1844-1900. (1998). Twilight of the idols, or, How to philosophize with a hammer. New York :Oxford University Press.*

132) Hovey R. B. (2016). Cathartic narratives for chaotic thinking. *CMAJ:Canadian Medical Association journal = journal de l'Association medicale canadienne*, *188*(17- 18), 543–544.

133) Hovey, R. B., Khayat, V. C., & Feig, E. (2018). Cathartic Poetry: Healing Through Narrative. *The Permanente journal*, *22*, 17–196.

134) Dossey,L. (2018) The Helper's High. Explore, 14(6), 393-399.

135) Post, S.G. (2005) Altuism, happiness, and health: it's good to be good. *International Journal of Behavioural Medicine*. 12(2), 66-77.

136) Patrick, H., & Williams, G. C. (2012). Self-determination theory: its application to health behavior and complementarity with motivational interviewing. *The international journal of behavioral nutrition and physical activity*, *9*, 18.

137) Ratcliffe, M., Ruddell, M., & Smith, B. (2014). What is a "sense of foreshortened future?" A phenomenological study of trauma, trust, and time. *Frontiers in psychology*, *5*, 1026.

138) Bak W. (2014). Self-Standards and Self-Discrepancies. A Structural Model of Self-Knowledge. *Current psychology (New Brunswick, N.J.)*, *33*(2), 155–173.

139) Carel H. (2013). Bodily doubt. *J. Conscious. Stud.* 20, 178–197.

140) Brown, C. B. (2010). *The gifts of imperfection: Let go of who you think you're supposed to be and embrace who you are*. Center City, Minn.: Hazelden. (pp. preface xiv)

141) Cutcliffe, J. R., & Ramcharan, P. (2002). Leveling the playing field? Exploring the merits of the ethics-as-process approach for judging qualitative research proposals. *Qualitative Health Research, 12*(7), 1000-1010.

APPENDIX

PROJECT PROPOSAL

Faculty of Dentistry
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Division of Oral Health and Society

Study Title:

Lived experiences and social implications of adolescents living with chronic pain

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Background and study rationale:

According to the Institute for Chronic Pain, chronic pain (CP) is defined and distinct from acute pain in that it occurs for longer than three months and persists independently of the already-healed underlying injury or illness (1). Unlike most musculoskeletal injuries, CP is invisible and often there is no timeline for recovery, yet the seriousness of the physical and psychological implications of chronic pain are as serious and life-altering as those of other musculoskeletal injuries. Research conducted on CP patients indicated that longer pain duration is associated with increased depression (2) and that clinically depressed subjects differ from healthy peers in terms of enhanced catastrophizing tendencies and greater perceived disability (3).

These attributes of CP pose limitations for those living with CP who cannot return to their regular lifestyle and the invisibility of CP challenges medical practitioners who are trained to measure and treat conditions. In terms of the devastating effects associated with CP, there is clinical research suggesting that up to 85% of CP patients are affected by severe depression and that psychological symptoms affiliated with CP include depression, isolation, and anxiety (4). And, a systematic review of brain changes in CP patients studied using magnetic resonance imaging (MRI) provides medical support for these effects given that CP patients display alterations in brain regions involved in both pain processing (pain catastrophizing and attention to pain) and sensory and cognitive tasks (5).

Pain management is primarily concerned with patients’ conscious experience, and therefore, defining the patients’ understanding of their pain is imperative to implementing effective pain care programs (6). Understanding the perspective of CP patients as they describe and make sense of life with their pain would complement medical institutions and inform tailored, individualized psychological programs.

Chronic pain, particularly in youth, disrupts school functioning (6) and impairs one’s opportunities to interact with and form relationships with peers (7). With this knowledge, adolescents with CP not surprisingly report more loneliness and depressive symptoms (8). However, to date, very little research exists regarding how adolescents perceive their experiences living with CP.

Objectives of the study:

The primary purpose of this study is to understand the meanings and lived experiences of chronic pain in adolescents using hermeneutic approaches within an interpretative phenomenological analysis.

The interviewers will be two McGill graduate students, and the questions will be geared towards discussing the adolescents' physical and psychological symptoms and how these symptoms influence their relationships and quality of life. These findings are of interest to pediatric pain management clinics and community centres as they highlight the usefulness of community peer support and mentorship programs that the medical healthcare system cannot provide. The application of our findings may enhance the breadth of programs and services offered to those suffering from CP both inside and outside of the clinic.

The secondary purpose of this study is to gain a greater understanding of which programs or lifestyle changes these adolescents living with CP feel would be of most benefit.

Methodology:

We will adopt an interpretive phenomenological approach for data collection and analysis (IP) to explore how adolescents living with chronic pain (CP) perceive and make sense of their personal and social experiences. Interpretative phenomenology emphasizes a connection between what an individual vocalizes with their cognitive and emotional state, thereby making it possible to examine the deeper meanings of what one says about their experiences (9). In addition, IP studies delve deeply into the complexity of a small, well-defined group for whom the research questions will be pertinent rather than make general claims for a larger population (9). Therefore, a small sample size of 12 female adolescents in- and/or out- patients between the ages of 14 and 18 will be recruited from the Montreal Children's Hospital Pediatric Chronic Pain Management Clinic. We will select participants based on the condition that they meet the criteria of a chronic pain condition – i.e. they live with pain that has persisted longer than three months independent of the initial injury or illness (1). These musculoskeletal conditions include fibromyalgia, arthritis, back pain, widespread pain, related disorders, and orofacial pain conditions. The reasons for which we will be interviewing female adolescents only is because (a) the majority of the patients at the Chronic Pain Management Clinic are females and (b) we would like to keep our sample population as uniform as possible.

The link between the McGill Dental Sciences Faculty (Department of Health and Society) and the Montreal Children's Hospital Pediatric Chronic Pain Management Clinic is the following: we are Masters students (Rachel Szwimer and Manuella Widjaja) in the Oral Health and Society Department with our primary public health interest being to further the understanding of chronic pain and improve services offered to those suffering from chronic pain (this goal is in line with that of the Montreal Children's Hospital's Chronic Pain Clinic). The connection to McGill Dentistry is that our supervisor – Dr. Richard Hovey – is an Associate Professor in the Division of Oral Health/Society Unit of McGill's Dentistry Faculty.

The data collection instrument being implemented in this study is **semi-structured** open-ended one-on-one interviews because this method allows the researcher and participant to engage in dialogue that is guided rather than dictated by a set of questions and permits the researcher to probe important points as they arise (9). These interviews will be situated at the MCH and will be recorded. Following the interview, these recorded discussions will be transcribed verbatim and later interpreted by Dr. Richard Hovey and his MSc Students Rachel Szwimer and Manuella Widjaja. Each interview will last between 30 and 90 minutes, and each participant will be interviewed once. Patients will be recruited from the MCH Pediatric Chronic Pain Management Clinic. These patients will be approached by Dr. Hovey's graduate students only after discussing the study before-hand with Dr. Ingelmo and expressing a willingness to be interviewed. The interviews will be conducted in reserved, private rooms at the MUHC Glen Site as assigned by the MUHC Pediatric Pain Management Clinic Staff.

Study Population:

Inclusion and exclusion criteria

The individuals that will be included in this study are female adolescents between 14 and 18 years old who have been living with chronic pain for over 3 months and have given informed consent to participate in this study.

The individuals that will be excluded from this study are individuals who are younger than 14 years old or older than 18 years old, have been living with chronic pain for less than 3 months, have a condition that would limit their ability to partake in this study, and/or do not give informed consent.

Description of collected data:

The collected data will be in the form of audio-recordings and manuscripts of those audio-recordings. The audio-recordings will be of the interviews with the adolescent patients and the following is a list of exemplary questions that will be asked during the interviews:

- How has chronic pain affected your day-to-day life/social functioning? Do you feel that you miss school often due to your pain/doctor appointments?
- Do you find it hard to socialize or open up to your peers?
- Do you find your attitude different? E.g.: pessimistic, more motivated
- Do you find yourself isolated or misunderstood by your friends? Do you find yourself withdrawing from friends? Do you think you would feel any differently in a group of people with chronic pain conditions?
- Do you prefer to be alone or in the company of others? Is this any different from your preference prior to developing a chronic pain condition?

- Do you find you have to adjust your goals and/or activity patterns? Do you feel more disengaged from your goals?
- Do you find that the pain motivates or demotivates you? E.g.: determination, persistence
- Do you feel distant from your peers? Does it require a lot of effort to re-engage in your social group?
- What are three *things* you would like to do or try?
- What are three *things* that you think might help improve your quality of life? (e.g.: peer mentor programs to discuss the transition between pediatric to adolescent pain management care, *Skyping/FaceTiming* with school friends, pain education courses, etc.)
- What are your ways of coping day-to-day? Do you feel like you need to distract yourself from your pain?

Duration of the study

Each of the 6-12 adolescent patients will be interviewed once on a date that is convenient for each participant. Therefore, the data collection is expected to take place over the course of approximately 1-2 months. The process of analyzing the data will take place over the subsequent 3-4 months.

Data analysis plan:

The data will be analyzed using an interpretative phenomenological analysis (IPA) approach which aims to provide insights into how one makes sense of a given phenomenon. This approach focuses on the relevance of an individual’s experiential perspective. Therefore, we will be performing in-depth interpretations of each person’s responses to identify patterns of convergence and divergence across cases.

Ethical consideration:

Oversight:

This study will be conducted in accord with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (2014), as well as in respect of the requirements set out in the applicable standard operation procedures of the Research Institute of the McGill University Health Centre Research Institute and of the McGill University Health Centre Research Ethics Board. The McGill University Health Centre Research Ethics Board will review this study and will be responsible for monitoring it at all participating institutions in the health and social services network in Québec

Privacy, Confidentiality, and Risk:

This study is non-invasive in its nature and poses minimal risk on participants. We will be thoroughly explaining the research procedure and assessing their understanding of their role in the research study prior to the interviews and the obtainment of signatures for informed written consent. We will only collect information necessary for the study and the participants are able to refuse any question to which they would prefer not to answer.

For the purposes of patient privacy and confidentiality, these interviews will be conducted in private interview rooms at the MUHC Glen Site center of innovative medicine (CIM). The audio-recordings will be transcribed in a de-identified fashion and will be stored on Dr. Ingelmo's password-protected, secure personal computers at the MUHC Glen site. All data would be properly deleted/shredded 7 years after data collection.

Informed Consent:

The researchers will comply with the current laws and rules on research and informed consent and assent and conform to the code of good clinical practice and to the rules of ethics derived from the Declaration of Helsinki.

According to the recommendations of the Declaration of Helsinki and to the local laws, all the patients must be informed about the aims, the methods, the expected advantages, the potential risks and discomfort related to the study; the patient must know that he/she can refuse to take part in the study, without any effect on his/her medical care.
The patients will have all the time they need to evaluate the received information before giving their consent to participate.
The researchers must obtain the written informed consent before using the patients' information for research purposes. The informed consent will contain the date and the signature of the principal investigator or of a designated person instead of him at both The researchers will give the patient a signed copy of the informed consent and
Consent forms are available in French and English languages.

Dissemination plan:

Essentially, our idea is to publish scientific papers with our findings and establish bases for future studies. All investigators will contribute equally to an eventual submission as authors. All contributors who do not meet general conditions of authorship will be listed in an acknowledgement section

Whenever the study results are published or shared during scientific meetings or otherwise, it will not be possible to identify the participants.

14. Financial disclosure and conflict of interest

The funding for this project is provided by the McGill Faculty of Dentistry under the category of Graduate Excellence Awards. Between Dr. Hovey's two graduate students Rachel Szwimer and Manuella Widjaja, these awards amount to $6320.00.

Chronic pain service funding is through cost center 63440.

All study investigators declare no conflict of interest in the study.

References:

(1) Murray J. McAllister, P. (2012). What is Chronic Pain | Types of Pain. Retrieved from http://www.instituteforchronicpain.org/understanding-chronic-pain/what-is-chronic-pain

(2) Averill, P. M., Novy, D. M., Nelson, D. V., Berry, L. A. (1996). Correlates of depression in chronic pain patients: a comprehensive examination. *Pain, 65(1)*, 93-100. doi: 10.1016/0304-3959(95)00163-8

(3) Ruehlman, L., Karoly, P., & Pugliese, J. (2010). Psychosocial Correlates of Chronic Pain and Depression in Young Adults: Further Evidence of the Utility of the Profile of Chronic Pain: Screen (PCP: S) and the Profile of Chronic Pain: Extended Assessment (PCP: EA) Battery. *Pain Medicine*, *11*(10), 1546-1553. doi: 10.1111/j.1526-4637.2010.00933.x

(4) Sheng, J., Liu, S., Wang, Y., Cui, R., & Zhang, X. (2017). The Link between Depression and Chronic Pain: Neural Mechanisms in the Brain. *Neural Plasticity, 2017*, 9724371. http://doi.org/10.1155/2017/9724371

(5) Malfliet, A., Coppieters, I., Van Wilgen, P., Kregel, J., De Pauw, R., Dolphens, M., & Ickmans, K. (2017). Brain changes associated with cognitive and emotional factors in chronic pain: A systematic review. *European Journal Of Pain*, *21*(5), 769-786. doi: 10.1002/ejp.1003

(6) Jones, K., Nordstokke, D., Wilcox, G., Schroeder, M., & Noel, M. (2018). The 'work of childhood': understanding school functioning in youth with chronic pain. *Pain Management*, *8*(2), 139-153. doi: 10.2217/pmt-2017-0048

(7) Forgeron, A. P., McGrath, P., Stevens, B., Evans, J., Dick, B., Finley, G. A. & Carlson, T. (2011). Social information processing in adolescents with chronic pain: My friends don't really understand me. *Pain*, *152*(12), 2773-2780. doi: 10.1016/j.pain.2011.09.001.

(8) Forgeron, A. P., Chambers, C. T., Cohen, J., Dick, B. D., Finley, G. A., Lamontagne, C. (2018). Dyadic differences in friendships of adolescents with chronic pain compared with pain-free peers. *Pain*, *159*(6), 1103-1111. doi: 10.1097/j.pain.0000000000001191

(9) Smith, J., & Osborn, M. (2007). *Qualitative Psychology - A* Practical *Guide to Research Methods*(2nd ed., pp. 50-80). London: SAGE Publications LTD.

ETHICS APPROVAL

Centre universitaire de santé McGill
McGill University Health Centre

2019-01-21

Dr. Pablo Mauricio Ingelmo

c/o: Rachel Szwimer

email: rachel.szwimer@mail.mcgill.ca

Re: MUHC Authorization (Adolescent Chronic Pain Experience / 2019-5047)

> "Understanding the lived experiences, coping mechanisms, and social implications of adolescents living with chronic pain: a qualitative descriptive study"

Dear Dr. Ingelmo,

We are writing to confirm that the study mentioned above has received research ethics board approval and all required institutional approvals, namely:

- Use of pediatric resources

You are hereby authorized to conduct your research at the McGill University Health Centre (MUHC) as well as to initiate recruitment.

Please refer to the MUHC Study number in all future correspondence relating to this study.

In accordance with applicable policies it is the investigator's responsibility to ensure that staff involved in the study is competent and qualified and, when required, has received certification to conduct clinical research.

Should you have any questions, please do not hesitate to contact the support for the Personne mandatée at personne.mandatee@muhc.mcgill.ca.

We wish you every success with the conduct of the research.

Sincerely,

Sheldon Levy
MUHC REB Coordinator
for MUHC REB Co-chair mentioned above

NAGANO PM / Final Authorization Single Site 1 / 1

CONSENT FORM

Centre universitaire de santé McGill
McGill University Health Centre

☒ HME MCH ☒ HGM MGH ☒ HRV RVH
☒ HNM MNH ☒ ITM MCI ☒ CL LC

FMU-9997

PEDIATRIC RESEARCH INFORMATION AND CONSENT FORM

Exploring and Understanding Adolescent Chronic Pain

Research Study Title:	Adolescent Chronic Pain: An Exploration of Social Implications and Coping Mechanisms
Protocol number:	2019-5047
Researcher responsible for the research study:	Dr. Pablo Ingelmo ; M.D. Pediatric Anesthesiologist (Pediatric Chronic Pain Management)
Co-Investigator(s)/sites:	Dr. Richard Hovey; McGill Associate Professor in the Division of Oral Health and Society Rachel Szwimer and Manuella Widjaja Nada Mohamed :Research Assistant pediatric anaesthesia

WHY ARE YOU BEING INVITED TO TAKE PART IN THIS STUDY?

The Montreal Children's Hospital Pediatric Chronic Pain Management Clinic participates in research studies to try to improve treatments for children with chronic pain. Today, we are inviting you to take part in a research study. Please read this information to help you decide if you want to participate in this research project. It is important that you understand this information. We encourage you to ask questions. Please take all the time you need to make your decision.

We encourage parents to include their child in the discussion and decision making to the extent that the child is able to understand.

In this research information and consent form, "you" means you or your child.

WHY IS THIS STUDY BEING DONE?

You have a disease/illness called chronic pain.There is currently no standard treatment for this condition . Unfortunately, many children find chronic pain to interfere with their daily lifestyle. Recent studies have shown that researching this subject might improve the understanding of chronic pain and the health services offered these patients. You are being invited to participate in a research study that aims to understand the lived experiences of patients living with chronic pain.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 8- 12 patients will take part in this study

WHAT WILL HAPPEN IN THIS RESEARCH STUDY?

- we will do face-to-face interviews with you
- Number of interviews: 1 interview
- Duration of each interview: 30-90 minutes (based on your comfort level)
- Location(s) where procedure(s) will take place: a private room at the Montreal Children's Hospital Pediatric Chronic Pain Clinic as assigned by the clinic's staff members.
- When will the interviews take place: between January and February to accommodate any holiday schedules
- Who will be asked to be interviewed: participants will be female adolescents between the age of 14-18 years old who have lived with chronic pain for at least 3 months and who agree to sign this consent form.
- How much information do you have to share: only as much as you are comfortable with. We will not have access to your medical charts.
- Who will be interviewing you: two female McGill graduate students
- Will there be a record of these interviews? yes there will be audio recording to the interview. We will only be collecting information necessary for the study such as your answers to our questions. You can choose whether you give us permission to audio-record (not video-record) the interview. The interviews will be later transcribed. We will identify common themes among the interviews and interpret your perspective living with chronic pain.

FOR HOW LONG WILL YOU PARTICIPATE IN THIS STUDY?

if you agree to participate in this study ,you will receive 1 interview which will last for approximately 30-90 minutes. Your doctor or the doctor in charge of this research project can also decide to take you off this study, namely:

o If she or he believes it would be in your best interests;

o If you do not fulfill the expectations for your participation, as described in this form.

WHAT ARE THE RISKS?

The McGill University Health Centre Research Ethics Board reviewed this study and is responsible for monitoring it at all participating institutions in the health and social services network in Quebec.

This study is non-invasive and there is no inconvenience other than the time it takes to be interviewed. We will thoroughly explain the procedure and assess your understanding of your role in this research study before conducting the interviews and obtaining written consent.

Only Dr. Ingelmo will store the audio transcriptions and collected data on his personal, secure, password-protected computer at the Montreal Children's Hospital.

There are no foreseeable inconveniences that may result from participating in this study.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

There is no direct benefit to you for participating in this research. We hope that what we learn from doing this study will help us find better ways to help and/or patients with chronic pain in the future.

WHAT ARE THE COSTS OF TAKING PART IN THIS STUDY and ARE THERE OTHER FINANCIAL ASPECTS?

- There is no funding or cost necessary for this study.
- You will not receive financial compensation for participating in this research study.
- The researchers have no conflict of interest to declare.

HOW IS PRIVACY ENSURED?

All information obtained during the study will be kept confidential as required or permitted by law. Your identity will be protected by replacing your name with a research number. Only the research team at your own hospital will have access to the code linking your name to this number.

In order to ensure your protection and quality control of the research project, the following organizations could consult your research and medical records:

- The sponsor(s) of this project;
- Government regulatory bodies such as Health Canada;
- The research ethics committees of the Quebec hospitals where the research is happening or a person mandated by one of them;

These organizations all adhere to a confidentiality policy.

If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

The principal investigator (Dr. Pablo Ingelmo) at your hospital will be responsible for securely storing all the research data for 7 years.

Only coded data will be sent and stored by Dr. Pablo Ingelmo.

The audio-recordings and transcripts of the audio-recordings will be destroyed 7 years after the completion of the research project.

IS YOUR PARTICIPATION VOLUNTARY?

Yes. Taking part in this study is voluntary. You may choose not to be in this study. You can decide to stop being in the study at any time. If you decide not to be in this study, or to stop participating in the study later on, this will not affect the quality of care you receive from your doctor.

We will tell you about any new information that may affect your health, well-being, or your willingness to stay in this study.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you have any questions about this research project or if you suffer any problems you believe are related to your participation in this research, you can call the researcher responsible for the project in your hospital:
Montreal Children's Hospital: Dr. Ingelmo at 514 412 4400.
In case of emergency, please go directly to the closest emergency room.
If you would like information about your rights related to your participation in the research, you may contact the hospital Ombudsman (Patient Representative):

- Montreal Children's Hospital: 514-412-4400, poste 22223

WHERE CAN I GET MORE INFORMATION?

You may ask to receive a copy of the results of this research project; these will only be available after the entire project has been completed.
You will receive a signed copy of this form. You may ask the research team questions at any time.

RESEARCH ETHICS COMMITTEE

The research ethics committee of the Montreal Children's Hospital approved this project and will monitor the project.

Title of this research project: Exploring and Understanding Adolescent Chronic Pain

I have been explained what will happen on this study. I read the information and consent form including the annexes and was given a copy to keep. I was able to ask my questions and they were answered to my satisfaction. After thinking about it, I agree to, or I agree that my child will, participate in this research project.
In no way does consenting to participate in this research study waive your legal rights nor release the sponsor or the institution from their legal or professional responsibilities if you are harmed in any way.

Name of participant (Print)	Assent of minor, capable of understanding the nature of the research (signature) or Verbal assent of minor obtained by: ________________________	Date
Name of parent(s) or legal guardian (Print)	Signature	Date
Name of participant (18 years +) (Print)	Signature	Date

I have explained to the participant and/or his parent/legal guardian all the relevant aspects of this study. I answered any questions they asked. I explained that participation in a research project is free and voluntary and that they are free to stop participating at any time they choose.

Name of Person obtaining consent (Print)	(signature)	Date