

# Understanding the lived experiences of adolescents living with chronic pain: the personal and social implications

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A Qualitative Phenomenological Exploration  
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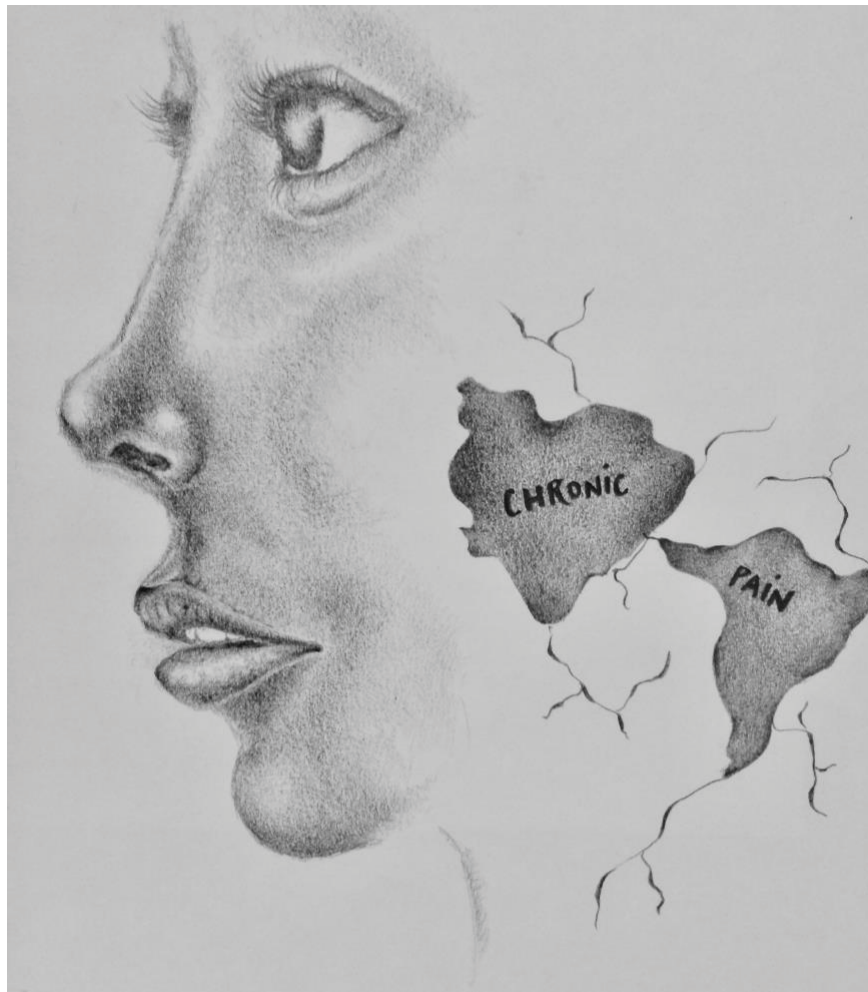


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*We wear **the** face that we want **others** to see.*



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## ABSTRACT

**Context:** Chronic pain (CP) negatively impacts everyday functioning resulting in significant physical and psychosocial stress and is a prevalent global issue. CP is mainly studied among adults; however, CP impinges on paediatric populations as well. Adolescence is a pivotal developmental period during which adolescents establish their personal and social identity; however, CP often interferes with this process. The majority of research studies conducted on CP patients are quantitative and explore CP through a primarily biomedical framework. However, research focusing on the barriers and facilitators contributing to the subjective CP experience is now shifting away from a predominately biomedical perspective over to one more inclusive of a biopsychosocial approach. The study that I am proposing is qualitative in nature and is based on patient-researcher interviews in order to gain insight into the lived experiences of adolescents suffering from CP.

**Objective:** To gain insight into and capture the voices of adolescents (14-17 years old, inclusively) living with CP to highlight the intricate ways in which CP affects both their personal and social life.

**Findings:** Findings revealed that **factors facilitating personal growth** among adolescents living with CP include processes that allow the individual to regain a sense of control over their life: occasionally disconnecting from reality to restore an internal sense of normalcy, recognizing which factors are within control (the psychological and not the physical), and re-engaging with reality in a way that is meaningful to them (actively seeking out a future that *they* envision). **Factors interfering with personal growth** relate to fixating on a purely biomedical approach of diagnoses and cures: facing the unpredictable nature of CP (which interferes with their plans, routines, and activities) and uncertain nature of CP (i.e.: the lack of answers with which medical professionals can provide). **Factors improving one's social belonging, sense of acceptance, and engagement in social settings** include having supportive family, friends, and/or healthcare staff that understand both the world of pain and adolescence. **Barriers impeding social development** include feeling different or abnormal relative to peers (in the sense that they are less independent, their priorities and maturity level differ from other adolescents their age, and they feel lonely due to CP causing them to miss many social

opportunities) and lacking accommodations in social and educational settings (due to facing disbelief, schools lacking proper resources to accommodate their needs, and feeling too ashamed to ask for help).

**Conclusion and future directions:** In showcasing the subjective adolescent CP experience, I hope the findings from this study will contribute to informing the practices of paediatric/adolescent CP management and rehabilitation clinics and school accommodation centres in order to better understand and assist these adolescents throughout their journey living with CP.



## RÉSUMÉ

La douleur chronique (DC) a des impacts négatifs sur le fonctionnement du corps au quotidien, entraînant un stress physique et psychosocial important et devenant un problème mondial croissant. La DC est principalement étudiée chez les adultes. Cependant, la DC est également présente et répandue dans les populations pédiatriques (enfants et adolescents). L'adolescence est une période charnière du développement au cours de laquelle l'individu établit son identité personnelle et sociale. Or, la DC interfère souvent dans ce processus tant sur le plan psychologique et social. La majorité des études de recherche menées sur les patients atteints de DC sont quantitatives et explorent la DC dans un cadre essentiellement biomédical. Cependant, la recherche axée sur les obstacles et les facilitateurs qui contribuent à l'expérience subjective de la DC est en train de passer d'une perspective essentiellement biomédical à une approche biopsychosocial de plus en plus inclusive.

L'étude que je propose est de nature qualitative (principalement basée sur des entrevues entre des patients et des chercheurs) afin de mieux comprendre les expériences personnelles vécues par les adolescents atteints de DC. L'objectif de cette étude est de recueillir les voix des adolescents (de 14 à 17 ans, inclusivement) qui sont prêts à partager leurs expériences et à démontrer comment la DC a changé le cours de leur vie personnelle et leur vie sociale. En mettant en valeur l'expérience subjective de la DC chez les adolescents, j'espère que les résultats de cette étude contribueront à éclairer les pratiques des cliniques pédiatriques de gestion de la DC, d'autres programmes de réadaptation de la DC, et des centres d'hébergement scolaire afin de mieux comprendre comment aider ces adolescents souffrant de DC.

Les résultats ont révélé que les **facteurs facilitant la croissance personnelle** chez les adolescents vivant avec la DC comprennent les processus qui aident l'individu à reprendre le contrôle de sa vie: prendre le temps de se débrancher pour rétablir un sens interne de normalité, changer sa perspective pour se concentrer sur ce qu'il peut contrôler (le psychologique et non le physique), et reprendre un engagement envers la réalité qui est important pour lui (par exemple, envisager un futur qu'il veut). Les **facteurs que interfèrent avec la croissance personnelle** sont la fixation sur la recherche d'un diagnostic concret et d'une solution permanente. Ces facteurs

comprene l'imprévisibilité de la douleur (qui nuit à leurs activités, plans, et routines) et l'incertitude de la douleur (c.-à-d. l'absence de réponses que les professionnels de la santé peuvent fournir). Les **facilitateurs** qui améliorent l'appartenance, le sentiment d'acceptation, et l'engagement d'une personne dans **un milieu social** comprennent le fait d'avoir des amis ou du professionnels de la santé qui comprennent à la fois le volet douleur et le volet adolescence. Les **obstacles au développement social**, quant à eux, comprennent le sentiment d'être différent ou anormal par rapport aux autres adolescents (en ce sens qu'ils sont moins indépendants, que leurs priorités et leur niveau de maturité diffèrent de ceux des autres adolescents de leur âge, et qu'ils se sentent seuls parce que leur DC leur fait manquer de nombreuses occasions sociales), ainsi que le manqué de logement à l'école ou chez leurs amis (à cause de leur manque de confiance et de ressources adéquates pour satisfaire leurs besoins et de l'honte trop forte de demander de l'aide).

## DEDICATION AND ACKNOWLEDGEMENTS

This thesis dissertation would not have been possible without my inspiring supervisor (Dr. Richard Hovey) and research participants. I am sincerely grateful for the insight with which the participants have provided me by allowing me to interview them and learn from their experiences. I am beyond thankful to Dr. Hovey for exposing me to the richness of qualitative research, giving me the freedom to study a topic that I find personally meaningful, and guiding me with his expertise of interpretive phenomenology. This opportunity has far surpassed my expectations in gaining a greater understanding of the diversity of human experiences and in appreciating the challenges with which different individuals cope.

Coming from a Physiology undergraduate degree, I am used to analyzing “patient-like cases” from a purely biomedical model: which *gene* is mutated, thereby making which *ionotropic channel* non-functional, underlying which *disease*, and requiring which *pharmacological treatment*. If you would have asked me what I thought of this model of medicine prior to embarking on my Masters degree, I would have sang words of praise for this “methodical”, “rational”, and “objective” approach that most *expert* physicians follow. However, I now understand that patients carry with them a degree of expertise to which most physicians are not privy: the expertise in understanding the personal and social implications related to living day-in and day-out with a chronic condition. As captured so perfectly by one of my participants,

***“We’re not specialists, but we’re almost like specialists in what we live”.***

Dr. Hovey has opened my eyes to the duty of clinicians to *learn* from the narratives of those they treat and to *address* the psychosocial and individual concerns in addition to the biomedical issues.

I would like to extend a special thank you to my collaborators at the Montreal Children’s Hospital Chronic Pain Management Clinic Dr. Pablo Ingelmo, Dr. Nada Mohamed, Dr. Marta Somaini, Yves Beaulieu, Rebecca Pitt, Cindy Grenier, and Sabrina Carrie for their kindness and assistance in recruiting participants from the clinic and for so willingly welcoming me into the community of CP care. Dr. Ingelmo’s team taught me the interdisciplinary expertise required for

CP management and ultimately taught me that living with pain is an obstacle that can be overcome and not a roadblock.

I would also like to thank Manuella Widjaja, my fellow researcher and someone who I can now call my good friend, for being an absolute pleasure to work with throughout this project.

Last but not least, I am infinitely grateful to my biggest fans and greatest supporters (my parents Cheryl and Joe and brothers Daniel and Benji) for their unwavering support as I continue striving to pursue an academic journey studying what I am most passionate about, and – perhaps most importantly – for leaving me all of the cut-outs in the world of journal articles on *anything* and *everything* pain-related. With age and maturity, I have come to realize how fortunate I am to have so many powerful role models in my immediate family alone who have profoundly shaped the type of person I am and the type of professional I will become and the rippling effect that their impact will have on all those whose lives I am and will be fortunate enough to touch as I embark on my journey studying medicine at McGill University.

## **PREFACE AND CONTRIBUTION OF AUTHORS**

The candidate, Rachel Szwimer, wrote all sections of this thesis dissertation. Dr. Richard Hovey was the supervisory author. The candidate obtained ethics approval for this study with the guidance of Dr. Nada Mohamed and created recruitment materials and research consent forms in both English and French. The candidate and a fellow Master's-level student in Dr. Hovey's research team (Manuella Widjaja) carried out the field work and data collection for this study, transcribed the data, and de-identified the transcripts between January and April 2019. The candidate performed the data analysis and review of the literature during this time as well. Any information utilized in this thesis that is based upon the work(s) of others has been cited in the "Bibliography" section of the Appendix.

## I. INTRODUCTION

### Structure of My Thesis

During my research inquiry, I explored the lived experience of adolescent females living with CP. My second chapter includes the literary review of current research on this subject while my third chapter focuses on the methodology of my exploration. My fourth chapter highlights my main findings from this study: the facilitators and barriers that CP imposes on the personal and social life of these adolescents.

### Self-Disclosure

When I was young, the pain I experienced was rare and came in the form of my scrapped knees throbbing after falling off my training-bike, bruises that my siblings left behind after a ‘play wrestling match’, or maybe even the heart-ache of losing my favourite teddy bear. Now *that* was real pain...until I turned twenty years old and was diagnosed with ulcerative colitis.

I rarely talk about my illness because – like many people who suffer from pain – I believe that there is always *someone somewhere* who is experiencing pain that is *actually* worth discussing. However, this hesitation begs the question: if I can choose when to hide or discuss my pain, can that ‘*someone somewhere*’ do so as well? And, if so, what does someone with CP look like? Are *they* necessarily walking around wincing in pain, or are *they* perhaps our best friends, our relatives, or maybe even the researchers conducting CP studies?

My interest in CP began in my third year of my physiology undergraduate degree when my professor called upon different students to guess the approximate number of hours allocated to the study of pain in medical school. I challenge you, dear reader, to take a guess. To my surprise, the answer was roughly 7 to 9 hours despite the fact that most patients book appointments with their physician(s) because of pain. Then, I stumbled across Dr. Richard Hovey’s article “Occasionally a Patient: Always a Person” while I was searching for a graduate supervisor. This article exposed me to the beauty of qualitative research and person-centred

narrative medicine; this branch of research emphasized the fact that there is a **person** behind the research statistics and a numerical value that needs to be humanized with a narrative.

Having studied physiology for 3 years at McGill University, I have taken courses in a wide variety of disciplines ranging from the molecular, physiological, and psychosocial levels of *the human*. Throughout my undergraduate studies, I have been involved in molecular research of diabetes at the Lady Davis Institute during which I was privileged to learn the importance of contributing to patient health from a cellular and tissue level. Now, I am eager to partake in research that focuses on the patient as a whole, such as learning about their personal experiences of suffering from CP and willingness to embrace treatment plans and coping mechanisms. In the future, I wish to be an active participant in patient care with a keen understanding of and sensitivity to the patient-perspective and the psychological sufferance that they endure as a function of lifestyle changes imposed on them by their condition(s). Richard was kind enough to guide me through a Master-Science Thesis Degree during which I was provided with an appropriate environment to study patients living with chronic disorders and pain and learn about the patient experience through the eyes of those that are coping with these chronic conditions.

## **Rationale for the Inquiry**

Pain is an invisible condition in the sense that many people trapped in a world of pain can often choose when and when not to let others know that they are experiencing pain. I care deeply about capturing the voices of those that are willing to share their narrative and shed light on the intricate ways in which pain has changed both their personal and social life. Pain research mainly focuses on adult and geriatric populations. However, adolescence is a pivotal period during which one establishes a personal and social identity. CP often robs one of that identity – whether it be the competitive soccer player or cross-country skier – and leaves one scrambling to find a new niche or ‘title’ that meets their new limitations. Understanding the transition from hopelessness to thriving with pain (both in one’s personal and social life) through the lens of a teenager is essential to developing strategies to help future adolescent pain-sufferers. I hope that my research will help healthcare practitioners better understand how to assist these adolescents throughout this life-long journey coping with pain by showcasing the experiences of adolescents

living with CP. Sharing my findings and liaising with Dr. Ingelmo's team at the Montreal Children's Hospital will help me meet this goal.

## Meet My Participants

In order to preserve confidentiality, I have used pseudonyms in the place of my participants' names. The following table provides a concise overview of the demographic variables included in this dataset: age (in years), high school grade, and duration of the pain (in years).

**Table 1.** Participant Demographics

Adolescent	Age (in years)	High School Grade	Duration of pain (in years)
Arianne	14	9	3
Jordana	15	10	6
Andrea	15	10	4
Mona	15	10	4
Jasmin	16	11	3
Jamie	16	11	4
Hilary	17	11	6.5
Callie	17	CÉGEP Year 1	5

This study did not oblige participants to consent to having their medical charts reviewed, and therefore I cannot comment on the accuracy of my participants' self-reported medical diagnoses nor the duration of their pain. In addition, each participant's journey with pain began with many misdiagnoses which also complexifies the estimation of the duration of pain. However, based on the interviews, these participants seem to vary in terms of their diagnoses with the most common self-reported diagnoses being back pain, stomach pain, and head pain. And, the average duration of pain seems to be 4.5 years.



## Getting to know the Person behind the ‘Patient’

### Arianne

As the oldest of 3 sisters, Arianne – who is talkative, has a bubbly personality, and enjoys the adventure of travel and trying new sports – jokes about how her teenage-mood swings have drastically influenced how much she can tolerate her siblings. Arianne’s father’s occupation requires their family to travel frequently, and Arianne fondly described the years that she enjoyed living in France, India, Australia, and London. She comes from a family of animal-lovers who train seeing-eye dogs for 18 months at a time. Arianne is currently in Secondary III and has lived with stomach pain for 3 years that began with an alleged bout of giardia and continuous antibiotic treatments. Due to the severity of her ongoing pain, Arianne is limited to low-impact physical activity and has had to give up several of her favourite sports such as cross-country skiing (her biggest passion), fencing, horse-back riding, as well as bi-athlons and proving that she is faster than the boys at the ‘beep-test’ in gym class. Yet, she views her limitations as temporary obstacles and meanwhile has become an avid reader and rock climber.

### Jordana

While waiting to meet Jordana in the waiting room, Dr. Ingelmo told me that I would know who she is when I see her: ‘a sweet one’. His definition could not have been truer. Jordana considers herself to be a strong student and is bothered by the fact that doctors’ appointments cause her to miss her classes. She believes that her perseverance and strong work ethic will help her achieve her academic goals. To date, Jordana has been a patient at the Montreal Children’s Hospital Chronic Pain Management Clinic for 3 years being treated for foot pain that makes it difficult for her to walk and play sports, yet Jordana remains positive by reminding herself of the importance of being grateful: grateful for her mother’s attempt to give her everything within her means and grateful for the fact that she is not battling a condition *worse* than CP. Jasmin claimed that her foot pain was triggered by several (4) foot fractures during her gymnastics training. Her mother and her are hopeful that she will undergo a successful surgery to ‘rectify’ this issue within the next 4 months.

## Andrea

Andrea is sandwiched between a younger and older brother and describes herself as a ‘tomboy’. Andrea suffers from recurrent head, back, and stomach pain that began 4 years ago, and she mentioned that she experiences ‘many other types of pain’ as well. Andrea’s head pain began with headaches that were dismissed by medical professionals as being concussion-related. However, after 4 to 5 months of ongoing pain, Andrea’s doctors began searching for an alternative diagnosis. Prior to the onset of her pain, Andrea was a competitive soccer player and enjoyed playing both the piano and saxophone in music class. Following the onset of her pain, the long commutes to and from school became unbearable so she transferred to a high school closer to home and stopped playing her musical instruments and soccer just before potentially being drafted for a regional-level soccer team. Andrea is motivated to improve her functionality and is slowly returning to soccer albeit in a less competitive league. She is determined that she will eventually return to her original league and – for now – has become interested in sewing.

Andrea’s mother joined us during our interview and contributed to our discussion.

## Mona

At the start of high school, Mona was diagnosed with spondylitis – a hairline fracture in her lumbar spine – that has left her with CP. As with many of my other participants, Mona’s diagnosis was not confirmed until months of misdiagnoses and unexplained pain. Her condition impinges on her unable to play volleyball and basketball, and her mobility limitations have rendered weight management an additional stress. This set-back in sports has allowed Mona to delve more deeply into her artistic hobbies such as opera singing, listening to music, and painting. Mona is exasperated with physiotherapy sessions from which she has yet to notice an improvement in her functionality, yet she recognizes the importance of adopting a more motivated mindset and is hoping that her exercises will *eventually* allow her to resume participating in gym class with her friends.

Mona’s mother joined us during our interview and contributed to our discussion.

## **Jasmin**

Jasmin was the first person I interviewed. From the information that Jasmin chose to share with me, she appeared to be well-supported by her family and friends. The fact that both of her parents and her younger brother came to the clinic for her appointment was a testament to her strong support system. Jasmin is currently in high school (Secondary V) and has been living with CP for 3 years (since Secondary II). Over the past 3 years, clinicians assessed the possibility of Jasmin's CP being arthritis-related before referring her to the paediatric CP management clinic at the Montreal Children's Hospital with an 'undetermined diagnosis'. Her frustration with her pain and her courage to continue progressing were apparent throughout our discussion. During these past 3 years, Jasmin has had to give up dancing and other physical activities that she enjoyed. She finds motivation to continue thriving through her new-found passions for music and art.

## **Jamie**

Jamie is a soft-spoken 16-year-old in Secondary IV who is a goaltender for her local hockey team, does yoga, and loves being active. Jamie experienced pain in her feet and knees several years ago and spent years being treated by doctors who suspected that the culprit was juvenile arthritis. In November 2018, Jamie's pain spread to both of her arms and hands. Jamie is the only participant I interviewed who had a visible limitation due to her chronic illness because her hands are now clenched in permanent fists. Jamie's condition requires her to have constant assistance. For example, she relies on her friends to open her goalie gloves up enough to fit her fists inside and her yoga teachers to adapt the exercise positions according to her physical capabilities. Jamie seems very patient and maintains an optimistic outlook of her course of treatment.

## **Hilary**

Hilary is a 17-year old in Secondary V who has a very close relationship with her mother and nephew and refers to herself as a 'homebody'. The mother-and-daughter duo enjoy spending most of their free-time together and have become increasingly close ever since the onset of Hilary's CP. Unlike the other participants, Hilary claimed that she is unphased by the limitations that have been imposed on her during the past 7 years living with CP due to severe migraines and

prefers to focus on staying positive. Hilary also mentioned that she does not care what others think of her and has shared powerful stories of experiences she has had defending other vulnerable students against bullies at school. After having to give up rugby and other sports, Hilary channeled her more artistic side and took up drawing and photography.

Hilary's mother joined us during our interview and contributed to our discussion.

## **Callie**

Callie is the oldest participant that I interviewed. She is turning 18 years old in April. I included her in my study particularly because I want to shed light on some of the daunting feelings these adolescents experience as they transition from the Montreal Children's Hospital Chronic Pain Management Clinic to the Alan Edwards Pain Management Unit at the age of 18. Callie suffers from vaginal and pelvic pain after a traumatic event at the age of 12. She explained how her pain completely changed her mentality and that she often found herself lacking the motivation to live. Callie is an independent young woman who had to see to it that *she* scheduled her own appointments at the Pain Management Clinic as of 12 years old. Although she continues to struggle physically and psychologically from her ongoing pain, she is now in CÉGEP studying Physical Education, holds a retail employment position, turns to her artistic drawings in moments of extreme pain, and appreciates the support of her boyfriend who accompanies her for her appointments.

## II. LITERARY REVIEW

### Timing: When I Reviewed the Literature

In most research studies, a review of the literature is carried out prior to the study so as to place the current study in context of the existing literature. In other words, a literary review is necessary for the researcher to justify why they have chosen a particular research topic and how their research inquiry will serve to fill a gap in knowledge regarding said topic. However, the literary review is postponed until after data collection and analysis in phenomenological research so that previous findings do not influence the questions that the researchers/interviewers pose. Performing the analysis before the literary review ensures that the researcher will not analyze data for themes that they know already exist and are supported in the pre-existing literature [1]. Therefore, I chose to time my literary review accordingly.

### Definitions

#### What is Pain?

In 1986, the International Association for the Study of Pain defined pain as “an unpleasant sensory *and* emotional experience that is associated with actual or potential tissue damage or described in such terms” [2]. However, those experiencing pain may prefer to define pain as a phenomenon that is “whatever the person says it is and exists whenever he/she says it does [3].

Pain is a phenomenon difficult to encapsulate in a few short words due to its multidimensional and highly complex nature and the fact that pain is individual to each sufferer. From a clinical perspective, pain can be diagnosed as acute, chronic, neuropathic, neuroinflammatory, referred, and/or phantom, among many other forms. Despite the complexity of pain, the biomedical model for treating pain generally follows 3 neat steps: diagnose pain as a physical condition, prescribe treatment, and monitor the pain with the expectation that the pain will be cured [3]. However, even within the group of individuals diagnosed with the same *type* of pain, the experience of pain is highly subjective and therefore the road towards recovering

functionality varies for each individual [4]. Researchers are beginning to explain this intersubjectivity using a biopsychosocial model rather than a purely biomedical model: this more inclusive model accepts that one's experience of pain is dependent not only on a physically nociceptive input (the painful stimulus) but also many other factors that influence how pain is perceived [3]. These influences include psychosocial factors (such as the person's beliefs, expectations, and mood) and behavioural factors (such as context, responses by significant others, and cultural acceptance of openly displaying pain) that contribute to shaping the subjective pain experience [3, 5, 6]. These psychosocial and contextual factors have an increasingly more prominent role for CP sufferers than acute pain sufferers because ongoing pain begins to affect or lead to poor sleep quality, quality of life, catastrophizing, and interference with socializing and daily activities [5]. Therefore, CP – a phenomenon involving psychological, behavioural, and physiological mechanisms – is multifaceted and has a much less straightforward relationship between nociception, suffering, and pain behaviour as compared to acute pain [3, 4].

### **What is Chronic Pain?**

CP is defined as pain that persists past normal healing time and is therefore experienced without the acute function of physiological nociception [3, 4]. The International Association for the Study of Pain defines “3 months [as being] the most convenient point of division between acute and chronic pain, but for research purposes 6 months will often be preferred” [7].

### **The Assessment of Chronic Pain**

The way in which pain is evaluated in clinical practice is essential in directing the course of pain treatment and management. Most clinicians follow a biomedical model of assessing pain beginning with a thorough history, physical examination, laboratory tests, and diagnostic imaging procedures in order to identify an underlying pathology causing the pain [6]. Often, clinicians will resort to having patients summarize the complexity of their pain experience with a neat self-reported number on a Numerical Rating Scale ranging from 1 to 10 in order to monitor the severity of the pain. This simple digit fails to describe the psychosocial and behavioural

factors that help shape the subjective experience of pain [6]. In pain management clinics, the psychosocial factors are weighted more heavily, yet there is still very little emphasis on and ways of assessing patients' sufferance. Sufferance is the power to withstand hardship or stress and relates closely to endurance [8]. This capacity is a valuable factor in the assessment of how one manages, tolerates, and copes with pain.

## Chronic Pain among Adults (18 years or older)

### The Prevalence and Gender Differences of Chronic Pain among Adults

Point prevalence is defined as the proportion of cases of a specific disease present in a particular population at a given *time*, whereas period prevalence is the proportion of cases of a specific disease that is present in a particular population during a given *time period* [9]. There are many issues with deriving an estimate of 'prevalence' from a meta-analysis of existing literature. Several of these issues include differences in the following:

- ⇒ definitions of prevalence (e.g.: point prevalence versus period prevalence), the definition of 'adult', or the definition of the condition in question;
- ⇒ modes of data collection (e.g.: questionnaires with 1-2 question have low validity and may lead to misclassification);
- ⇒ demographic characteristics of chosen participants in terms of sex, income, levels of comorbidity, age, etc.;
- ⇒ cultural contexts and regional differences; and/or
- ⇒ potential selection bias (e.g.: health surveys which individuals without health problems may be less inclined to complete, researchers who recruit participants from healthcare clinics that specifically treat chronic pain conditions) [10, 11].

However, I will proceed to discuss the prevalence of adults with CP despite these potential issues. The term 'adults' will be used to describe individuals 18 years and/or older.

The prevalence of CP for adults in Canada is reported to be 18.9% and appears to increase consistently with age. For instance, the prevalence of CP is reported in 10% of individuals sampled in the 15-to-24-year-old age category and 35% of those in the 75-years-old-

and-up age category [10, 12]. Other studies report a similar increase of CP prevalence with age: 17% of individuals sampled in the 18-to-34-year-old age range and 33% in 55-years-old-and-up age group [13]. The majority of CP cases across all age categories is reported as severe levels of persistent pain with the most common site and cause being arthritis-related chronic lower-back pain [14, 15]. In terms of functionality, an Ontario study of adults with CP reports that approximately 16% of adults have high pain intensity with moderate or greater interference with mobility and daily activities [16]. And, in terms of gender differences, more females appear to be afflicted by CP [17-19].

Although the above-mentioned studies focus on Canadian populations, CP has become a pressing global issue considering how disabling CP can be and how CP interferes with one's everyday life [11, 20]. 25-30% of the global population in industrialized countries suffer from CP [21] and the World Health Organization reports a 37% CP prevalence in developed countries [11]. CP is not only a global health concern but also a drain on economic resources. CP costs the US government 40 billion dollars annually due to the direct costs of health care, decreased wages, and loss of productivity and eclipses the cost of any other health condition [21, 22].

## **Chronic Pain among Youth (17 years or younger)**

### **Adolescence**

Adolescence is defined as the period between the physiological onset of puberty and the acceptance of an adult identity and behaviour [23]. Adolescence roughly corresponds to ages 10 through 19 and is the period of greatest and most rapid development after the fetal period and infancy because adolescents undergo final maturation of multiple organ systems and major central nervous system changes accompanied by psychosocial changes [24]. From a psychosocial perspective, adolescents' autonomous behaviour and identity emerge during this critical period as they become less dependent on their parents, more dependent on their peers, develop their emotional and social skills through social exposure, and experiment with their identity [24, 25]. Hence, adolescence is a time of crucial personal exploration and growth that is facilitated through social exposure and relations.



Any challenges that hinder this adolescent stage of development may pose barriers that carry over into adulthood. Often, adolescents suffering from CP have higher rates of school absences and parental protectiveness, and therefore have fewer opportunities for peer-group participation, social interaction, and social acceptance which are crucial for identity exploration and development [25]. CP interferes with normal adolescent social interactions in which a sense of self and autonomy are generally developed [26]. Adolescents that lack these social opportunities may suffer negative psychological consequences such as loneliness, role-loss, and depressive symptoms, however, these symptoms cannot be fully explained by lacking friendship features alone [27-29]. The combination of biological processes, psychological factors, and social and environmental factors impact how CP is experienced in children, adolescents, and adults alike [30]. Therefore, further research is required to identify the full scope of factors – social, and otherwise – that contribute to these negative symptoms and how these factors explain the maladaptive outcomes of CP.

For the purposes of this study, the adolescents recruited will include individuals ages 14 to 17 years old because those are the ages of most adolescent patients that frequent the Montreal Children’s Hospital Chronic Pain Management Clinic (the centre from which participants were recruited).

### **The Prevalence and Gender Differences of Chronic Pain among Adolescents**

Research on CP in paediatric populations (17 years and less) is less studied than in adult populations despite the fact that the prevalence of CP in children and adolescents is reported to be between 8 and 25% [29, 31]. Similar to findings in adult populations, prevalence rates appear to be higher in females and increase with age for most types of pain [30]. Therefore, among the paediatric population, the highest rates of CP are found among adolescent females – especially girls in middle school and high school [31, 32]. Sex differences also exist in how adolescents cope with their CP and how they respond to pharmacological analgesic therapies which may elude to a need for sex-specific CP management programs and treatments [33-35]. For instance, in terms of coping mechanisms, a study in the United Kingdom found that female adolescents have higher rates of seeking social support, entertaining positive statements, and even

catastrophizing than adolescent males with a corresponding pain chronicity and type, while the adolescent males engage in more behavioural distraction [33].

### **The Social Implications of living with Chronic Pain as an Adolescent**

Adolescence is a developmental period during which one tests various social skills in the absence of parental monitoring in order to establish the necessary abilities to maintain peer relationships as one matures into an adult [36, 37]. Transitioning from childhood to adolescence and adolescence to adulthood is a challenge in its own right, however, those suffering from or living with CP face the additional stress of trying to make sense of a condition that is still not entirely clear to the medical community. For instance, friendships are reported to help reduce the rates of victimization, loneliness, and depression in children [38, 39], however several studies report that adolescents suffering from CP feel misunderstood by their friends and have decreased social functioning and peer relationship deficiencies [30, 36, 40-42]. Due to the uncertain and unpredictable trajectory of CP, these adolescents often face stigmatization and disbelief from their peers, family, and professionals which leads many of these individuals to shy away from discussing their condition [36] as they may feel as though they are ‘weak’ or ‘unworthy’ of others’ compassion. Considering that many adolescents suffering from CP have to give up leisure activities, school becomes their primary location for socializing. However, living with this (often) invisible illness of CP distinguishing them from their peers and can often make these in-school interactions feel far from ideally supportive in the sense that they may feel as though their peers do not understand their needs and/or challenges [36]. A 2011 adolescent pain study suggests that “[w]hen adolescents with chronic pain do not perceive their friends as providing support, they tend to avoid social situations” [44, p.1]. Therefore, a lack of support introduces self-imposed limitations that further impede on their engagement in social activities in addition to the already-present physical limitations [45]. This social avoidance perpetuates a vicious cycle of weakening one’s social ties and even further limiting participation in social situations. A 2014 “Painful Truth Report” survey conducted by the Canadian Pain Coalition found that CP sufferers wait on average 18 months to see a specialist [43]. Therefore, many children and adolescents suffer from the psychological stress and isolation of living with a CP condition that distinguishes them from their healthy peers without having a specific diagnosis to explain said difference.

The combination of an adolescent's psychological experience living with CP, increased parental protection, decreased energy levels, and school and extracurricular absences contributes to adolescents with CP spending more time apart from their peers, thus threatening their *existing* relationships and stunting their opportunities for social growth [36, 45]. For example, adolescents with CP due to headaches miss an average of 2.5 days of school in a 1-month period [46].

The fact that the prevalence of CP is lower in minors in comparison to adults also indicates that fewer children and adolescents with CP have peers who experience similar pain which further contributes to feelings of isolation [36]. Similarly, the increased dependence on their parents and healthcare team puts adolescents with CP in a more helpless and vulnerable position relative to their healthy adolescent peers who are becoming increasingly independent and autonomous. In brief, adolescents with CP report social isolation and difficulties developing and maintaining relationships with their peers as the differences between them and their healthy peers become more and more pronounced [46]. The fact that CP is less prevalent in youth also translates into there being fewer healthcare professionals treating paediatric CP. In turn, these children and adolescents are left with fewer specialists in an area of medical research that already has many unknowns, and therefore, wait even longer between follow-up appointments and before arriving at a 'diagnosis' compared to adults with similar conditions. Consequently, these long delays mean *another* day at school missed, *another* missed social opportunity, and *another* day without a *believable* and *tangible* explanation for why they are experiencing crippling pain incomparable to those around them.

Furthermore, adolescents suffering from (or living with) CP often experience a confusing change in their emotional climate even at home. The majority of parents become more loving, more indulgent, and less disciplinary of their children living with CP, while in far fewer cases family members reject the ill child/adolescent and criticize him/her for causing inconvenience [47]. Ultimately, one's social and contextual influences both have a significant role in shaping an adolescent's identity and perceptions of their lived experiences.

## The Personal Implications of living with Chronic Pain as an Adolescent

The effect of CP on both social relationships and personal development are not isolated concepts. Social issues faced by those with CP often infiltrate their personal life. Adolescents with CP often describe themselves as more *emotionally mature* than their peers because their pain has taught them to be more concerned with the consequences of their actions and has exposed them to intense experiences managing unexplainable and unanticipated pain [36, 48]. However, these same adolescents often feel less *socially mature* due to their more limited experience engaging in social contexts [36]. Again, this social and emotional disconnect between adolescents with CP and their peers reinforces feelings of not belonging to a group and fuels feelings of loneliness [45]. In addition, CP is associated with comorbid anxiety and/or depression [49-51]. These comorbidities may be related to the fact that individuals with concealable stigmatized identities – such as CP – can potentially withhold how they are feeling from others (to a certain extent) and may therefore be vulnerable to psychological distress which can influence daily functioning and quality of life [52].

Apart from the effect of CP on peer relationships, CP often also pervades one's personal thoughts and identity. CP challenges adolescents to “rethink the way they viewed themselves” [36, p.3] as the thought of possibly living with CP *forever* sets in and the possibility of returning to leisure activities enjoyed prior to the onset of pain begins to feel less likely. Many adolescents suffering from CP perceive the uncertain nature of pain to be limiting in terms of their ability to plan activities in advance [36]. Therefore, the possibility of goal-setting and the sense of personal accomplishment that one experiences upon achieving said goals begin feeling farther from reach, thereby feeding into one's sense of hopelessness and worthlessness.

Personal beliefs about pain may influence how one copes with its chronicity and how readily one can adopt a new perspective, identity, and suitable hobbies. Individuals who cope with their pain by catastrophizing their condition (or have parents who catastrophize the pain) tend to have greater psychological distress, pain, and functional impairment [53-55]. Likewise, adolescents and parents less willing to accept the importance of the psychological, social, behavioural, and contextual factors influencing the ‘*pain problem*’ will be less likely to engage

in treatments targeting these diverse realms of functioning and often experience later functional recovery [56, 57]. In adult CP research, readiness to self-manage one's pain is associated with improved pain treatment and coping [58]. An adolescent's motivation and readiness for change may also contribute to successful pain self-management as one transitions from health literacy to health agency [56]. In Hovey's publication "*The gift of pain with transformative possibilities*", the '*gift of pain*' is a metaphor used to describe the transformative potential that becomes feasible only when one becomes receptive to the possibilities available to them while living with their pain. Hovey describes the Hermeneutic Wager – introduced by Kearney – which is a self-reflective step-wise process of assessing the risks of decision-making as one moves from hopelessness towards discovering this '*gift of pain*' [59]. With each additional stage of this process, one moves one step closer to engaging in a transformative possibility and thus the risk involved is higher. For instance, imagining partaking in an activity is stage 1 and involves very little risk because the individual with CP has yet to share their thoughts or plans with others. The 5 steps that Hovey used in his own personal experience are as follows:

- ⇒ **Stage 1** - Imagination: this stage involves simply **imagining** your possibilities and contemplating which seem most realistic. One might ask themselves: *What might be of interest to me and what information must I gather to partake in this possibility (e.g.: do the research to find the activity location)?*
- ⇒ **Stage 2** - Humility: **assessing** whether you are prepared to take the risk of engaging in and continuing to attend said activity despite possible failure or humiliation
- ⇒ **Stage 3** - Commitment: planning to **attend** the activity. This stage is the stage of action as one transitions from health literacy to health agency because the knowledge gained about how to live with CP is beginning to be put into effect.
- ⇒ **Stage 4** - Discernment: this stage of self-awareness involves **reflecting** on and processing the meaning of and effect that attending that activity had for you. One might ask: *would I attend that activity again in the future?*
- ⇒ **Stage 5** - Hospitality: **welcoming** all new experiences and recognizing that there are no absolute successes or failures and that incompatibility with a certain activity/possibility may simply indicate a need to try that activity again at a later date.

Essentially, these 5 steps outline the stages that many individuals with CP encounter when learning how to live their life well with CP. Adolescents with CP may adopt new hobbies or goals that seem feasible in the short-term irrespective of their pain. However, to date, there is very little research on the kinds of activities that adolescents with CP tend to adopt while embracing this transition or how they come to the decision to choose certain activities. Most research regarding adolescent CP experiences instead focuses on quantitative factors such the rate of absenteeism from extracurricular and academic activities as opposed to giving voice to the adolescents living this condition day-in and day-out.

## Need and Purpose for Study

Patients and physicians prioritize different goals with respect to CP management [60]. Perhaps most adolescent patients with CP prefer to continue hoping that their pain will magically disappear while the medical professionals are already focusing on approaches to manage their pain long-term, or perhaps adolescent patients may have different long-term goals or ways of coping with their CP compared to those planned and anticipated by the healthcare team. The purpose for this study is to compliment quantitative adolescent pain research using a qualitative approach that emphasizes the *patients'* perspectives. In doing so, I hope to highlight more of the psychosocial aspects (of the bio-**psychosocial** model) implicated in one's journey to becoming functional despite the ongoing pain. Adult pain literature is far more extensive than paediatric pain literature, yet adult pain management techniques are not necessarily directly applicable to children and teenagers. This gap in paediatric pain management research is detrimental to the individual suffering and to society as a whole because this lack of understanding of the paediatric pain experience often means these children and adolescents are not being equipped with the necessary pain management coping skills. Failing to adequately manage pain in youth likely means these individuals will age into **adults** that lack the proper mechanisms to cope with their CP. As mentioned above, pain is a multidimensional phenomenon and the perception of pain is influenced by behavioural, emotional, and other contextual factors that require further understanding. Appreciating how adolescents with CP perceive their condition, the personal and social lifestyle changes they have to make, and the goals they wish to set is a crucial step towards developing appropriate therapies and interventions that target *their* needs.

## Central Research Question

The central research question for my thesis is:

What are the psychological and social implications (barriers and facilitators) faced by adolescents living with CP? In other words, I am interested in exploring (through the perspective of adolescents with CP) how their thoughts/feelings and social life are affected by their CP condition.

Qualitative research does not aim to test a hypothesis. Instead, this research is an inquiry into personal experience.

### III. METHODOLOGY

#### Interpretive Phenomenology as a Philosophy and Research Approach

At a time when truth and reality were considered to be objective and external to human experience, Edmund Husserl countered this worldview with the introduction of the phenomenological philosophy in the 20th century. Phenomenology explores the essence of lived experiences according to how they appear to those that experienced them [61].

Husserl believed that describing a phenomenon in its purest form required ‘bracketing out’ extraneous and contextual factors that would otherwise influence how phenomena are understood. In other words, Husserl’s branch of phenomenology – commonly referred to as **descriptive phenomenology** – focuses on the objective and universal essence of lived experiences as they appear through consciousness [62]. Ultimately, Husserl’s work lends itself to a research approach grounded in both philosophy and lived experience [63]. However, criticisms surfaced as to how a philosopher-researcher can completely ‘bracket out’ the influences that their own beliefs and contexts may have on their findings. In response to these arguments, the following more comprehensive definition of ‘bracketing’ was proposed. Humans are not blank slates, but rather apply their attitudes, prejudices, and prior knowledge to each situation. Therefore, ‘bracketing’ involves being aware of such biases and bringing them to the foreground as much as possible so as to acknowledge and reduce their power over the conclusions drawn [64].

A new branch of phenomenology as an interpretive inquiry arose from these criticisms: **interpretive phenomenology**. This branch arose based on Philosopher Martin Heidegger’s notion that humans are “always already embedded in a world of meaning” [62, p.2]. Heidegger’s view insinuates that researchers cannot be separated from their assumptions about the phenomena under investigation and that these preconceptions are necessarily integrated into their findings. In the mid 1920s, Georg Gadamer – colleague of Heidegger – contributed to interpretive phenomenology by emphasizing the importance of *language* revealing *being* and *existence* [65]. This statement implies that the language one chooses to represent their experience



forms the window into which the researcher/philosopher peers and interprets. Gadamer also claimed that “dialogue seeks resolution in a fusion of horizons” [66, p.1] whereby horizons are intellectual beliefs and limits of our understanding while the integration or ‘fusion’ of different perspectives lends itself to forming a broader horizon from which multiple interpretations may be drawn. Therefore, the experiences of others and the language into which those experiences are sedimented is accessible to the researcher only through their own knowledge and perspective of the external world [63, 67]. This metaphor of horizons fusing also suggests that interpretation is dynamic considering that perspective is constantly changing as a function of time and the conclusions drawn from a phenomenological study provide us with only a snapshot in time. Therefore, I acknowledge that the findings that I drew from this inquiry are influenced by my own knowledge and the time in which I chose to study the data.

My preferred conceptualization of the context-dependency of interpretive works is Hovey’s proposed metaphor of a *hurried walk in a museum* to illustrate the haste with which observers may rush past artistic masterpieces without deeply engaging with the artworks’ history, meaning, nor context [61]. Museum artworks have been taken out of the original place and time in which they were created and relocated onto the walls of a contemporary museum, thereby requiring much more time and effort to imagine the artworks in their original context, understand their richness, and interpret their meaning using a phenomenological framework [61]. Qualitative research seeks to portray a world in which reality is socially constructed, complex, and ever-changing. Interpretive phenomenology as a qualitative research approach focuses on individuals’ perceptions of that reality and phenomena as they experience it [65]. This approach involves analyzing text describing lived experiences in order to identify themes and patterns of meaning. In interpretive phenomenology, text is regarded in the form of its content as opposed to its physical form. Therefore, *text* can be written or spoken language, metaphors, photography, artwork, or poetry as long as these mediums of text are describing a lived experience.

## **Reasons for Choosing this Methodology**

In this inquiry, interpretive phenomenology was employed as a research methodology in order to give voice to the lived experiences of adolescents suffering from CP for the purposes of contributing to knowledge of the paediatric patient perspective in relation to chronic conditions

and improving services offered to this specific population. This research methodology shares many commonalities with “narrative medicine” in terms of trying to “capture medicine from the inside out [...] by emphasizing its subjective and experiential dimensions” and reminding us that “the patient’s experience should be considered the fulcrum of treatment [because] the doctor’s [and researcher’s] perspective is more limited in scope” [68, p.33-34]. Unlike other research methodologies, interpretive phenomenology places the participant in the position of power as they are the beholder of their own experiences and descriptions of their personal and social world. As quoted from Dr. John Davis, this particular researcher-participant dynamic respects the fact that the “narrative people keep about themselves [details] why they are doing what they are doing, what their goals are, and what their views of their past are – all components of ongoing stories people maintain about how they see themselves as distinct persons, whether rightly or wrongly” [69, 70]. This quotation emphasizes the narrative and subjective nature of lived experience and the importance of addressing these topics from the perspective of those being treated. Interpretive phenomenology is a useful research approach to study the subjective CP experience considering that interpretive phenomenological analysis allows for the interpretation of how one has made sense of their own experiences [71].

Qualitative research seeks knowledge of experience which depends on depth of meaning rather than abundance of participants [72]. As Merleau-Ponty wrote, “the world and man are accessible to two kinds of investigations, in the first case explanatory [scientific] and in the second case reflective [philosophical]” and Gadamer emphasized that “the job of philosophy is to clarify concepts, not to present a new body of knowledge through empirical research” [73, p.497]. Ultimately, a scientific and clinical approach to understanding the manifestation of pain aims to improve treatment, while the person living with CP understands pain through reflection of their lived experiences [74].

## Selecting Research Participants

In phenomenological research, “the phenomenon dictates the method (not vice-versa) including even the type of participants” [75, p.45], therefore, participants are selected based on who the researcher believes has had experiences relating to phenomenon in question [76, 77].

The perspectives and experiences that I am interested in are those of adolescents living with CP. These adolescents were recruited from the Montreal Children's Hospital Chronic Pain Management Clinic (MCH CPMC). At the MCH CPMC, a multidisciplinary team (Director Dr. Pablo Ingelmo, Psychologist Dr. Yves Beaulieu, Physiotherapist Rachel Gauvin, Social Worker Stephanie Stabile, Nurse Clinician Rebecca Pitt, and Clinical Fellow Dr. Marta Somaini, and Dr. Nada Mohamed to name a few) target the challenges associated with CP conditions. Approximately 120 new patients join the clinic annually and the majority of which are female [78].

Interpretive phenomenological studies delve deeply into the complexity of a small, well-defined group for whom the research question(s) will be pertinent rather than focus on frequency or make general claims for a larger population [79]. The minimum number of participants for qualitative research suggested is three [72, 79], however, 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 occurs when adding more participants to the study does not add perspective nor information [80]. The small, well-defined group of participants in this study includes 8 female adolescent out-patients recruited from the MCH CPMC who have a CP condition. These adolescents' CP patients' condition(s) may include fibromyalgia, arthritis, back pain, widespread pain, related disorders, and/or orofacial pain conditions. These participants range between the ages of 14 and 17 years old. The main purpose for choosing females in particular is because the majority of the patients at the MCH CPMC are female. The MCH CPMC patient population is over 75% female. Also, recruiting only female participants controls for gender as a confounding variable.

I specifically recruited adolescents that have already joined the CP management clinic because I am interested in studying the barriers faced (and continue to be faced) by those who are actively seeking help, eager to improve their functionality or manage their pain, and may have already developed certain coping strategies that help them overcome their physical, social, and personal challenges living with CP. I want to contribute to qualitative research evaluating the effects of CP on adolescent development in both a personal and social context in order to help

youth who are in the midst of figuring themselves out as both an adolescent and as someone living with CP.

## **Participant Recruitment and Consent**

For the participant recruitment process, Dr. Ingelmo and his team presented the study to patients that fit the inclusion criteria and asked if they would be willing to let the researchers contact/approach them. The researchers included Manuella Widjaja (who is also a Master-level student studying a similar topic as myself) and I. Patients willing to participate were then contacted or approached by Manuella and I following their appointment at the MCH CPMC to set up an interview appointment at their convenience. As will be discussed below (see section Conversations with Participants and Data Collection), I am using the word ‘interview’ leniently considering that interviews in phenomenological research are more conversational than they are formal. Participants were requested to complete a consent form before the interview began and were given a copy of the consent form to keep. Appendix C includes a template copy of this consent form.

### **Inclusion Criteria**

Individuals included in this study were:

- female;
- 14-17 years old, inclusive;
- out-patients of the Montreal Children’s Hospital Chronic Pain Management Clinic;
- living with pain for longer than 6 months (i.e. CP);
- comfortable communicating in either French or English; and
- had given informed consent to participate in this study

### **Exclusion Criteria**

Individuals excluded from this study were:

- not female;
- younger than 14 years old or older than 17 years old, excluding;
- living with pain for less than 6 months;

- had a condition that would limit their ability to partake in this study; and/or
- had not given informed consent to participate in this study

## **Research Ethics Consideration**

This research study underwent review beginning in November 2018 and ethics approval was granted in January 2019 by the McGill University Health Centre Research Ethics Board (MUHC REB). Appendix B includes the Final Authorization Letter from the MUHC REB approving this research study and authorizing its commencement.

## **Conversations with Participants and Data Collection**

The medium through which participant narratives can be expressed in phenomenological research includes face-to-face interviews, written or recorded accounts (poems, transcriptions, etc.), musical lyrics, and/or behaviours or lack of behaviours [79, 81]. The reason for which I chose to use face-to-face interviews as the mode of expression for this study is because the interview – conversational in structure – has a collaborative aspect in which I can observe the participants’ responses, facial expressions, and body language in real-time and follow-up with questions that may help the participants reflect more deeply about their experiences.

Between January and March 2019, Manuella and I interviewed 8 participants for a one 30-90-minute session each. The interviews were conducted in private rooms in the Centre for Innovative Medicine (CIM) at the MCH – a centre that patients of the MCH CPMC frequent regularly – in order to ensure that participants felt comfortable in and were familiar with the environment. The interview style was semi-structured: the interviewer develops a list of questions to guide the conversation while still allowing for flexibility in order to stray from this ‘interview guide’ when appropriate to probe certain trains of thought [82]. Manuella and I digitally recorded these conversations and transcribed and de-identified them.

All information collected during this study was kept confidential. The participants’ identity was protected by replacing each name with a unique randomly-generated name and only the research team at the MCH had access to the code linking the assigned pseudonym to the

corresponding name. Apart from the research team, only the government regulatory bodies (such as Health Canada) and the research ethics committees of the Québec hospitals could consult the research. Dr. Ingelmo was responsible for securely storing the research data. The audio-recordings were destroyed immediately after being transcribed. The transcriptions will be destroyed 7 years after the completion of this research project. Participants' personal information will not be published or presented at scientific meetings.

## My Identity

For all intents and purposes, I believe that we cannot precisely understand the pain that someone else is experiencing. My flare-ups of ulcerative colitis are often accompanied by pain, yet I often downplay or hide my pain because I *know* that there must be *someone somewhere* who is suffering much, much more than me and that I should be *grateful* that my pain is not as intense as *theirs*. On the other hand, I am aware that other individuals may catastrophize their pain in the presence of someone else suffering from pain as though they are playing a *game* of 'whose pain is worse'. Therefore, I chose not to reveal my history with pain during the participant interviews out of concern that my history with pain would affect the way participants related to me. However, I am aware that participants' willingness to disclose certain information or their choice of wording may have differed based on their perception of my understanding of CP. For instance, some participants may have felt that explaining CP to someone who they assume does not have CP is a hopeless feat.

The following is a brief list of the many other factors influencing how at ease one is to disclose personal information during research interviews: how non-threatening the participants perceive the environment, how respectfully and non-judgementally the participant feels their responses are being received, and how accustomed participants have become to answering questions in a purely medical context [83-85]. The aim of the conversations I had with my participants was to democratize the research process by promoting equal participation from both the researcher and participant and encouraging authenticity and disclosure [83].

## Data Analysis

Phenomenological research does not prescribe a strict method of data analysis and qualitative analysis is inevitably a personal process [71]. The reason for this freedom is because, according to Max van Manen, phenomenology is a “way toward human understanding” [86] which can be achieved multiple ways. For instance, one can ask critical questions of the texts from participants such as: What is the person trying to achieve here? Do I have a sense of something going on here that maybe the participants themselves are less aware of? [71]. The fundamental assumption of this methodology is that the researcher is interested in learning about the respondent’s psychological internal world and is striving to understand the complexity of its meanings [71].

The following is a description of the steps that I found to be personally useful in analyzing the data. These steps are inspired by Jonathan A. Smith and Mike Osborn’s *Doing Social Psychology Research* [87].

### 1. Interview transcription

Interviews were recorded because writing down the interview dialogue and content in real-time would likely lead to missing important nuances, making less eye-contact with the participant, and making the participant feel as though I am only interested in the parts of their narrative that I write down. Interviews were transcribed immediately following the interview (the day-of), thereby facilitating the recall of essential non-vocalized parts of the interview such as when a participant became emotional or when a participant volunteered to show me their artwork. Transcribing each interview verbatim without transcription software was especially useful in terms of engaging deeply with the text of the interview and learning from each interview regarding how to enhance the quality of the questions asked during the subsequent interview considering that data collection and analysis occurred concurrently.

## **2. Identifying subthemes in the individual transcriptions**

This step required reading and re-reading an individual transcript closely several times while making note of the significant language and/or points of interest. For instance, perhaps the respondent repeated certain key phrases that they wished to emphasize, was at a loss for words when describing a powerful phenomenon, contradicted themselves, or became emotional during certain parts of the conversation. I used the margins of the transcript to indicate my interpretation of the underlying meaning of each of the respondent's sentences that I found to be pertinent to the research question. I also took into account that certain phrases may not carry deeper meaning. I then identified themes based on observing a shared meaning between several sentences. This preliminary stage of interpretation allowed for emergent themes (which will later be considered subthemes) or patterns to begin to come into focus within each separate transcript.

## **3. Connecting subthemes to form themes from individual transcripts**

For this third stage in the data, I made a list of the (sub)themes from step 2 on a separate sheet of paper. I identified commonalities between these subthemes which I then clustered into an overarching theme. I drew the evidence for these commonalities from the raw data (i.e. the respondent's words themselves) because the words chosen by the participants offer important insights into the meanings they ascribe to their experiences [85] and I wanted to ensure that my interpretations were as closely related to the participants' perspectives as feasible. Therefore, I re-read the transcriptions once again to confirm my reasoning for labelling certain phrases with a particular (sub)theme. I also saved a file of particular phrases from the initial conversation that best supported related subthemes. I made a table of these overarching themes – each with its own separate list of supporting subthemes as well a list of key phrases and powerful examples supporting those subthemes. I continued this clustering process until each overarching theme appeared to be superordinate and overlapped minimally or not at all with other themes.

## **4. Interpreting themes and subthemes for individual transcripts**

From the overarching themes, I analyzed how CP and identity evolved throughout each participant's narrative and how these themes related to the participants' social and psychological



states. I treated each transcript separately for this analysis step as I believe that certain themes may converge across many transcripts but may also have a unique meaning for each participant. This step allowed me to respect the individuality of each participant as I moved into the fifth step of data analysis which aimed to analyze themes **across** individuals and determine whether individuals experiencing similar phenomenon find similar meaning in those experiences.

## **5. Analyzing the transcriptions together**

I compared convergences and divergences in themes across the different transcriptions. I often had to find a higher-level convergence between themes that had a deeper link that was not immediately evident. The criteria for the themes that I chose to discuss in my ‘Findings’ section was based on the *depth* of the theme, rather than how *frequently* said theme appeared. This decision was in line with the fact that – as mentioned above – qualitative research is focused on depth of meaning rather than frequency [72]. Also, I was fortunate to have conducted these interviews with my fellow Master-level lab-mate, Manuella, with whom I was able to brainstorm and compare findings. I also presented my preliminary notes and findings to my graduate supervisor (Dr. Richard Hovey) who is fluent in interpretive phenomenological research.

## **6. Discussing and elaborating on the findings**

This stage translates themes into a narrative account by explaining themes using differentiations made between the various participants’ wording and what the analyst interpreted [87]. This step also aims to relate the findings to existing literature.

## **Reflection and Recognizing Interpretation as Fluid**

I recognize that interpretations of research using an interpretive phenomenological approach are flexible and ever-changing depending on the steps one uses to analyze the data, the breadth of experiences and knowledge of the researcher, and how deeply the researcher analyzes the essence of the transcripts. I also recognize that analysis that occurs much later than the time of the interview itself also means that the memory of the patient’s intonation and emphasis are less vivid and less influential on my interpretation. I tried to avoid this detachment from the

participants' expression as much as possible by performing the initial stages of analysis of the transcripts immediately after the interview. However, the exploratory nature of an interpretive phenomenological study requires reading and re-reading of the text which may occur over several days. Also, these reported themes characterize the meanings of living with CP as an adolescent at this particular moment in time considering that the participants' and researchers' understanding of the essence of living with CP will continue to change with time. Therefore, the analysis and findings would inevitably be different if I were to repeat the data analysis.

## **Generalizability and Transferability**

**Generalizability** refers to extent to which research findings and conclusions drawn from a sample study population can be applied to the general population. Previously, generalizability was thought of as a privilege reserved for quantitative research with a sample population that is selected randomly. Contrarily, findings derived from qualitative research were not considered generalizable based on the fact that study populations are often small and purposefully-selected [88]. However, this claim is not entirely accurate because the criterion for generalizability differs for qualitative and quantitative research. In quantitative research, results are assumed to be generalizable to the population in question if the demographic characteristics of the sample population are similar to those of the population from which participants were drawn. In qualitative research, each participant is purposefully selected based on the assumption that they will contribute significantly toward the emerging theory [88], and yet certain qualitative researchers reject generalizability on the basis that "every topic [...] must be seen as carrying its own logic, sense of order, structure, and meaning" [89]. Despite these rejections, phenomenology achieves generalizability by allowing the researcher to identify a general meaning or structure of experiences related to the phenomena being studied [72, 89]. In my study, I identified some of the implications that adolescents living with CP experience in both their personal and social lives.

**Transferability** can be defined as the degree to which research findings can be meaningful to those in similar contexts, settings, times, and populations. In order to promote transferability, the responsibility of the researcher is to "provide a basis for the data that makes transferability judgements possible on the part of potential appliers" as opposed to proving that

the study's findings will be applicable [90, 91]. This data 'base' requires an in-depth description of the phenomenon being studied and a robust and detailed account of the data collection process such as where the data collection occurred, whether the participants were interviewed at the end of an exhausting day, and any other information that enriches the understanding of the research setting [90]. Those who may apply these findings are invited to reflect on how closely they feel connected to the descriptions that participants shared regarding their own lived experiences.

Generalizability and transferability are terms often used in the context of 'external validity' because the ability of research findings to be generalized to a larger population inevitably means that the findings are being used to describe populations in settings external to those in which the study was conducted.

## IV. FINDING #1: Personal Implications of living with Chronic Pain

Although there are aspects of each individual's experience living with CP that are unique, I identified 3 common facilitators and 2 common barriers that most of the participants encounter in their personal life living with CP. The following is a list of these themes and the subthemes that I grouped under each theme:

### Facilitators

1. Creating a *safe* (internal) space in which one feels “normal”: the concept of “the *bubble*”
  - ⇒ Incorporating new activities into their repertoire that do not remind them of their limitations
  - ⇒ Taking a break from reality and re-engaging with society at their own pace
2. Accepting the possibility of flourishing with CP
  - ⇒ Acknowledging what can and cannot be controlled and recognizing that being positive or negative is a choice
  - ⇒ Actively trying to maintain/adopt a more positive outlook
  - ⇒ Acknowledging that the acceptance of CP is a process
3. Finding the motivation to improve/accept their reality by envisioning a positive future
  - ⇒ Striving to achieve a state of happiness by adapting their goals to align with their new limitations
  - ⇒ Striving to achieve a state of happiness by adapting the path they take to achieve previously-set goals

### Barriers

1. Facing the unpredictability of pain
  - ⇒ Hinderance in goal-setting
  - ⇒ Forming a new identity while trying to incorporate pain
2. Facing the uncertainty of pain
  - ⇒ Lack of answers from adults/medical professionals

I will address each theme and subtheme in greater detail.

## Facilitators

### 1. Creating a Sense of Normalcy

PAUSE – I'm in my *bubble* ◦ [Taking a *BREAK* from the pain]

Most of my participants spoke about this intriguing concept of having their own personal “bubble”. The following is a definition of ‘living in a bubble’ that I believe best describes my interpretation of the metaphor of the *bubble*:

“Living in a bubble” implies that you are separated from society and living in a world impervious to what lays beyond the shield you have built for yourself. Yet, bubbles are translucent. Therefore, someone living in a bubble observes life beyond their bubble and understands that life continues outside the bubble and can still choose to remain sheltered. The best parts of the world may be outside of one’s comfort zone – but... it’s uncomfortable (at first). When one is ready, popping one’s bubble or breaking the barrier that separated them from the rest of the world can seem easy [92].

The *bubble* serves as a safe place of retreat from pain and external pressures, yet the thin film of the *bubble* is still flexible enough to burst when my participants feel ready to emerge from their quiet, safe space of reflection. Within their *bubble*, these adolescents living with CP seem to be able to regain control of their thoughts and emotions and restore a sense of calm and normalcy. The following are excerpts from several of my participants describing the essence of what their *bubble* means to them.

Jasmin described her *bubble*:

*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. And it just helps me to get my mind off my pain.*

Jasmin inspired me to turn to my own artistic passion for drawing to shed light on the emotions captured in the participants’ words. I asked Jasmin to share with me some of her own

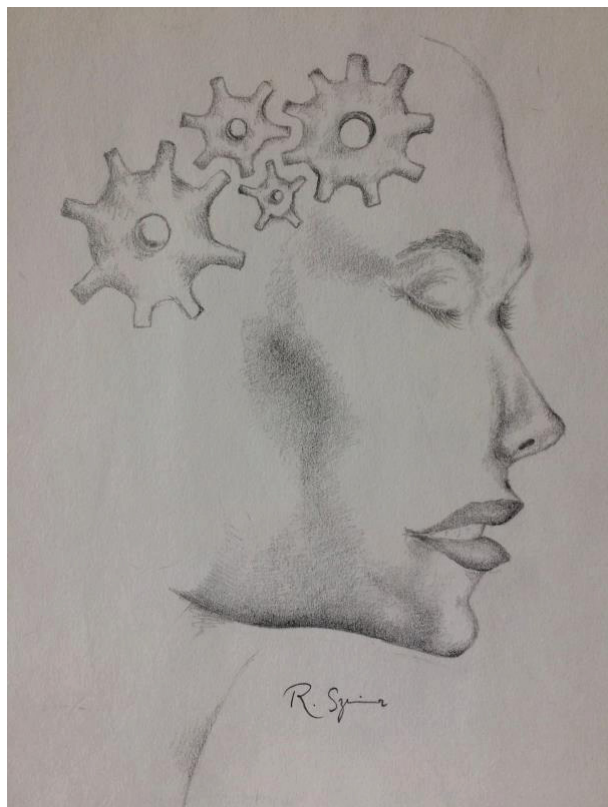
artwork. She self-declared her art to be ‘abstract’ because, as she mentioned, “I cannot do realism”. Realism is the art movement that attempts to showcase matter truthfully. In my opinion, Jasmin’s pictures were her way of depicting matter as clearly and as real as it felt to her. She drew pictures of a Sun and Moon which I interpreted to be her conflicting emotions experienced during her painful episodes and her adolescent development. I interpreted Jasmin’s choice of expression through art to be her way of vocalizing pain – a concept for which she has not yet found the words to make sense and a concept which she understands in a non-biomedical sense. Other participants have found their means of self-expression and/or relaxation in sewing, singing, and other creative passions.

My drawing depicts the swiftness and gentleness of the paintbrush that portrays the ease with which Jasmin can move around in her *bubble*, as well as the ease with which she can move between reality and her *alternate universe*. Her possibilities seem limitless in this creative space that is bound by her imagination and not by her pain. In this world of possibilities, Jasmin has chosen activities that allow her to “*just go*” without constantly having to test whether her pain will interfere. Therefore, the activities with which Jasmin fills her *bubble* are the types of activities that do not remind her of her pain and physical limitations.



Similarly, Arianne expressed her *bubble* as her ‘safe haven’ and explained how her *bubble* helps her cope with the pain:

*I know how to relax now. [...] Reading is kind of my happy place. It's like I enter inside the book and I kind of forget about my pain for a while. Having something like that sort of helps 'cause as soon as I am in pain – like big pain – my go-to is my kindle.*



Arianne had a very bubbly and chatty personality. She mentioned that she loves being the centre of attention. However, she too admitted to needing this balance between her internal and external world. I interpreted Arianne's description of her *bubble* to be the balance between the *personal* and the *social* through the metaphor of grinding gears. Each gear is constantly grinding to fit in with the other gears much like these adolescents with CP want to participate in the commotion that is adolescence. However, the constant worrying about their social life and pain progression fuels the gears to grind louder and faster as they begin to fall more and more out of place with

the gears around them. Retreating into a reflexive, personal space – like the pages of a book or the canvas of an art piece – liberates these adolescents from the grinding, quiets their worries, and allows them to restore their equilibrium.

Jamie is the only one of my participants with a visible limitation due to her CP condition. She is unable to use or unclench her hands. However, much like the other participants, Jamie fills her *bubble* with activities that allow her to forget her pain and regain a sense of control over her life. The time she spends in her *bubble* includes taking walks outside, taking baths, and listening to music. She said:

*When I'm in a lot of pain, it seems strange, but I'll go walking. I like to move, get fresh air. If I take baths, it relaxes not my hands but the rest of my body. And listening to music – it occupies my thoughts. I try to think of something else – skate, do any activity because I try not to just sit there doing nothing. I try to occupy myself to try to forget the pain.*



Jamie's words illustrate how the mind and body are separate entities considering that she can feel at ease while engaged in certain activities even while her hands are still clenched in fists. If her words could paint a picture, I believe that the resulting image would look similar to the one above: the physical hand not fully unclenched, and yet portraying a sense of "letting go" of the pain in that moment. Much like Arianne and Jasmin, Jamie repertoire of activities serve as her personal outlets to quiet the gears and ease her mind even though there may not be any physical relief from the pain. She creates this internal sense of normalcy by engaging in activities that allow her to relax.

This concept of the *bubble* also highlights the difference between isolation and solitude. Isolation is a state actively avoided and brought about by external forces. Contrarily, solitude is actively sought after as a personal choice, allows for freedom and expansion of thought and perspective, and provides the chance to return to the world refreshed and invigorated [93]. The *bubble* provides these participants with a safe personal space of solitude in which they can choose when to block out the external world, re-gain equilibrium, and then return to their social world when they feel ready.



Arianne highlighted the importance of having the ability to move back and forth between her personal space and the outside world:

*When I am in pain, my mood darkens a lot. I am a lot grumpier, and I snap. And people kind of know this and they kind of stay away from me when I am in pain... which I am fine with because I will be reading. And when the pain dulls down, I will go chat with them and we will play a game or something like that.*

Arianne's narrative sheds light on the transformative nature of pain in the sense that it disguises her as someone who is 'grumpy' and someone from which to stay away, yet the disguise disappears and allows Arianne to re-engage in a social setting once her internal equilibrium is restored. The fact that one must *break* from and then re-engage with reality indicates that this phenomenon is an effortful transition. One must recognize when the grinding of the gears is becoming unbearable in order to know when to escape into their *bubble* of refuge.

In terms of seeking this 'refuge' from the outer world, Andrea perceives her *bubble* to be a world of distraction from the pervasiveness of her pain and as a shield that keeps out the negative thoughts that often accompany her pain. She claimed:

*I just want to be occupied because [otherwise] the pain will invade, and it would be the only thing on my mind – which is harder – so I just try to be occupied and do other things.*

Interestingly, Andrea mentioned that she prefers to spend time with her boyfriend and one close friend when she is in pain and she was not the only participant who mentioned letting friends into her *bubble* when experiencing excessive pain. Jasmin mentioned:

*I know I can just text my friends and say, "hey, I'm in pain, can you cheer me up?" and they'll send me some memes and stuff to try to make me laugh.*

Andrea and Jasmin's friends seem to serve as a break for them from their world of pain and draw them back into the world of an *average* teenager spending time with a boyfriend and/or sharing jokes. These passages highlight the importance of the *bubble* being filled not only with distracting activities but also people that re-focus their thoughts on aspects of their adolescent life that seem *normal* such as having friends and significant others. The key to gaining access

into the *bubble* is to be understanding and a means of helping the individual forget about their pain.

### **DISCUSSION of the FINDING: Creating a Sense of Normalcy (Personal Facilitator)**

According to Gadamer, human beings may achieve reflexivity by elevating into the realm of the mind which is at a distance from themselves and “lifts them out of the constraints of their finitude and actuality” [94, p.51]. The concept of the *bubble* is in fact a reflexive space in which these adolescents seek refuge from the pervasive, negative thoughts of CP. Gadamer also claims that “insight into the self and the other remains possible so long as [...] distance is perpetuated” [95, p.245]. Gadamer goes so far as to claim that “hermeneutic consciousness [being privy to a *thing* within oneself] is grounded in distance that allows the difference between one’s own horizon and that of the text to assert itself” [95, p.238]. Time spent in one’s reflexive space provides a much-needed distance between one’s thoughts and the all-consuming nature of one’s chronic health condition. Based on these quotations, I believe that the time spent in one’s reflexive space provides these adolescents with time to focus on enjoyable hobbies much like a *normal* teenager (i.e.: the time of which pain otherwise robs them). These adolescents can re-adjust into their external world once they fulfill their quota of *normal thoughts*.

These adolescents demonstrated an appreciation for the time they can spend reflecting in their *bubble* as this time spent ‘regrouping’ their thoughts seems to allow them to re-engage with the world in a less stressful and more meaningful way, thereby improving their quality of life. Perhaps therapeutic approaches helping these adolescents create this safe, reflexive space is an objective worth integrating into chronic pain management clinics. For example, perhaps the CPMC specialists can guide or assist adolescents in sampling different activities/hobbies until they find at least one activity that they can perform with relatively little pain and are motivated to pursue. In this way, the specialists can ensure that the chosen activity is safe and geared towards the adolescent’s needs and interests. This personalized approach may help adolescents living with CP begin building a repertoire of activities that they can incorporate into their *bubble* and that they would gladly turn to in moments of desperately-needed repose.

Overall, the participants who seem to best manage their pain have formed a safe-haven that lies within their metaphorical *bubble*. They fill their *bubble* with activities and compassionate individuals to distract them from their struggle with pain. And, when they have relaxed their mind, collected themselves, and re-positioned their *gears*, they can deflate their protective shield and fall back into place with the external world. Therefore, their *bubble* is a retractable comfort zone into which they can choose to withdraw (solitude), rather than a cage from which they cannot break free (isolation).

## 2. Deciphering what can be Controlled

SURRENDERING – Accepting that CP is Long-term allows for Personal Growth

As defined by Hovey, surrendering is “not a negative surrendering, [but rather] surrendering to the **implications** of [living with a chronic condition] as a life to be lived differently. [...Surrendering] means giving into the functional reality of their situations with the inherent difficulty and uncertainty of attempting to negotiate and piece fragments of their lives back together as *different*. The capacity to let go of previously-held perceptions of oneself enables the consideration of new possible ways of being in the world” [61 p.7, 100].

A brief definition of coping style is a mixture of attributional style (such as perceived locus of control and optimistic or pessimistic outlook on finding a solution) and personality characteristics (such as a sense of self-efficacy, introversion or extroversion, and risk tolerance) [96]. Many of my participants acknowledged their transition from pain literacy (knowledge) to health agency (action) occurring once they acknowledged which aspects of their life were within their control. This transition often seemed to be accompanied by participants adopting a more positive outlook on finding ways to thrive with CP and forced participants to draw upon their resilience. For instance, many participants have begun recognizing that the acceptance of pain is an ongoing process. While making this realization, they have adopted *transitional language* which showcases how they are beginning to imagine themselves living positively with their pain. The following excerpt from Jasmin’s narrative highlights this finding:

*Well I’ve just basically realized: this is 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.*

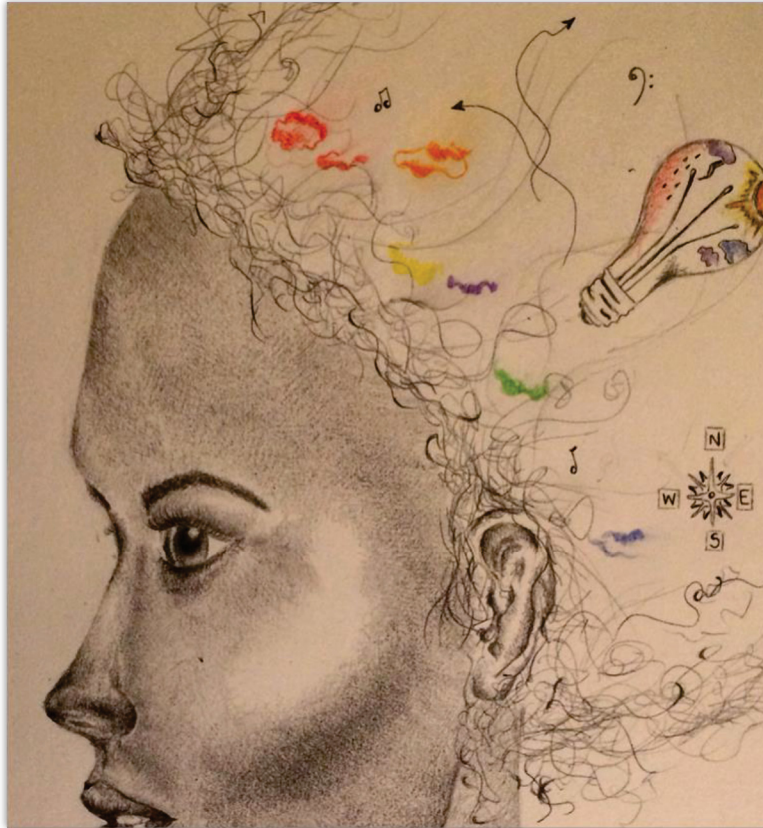
Jasmin shed light on her understanding that adopting a positive or negative attitude is a *choice* she must consciously make. Andrea had a similar realization when she transitioned from suffering with CP to becoming receptive to learning how to *live* with CP:

*I tried everything to get my pain to go away but it didn't work, so at one moment I realized that I just have to **accept** it. I have to **live** with it. I don't know what I did but I just told myself you have to live through it. The pain never really goes away but I just get used to it and I just live through it. [...] My psychologist will give me solutions about what I think in my mind – like how to control my thoughts.*

These adolescents have understood that CP is a long-term condition and that the physical presence of pain is out of their control. However, many also recognize that their mindset and perspective are malleable, and how much effort they apply to change their outlook of life with pain can influence how well they live with their condition and their overall quality of life.

My participants also demonstrated awareness of their alternative option: allowing their pain to control *them* would keep them grounded in negativity and hopelessness. Jamie – who has restricted mobility in her hands due to her CP and often struggles to get her hands into her hockey goalie gloves – recognizes how easily she can retreat into a negative mindset and must make a conscious effort to continuously strive for positivity. Jamie said:

*I know that being negative will just make it worse, so I try to be the most positive I can be. I practice. I take off my goalie pads [when my hands are too sore to fit in the gloves] and I'll still just skate. [...] [This positive attitude] really came naturally for me. I've always been an optimistic and rational person. I know I can't do anything about [the pain] so it is ridiculous to beat myself up about it and suffer and think "I can't do anything and I'm not worth anything". Negative thoughts won't help me. I try to keep my imagination open, stay open, see my progress, and think to myself that "today I feel a bit better".*



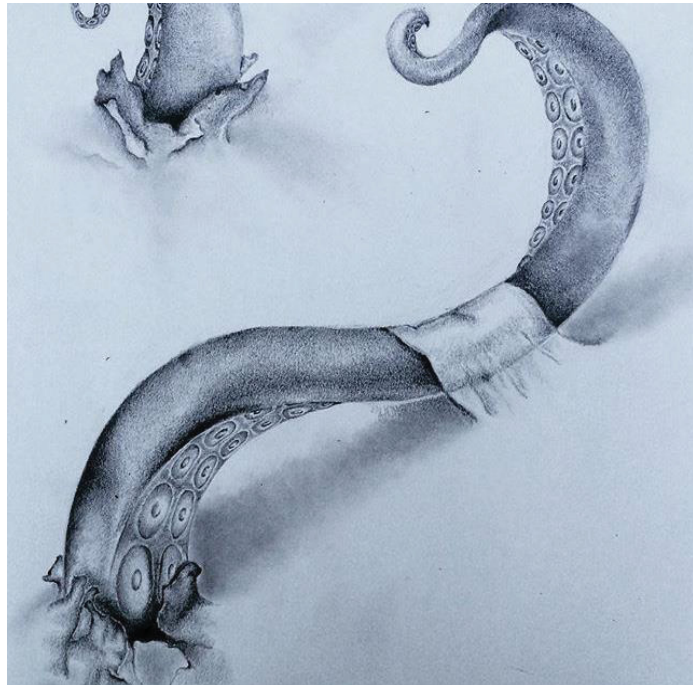
I interpreted Jamie's narrative as living with a constant battle between negative and positive thoughts. The volume of the chatter of negative thoughts intensifies with each additional set-back one experiences as a result of living with CP, such as not being able to partake in a favourite sport or activity. Jasmin's positive outlook seems to stem from her ability to focus on what she *can* control in order to dial down the negativity. Pushing these negative thoughts out of her mind creates space for personal growth, acceptance, and a

life *thriving* with CP. My image represents the breadth of possibilities and creativity available once positivity overrides the intrusive negative thoughts.

Some of my participants that seem less accepting of the possibility of living with CP long-term are those focused on returning to their past self. They seemed to be dwelling on a cure (i.e. a factor that is out of their control) rather than looking forward to their possibilities of life thriving *with* CP. These participants seemed to slip back into a state of hopelessness throughout our conversation each time they were reminded that an opportunity to cure CP has yet to present itself. The following participants seemed increasingly dependent on a 'magical cure'. Mona's narrative exemplified her view of the healthcare team as a means to returning to her state prior to the onset of her pain. She mentioned:

*Doing physio – for me – it's a waste of time because it hasn't **worked** yet. And maybe it's because I'm so overwhelmed and I feel like there's no other way to get through this. It's just like...physio's just not helping so it's like there's nothing else, so why even try? I don't have a lot of motivation for physio, I'm not going to lie, I do **not**.*

I believe my image captures Mona's frustration in the sense that she feels physically tied down or caged by her pain. Her life seems blanketed by the ominous presence that is CP. **Loosening** the ropes that restrain her is not nearly sufficient when her goal is to completely **break free**. The immense psychological drain of living with CP makes smaller successful progressions in her functionality through physiotherapy seem trivial and insignificant considering that she wants to be completely free of any functional limitations.



Although Andrea had endorsed the idea of *thinking* positively about her life with pain, she often slipped back into the mentality of a purely biomedical model of treating pain during our conversation. Similar to Mona, Andrea seemed to place greater value on physical improvements than she did on the potential relief one can experience through psychological changes. Andrea said:

*My psychologist will give me solutions but more about what I think in my mind – like how to control [my thoughts]. He's the one that helped me get used to it and live through it. But when I have pain and want a physical solution and help, it's really my physio that gives me solutions.*

And, when I asked what she thinks the MCH CPMC could do differently to help, Andrea replied:

*Maybe just a special treatment and then...pouf!*

I interpreted Andrea's narrative to mean that she prioritizes the physical, tangible solutions with immediate effects over her psychological self-growth. Hilary had a similar response when asked which services she feels could improve her experience living with CP. Hilary said: one that would simply "*remove it*". Whereas, my participants that have accepted that CP is a long-term condition have the commonality of striving for psychological/personal self-growth despite not being able to eliminate their physical limitations altogether.

## DISCUSSION of the FINDING: Deciphering what can be controlled (Personal Facilitator)

Gadamer discussed the importance of interpreting illness both through the lens of the medical practitioner and the person experiencing the illness:

*It is clearly a misrepresentation of the phenomenon to look at the concept of illness solely through the eyes of the doctor and from the standpoint of scientific medicine, and to think that medical knowledge is the same thing as the patient's insight into one's own illness is clearly not simply insight in the sense of knowledge of a true state of affairs, but rather, like all insight, it is something which is acquired with great difficulty and by overcoming significant resistance. [...] The patient experiences his or her illness through the felt absence of something. What does this absence of something tell us; what does it tell us about that which is missing? It must occasion reflection. [...] Often even the initial stages are closed off to such awareness. [95, p.52]*

This quotation emphasizes a need for patient involvement and perspective in order for healthcare professionals to best characterize and treat the illness. However, in order to gain access to the patient experience and perspective, the person experiencing the illness must self-reflect upon and conceptualize their barriers and facilitators living with CP. Hovey's doctoral dissertation on the lived experiences of osteoporosis – which illustrates the process of *surrendering* – places a similar emphasis on acknowledging one's own pain/illness. As stated by Hovey, “this is not a negative surrendering as in giving up hope or losing a battle; rather, this is a *surrendering* to the implications of [pain] as a life to be lived differently” [85, p.7]. *Surrendering* allows these adolescents to adapt to their new limitations, recognize what is within their control, and begin to imagine their possibilities in this new state of living. Therefore, this process of *surrendering* requires acknowledging the control one has over their psychological state and the lack thereof over the physicality of illness. As mentioned in the ‘Literary Review’ section of this thesis, adolescents less willing to accept the importance of the combination of psychological, social, behavioural, and contextual factors influencing the ‘*pain problem*’ are less likely to engage in treatments targeting these diverse realms of functioning and often experience later functional recovery [56, 57]. Gadamer holds a similar position regarding the importance of giving voice to our lived experiences and perspective of our reality to bring us closer to recognizing our possibilities within that reality. Gadamer claims that “the ‘true being’ and ‘reality’ of such

moments only become apparent when we do strive to speak about them” [95, p.149]. My findings reinforce the notion that adolescents who value a biopsychosocial model over a biomedical model of healthcare seem more likely to imagine their life differently than it was prior to their pain, less reliant on an acute fix to a long-term issue, and more receptive to new opportunities. Therefore, perhaps clinical interventions for pain management in adolescents should include stronger focus on mindfulness techniques that expose these adolescents to the benefits of improving their psychological wellbeing and social development. I believe that surrendering to one’s CP condition is a way of seeking comfort in one’s potential to live well with CP despite the uncertainty of this condition and unsettling feelings that accompany knowing that life will likely not return to how it once was.

In brief, the adolescents that seem to be the most adjusted to their life with CP are those that recognize that they can influence psychological and mental/emotional factors involved in CP but cannot control the physical aspect of CP. Those that have not acknowledged this distinction regarding what is and what is not within their control appear to have put their ability to live and thrive on ‘pause’ as they wait for their life prior to pain to resume.

### 3. Deriving the motivation to improve from envisioning a future

#### PLANNING

Many of my participants endorsed the fact that their motivation to improve stemmed from their ability to envision their future. For some, envisioning a meaningful future meant adapting their goals to meet their current limitations. For others, envisioning a meaningful future meant adapting *how* they were planning to meet their previously-set goals.

Among those that adapted their end-goal(s) to meet their current needs, Jasmin explained what motivated her to strive for improvement:

*Well, I mean, it’s just that **I have plans**. I love music and I go to a lot of concerts. I know I have a lot of concerts coming up, and I know I really want to go see them. And I know it’s going to be difficult because [the venue] is far from me, so I have to walk a lot, I have to stand up in the metro for around 30 minutes, so I tell myself ‘okay, I need to prepare*



*for this concert and so I need to try a bit more'. [Having something to look forward to] is one of the biggest things that is keeping me from giving up.*

Jasmin used to aspire to be a dancer prior to the onset of her CP, however, she recognized that she had to re-adjust her goals in order to meet her current reality. She now aspires to be able to get to concerts to listen to her favourite bands – a feat that is perhaps just as challenging in comparison to a healthy adolescents training to become a dancer. Jasmin recognized that her love for music and concerts are some of the many reasons why she keeps pushing herself to leave her personal *bubble* and explore her possibilities. She recognized that her plans, aspirations, and goals outlined before the onset of her pain cannot be met within the confines of her ‘present-self’, and therefore embraced this opportunity to ‘re-story’ her life. Hovey uses the metaphor of *dance* to represent “a transformation from the initial *shattering* of the person’s life toward negotiating a partnership with the illness [...] and the movement towards self-renewal” [85, p.8]. I believe that my participants that chose to adapt their goals to meet their current needs embodied this transition from ‘initial shattering’ to ‘partnering with the illness’ by adopting activities or hobbies that are less reliant on my participants having a pain-free day. For instance, Andrea (a former competitive soccer player who hoped to become a professional soccer player later in life) has accepted that perhaps she could no longer compete at the highest level of soccer, and therefore adopted a new attitude:

*I just said “I like **playing** soccer” [I don’t **need** it], so I just play for fun.*

Now, she can enjoy her favourite sport while playing at a level that is better suited to her condition. This transition required her to first recognize and accept her limitations so that she could then choose a version of her favourite activity that accommodated her new physical challenges. Arianne – a sports and outdoors enthusiast – embodied this transformation as well by transitioning to lower-impact sports:

*I am not going to give up sports. Taking medication isn’t going to solve what I have, it’s definitely more that I have to accustom my body to get [to where I want to be]. [...] heavy impact causes me problems, so yes, **I have had to adapt to choose different sports than the ones I did before.** I love skiing and yes, I can no longer to moguls and jumps, but I can ski [downhill] and not have a major 4-day recovery – it will be more like a few hours of recovery – but I had to train really hard to get to that point.*

Arianne's narrative highlighted this process of self-renewal that required her to first 'give up' what she loved before adding activities back into her life and finding an optimal point with which she is comfortable. This self-renewal process speaks to a need for surrendering into a new identity that is considerate of both one's pain *and* their need to thrive or – at the very least – to be able to envision oneself thriving.

On the other hand, participants that wished to achieve their original goals and simply adapt the path they will take to reach said goals perceived their positivity as coming from within and as a direct function of their perseverance. When asked where or from whom she learned to be so positive, Jordana attributed her attitude to her perseverance that allowed her to continue pursuing the goals she set prior to the onset of CP. She claims:

*It's just me, just me, just **the force of me**. I say, from within myself, that I **need** to do this. It's the perseverance. [...] [My mom and I] were never the richest people, so if I wanted something my mom would have to say, 'you know we can't afford that'. But that helped me understand that in life you have to **stay positive and work for what you want**. I think that is the difference between me and [my friends].*

Jamie shared a similar perspective of her internal drive urging her to continue trying to improve and strive for her original goals:

*In hockey, I have my little challenges [that I did not have before], but I keep my [big] goals the same as they were before. It might take more time. We have a tournament next week, I'm going to be goalie and my goal will still be to win – I just have to separate that challenge into smaller goals, but **I don't have to change my main goal**. Sometimes we underestimate ourselves, so I prefer to keep my stay true to my main goal. I think my biggest challenge is, each day, I have to find positive points and remind myself of the wins I already have so I know 'okay, I already stopped that puck' so I might be hurting, but [these are] like my little personal motivations.*

However, many participants from both schools of thought (those changing their goals or those changing their methods/approaches) recognized that acceptance of their life with pain is an ongoing process and challenge that requires positivity. Interestingly, many of my participants

make an active effort to view their CP condition as a positive part of their life that has helped shape them for the better. For instance, Jasmin claimed:

*I got mature way faster [than I would have] because of [my pain] and it's kind of sad because **it's not like I had the choice**. It's not like I was like "I want to be an adult", it was more like 'just be an adult' and just 'be more mature'. [...] So, I am not grateful for my chronic pain, but I am grateful for everything that [has come from it] – like that I can finally see the true faces of my friends and that they stuck by me. I am grateful for that. And I am more mature than most people my age – I am grateful for that too. I am not grateful for the fact that I have chronic pain, but I am grateful for everything that it brought and everything it made me become.*

Jasmin's narrative brought to mind my image of a flower in that she seemed to be drawing from within (a place rooted in her world of CP and that stemmed from the hopelessness that comes with living with this condition) to build herself up into someone beautiful and strong. Similar to Jasmin, most of these young adults seem to treat their relentless battle with CP to be a testament of their endurance, strength, and positivity.



Importantly, when asked what my participants would advise other females their age visiting the MCH CPMC for the first time, they all hoped to inspire others to **never give up**. Jasmin left me with the following words that I believe best capture the essence of remaining positive and envisioning a brighter future:

*Well it's going to get better one day, it will. Even me, I got better. [...] It's going to be difficult, that's for sure. But you will get through it. Everyone does. Just try your best.*

## **DISCUSSION of the FINDING: Motivated to Improve by Envisioning a Future (Personal Facilitator)**

Similar to the discussion of the previous finding (surrendering into what one cannot control so that one can focus on what can be controlled), this finding of ‘envisioning a future’ deals with the possibilities available to those who are willing to look forward to their opportunities rather than ruminate over the loss of their past-self. In Hovey’s publication “*The Gift of Pain with Transformative Possibilities*”, Hovey claims that we are “suspend[ed] within the [stagnant] liminal space of unrevealed potential [i.e. the time spent between the ‘what was’ and the ‘what is next’]” if we choose not to embrace the change that pain imposes on our life [59, p.1] because we are looking backwards at a version of our *self* that no longer exists. Therefore, the ability to envision a future relates quite closely to the concept of surrendering into a new identity and new possibilities and looking forward to the ‘what is next’.

Dr. Nicholas Davey, a philosophy professor at University of Dundee, claimed that identity emergence is only possible “by virtue of the alteration of previous forms of self-understanding” [95, p.142]. I interpreted this quotation to mean that one can begin to build a new identity that incorporates their life with CP only after surrendering into their reality by committing to better understand their new limitations and possibilities. Poet and novelist Rainer Maria Rilke stated that “pain cause[s] us to withdraw from all external experience of the world and turn us back upon ourselves [...] On the other hand, there is a remarkable protected state in which we let ourselves safely unfold so that we are able, lightly and effortlessly, to embrace our desire for active participation in life” [94, p.75]. Rilke’s statement emphasizes a state of hopefulness in which one can imagine, plan, and actively seek to re-engage in their community and continue living. Therefore, perhaps CP management clinics should include more education on how to live *well* with CP – as opposed to solely focusing on how the CP can be ‘cured’ – in order to better prepare these adolescents for the possibility of living with CP long-term.

Ultimately, my participants embodied the essence of *surrendering* into life with CP in accordance with Hovey’s explanation of patients’ transformation from shattering to surrendering which involves cycling in and out of finding meaningful ways of re-engaging in the world [85].

## Barriers

### 1. Facing the unpredictability of pain

The acute model of healthcare involves immediate solutions and cures, yet a life with CP includes episodes of flare-ups, ambiguity, uncertainty, and unpredictability. Many of my participants addressed this issue of unpredictability as being a psychological barrier because they are unsure if the pain will *let* them engage in certain activities or achieve certain goals. When asked how she could imagine her life differently without her pain, Jasmin replied:

*I [wouldn't] need to worry about the question of 'am I going to be able to' [...] because [right now] there's still this little voice in the back of my head saying, 'be careful', 'don't do it too much because you're going to be in pain', 'no, be careful, stop it!'*

Jasmin highlighted the fact that living with CP causes her to expect and anticipate a negative outcome from engaging in certain activities. Jasmin's message relates to the Hermeneutic Wager because this voice telling her not to take risks may potentially be pulling her away from the essential risks necessary to grow and recognize her possibilities to thrive with CP.

Callie explained how she felt herself giving up on life a few years ago because imagining a future living with the unpredictability of her pain did not seem like a life worth living:

*I told myself, "I can't live like this anymore". Every little thing scared me: just going to work. It even got to the point where I was panicking about my future. [...] it just brought my mindset to a very dark place. [...] The pain is really unbearable, but the psychological pain [of living with these unknowns] that I get from it is... well it's crazy.*

Callie's narrative shared the intense psychological impact that *unpredictability* and *lack of control over one's life* alone can have on these adolescents living with CP. Likewise, Arianne captured the unpredictability of pain that these adolescents face every day and how limiting this aspect of 'not knowing' can be:

*[My family travels to] Australia would have been a lot better if I could have participated a lot more, but because of stomach, I couldn't. That kind of made me sad because it was the trip of a lifetime and I [was] bed-bound...but on the good days, I went snorkeling, I was holding koalas.*



I particularly appreciated how Arianne phrased her experience because she shed light on how she copes with this constant unpredictability: she classifies her days into the *good* and the *bad*. Throughout our conversation, Arianne tended to bring up *positive* aspects of her experiences when reflecting upon her *bad* moments as though her coping mechanism is to draw upon her bank of positive memories to counteract the bad ones. However, Arianne and my other participants each mentioned how conflicting and frustrating this loss of

functionality and routine can be. The combination of their narratives demonstrated the significant grief over the loss of control of their functionality that these adolescents experience and must overcome considering that CP is a constant roller-coaster of *better* and *worse* moments and that these adolescents are aware of the *good* that they are missing out on in those *bad* moments.

My participants further exemplified the desperation to find stability or routine throughout their CP journey by claiming that they have tried to find patterns within their pain experience. For instance, Arianne mentioned that:

*Every 2 days, I maybe have to lie down for 15 minutes just to kind of calm down, relax, read, okay, feeling better again, back to class. [...] I kind of pick and choose my moments. It has been 3 years now since I haven't been able to do very much. ... I've gotten pretty good at sucking it up and moving on.*

I interpreted Arianne's description of being able to *avoid* feeling pain altogether to be Arianne's attempt to normalize and/or compartmentalize this unpredictable factor in her life. She tries to block out these *bad* moments which serve as a constant reminder of the power pain has over her day and her inability to control when these moments present themselves.

## 2. Facing the uncertainty of pain

In addition to the unpredictability of pain that is more intense than my participants' baseline pain, my participants also commented on the long-term frustration they experience in reaction to the uncertainty of the diagnosis, root cause, and future course of treatment. For instance, many participants faced years of misdiagnoses. Jordana emphasized this issue best when she said:

*Yes, [it was frustrating] because I was hurting, and they would say 'it's nothing'.*

Jamie added:

*At parties, people will ask 'what is wrong [with your hands]? Why are you like that?' ... I don't really know how to answer them because **I don't even know what I have.***

Individuals among the paediatric population living with CP are particularly at the mercy of medical professionals because identification of their condition validates and normalizes their pain experience, thereby allowing them to move towards acceptance and coping. Other participants described their frustration of living with an inconclusive diagnosis. Jamie mentioned:

*There were many **months** when I was waiting to see my doctors. [...] There's a lot of time between the tests just to see the doctor and for them to get an answer, a diagnosis, so you start to get a bit desperate, a bit **disappointed. I just want to know and have answers.** But I know they are doing everything possible, **it's just such a long time.** And when you go see the doctor, you are so **desperate for an answer.** It's just that.*

Callie added:

*Honestly, at some point, I gave up. After a year, you know, I was pushing for doctors to give me answers, I was trying to understand myself, I was looking on Google, I couldn't understand. I just gave up. [...] The pain is just so bad that I just don't even understand. And the **doctors didn't know what my pain was so that just made it like 20 times worse.***

These adolescents emphasized the devastating psychological impact of living with an undiagnosed condition particularly among youth who are dependent on adults and professionals for answers. Interestingly, individuals in this age group tended to be forgiving of their healthcare providers for not being able to immediately label their condition. For instance, the following are excerpts from Andrea and Jasmin respectively:

⇒ Andrea: *I don't know really what [Dr. Ingelmo's team] can do differently. We know that [knowledge about] what I have is progressive and, if we go ten years back, they didn't know much about this. It's a new science.*

⇒ Jasmin: *There are theories. They are not facts. [...] I really hope that there's going to be more research about it, more treatments that are going to be created, and more research about how this is happening.*

Mona shared a powerful statement about her experience facing the uncertainty of her condition and her awareness of the limited knowledge on CP treatments:

*Everyone goes through something in life and everyone has different problems. But, when you live with chronic pain, you don't have the answer. They are trying to figure it out, but there is a lot of push-back. They say, 'we don't know what we are going to do', and you have to wait months to know your next step. That, for me, is a bit sad to know. Sometimes I think of what the outcome of living like this could be. Sometimes I think really negative to the point where I am thinking, 'I am not doing this anymore', but a lot of times I think 'I may live with this for the rest of my life but I can maybe fix the pain in another way'. So, for me, if I could get through the pain, then I can get through it all.*

Mona demonstrated the **resilience** common across all of my participants in terms of coping through years living with an unidentified or poorly understood condition. The combination of these quotations indicates that perhaps surrendering into the unknown and incurable aspects of a CP condition – factors that pose a barrier to psychological wellbeing – is a critical step in psychological healing.

Lastly, some of the participants believed that they face these issues of misdiagnoses and uncertainty because they themselves do not yet know how to describe their pain in ways that make sense to their healthcare providers. Jamie expressed this view:

*Sometimes **we lack the words**. [The healthcare professionals] will say "describe your pain" but sometimes it's hard to describe what you're feeling. So, maybe if we had a list [of descriptors] – not a list of medical terms – because sometimes it's just hard to compare your pain and express it. It's hard to know if a doctor will really understand what we are trying to say. [...] It's almost like we need a bank of words that we can check off – like 'oh ya it's that' and 'it's like that' – like a questionnaire and you check*



*off the words. It would help if the doctor isn't the only one with this word-bank, but if we have them too because we don't mentally prepare our discussion of pain before going to see a doctor. [...] **We're not specialists, but we're almost like specialists in what we live,** so it could be good if someone helped us find the words to explain what we live.*

Jamie's narrative highlighted the fact that part of this uncertainty stems from the adolescent's lack of opportunities to practice *vocalizing* their experience living with pain. This lack of words often leaves these adolescents living with CP feeling useless in helping the professionals reach a more conclusive diagnosis. Other participants did not feel that the words that they *do* vocalize are appreciated. For example, Andrea described feeling as though entering the doctor's office immediately reduced her from a person to "numbers and stats". Andrea spoke about feeling misunderstood by the healthcare team:

*I know they understand me and want to help me, but when I tell them how I feel, they say 'oh okay, it's better than what it was [during our last appointment] so you're good, you're good, something has improved so it's okay, you're **good**' but... I'm not good.*

Even Andrea's mother claimed that the doctors "are just getting straight to the point and to the scale of pain with those numbers". When asked how Andrea felt the doctors could rectify this communication issue, her mother explained:

*Sometimes I find [the healthcare team members] are too direct. She will leave after the appointment and say...well what?*

Jamie and Andrea's statements emphasized a need for more comprehensive pain language and pain dialogue that can be understood by both the adolescent and the medical professional. The miscommunication that ensues without this dialogue highlights the role of the professional to not only diagnose and treat the patient but also to help their patients find the words to accurately describe how they *feel* living with CP. Without this patient-physician partnership, important information is missed which contributes to further confusion and uncertainty.

## **DISCUSSION of the FINDINGS: Facing the Unpredictability and Uncertainty of Chronic Pain (Personal Barrier)**

According to Gadamer, the process of *understanding* carries with it the possibility of transformation [95]. As explained in philosophical hermeneutics, “*understanding* potentially changes one’s knowledge so that one cannot return to a practice or a discourse” [95, p.68] and instead must ‘carry on’ as a different version of themselves. Werner Hamacher, a German literary critic and theorist, adds to the definition of *understanding* that *understanding* is at odds with *reason* in that *understanding* forever seeks “new transformations of itself in order to maintain itself” [95, p.184]. Hamacher’s description of ‘understanding’ emphasizes the continuous movement of our ‘understanding’ in that we are always learning and acquiring deeper meaning. Therefore, acceptance of one’s reality is an ongoing process that requires continuous dialogue. Uncertainty and unpredictability are often psychologically distressing for adolescents with CP as they are in a more vulnerable and helpless position than their healthy peers. Many adolescents with CP long for a concrete diagnosis and treatment plan, yet the unpredictability and uncertainty of their condition often limits the answers that medical professionals can provide. Providing these adolescents with opportunities to share how they feel, be understood, and be actively involved in their healthcare decisions can help them regain some control over their life. Jamie’s request for patients to have a word-bank of pain and sufferance descriptors on their pre-appointment questionnaires would help bridge this gap between patient-physician pain vocabulary and facilitate dialogue.

In interpretive phenomenology, a concept is meaningful not because a final interpretation has been reached but because said concept is brought to light by an unexpected conflict of interpretations which parallels the meaningfulness of one’s life as their unpredictable condition changes their trajectory while simultaneously providing new possibilities [95]. Ultimately, participants stuck in their ‘past-self’ identity are those searching for a concrete and permanent label and solution for their pain rather than appreciating that the truth and understanding of how to live best is in constant flux and must be updated according to their current conditions.

This process of understanding is supported by Immanuel Kant's saying that "there is no doubt that all our knowledge begins with experience" [94, p.1]. This quotation highlights the importance of gaining understanding through personal existence and experience living in one's body rather than waiting to inherit a diagnostic label and having professionals tell you how to live best with that condition. As stated in Nicholas Davey's interpretation of Gadamer's work, "promise of an unrealizable certainty persuades us that we do not have to respond to the challenges and instabilities that spring from our life worlds" [94, p.101]. The misconception of believing what we know to be a "certain" and "foolproof" answer is a failure to allow for the fusion of future understandings with our own, thereby serving as a barrier impeding on personal growth and acceptance of one's ever-changing condition. This gift of openness to the unknown "places us between what is disclosed of how we have in the past understood ourselves as being and what is intimated of how we might be transformed by future understanding" [95, p.16].

## V. **FINDING #2: Social Implications faced by Adolescents living with Chronic Pain (Facilitators and Barriers to Social Engagement and Social Belonging)**

I have identified 1 main facilitator for social engagement and/or experiencing a sense of belonging in a group and 2 main social barriers that pose challenges in my participants' social lives. The following list highlights each of these themes and their corresponding subthemes:

### **Facilitator**

1. Having a strong support system of individuals who understand them as someone living with CP *and/or* as an adolescent
  - ⇒ Supporters that understand the world of an adolescent
  - ⇒ Supporters that understand the world of pain
  - ⇒ Supporters that understand both the world of an adolescent and of pain

### **Barriers**

1. Feeling different compared to other adolescents
  - ⇒ Struggling with everyday activities that they used to consider 'easy'
  - ⇒ Having different priorities compared to other adolescents (feeling more mature)
  - ⇒ Experiencing feelings of loneliness and missing opportunities to socialize/to feel included
2. Lack of accommodations
  - ⇒ Schools lacking the infrastructure/resources
  - ⇒ Facing others' disbelief
  - ⇒ Not asking for help

I will address each theme and subtheme in greater detail.

## Facilitator

### 1. Having a strong support system of individuals who understand them both as someone living with CP *and* as an adolescent

#### a. Supporters that understand the world of an adolescent

My participants repeatedly expressed how fortunate they are for their friends' and family's unwavering support even though their friends and/or family do not struggle with CP themselves.

Jasmin said:

*I'm lucky to have a really good group of friends. They are just really supportive. If we have plans and I say, 'I can't go, I have too much pain', they'll be like 'Okay, ya, that's fine, we just want you to take care of yourself'. My parents are also really supportive.*

Andrea raised a similar argument:

*My closest friends and my boyfriend **really understand me even though they don't live it.** Even if I don't look it, when something's wrong, they know it, so it feels good to have somebody that knows you that well. Like when you don't want to do something because of the pain.*

Jasmin and Andrea's narratives captured the importance of having a strong support system of individuals that empathize with their CP-related challenges, especially among adolescents struggling with CP because many of them have yet to accept themselves. Living with CP seemed to have given these adolescents a heightened sense of gratitude for their support systems as though their pain was an added nuisance to both them as well as to their friends that they must tolerate collectively. Jamie said:

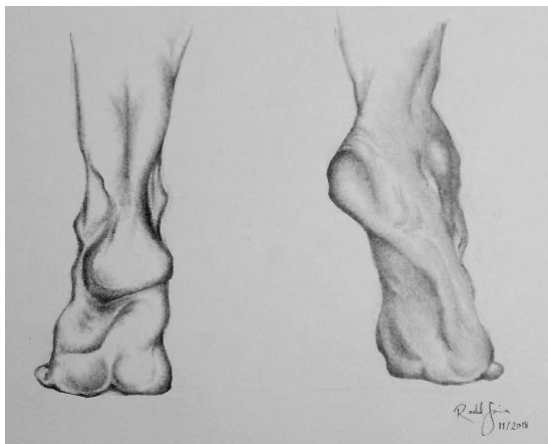
*My friends don't live like me. They try to understand, but [living with pain] is a difference between us. It's like for someone who never plays hockey and then me, who is a goalie, there will always be that difference in understanding. [But] I'm lucky that my school friends are **exceptional** [...] **they** adapted well [to me having pain]. My friends help me when I need them, they're very understanding.*

Jamie's referral to her friends as 'exceptional' and 'adapting well to her pain' represents how she believed that her pain is a factor that also affected and must be tolerated by those around her. She is grateful that her friends stick by her despite this added condition of CP. Considering that Jamie's friends even helped her put on her goalie gloves, this example emphasized how her friends understand their role in helping her pursue activities that are important to her as an active adolescent.

Many participants considered their support system as a facilitator for social engagement and belonging. Participants valued having friends who (are compassionate yet) do not experience pain because these friends lead a 'typical adolescent life' and motivated these adolescents with CP to partake in more social situations with them (despite the pain). For example, Jasmin – who feels well-supported by her friends – told me about the adventures she allows herself to enjoy with friends despite the pain she experienced following their plans:

*I went to see Panic at the Disco and it was really good. We had amazing seats. I went with one of my best friends and it was **so much fun**. We danced all night and we just screamed the lyrics of every song, it was really just very, very nice. [...] The day after, of course I was in so much pain, but I had so much fun that night that it was just **so worth it**.*

Jasmin's story emphasized how sometimes the importance that these participants placed on having a normal 'teenager experience' with their friends, such as singing and dancing at a concert, could trump the physical price they pay to have that experience. The majority of participants with a strong social support system were seen to be more motivated to break down the barriers that pain set up between them and their social circles.



I related to Jasmin's narrative through this image: a strong support system of close friends seemed to form the solid foundation necessary for her to want to 'lift off', be receptive to exciting opportunities, and take the next step toward living her best life with CP.

## b. Supporters that understand the world of pain

After years of misdiagnoses, all participants (as well as any parent that joined our interview) expressed their frustration with the healthcare system. However, upon their arrival to the MCH CPMC and years of being treated at the MCH CPMC, almost all of my participants described the clinic's interdisciplinary team as supportive and eager to help. For instance, Jordana's mother claimed that:

*It is only here that we have the whole Ingelmo team that has been helping us with her feet. [...] They have everything. A psychologist, physiotherapist, Ingelmo for the surgery. I think it's the best thing that happened to me and to her: **to have somebody that you can really come to and that has everybody in one place.** [...] It took a long time to find out what the problem was, but I think that they really went through the whole protocol of trying to find out what's wrong and that's why today we have hope that it could be fixed.*

Jordana's mother's statement emphasized the **hope** that her and her daughter derived from having the support and validation of a healthcare team. Arianne expressed a similar view:

*It took a long time when I was getting my Medicare red card, but [once I came to the MCH CPMC] a bunch of options came out. They take really, really good care of you. [Even when I was struggling to explain to my school what I was going through] I had help from the chronic pain management team, so I had back-up in that sense.*

Arianne's narrative reiterated the hope that came from being supported by professionals that understood her pain from a medical perspective.

Callie is the oldest adolescent that I interviewed and was being transferred to the adult chronic pain management centre a few weeks following our interview. Callie raised her fears regarding this imminent transition despite the fact that a pain specialist from the adult pain management unit assisted Dr. Ingelmo in her last pain-block treatment at the pediatric clinic:

*It's kind of scary because I've been coming [to the MCH CPMC] my whole life pretty much and all of a sudden they find my pain, they find what the problem is, they treat me, they help me, and now all that is going to completely **go away** when I get transferred 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.*

The combination of these excerpts exemplified the supportive environment that the MCH CPMC provides for these adolescents with CP. The members of Dr. Ingelmo's team are generally among the few adult figures in these adolescents' lives who validated that their pain is **real** and continuously try to work with them to manage the pain long-term. Having support from a healthcare team that do their best to take care of them is of comfort to these adolescents who live with so many unknowns.

### c. Supporters that understand both worlds

Some of my participants have someone in their life that understands them as both someone living with CP *and* someone who has the same concerns as any other teenager their age. For the most part, those that understood both the participants' world of pain and adolescence were likewise adolescents who live with CP. Callie mentioned:

*When my pain started, I kind of pushed all my friends away because I was really focused on trying to find out what my pain was. But I do have one really close friend that **really** understands my pain.*

Jasmin shared a similar testament:

*I'm lucky to have a really good group of friends, but one of my good friends in particular has arthritis so we both connect in that way where **we both have [and understand] pain**.*

Callie and Jasmin eluded to the fact that having these friends supporting them is less exhausting because they do not have to explain their pain nor their adolescent concerns – “they just get it”.

The MCH CPMC recently founded a support program that brings together CP patients from the clinic to discuss their experiences and share how they have been coping with their condition. This opportunity to unite with those facing similar challenges both in terms of adolescence and CP serves to normalize one's experiences. My participants that had attended the support program sessions expressed mixed reviews with most agreeing that finding individuals that understand ‘both of their worlds’ is a positive addition to their healing process, yet many felt that the way in which the clinic has implemented this program is not best-suited to their needs.

Those that enjoyed the support program expressed a similar feeling as shared by those who have close adolescent friends living with CP. Jasmin said:



*It's not that [the group program] is more supportive – because my friends are really supportive anyway – it's just that you **don't have to explain**. It's just nice to be **surrounded by people who know exactly what you're going through** because I can talk to my friends for hours about what I experience, but they'll never get it because they don't have it. But with [the girls in the support group], I don't have to try to explain how I feel because they already feel that way, they already have all those pains. [Whereas my physiotherapists] help me but in just a **physical** way. Like they say, 'do this exercise, I'm going to try to work a little bit on your lower back to see if it helps you.'*

Jasmin's recount of the group sessions spoke to the fact that the program addressed her psychological and social needs as opposed to having a CPMC that focuses solely on the physical aspects of CP. Even Jamie, who has not yet attended the support group, agreed that this program (in theory) is a promising initiative:

*Between us, we can talk, we can feel like we are not alone which is nice. We can discuss, give tricks, discuss our activities, and it distracts us. It would be nice to be surrounded by people to talk to about this – which is something we don't often talk about – we could talk about really anything and we would also get a chance to make relations with new people.*

***They would understand because they know a bit about what it's like to live like you.***

Jamie's hope for the program emphasized the fact that CP is not a popular topic of everyday conversations, yet she felt that she would be able to speak more freely about her challenges with a group of adolescent girls who experience similar pains and obstacles.

On the other hand, some of my participants felt that the psychologists running the program placed too much emphasis on the negative aspects of CP. These adolescents expressed a desire to learn more positive techniques from others about how to cope with their pain. Hilary's mother explained that the group sessions were 'so depressing for her and that's why she refuses to do them' because her and Hilary felt that the questions asked during the sessions revolved solely around suicidal tendencies. Jordana engaged in the support group the longest among my other participants: 7 weeks. She said:

*I don't like the therapy program because people don't understand, like the psychologists. They don't know who I am. They only know to ask about suicidal thoughts. [...] The other people that go there are going as their first time seeing a psychologist, but not me. It's*

*been 3 years that I've been seeing a psychologist, so I am better now. And [these other teenagers] are not good. I think if I had the [support group] in the beginning of my treatment it may have helped me. But now, people ask, 'why is she here? She is positive.' The psychologists say, 'tell us an emotion' and I say, 'happy' because I think positively. And they say, 'no, no, think of another emotion, not happy'. And I'm like why? People were just telling bad stories and I'm like 'why am I here?' They cannot do anything [to take away my pain]. They can just give us tricks like about how to have gratitude, be happy with what you have, and to hope that one day it will be better, to show us teenagers that there is something else in life than the pain we have.*

Jordana's dissatisfaction with the program speaks to the fact that some participants see potential in the group therapy sessions but would prefer that the psychologists take a different approach. Her testimony highlighted the negative associations that some of my participants are making with this program despite the fact that the psychologists attempt to portray this program as one of skill-learning and sharing of coping mechanisms. This finding calls for a reform in the focus of the program (i.e.: a shift from the negativity of living with CP to the positive transformations these adolescents can make) and/or how the program coordinator(s) explain the program to their patients so that more adolescents are intrigued to partake and benefit from this program.

In summary, the participants felt that surrounding themselves with supportive medical staff (who understand their CP condition), friend-group outside of the clinic (who understand their life as an adolescent, their interests, and what is important to teenagers), and those that understand both their interests and their pain alike created a supportive environment that facilitated engagement in social settings and fostered a sense of belonging. The combination of these supportive groups allowed these adolescents to feel as though the different parts of their identity were understood as opposed to focusing solely on being someone suffering from CP or only as an adolescent.

### **DISCUSSION of the FINDING: Having a Strong Support System (Social Facilitator)**

Being able to explain oneself, share one's uninterrupted narrative, and rely on others is a cathartic process that liberates the individual living with a chronic condition. Through my

inquiry, the adolescents that seemed the most hopeful for their future were those who felt validated by their healthcare team (i.e.: Dr. Ingelmo's team) and others their own age. The tactic and structure of Dr. Ingelmo's team during individual appointments seemed to be successfully implemented and was reported to make all 8 participants feel comfortable and validated. In terms of feeling a sense of social belonging and motivation to engage in social settings, my participants who reflected the greatest feelings of support and belonging were those with friends who understood both their social and CP world (i.e.: close friends who also experience pain or who are extremely empathetic) in addition to feeling validated by Dr. Ingelmo's team. The cathartic narrative is perhaps best achieved in a social setting – beyond the hospital walls – where the adolescent suffering can share their story without following a strict rubric outlining pain description, pain location, and pain intensity. Considering that CP is lived internally, cathartic narratives allow for the vocalization of the pain and provide a unique relationship to a personal truth [70]. Therefore, having a social context in which one can disclose the intricacies of their pain story is imperative to healing. Those who struggled to feel understood by either the healthcare team or by their close friends seemed the least adjusted and, perhaps surprisingly, were also least receptive to the group support program. A possible approach to make the support program more attractive to these adolescents is to adopt a peer-based approach whereby 2 patients are paired together based on the similarities of their limitations, time spent managing their pain, and the compatibility of their personalities, experiences, and mindset. In this way, the one-on-one setting would be more similar to a real exchange of stories between 2 friends. Each of my participants expressed a sincere interest in mentoring someone living with a condition similar to their own when asked if they would be willing to help other adolescents living with CP. Therefore, a peer-mentoring program may help give hope to the individual being mentored and may help to give purpose to the lived CP experience of the mentor. Peer mentoring has been shown to improve positive health behaviours and acceptability of self-management in adolescents with a chronic disease while simultaneously providing social support [99] and may provide these individuals with a more appropriate intimate setting to form friendships that support both the understanding of life as a CP patient and as an adolescent. The appropriate pairing of adolescents would require monitoring by a professional, such as a psychologist at the CPMC, to ensure that these relationships are in fact nurturing and not detrimental to the adolescents' wellbeing.

In addition, Callie’s fear of transitioning to the adult pain management clinic highlighted the distress that these adolescents face as they transition from the care of paediatric healthcare providers that *understand their pain* to a new and unfamiliar adult-care setting. Callie’s narrative emphasized the importance of facilitating the transition of care from adolescent to adult pain management in order to ensure that these adolescents feel secure within and supported by their new healthcare team. Therefore, perhaps a mentoring program that pairs an adolescent living with CP (approaching the age of 18) and an adult treated in an adult CP management centre who recently underwent this transition would help facilitate this transition by informing the adolescent of the differences between paediatric and adult pain management and guiding the adolescent throughout this process.

The following quotation by Richard Kearney encapsulates the essence of this finding: “Forgiveness gives the past a future (where you’re not caught in that thing/liberated from the incarceration of your own anger)”. I interpreted this saying to mean that opening up to others (forgiving themselves for being different by liberating themselves from the burden of suffering alone and silently) opens them up to a future of possibilities to continue trying to connect with others and seek out opportunities socialize.

## Barriers

### 1. Feeling different or “ab”normal compared to other adolescents

CONFESSION – I am not an alien

#### a. Struggling with activities that used to be ‘easy’

Many of my participants admitted to feeling ‘different’ from or ‘abnormal’ relative to their healthy peers and – at times – lonely. However, this sentiment of feeling ‘different’ or ‘abnormal’ was not necessarily (always) accompanied by feelings of alienation, isolation, nor a lack of peer support. Excerpts from Jamie and Jasmin’s interviews encapsulated this feeling of ‘differentness’.

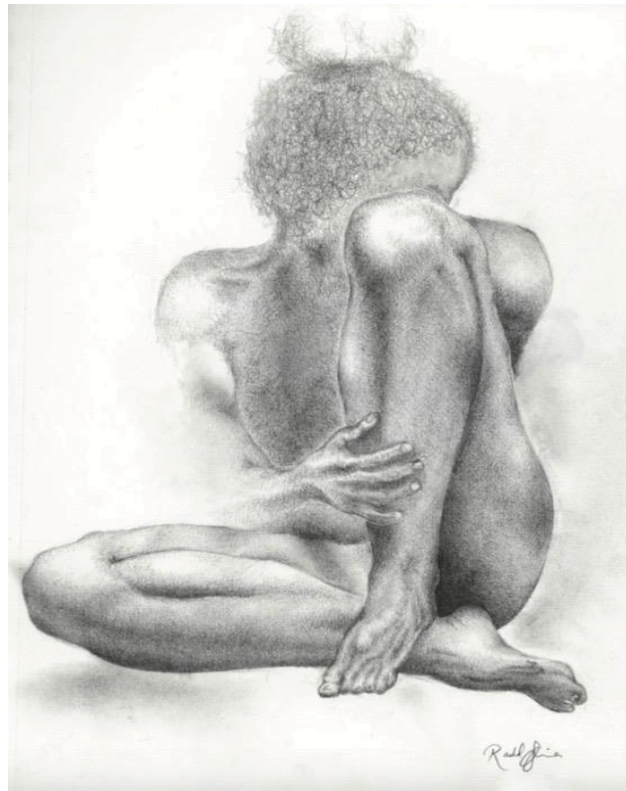
Jamie explained:

*In my school, we are only 500 – we are a small school. I think it's better that way because there are fewer people that I need to explain myself to, [fewer] people looking and asking questions, even though it's completely normal for them to ask because there are things that they see I cannot do – I cannot go skating alone [like I used to] because I cannot do up my skate laces.*

Jamie gave another powerful example of how CP interfered with her sense of 'normalcy' and singled her out among those her own age. She said:

*Let's say there's a glass of [punch] at a party. You can hold it, but for me with my pain in my hands I can't hold anything. I want to socialize with people [with my drink in my hand] – everyone wants to socialize, we are 16 years old, we want to live our life! And we want to go out on weekends. There are things I just can't do. The pain makes me very tired.*

Jamie's narrative demonstrated the fact that her pain often held her back from socializing. I related to Jamie's narrative through this image that symbolizes the 'raw', 'exposed', 'bare', and 'natural' beauty that lies beneath our coat of armour. CP seemed to shave off a layer of armour from these young individuals and revealed their uniqueness, maturity, and resilience. I was most impressed by Jamie's ability to accept the fact that her clenched fists are in fact a 'talking point' that drew attention from her peers. She felt that her CP made her 'different', and yet recognized that this 'abnormality' did not make her any less deserving of the chance to be a teenager. Her positive attitude was contagious.



Jasmin, whose school accommodated her pain by providing her with a laptop in classes, noted that:

*[My classmates] see it if I just get my computer out of my backpack because they'll be like 'why does she have a computer and not me' and then they'll ask questions and I'll answer them. It's not isolating. It just **is** different.*

Jasmin's narrative captured the commonality across participants of feeling that their CP condition differentiated them from their peers and undoubtedly made them a target of others' questions and stares. This 'uniqueness' may be perceived as a barrier to social belonging because adolescents tend to want to fit in with their peers and not draw attention to themselves. The concept of 'belonging' intimates a sense of membership and comfort, whereas the term 'inclusion' refers to merely being present among a group. Interestingly, the geological definition of 'inclusion' is "a body *recognizably distinct* from the substance in which it is embedded" [97]. In terms of their peers (distinct from friends), these adolescents living with CP seemed to feel like just that: a *recognizably distinct* body embedded within a sea of *regular* teenagers.

Considering that CP is a condition often experienced internally, these adolescents felt a need to prove that they are able to 'fit in' with and impress those around them and do what is considered to be 'normal' for adolescents their age. Arianne explained how her CP drove her to push herself past her functional limits:

*I never really participate in gym, I am not really supposed to, but [that day] I was like 'I will do [the beep test] for participation and to support my peers, I will only do 10 laps so it shouldn't be that big of a deal' but I did **56!** I **beat** most of the girls in my class and I was like 'I haven't run in 3 years! Go me!' But then, it took such a long time for me [to recover]. I had to miss the classes after that gym class because I had to go to the guidance counsellor to lie down. [... Even] my dad was like 'what were you thinking!? You shouldn't have! This is going to backfire on you' and I am like 'Ya, I know, I know. But I was just having fun, I was showing off'.*

Based on my conversation with Arianne, she seemed to be very athletic prior to the onset of her stomach pain. She enjoyed skiing and horseback riding amongst her many other extracurricular activities. The pride with which she recounted her gym Beep-Test success emphasized how her CP has made her feel the need to reclaim her status and identity as the *athletic one* and to *prove*

to herself and others that she is still capable of fulfilling the gym-class requirements expected of others her age. In addition, Jasmin's narrative emphasized the frustration that these adolescents living with CP experienced as a result of no longer being able to perform tasks that they used to consider easy and trivial. She said:

*Just walking, going up and down the stairs, doing some sports, just normal stuff would hurt. [...] I have to adapt my whole life around it. Something as stupid as just brushing my teeth can be really difficult because of my pain. And [pity is] the worst thing ever because I'm not an alien. I'm not going to die. I'm fine. It's just that I have some pain.*

The fact that Jasmin labelled everyday activities with which she struggled as 'stupid' highlighted her feelings of embarrassment over the fact that she cannot complete these activities like *everyone* else. She did not only feel abnormal in her own eyes, but she felt that others saw her as *alien*. Therefore, experiencing CP in a social context amplifies feelings of inadequacy, insecurity, and differentness.

Similarly, Callie explained how commitments that 'normal' teenagers should be able to make, such as committing to employment positions or plans with friends, were not possible for her. The following was her reply to the question *What is one aspect of your life that you would really want to do but that the pain is stopping you from doing*:

*Just to live a **normal life**, honestly. To be able to go out with my friends, to be able to work – honestly, it's [horrible] when I go to work, I have a big shift ahead of me, and it's only 30 minutes in and I can't do it anymore and I have to leave. It's... it's awful. So, I would want a **normal life**.*

Even Jordana's mother mentioned that:

*She wants to run, and she wants to jump **like a normal person**. And it's because of the pain that she cannot do it.*

And, lastly, Mona added:

*There are some moments where I feel **less confident** because I feel like everyone else around me could go, for example, on a ski trip coming up, can go outside, they have all these things. I am young and I **want** to move too. It hurts to know that when everyone else my age is playing sports and this and that, I can't even go on a trip really far with my friends because, imagine something happens, like if I fall, and this and that... It all*

*connects in the sense that **being young is not easy because you are still growing up and learning how to deal with emotions and relationships, and then you have this [chronic pain] which doesn't help, it makes you just 10 times worse. [...] I don't just want to be sitting there watching my friends have fun during gym class.***

Mona's narrative emphasized the distress with which she struggled on a daily basis, especially when she had to give up activities that she enjoyed and had to watch others partake in those activities with ease. Mona recognized that relationships and social belonging are particularly important to adolescents and that her CP has made this stage of development increasingly more difficult and different for her. This added strain on her social and personal life made her feel vulnerable and increasingly less like 'everybody else' her age.

These participants shed light on the feelings of differentness and abnormality that commonly pervade the lives of those living with CP and that often make functioning in social spaces difficult. However, my participants and their parents placed a strong emphasis on the limiting factor being the physical disability related to CP as opposed to the psychological factors (such as feeling inadequate, incapable, etc.).

#### **b. Struggling to relate to those their age due to differences in priorities and maturity**

*I just skipped that whole superficial phase where all I focus on is material and wear a lot of makeup. I've never been in that self-conscious phase because I've never really had the time to think about it. All my friends are kind of going through that now and I'm just not. Those things are **not necessary**. You know? **You do not need them to survive**. [...]*  
*Sometimes [their superficiality] does bother me because my friends are like 'let's take a picture!' and I'm like 'why?' ... It's not an important thing. And so, I think **I got mature way faster** because of [my pain] and it's kind of sad 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. [...But chronic pain] is not the best, but it's not the worst either.*



This excerpt from my conversation with Jasmin pointed to her list of priorities that was forced on her by her CP. In other words, CP had pushed her into *survival mode*. Her priorities were not based on taking the time to explore and figure herself out as a teenager like those of her friends. Instead, Jasmin felt forced into a new identity before she was ready to let go of her previous self. Many of the other participants exemplified a similar level of maturity. For instance, Callie mentioned:

*I have the mindset of a 40-year-old with 3 kids, like that's literally my mindset. So, I just **felt different** [in high school], you know? [...] I've never really been the type of person that cared what other people think. So, like let's say I have pain and have to leave class and people are looking at me... personally I don't really care because I **care more about my health than anything else**. But I understand how certain people could feel like an outcast if they have to leave.*

Callie's narrative emphasized her maturity and her main priority being her health as opposed to her looks or 'fitting in' which are often priorities of others her age.

Importantly, these adolescents recognized that their maturity is yet another factor differentiating them from those their age while still embracing their maturity. Many participants stated that having undergone suffering at such a young age equipped them with the emotional credibility, sensitivity, and empathy necessary to identify when others are suffering and help them. For example, Jasmin said:

*Now I know that if someone is asking for a seat in the subway, I'm not going to say no. I'm going to say 'Yes! Of course!' because I know that if I ask someone for help, I would **love** for someone to help me.*

In addition, this sense of maturity helped some of these adolescents recognize the parts of their life for which they are grateful. Arianne mentioned:

*I am mature in a sense that [I realize that] my grades are fine, my friend group is fine, my family life is fine... Yes **having pain has given me a new perspective about how lucky** I used to be and how lucky I am compared to some other people.*

Children and adolescents often get to live care-free while their parents worry about the risk-taking and negative consequences. However, these participants all felt that having their childhood taken away because of CP gave them a new perspective on what is of value. My

participants demonstrated the self-awareness to recognize what set them apart from others their own age and the ability to recognize pain that others were feeling. These capabilities are rare for children and adolescents who are generally described as being more egotistical. Their maturity and priorities were yet another barrier distinguishing them from other adolescents their age and that made relating to others their age even more difficult.

### c. Loneliness and missing opportunities to socialize and feel included

Some of my participants expressed a sense of loneliness accompanying their differentness. Mona emphasized how different she felt from friends when they did not support her in the ways she felt she needed. She said:

*When I am in pain, my friends will be like ‘why are you here if you are in pain, go home’, and I get mad because if I want to be home, I could be home. But I am not going to stay home [every time I’m in pain], otherwise I might as well not go to school anymore, so when they say things like that it makes me feel a bit **separate from them** – as if they don’t want to listen to me anymore. That’s why I keep a lot of it inside.*

Mona’s words captured her sense of loneliness when she could not partake in social situations to the extent to which she wanted and when her friends reminded her of her limitations instead of letting her share her story. She felt lonely on an emotional level despite being physically surrounded by her friend-group.

A common issue among members of the CP community is a loss of opportunities to socialize, thereby losing touch with friends and peers. These missed opportunities are of increasing importance during adolescence because teenagers explore their social skills and identity within a group. My participants frequently raised the issue of missing school for doctors’ appointments or due to unbearable pain. Jordana mentioned that she self-identified as being very studious, therefore, the fact that she had to miss school every week was conflicting and stressful for her. Hilary’s mother claimed that Hilary was out of school all week:

*School-missing is a big, **big** issue right now.*

Jamie commented on how special her friends are but that:

*[...] definitely there is some change because I am with them less because of my pain.*

This issue of missing opportunities to socialize was common among all of my participants.

Participants who partook in group sports or group activities with friends prior to the onset of their pain and who had very few friends outside of those group activities tended to report feeling lonelier than those who either preferred independent exercise/activities or had friends outside of their group activities. I believed the reason for this finding is because CP forced them to give up those sports/activities, thus driving them further away from the friends they made through those activities. When asked whether CP has changed her relationships with friends, Mona replied:

*It has in some way, not going to lie, because it is harder to do things and work with them and do the same activities. Me and my friends loved to play volleyball and basketball. And it's hard [not being able] to play those activities. Going out is even sometimes a struggle because let's say we go shopping I have to stop and sit for a good 5 minutes because it's too long.*

Similarly, Andrea – who was a competitive soccer player – felt that her soccer friends could no longer relate to her and her pain. Many of my participants experienced a loss of identity in the sense that they were no longer the *soccer player, dancer, or skier* and had to re-story themselves as mentioned in the Findings #1 Section. This re-storying was often accompanied by feeling emotionally distant to the friend and/or sport group to which they previously belonged.

### **DISCUSSION of the FINDING: Feeling Different or Abnormal (Social Barrier)**

Gadamer speaks to the idea of there being “an unacknowledged idea of a *norm* in the light of which the fullness of the noticeable variations and deviations from what we expect from human beings and find valuable is articulated” [95, p.29]. Gadamer highlights the concept of a societal norm and how individuals who fail to fit this mould are *noticed*, and yet ‘being noticed’ varies tremendously from being an ‘outcast’ or a ‘reject’. However, being noticed still means that these adolescents with CP are constantly subjected to feel *different* from those among whom they wish to *belong* and not simply *included*. These noticeable differences present themselves as functional disparities and differences in maturity and priorities that set these adolescents apart from their peers.

Gadamer describes ‘tact’ as a “special sensitivity and sensitiveness to situations and how to behave in them, for which knowledge from general principles does not suffice [...] Tact functions in the human sciences not simply as a feeling and unconscious but is at the same time a mode of knowing and a mode of being” [95, p.88]. Essentially, tact is achieved through lived experiences and helps shape how one acts in future situations. Therefore, constantly feeling different makes these adolescents define themselves as and foresee themselves as remaining ‘different’ or ‘other’. These adolescents naturally attributed this differentness to their CP condition which was often accompanied by shame, embarrassment, and loneliness. Many of these adolescents felt a need to prove themselves as normal and actively resisted giving into a sense of hopelessness of ever fitting in. Trying to fit in is a challenge most adolescents face, however, the additional pressure of CP serves as a barrier preventing many of these adolescents from thriving within their community and social circles.

This sense of otherness drew these adolescents living with CP back into a liminal space in which they no longer felt a sense of belonging in their present reality, longed for the past, and yet could not return to who they were. Gadamer claims that to be ‘hermeneutically aware’ one must understand that the “between ourselves being” is placed in between their past and future selves in this “differential space between ‘what we understand ourselves to be’ and ‘what others think us to be’” [95, p.29]. Perhaps CP management must incorporate strategies to help adolescents recognize this stagnation in liminal space so that they can find coping mechanisms to accept their differentness and realize their potential to thrive in their *new* reality.

## **2. Lack of Accommodations**

### **a. Schools lacking infrastructure/means to accommodate adolescents with CP**

School administration tends to be ill-equipped with the tools or education to properly accommodate adolescent CP issues as they arise, and those suffering from CP perceive a lack of accommodations as a problem that limits their ability to achieve optimal pain control [46, 98]. My participants perceived this lack of accommodations to be a barrier inhibiting them from

experiencing a sense of social belonging in a school setting. Andrea described her school's lack of infrastructure available to support her CP condition:

*[My school needs] more places to relax because my school is very small, so you can only sit in the cafeteria and the gym, there are no other places to go. So, it would be great to have a room with things like a silent area just to relax.*

Andrea's headaches required her take frequent breaks from school (as was the case for many of my other participants), however, she either was not being made aware of the resources available to her at school (e.g.: a nurse's office to lie down) or her school lacked the means to accommodate her needs. Regardless, Andrea's narrative resonated as a lack of support provided to her by her school. Jasmin added:

*My school does not have elevators. We have a freight-elevator so, first of all, you have to ask for the key. Second of all, there's only one key, so if 4 people need it, it's difficult to actually get it. And, how it works is you have to get the key in the lock and have to turn but that hurts me! I cannot do that. I am physically not able to do that! So, I know there is no budget for it and that it's impossible to have an actual elevator, but it would be amazing if we did so I can just go up and down without any pain.*

This lack of resources forced Jasmin to struggle going up and down the stairs with her mobility limitations – a process that made her stand out even more among her peers who could move between classes with ease. Mona also endorsed this lack of infrastructure when she said:

*I feel like there [needs to be] more equipment at school. Like [for example] chairs at school: they are not comfortable – let me tell you – I feel like I am sitting on plastic and it's not the easiest to deal with [when you have pain].*

Ultimately, Andrea, Jasmin, and Mona pointed to the additional difficulties they faced (on top of their persistent pain) due to the lack of suitable equipment available to them at school. Struggling to function with the limited resources they have is yet another barrier that made my participants feel disadvantaged relative to those around them in public, social spaces such as at school.

## b. Facing disbelief

The subtheme of *disbelief* was endorsed by all participants. Disbelief came in the form of accusatory and/or suspicious teachers, school administrative staff, and/or friends. In terms of facing disbelief by adults at school, a popular issue among all participants was the fact that teachers and administrative staff did not seem to take these adolescent students' need for accommodation(s) seriously despite having access to medical notes. For instance, Jasmin said:

*It's awful. Every single thing I asked [my school] for, I had to get a paper for it. I have limitations in physical education, had to have a paper for that. Then, to have more time to write my exams, I had to have another paper for that. And then, I asked for a computer [because it hurts to write], had to have another paper for that, so we had to make appointments each time just to get that stupid paper that they need. And the worst part is that the school principal did not even read them!*

Schools are entitled and necessarily require documentation for accommodations, however, the issue that I noticed while speaking with Jasmin is how the school is making her *feel*. Constantly bombarding her for notes made her feel as though they do not believe that her pain is real.

Arianne also spoke about the 'note' issue:

*The vice principal is really **unhelpful**. He is like 'I heard that you have been skipping class, you keep having to go down to the guidance counselor' and I am like 'no, that's because of my pain' and he'll tell me 'well then you are going to need to get me a doctor's note for that' and I'm like 'you already have a doctor's note! But I will get you another one that specifically says that I have to skip 15 minutes here and there.' [...Even] teachers are a little unhappy when I miss some of their class and cause a disturbance when I leave early and come back, but that's just stuck-up teachers. [Chronic pain] is just **not as obvious as a broken foot** where **of course** you can leave 5 minutes before class to avoid the hustle of the hallways.*

Arianne's narrative reiterated this constant doubt to which these adolescents are subjected.

Arianne's comparison of her condition to more visible disabilities shed light on the internal nature of CP and how she felt that her illness subjected her to greater scrutiny than someone suffering from a visible illness. In terms of an adult's perspective of the reason for this lack of support at school, Andrea's mother reinforced the *invisible* nature of CP:

*A big reason why people don't understand her is because she doesn't **look** like she has anything wrong.*

Certain participants went as far to say that the administrative staff made them feel as though they were 'troubled'. Callie said:

*[My high school was] always asking for notes. They were always wondering why I was skipping school. They thought that I was just 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 the emergency, I had appointments here at the clinic, and I was missing school like 3-4 times a week. It was really hard because **no one** understood. **Even when I tried** to sit down and explain it, no one understood. It's not that no one really cared, but that no one really **understood**.*

Callie's narrative represented how the breakdown in communication between students with CP and their school administration left them feeling further misunderstood and alone. These excerpts are just a few of the many frustrations shared across all participants. My participants felt that this constant inquiry translated directly into others' distrust and disbelief of them. They felt defined by the doctor's notes as though their reasoning for accommodations was an ongoing lie or excuse and put them in a separate category from the other students their age who can function 'normally' without constant inquiry.

Many participants also felt that medical professionals **initially** met their complaints of pain with disbelief. For instance, Jordana summarized her years of misdiagnoses as frustrating because: "*I was hurting and [the doctors] would say it's nothing*". Her mother added:

*They would say 'no, everything is okay', but the more time this took meant the more her feet would hurt, so at one point I had to get mad with everybody and say 'Come on! Are you stupid?'*

Jamie voiced a similar concern of not being believed by specialists:

*I sometimes really have pain at 9-9.5 [on a scale from 1 to 10], but I **don't** have a face that says that it's a 9-9.5. So, sometimes I'm scared the doctors will doubt [how intense] I tell them it is. But [exaggerating my pain is] not my goal, my goal is just to be honest with them, so we get to the right diagnosis.*

As mentioned previously in the ‘Findings #1’ Section, receiving validation from supportive healthcare staff helped normalize these adolescents’ lived experience with CP. Contrarily, disbelief from the medical professionals made them feel as though their experience was not real and therefore not worthy of attention nor compassion from other adults, such as school teachers.

Some participants even felt that their friends or peers did not believe that they were truly in pain. According to Andrea:

*When I told my school friends, none of them believe me. I know they won’t call me a liar, but I see it. When I tell them that I am in pain, they’re like “oh...ya...okay sure...” [...] I feel like they couldn’t understand, they thought [my pain] wasn’t real, like I just wanted attention or something, and then I saw who my **truest** friends were.*

Mona added:

*There’s even the [friends] that **pretend** to care.*

Arianne shared similar feelings about her school peers, but not about her friends. She said:

*[Those that do not understand my pain] were kind of like ‘oh, she is one of those girls who is trying to avoid gym by saying she has a headache or something like that’. I try to explain to them that no, I have chronic pain! But it’s kind of a really long explanation, they don’t really understand what’s happening, so whatever.*

These participants expressed their exhaustion over having to live with the CP in addition to having to re-explain themselves to each person that questioned the truthfulness of their story. And, as mentioned previously, many of these adolescents living with CP did not yet know how to explain their CP condition.

Overall, most participants found their school administration to be the most untrusting of their need for accommodations, and (to a lesser extent) their friends and/or peers as well. This lack of accommodations disadvantaged those living with CP and exacerbated their feelings of differentness. Therefore, a lack of accommodations is a barrier to social engagement and belonging.



### c. Not Asking for Help

Many of my participants were not properly accommodated or felt singled out for any accommodations that they managed to obtain. However, in addition, my participants were even further disadvantaged because they were too embarrassed or shy about asking for help. A commonality among almost all of my participants was that they did not want to be perceived as ‘a bother’. Jasmin said:

*Sometimes I just don't want to be a **bother**, so I won't ask friends for help.*

Mona claimed that:

*It hurts to know that [my friends] are there [for me] because **why do they need a friend like me?** Why do they put up with so much? It's been long. [...] It's been a really long time [that I've lived this way], and no one really gave up on me.*

These sections from Mona and Jasmin's interviews highlighted how some adolescents living with CP feel unworthy of their friends' empathy, unwavering support, and understanding and how determined they are to not be considered the nuisance or the ‘weak friend’. Therefore, their strong desire to be perceived as ‘normal’ and not as someone in need of help prevents them from asking for help altogether.

### **DISCUSSION of the FINDING: Lack of Accommodations (Social Barrier)**

Schools and friends that fail to accommodate their student's/friend's CP condition contributed to the emotional burden of the individual experiencing pain because this adolescent *felt* misunderstood, different, and/or labelled as the ‘drama queen’ or ‘faker’. These negative experiences facing disbelief and lacking social and administrative support contributed to shaping the identity of those with CP as they began to feel increasingly more defined by and reminded of their condition and lack of independence. Not asking for help and not wanting to be a bother was an extension of the previous finding (feeling different or abnormal) from which I suggested these adolescents with CP pushed themselves beyond their limits in an attempt to prove that they can fit the image of an ‘ideally healthy and independent adolescent’.

However, not being believed also means that these individuals were lacking in opportunities to feel as though their complaints and struggles were validated, appreciated, and of interest to those around them. Individuals tend to share personal information in comfortable and non-judgmental environments. The disbelief that these adolescents faced harboured a more hostile environment which prevented these young adults from wanting to share their story with others. Therefore, they tended to feel forced to struggle in silence in social settings considering that their peers did not understand (nor had they been given the opportunity to understand) what these individuals are enduring.

As mentioned previously, suffering silently makes one's *gears* grind faster and louder. The cathartic narrative can break this vicious cycle and liberate the individual from the emotional and psychological tension of fighting their pain alone. Gadamer's notion of being human is to be a 'linguistic being' and that "communicative practice is central to our mode of existence [...] We are what our cultural and linguistic practices have made us" [95, p.243]. I interpreted this passage to mean that the telling of our own narrative can change the way we perceive ourselves and paves the way for self-realization and feeling more comfortable in our own skin. When we feel that we have found our identity, we can begin to feel more secure in social contexts. Therefore, this lack of accommodation that singled out and shamed the adolescents experiencing pain limited the potential for them to tell their narrative and forced them individual to feel *different* within their social settings. This finding calls upon authoritative figures, such as school teachers and medical professionals, to create a supportive space in which these adolescents feel at ease to disclose the intricate ways in which their life is affected by CP and to be able to help sensitize their peers to their struggle with pain.

# SUMMARIES of my FINDINGS, SUGGESTIONS, and CONCLUDING COMMENTS

## 1. Personal Implications experienced by Adolescents living with Chronic Pain

CP often leaves the afflicted individual with a perceived loss of control over her life. Findings revealed that factors **facilitating** personal growth among adolescents living with CP include processes that help the individual regain a sense of control over her life:

- a. taking a break from their worries and reality to create an internal sense of normalcy;
- b. finding the tools necessary to regain control over their thoughts (e.g.: recognizing what is and what is not within their control, and changing their attitude and/or perspective); and
- c. re-engaging with reality in a way that is meaningful to them (e.g. envisioning a future that *they* want).

Factors that **interfere** with personal growth among adolescents living with CP relate to feeling dependent on a concrete diagnosis, solution, and routine to help manage and **cure** their pain completely. These factors include facing the unpredictability of pain (which interferes with their activities, plans, and routines) and the uncertainty of pain (i.e.: the lack of answers with which medical professionals can provide).

Currently, many chronic pain management clinics choose to focus on helping patients reach a set list of specific functional goals and provide psychological counselling to alleviate the psychological burden of living with CP-related disabilities. However, perhaps these adolescents would prefer learning about how they can achieve goals that *they* set for *themselves*. And, perhaps these adolescents would benefit from a greater emphasis being placed on how to embrace the possibility of living with CP long-term and counselling to help them recognize that – sometimes – the greatest improvement that they can expect to achieve from CP management is psychological in nature as opposed to physical.

## 2. Social Implications experienced by Adolescents living with Chronic Pain

One's sense of social belonging, acceptance, and engagement are also affected by CP. **Facilitators** that improve one's belonging, sense of acceptance, and engagement in social settings include having a strong support system of understanding friends and healthcare staff that understand both their world of pain and adolescence. Whereas, **barriers** that impede on one's social life include feeling different or abnormal compared to other adolescents (in the sense that activities that they could once do with ease are now difficult, their priorities and maturity level differ from other adolescents their age, and they feel lonely due to CP causing them to miss many social opportunities) and lacking accommodations either in school or amongst their friends (due to facing disbelief, schools lacking the proper resources to accommodate their needs, and feeling too ashamed to ask for help).

A significant issue that linked many of these findings regarding social implications of living with CP was feeling as though they were not believed. The great deal of psychological and physical pain that these adolescents face due to their CP condition alone is compounded by the psychological distress of a lack of support, accommodations, and belief/understanding of others. These issues may be rectified with proper sensitization programs at school and the fostering of a more comfortable environment in which these adolescents can feel at ease to share their lived experience of CP.

## APPENDIX

### Appendix A: Sample Interview Guide

- 1) Tell me about yourself.  
*Probe: tell me about your friends, family, hobbies, pain, etc.*
- 2) Can you tell me what you do on a typical week**day**? How is this affected by CP?  
*Probe: school, sport, meet with friends, time with family, etc.*
- 3) Could you tell me what you do on a typical week**end**? How is this affected by CP?  
*Probe: weekend getaways, cinema, meet with friends, etc.*
- 4) Which activities or occupations help give you identity/meaning in your life? Has CP changed your involvement in these activities/occupations?
- 5) What does the word “development” in terms of being a young person mean to you? What do you think are important things people need to do before becoming an adult?  
*Probe: do you think relationships, school/jobs, university, friends, and/or independence are necessary/important?*
- 6) How you feel about your own development? How would you compare your development with that of your friends?
- 7) What have you enjoyed about developing into a young person? What have you disliked? Can you tell me what it is like to have long-term pain and also be developing as a young person?
- 8) How do you imagine your life might change as you develop into an adult?
- 9) Did your friends know you before you had pain?
- 10) Do you feel that your friends understand your pain? How has your pain changed your relationships? How do you think these relationships would be different if you did not have pain?  
*Probe: would you be in school more, doing more activities, cancelling plans less, etc.?*
- 11) Do you feel that pain poses any challenges or any benefits on how you relate to others?
- 12) Can you tell me any really positive opportunities you have experienced living with CP?  
*Probe: a change in perspective, change in how you value certain relationships, challenge you have overcome, etc.*
- 13) What 3 ways could you imagine your life differently if you did not have CP?
- 14) Do you feel defined by CP? Do you feel others define you by your pain?
- 15) How has CP changed how much you engage with your peers?

16) Is there anything that and/or anyone who helps get your mind off of your pain?

*Probe: friends, music, art, a new hobby, etc.*

17) What sort of services/programs would you like to see developed both inside and outside the clinic? Have friends or school accommodated your needs to your satisfaction?

18) What advice would you give to someone your age or younger living with CP?

## Appendix B: MUHC REB 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](mailto:personne.mandatee@muhc.mcgill.ca).

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

Sincerely,

A handwritten signature in blue ink that reads "Sheldon Lewy".

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

## Appendix C: Consent Form (English Version)

### CONSENT AND ASSENT FORM

**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.

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

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Name of person obtaining consent (Print)	Signature	Date
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