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Piloting a study to examine children's understandings of chronic pain and coping

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences

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Abstract

Many of our understandings of how children conceptualize and cope with chronic pain are drawn from adult accounts or extrapolated from research in adult populations. Accordingly, there is scant knowledge relating to children's own experiences of chronic pain and coping. This study begins to address this gap by piloting a methodology combining arts-based methods with semi-structured interviews to generate data with children aged 6-13 years. Participants with chronic pain were invited to draw and/or photograph what represents a 'good pain day' and 'a bad pain day', before engaging in a tailored, semi-structured interview. Results, interpreted using a constructivist lens, contribute modest preliminary insight into children's understandings of chronic pain and coping, and lend support to the quality of data generated using this methodology. Insights pertaining to what worked well, and lessons learned regarding the methodology are contained herein for reference prior to producing scaled-up versions of this work.

Keywords

Chronic pain, coping, children's perspectives, children, arts-based methods, qualitative research

Summary for Lay Audience

Most of what we know about the ways children understand living and coping with chronic pain relies on adult accounts or drawn from research about pain in adult populations. Accordingly, there exists little research examining what it's like to live with chronic pain from a child's perspective. This study begins to address this gap in pain-focused research by trialling a new methodology to conduct research with children with lived experience of chronic pain. This study combines art-based methods (visual art and photography) with semi-structured interviews tailored to each participant, in order to present preliminary knowledge of children's own experiences of chronic pain and coping. For this study, three participants with chronic pain aged 6-13 years were invited to draw and/or photograph what comes to mind or represents a 'good pain day' as well as 'a day when my pain is worse than usual', prior to discussing their perspectives in a tailored semi-structured interview. The study results lend support to the quality and type of data that can be generated using this methodology with children with chronic pain and share these insights as a preliminary step towards contributing to the lack of knowledge of children's experiences of chronic pain.

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When accepting my offer of admission to this master's thesis, I had little idea that the next two years of my academic life would occur virtually because of a worldwide pandemic. At the beginning of this journey, I grappled with how I would thrive throughout this master's, being in a different city than my school campus and so far away from my classmates and supervisors. Despite this unique academic experience at no point did I feel lonely, isolated, or disconnected. For this, I am grateful and indebted to so many.

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List of Abbreviations, Symbols, Nomenclature

IASP	International Association for the Study of Pain
BMM	Biomedical Model
WHO	World Health Organization
QoL	Quality of life
ASD	Autism spectrum disorder
AAC	Augmentative and alternative communication
SKIP	Solutions for Kids in Pain
SDM	Substitute Decision Maker
LOI	Letter of Information

Chapter 1

Introduction

The contemporary understanding that children can feel pain is a relatively new acknowledgement in the field of medicine (McGrath, 2011; Carpenter, 2020). Until the late 1980s, many clinicians believed children did not experience pain the same way adults do, thus analgesics were less often administered to young children during surgical and medical procedures. Instead, children were considered to be ‘primitive beings’ who reacted reflexively to noxious stimuli and therefore did not experience pain as adults did (Carpenter, 2020). This failure to recognize children’s sensitivity to painful stimuli caught the attention of child advocates and researchers, causing the field of childhood pain research to grow exponentially over the ensuing years (Caes et al., 2016). As time progressed, this medical stance on children’s ability to feel pain was eventually overturned; it was agreed children could in-fact feel pain and experience these effects and implications. It is still unclear if pain is felt, perceived, and understood by children the same ways that parallel adults’ pain experiences; this lack of knowledge regarding children’s pain is the key impetus for the research described in this thesis.

With increasing attention to childhood pain came the understanding that children can experience chronic or recurring pain. The most recent systematic review exploring the epidemiology of chronic pain in children was conducted back in 2011 and, although somewhat outdated in terms of statistics, this work reported: “prevalence rates vary considerably across studies, [rendering it] difficult to make conclusions regarding the pervasiveness of different pains on children and adults” (King et al., 2011, p. 2729). The impact of childhood chronic pain is thus perhaps better described in terms of its effects for children on quality of life both throughout childhood and later in life. In the short term, children living in painful bodies might experience more school absences, withdraw from social activities, and experience emotional distress, all of which have the potential to affect their well-being (King et al., 2011; Lisman-van Leeuwen et al., 2013; Kosola et al., 2017). As a child with pain transitions into adulthood, the chronic pain they

experience is likely to persist, along with the psychological, social, and occupational effects of under-managed pain (Hasset et al., 2013; Lauridsen, 2020).

The effects of under-managed pain in children are multifaceted, impacting psychological and emotional well-being and increasing their reliance on healthcare systems.

Overreliance on health services use has potentially devastating social and economic effects for children and their families, both in the present as well and into the future. For instance, the financial costs of adolescent chronic pain in the United States exceed that of other chronic conditions affecting this group such as asthma, attention deficit hyperactivity disorder, and obesity (Lauridsen, 2020). Childhood chronic pain is a significant problem that demands further research attention.

Prior to 2019, the International Association for the Study of Pain (IASP) defined pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (IASP, 2019). A pain Task Force was created to rethink this definition of pain, and after two years of collaboration between leading pain experts and members of the public, pain was redefined as: “an aversive sensory and emotional experience typically caused by or resembling that caused by actual or potential tissue injury” (IASP, 2019). One of the supporting arguments for this reworked definition acknowledged the need to understand pain as a subjective experience, mediated by factors other than the somatic (i.e., relating to the body), including contextual and sociocultural components. It can be argued that this new definition is still lacking with regard to the contextual, sociocultural, and psychological mediators of the pain experience, however, the several footnotes included as part of this definition emphasize pain as deeply personal and socially embedded (IASP, 2019).

In addition to biological and psychological factors, one’s life experiences and sociocultural landscape affects how pain is experienced and addressed. Given the documented biopsychosocial influences on chronic pain, a natural curiosity exists when it comes to understanding how different individuals, namely those who differ in each of these three dimensions, experience and understand pain. As it relates to coping, one’s means of and ability to cope is strongly related to one’s social context (Gifford, 1998),

including what is appropriate to engage in, communicate, and express. This is particularly relevant for young people who experience the effects of power relations throughout their daily lives. Children, in Western neoliberal society, are positioned as immature and dependent on adults for support related to most if not all matters, including those related to health and illness. Thus, children with chronic pain are expected to reach out to a trusted adult for advice, support or coping strategies related to their pain. Depending on a young person's sociocultural context, particular requests or understandings of pain might be encouraged or silenced.

In empirical research, pain has most often been framed through a biomedical lens, with quantitative methods being used to elucidate objective pain states and traits. Accordingly, there is a paucity of qualitative research examining pain in general, and even less that has focused on exploring children's perspectives of living with chronic pain. Recently, a participatory "Partnering for Pain" research project led by Birnie et al. (2019) partnered with youth living with chronic pain and their families to identify priority areas for future pain research. Two of the proposed priority areas for research identified by youth patient partners in this study were as follows: "What interventions are effective for managing acute pain flares in children and adolescents with chronic pain?" and "What physical and psychological treatments are effective for improving pain and function in children and adolescents with chronic pain (for example, functional outcomes including quality of life, depression, fatigue, sleep, acceptance, concentration, resilience, coping, self-management)? (Birnie et al., 2019, p. E660). The primary aim of this dissertation was to design and pilot a methodology for producing knowledge of children's pain from their perspectives; in so doing, this work also lays the groundwork for beginning to address these research priorities by generating initial results on children's experiences and perspectives on pain and the strategies young children use to intervene, or 'cope' with chronic pain flares, into the research questions, due to their stated importance by children with chronic pain.

Purpose

The primary aim of this research was to design and pilot a novel methodology incorporating arts-based elicitation methods to examine children's understandings of

chronic pain and coping. Reflections on what went well, the lessons learned through executing the methodology, and empirical results of the pilot with three study participants are included in this dissertation to illustrate the type of and quality of data that can be generated using this methodology and share early insights into children's experiences of chronic pain, from their perspectives.

The following two questions guided this study:

1. How do young people understand chronic pain and describe the ways they cope with flare-ups of chronic pain?
2. How can researchers generate knowledge about young people's understandings and ways of coping with chronic pain?

This interpretive qualitative study design integrated arts-based elicitation methods with interviews to respond to these two research questions. Results provide preliminary evidence and reflections regarding the use of this novel methodology to learn more about pain in a population of children of primary-school age. In the discussion that follows, I suggest this research methodology, when leveraged in larger future studies with similar groups of young people with chronic pain, has the potential to inform best practices by contributing novel understandings of pain from children's own perspectives.

Terminology

Prior to expanding on the study methodology and procedures, key terminology and language will be presented and explained. Specifically, I discuss or introduce herein: childhood & children, the biomedical model, chronic pain, and flare-up.

Childhood & Children

Defining children and childhood is inherently difficult, as children and childhood are concepts shaped by one's society and culture (Christensen & James, 2017). There is no universal definition of childhood, nor does there exist a prespecified age range of who can be considered a child. Due to the ambiguousness of universally defining children and childhood, the research drawn upon and discussed throughout this text might have

conceptualized and defined this demographic differently. This research study recruited young children of primary school age, which includes children aged 6 to 13 years.

The Biomedical Model

The biomedical model provides a framework for understanding, conceptualizing, organizing, and delivering medicine and clinical care (Gifford, 2016). Driven by enlightenment-based thinkers like Galileo and Descartes, the biomedical model has dominated ways of thinking and enacting care in traditional Western medical practice over the past 300-400 years. The biomedical model concerns itself with discovering the underlying pathophysiology causing the signs and symptoms of disease. This model, which also “assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables” (Gifford, 2016, p. 447), dominates ways of thinking and enacting care in traditional Western medical practice. In this study, the biomedical model is understood as the central paradigm that informs the medical sciences, including how pain is understood and addressed in a clinical sphere.

Chronic pain

Chronic pain is understood as any persistent or recurring pain lasting longer than three months which causes significant distress or significantly interferes with daily function (WHO, 2020). Only recently has chronic pain become recognized as a distinct condition in the International Classification of Diseases-11 (ICD-11), which was adopted in 2019 and came into effect January 1st 2022 (WHO, 2019). Chronic pain can be classified into one of two groups: chronic primary pain and chronic secondary pain (Strub, 2021). Chronic primary pain involves pain conditions which are classified as an inherent ‘pain disease’ (e.g., fibromyalgia). Chronic secondary pain includes the presence of pain as a symptom of a disease state or underlying condition (e.g., chronic pain related to cancer) (Strub, 2021). Importantly, chronic pain is not just somatic pain (i.e., pain relating to the body) or of physiologic origin but is understood to be influenced by psychological and sociological factors (WHO, 2020). In this study, chronic pain is understood as pain, either primary or secondary, in any body region lasting longer than three months.

Flare-up

At present, there is no agreed upon definition of what constitutes a pain flare-up in the pain-focused literature. In 2019, Costa et al. published an article outlining the results of their multi-phase study which aimed to generate a universal definition of what can be considered a pain flare-up. Their agreed-upon definition is used to conceptualize a flare-up in this study and constitutes “a worsening of [one’s] condition that lasts from hours to weeks that is difficult to tolerate and generally impacts [one’s] usual activities and/or emotions” (Costa et al., 2019, p. 1272). The term flare or flare-up are used interchangeably within these pages.

Statement of Personal Interest & Positionality

Prior to October 2015, my understanding of pain aligned with ‘typical’ pathology-focused Western cultural views. Similar to many others, I would occasionally experience short-lived or ‘acute’ pain, which could generally be traced back to an obvious initiating event or root cause. For instance, I would feel pain for a period of days after twisting my ankle at dance practice, or I would experience stomach pain and upset after eating one too many sweet treats. Only recently has my understanding of pain shifted, as I have learned to live and cope with chronic primary pain.

My symptoms first began in my late adolescence and have persisted into what is now my early adulthood. My pain began in 2017 with headaches, neck and jaw pain, and facial pain/numbness, and soon spread to other areas including my shoulders and lower-sacral region. On the worst of days, my pain took over my body from head to toe— starting at my head and neck and extending down into my legs. From the beginnings of my pain journey, coping with flare-ups of my symptoms became part of my habitual routine. Over the past several years, I have navigated several biomedical, allied, and alternative health environments, in search of a diagnosis to help me cope with, and eventually rid myself of pain completely. Over the years of searching for answers, I became fixated on uncovering some objective ‘reason’ or initiating event to render my symptoms ‘valid’ and credible, from a biomedical perspective. Without a true diagnosis, I did not believe I could ever learn to live with, and eventually overcome, my illness.

In late 2017, I received a diagnosis: Thoracic Outlet Syndrome. I thought this diagnosis would positively influence way I felt about my pain, however, it left me devastated. My symptoms continued to hold me back. After reflecting on my experience thus far and how I have come to understand my illness, I realized a reframing of my relationship with pain was needed to jumpstart my road to recovery. I needed to reconceptualize my pain in a positive light and build a repertoire of tools from which I could pull to alleviate exacerbations of my symptoms. I slowly began coming to terms with my new reality.

I would love to share that I am now symptom-free, however, this statement would not be truthful. I still experience exacerbations of my symptoms, yet they no longer take over my life as they had in the past. My experience of living with and overcoming the psychological burden that chronic illness poses on one's psyche is one of the driving forces behind my decision to pursue a master's degree and ultimately this research project. My interest in examining the unique experiences and understandings of pain in children has the potential to inform an understanding of how children frame pain, and how this framing does (or does not) help them overcome and cope with their chronic symptoms.

Because of my experiential knowledge of chronic pain described above, I engaged in critical reflexivity throughout this research project; from the beginning stages of formulating my research questions all the way through to the data analysis and polishing of this thesis. The reflexive practices I engaged in were diverse and included recording independent reflexive memos, engaging in co-reflexive meetings with one of my co-supervisors, GT, and recording interview field notes after each interview. Approaching this work reflexively, it was imperative that I worked carefully and deliberately through my preunderstandings of what it means to identify as a young adult with chronic pain, and how I conceptualize this part of my self-concept (Finlay, 2002). This critical reflexivity helped me better engage with, accept, and understand participants and their unique experiences. My lived experience was part of my co-analysis of the results generated with the young participants in this study, as these experiences have cemented themselves in my beliefs about pain and coping. In constructivist qualitative research, it is considered impossible to separate one's past experiences or 'bases' from the research

process. Rather, these experiences shape and influence what is called the “creative presence” of the researcher (Eakin & Gladstone, 2020), which will be elaborated on further in section 3.5 of this dissertation. Nevertheless, when young peoples’ beliefs ran counter to my experiences as a ‘chronic pain insider’ I was mindful of leaving space for these opposing experiences (Smith & Sparkes, 2008). I acknowledged early on in this research there are multiple ways that my own positionality might influence this research. This consideration is brought up once more and explained further in section 3.1 of this dissertation.

Chapter 2

Literature Review

The following chapter presents a review of literature, situating this study within existing bodies of knowledge. To do so, understandings of how pain, children and childhood have been conceptualized in the past are introduced and discussed. Subsequently, a background on research with children and art-based methods is provided, to provide evidence of the opportunities and gaps that exist in both these areas.

Pain and Biomedicine

A background on biomedicine

The idea of leveraging empirical research as scientific ‘evidence’ for medical protocols and procedures dates back to the 18th century (Bueno-Gómez, 2017). At that time, the classical method of identifying disease was not much different from how it is currently understood: disease or illness presents as a deviation from the norm, through an altered physical appearance, functioning, feeling, performance or behaviour, that often brings up feelings of deviance or unpleasantness (Engel, 1977). As a rule of thumb, illness and disease are framed as unwanted or harmful, with the sick person deemed a victim or sufferer (Engel, 1977; Cassell, 1998). Accordingly, medicine evolved as a discipline as a way of assigning a role to a group of individuals in society who could credibly interpret and correct these deviations (physicians). As the biomedical discipline evolved in the Western world, this view of health and disease became accepted as part of our sociocultural customs and norms.

Several key principles inform the biomedical paradigm informing medicine, chief of these being the existence of a mind-body dualism; the understanding of the mind and body existing as distinct entities (Cassell, 1998; Bueno-Gómez, 2017). Mind/body dichotomy dominated early biomedical understandings and largely informed how deviations from ‘normal’ health were addressed. For instance, pain at this time was considered to be of physiologic origin, whereas the effects of pain, such as suffering for example, were considered to be separate manifestations of the mind (Cassell, 1998). The

physical and psychological expressions of pain were nonetheless considered to be distinct and unrelated to each other.

Early biomedical understandings also embraced reductionism as another central principal, positing that disease can be reduced to a single causal factor (Engel, 1977). This factor was understood to be somatic, meaning that it can and must be objectively identified as a biochemical or physiological difference in the body. A. M. Ludwig, an American psychiatrist who advocated for mental illness recognition in the medical field, explains reductionistic thinking in biomedicine as such: “the medical model premises ‘that sufficient deviation from normal represents disease, that *disease* is due to known or unknown natural causes, and that elimination of these causes will result in cure or improvement in individual patients’” (Ludwig, 1975, as quoted in Engel, 1977, p.129). In this sense, the clinician operating from a biomedical paradigm should not concern themselves with ‘subjectives’, but rather be concerned by objective, quantifiable, and universal markers of disease, as this is where deviations from ‘normal’ lie. This framework solidified the understanding that a ‘good’ clinician must be able to separate biases about their patient’s social worlds when treating disease, focusing solely on objective makers of health and disease. Accordingly, psychological, spiritual, cultural, and social beliefs were historically excluded from the underlying framework used to understand and treat illness biomedically, presumably due to their lack of identification via measurable biological variables (Engel, 1977).

The biomedical model of pain

The biomedical model informed initial understandings of pain as a medicalized phenomenon, focusing primarily on the physical body (Bueno-Gómez, 2017). According to René Descartes, the body was considered to be a flawed and frail machine that contained one’s experience of pain (Damasio, 2001). Pain was deemed a ‘lesser experience’; one that could be felt by primitive, non-human beings thus lending support to its ‘origin’ in the body rather than the mind. As opposed to the body, the human mind was considered powerful and sacred, and Descartes believed that if it could break-free from the confines of the physical body, it could exist as a fully actualized ‘immortal soul’ (Damasio, 2001; Bueno-Gómez, 2017). For many years, this way of thinking about pain

dominated traditional biomedical thinking; positioning pain as a lesser experience, located solely in the body, and largely irrelevant to the human mind.

The understanding of pain as a physical experience, distilled down into causal biochemical and/or physiological indicators, has been argued as lacking a wholistic view of the individual experiencing pain. The humanistic turn was born out of this tension and marks the turning point in recognizing the influence of the mind when it comes to pain, overturning the notion of the mind and body as separate entities (Cassell, 1998). Eric Cassell, an American physician and bioethicist, was a major contributor to this paradigmatic shift in biomedicine. His medical humanistic model foregrounded the understanding that pain can be rooted in the somatic but cannot exist separately from the mind. Cassell believed pain, like other illnesses that caused suffering, was strongly “embedded in beliefs about causes and diseases and their consequences” (Bueno-Gomez, 2017, pp. 4-5) and thus advocated for the understanding that the mind shapes pain through subjective experiences and understandings (Cassell, 1998). Two primary rectifications to the existing biomedical paradigm were born out of Cassell’s input regarding the relationship between the mind and body in relation to pain: 1) psychological pain was acknowledged as ‘real’, and 2) the experience of physical pain was acknowledged as being related to and interlinked with the psychological aspect of the human condition, including the psyche and the mind in all its intricacies (Engel, 1977, 1981; Melzack, 1999).

The biopsychosocial model addresses what the biomedical model lacks with regard to the human experience of health and illness. It considers psychological and social components to be interrelated with the biological components of health and disease, including pain conditions, the latter being the sole focus of the biomedical model (Engel, 1981). As opposed to the biomedical model which is ‘disease-oriented’, the biopsychosocial model is ‘patient-’ or ‘person-oriented’ (Engel, 1981). The way pain is understood and conceptualized in this thesis as a medical phenomenon is more in line with a biopsychosocial model than a purely medical model.

Childhood and The New Social Studies of Childhood

Understandings of what it means to be a child and experience childhood are so deeply engrained in Western ways of thinking about one's early years of life that they are seldom acknowledged as socially embedded concepts. Instead, these concepts and what they represent are often taken at face value and accepted as universal facts. Childhood can be considered a relatively new concept, which can be defined and understood differently depending on a number of biological, psychological, sociocultural, geographic, and socioeconomic underpinnings/influences (James & James 2004; Carnevale 2020).

Prior to the early 1980s childhood was primarily considered a precursor period to adulthood, without much inherent value or importance (James, Jenks & Prout, 1998; Prout & James, 2003; Gibson, Teachman & Hamdani, 2016). The study of childhood was thus centred around children as 'future adults', where children are considered 'human-becomings' on the path towards adulthood but not yet fully human (Gibson, Teachman & Hamdani, 2016). Developmental models of childhood are rooted in child psychological theory, whereby empirical research popularized by early psychology scholars such as Freud, Piaget, Locke and Rousseau, provided evidence for a linear, stage-based model of child development (James, Jenks & Prout, 1998; James & Prout 1997; Qvortup, 1985). Developmentalism reduces childhood to markers of age-and-stage based growth, with the expectation that children will 'progress' along a predetermined developmental trajectory into adulthood. In this way, the biomedical concept of 'development' becomes inextricably linked to understandings of childhood and creates space for labels of im/maturity and in/dependence. In other words, according to developmental models, children are considered biologically immature, and thus dependent on adults until the developmental processes are 'complete' (Prout & James, 2003). Until children reach an acceptable age of developmental maturity, they are considered less capable of understanding and expressing their experiences, thus requiring adults to protect them in enforcing their 'best interests' (James, Jenks & Prout, 1998). 'Best interests' is an ambiguous term without a clear definition. However, protecting or promoting children's best interests is broadly operationalized through adults deciding, or at the very least,

mediating which occupations children ought to engage in, in order to maximize their future participation in an adult world (Carnevale, 2020). Within this perspective, children have limited agency compared to their adult counterparts, making the child the object of adult protection through governance (Prout & James, 2003; Carnevale, 2020).

Christensen & James (2017), frame the difficulties of uniformly conceptualizing childhood in that definitions of who can be considered a child, and what can be considered childhood both shape and are shaped by society and culture. For instance, young people born into different cultural and economic worlds likely experience distinctly different ‘childhoods’, making it difficult to universally describe experiences that signify what it *means* to be a child. In the same vein, these children might ‘progress’ along slightly different ‘developmental timelines’, or what is considered to be their ‘best interests’ might not be identical. Moreover, two children in the same geographical location, with a similar family structure, culture, religion, and worldviews, for example, might still experience vastly different childhoods simply because of differing socioeconomic standings (Qvortrup, 2017). Accordingly, childhood is a pluralistic and relational experience whereby its understandings and experiences are strongly linked with one’s environment (James, Jenks & Prout, 1998; Christensen & James, 2017).

The ‘new’ social studies of childhood was born out of the framing of children as ‘human-becomings’ and represents a paradigmatic shift in the ways children and childhood are conceptualized, primarily aiming to address tensions related to child rights (Jenks 1982; James & Prout, 2003). The construction of the sociological child is often preceded by discussions of ‘child voice’ or ‘giving voice’ to children (Facca, Gladstone & Teachman, 2020). Although well intentioned, definitions of what it means to encourage child voice are incomplete, heterogeneous, and often exclusionary. For instance, childhood ethics scholars argue child perspectives in research should not be limited to their overt speech, but rather, should include both what is said, and what is not said (e.g., when children choose to pause, hesitate, or remain silent after being asked to share knowledge). Further, definitions of what can be considered child ‘voice’ often exclude children who communicate in ways other than verbal speech (e.g., through augmentative and alternative communication (AAC)). This ableist perspective further discriminates against

these young people in research, as these other ways of sharing are considered difficult to elicit and understand (Facca, Gladstone & Teachman, 2020). The notion of ‘giving voice’ to children, although well intentioned, includes assumptions about how children can and should share their views. These assumptions have implications for how and whom is engaged in research; privileging children who express themselves using verbal speech over other means of communication (Mah et al., 2019; Facca, Gladstone & Teachman, 2020).

A background on research with children

Recognizing children as able to contribute knowledge about their own lived experiences is being increasingly recognized. Still, there are many documented ‘barriers’, some legitimate and some less so, that limit children’s meaningful contribution to research that concerns them. This is especially prominent in biomedical and health science research, where parents, caregivers, and clinicians are often called upon to contribute knowledge to research on behalf of children. Despite children having experiential knowledge, adults are considered ‘knowledge holders’, consulted when seeking to understand children’s thoughts, views, and opinions through research (Mah et al., 2020). One of the problems with engaging parents to contribute to research on behalf of their children is that self- and proxy-reports have been shown to be incongruent. For example, a study by Egilson et al. (2017) compared child and parent proxy-reports of quality of life (QoL) in groups of children with and without high-functioning autism spectrum disorder (ASD) and noted that parents rated most QoL measures lower than their children. These findings are one example of the many studies that highlight the difference between child and parent proxy-reports (Bastiaansen et al., 2004; Potvin et al., 2013; Sheldrick et al., 2011), providing evidence for the need to engage children directly in research that concerns them. In addition to proving to be unreliable, engaging adults to interpret and communicate children’s perspectives tacitly assumes that the knowledge held by these young people is less important or less valid (Mah et al., 2020). This perpetuates power differentials between adults and children and reinforces beliefs about children being incapable of their own opinions and views. Studies aiming (and claiming) to examine

children's experiences or understandings have the duty to ensure children are directly engaged in this research as a primary source of knowledge.

Most research examining childhood pain relies on adult accounts as a primary means of understanding children's pain. For example, a recent study by Plummer et al. (2021), examining children's experiences of pain following hematopoietic stem cell transplantation and therapy, engaged parents and clinicians first, and children secondarily, to generate research data. Although parents and clinicians have valuable insight to provide and might be well informed of the pain the child is experiencing, their perspectives should not be conflated with those of the children themselves. Pain is inherently subjective, making those who are experiencing pain the best sources of knowledge with regard to their own views and understandings.

There are several arguments as to why children are excluded, or only marginally included, in pain research. For example, children have been considered difficult to communicate with, difficult to understand, or unable to form complex opinions due to limitations of age and stage-based development (Pate et al., 2019). Other documented barriers, specifically related to pain research, include the ethical tension of engaging children in research with severe pain, as they have been considered in 'too much pain' to share their perspectives (Plummer et al., 2021). While barriers to eliciting children's perspectives on difficult or sensitive topics (e.g., pain) exist, this should not preclude children from contributing their insights to research. It is important to recognize that conducting research with children does not exclude the presence or input from meaningful adults in supporting or secondary roles. Both parties can be included, while also granting children autonomy to share their views.

What are arts-based methods?

Although still gaining recognition in the health sciences, visual/arts-based methods have been widely used in anthropological research to overcome the limitations of words-based data generation approaches (e.g., interview transcripts, field-notes, reflexive memos) (Guillemin, 2004a; 2004b Teachman & Gibson 2013; Teachman & Gibson 2018). One of the first research studies to use arts-based methods (drawing in particular) to examine

health and illness was work done by Martin (1994). In this work, Martin (1994) engaged adults in conversation about their understanding of the immune system. Some participants, when asked to comment on images of the immune system, asked to draw images to help explain their understandings. This study marks one of the first uses of drawing in research to explore the ways in which illness is conceptualized, and interestingly only leveraged drawing because participants thought it would be useful to help them express their insight (Martin 1994; Guillemin 2004).

Guillemin's (2004a; 2004b) seminal work engaging adults using art-based methods, drawing in particular, has been cited numerous times by those who integrate drawing and interview methods. Guillemin's research examined how women living with heart disease understand and make sense of their illness. Drawing was considered data and analyzed with the understanding that they represent the participant's experience and understanding of their condition at this specific time and place. Further, Guillemin also emphasizes drawing as a reflexive exercise; explaining that the process participants underwent to create their artwork included reflection and meaning making, where the female participants constructed knowledge about their condition in the process of creating their drawings (Guillemin 2004a; 2004b). Thinking about, or theorizing, drawing in this way allowed Guillemin to gain insight into the diverse and complex ways the women in her study made sense of their experience of heart disease while analyzing their visual art.

Art-based methods are a diverse set of methods that have been shown to engage groups of all ages in reflexively sharing their views (Teachman & Gibson 2013; Teachman & Gibson 2018; Mah et al., 2019). These methods include drawing or painting activities, photo-elicitation tasks, marionettes, and vignettes, to name a few. Art-based methods can be leveraged in many ways and at different time points throughout a research study. For example, visual methods were used by Dr. Gail Teachman in her doctoral work engaging youth who use AAC. The two visual methods, photo-elicitation and Belonging Circles were used during dialogical interviews with participants to examine how these young people understand inclusion (Teachman & Gibson, 2018). In another study, Pate et al. (2019) used drawing activities during their one-on-one interviews with children to get at their knowledge of pain and the nervous system. They used drawing twice throughout

their interviews: the first time to explore what children display when asked to draw “whatever the word pain makes [them] think of” (Pate et al., 2019, p.3), and a second time to label a diagram of the human nervous system. They explain their rationale for using drawing directly during the interviews as it engages children and maintains their attention to subjects the interviewer/researcher is interested in but might be considered by participants to be ‘boring’ to discuss. A downside to using drawing in the interview is that children are usually not offered enough time to reflect on their experiences prior to engaging in the task. Depending on the aims of using drawing as a method (i.e., will it be considered data and unpacked with the participants, or simply used to keep the participant engaged?) the decision as to when and how these methods should be employed to optimize to type and quality of data generated differs.

Arts-based methods can be adapted to suit diverse needs and research questions, making them a flexible way to generate rich data with young people (Guillemin, 2004; Teachman & Gibson 2013; Teachman & Gibson 2018). Further, they are successful when aiming to examine questions that are abstract or difficult to explain such as their perspective on health, illness and risk (Piko, 2006), and their perspective on healthcare environment designs (Walter et al., 2017). Similar to childhood pain, childhood concussion can be considered an illness experience that is difficult to explain and thus has most often privileged adult-accounts of the experience over children themselves. Dr. Katie Mah set out to bridge this knowledge gap through her doctoral thesis, where she combined drawing and semi-structured interviews to generate data related to children’s experiences of concussion. Her work employed a novel arts-based methodology to generate knowledge of how children ‘at risk’ of concussion understand childhood concussion and how they have come to understand it in this way. Mah generated data with young people using semi-structured interviews and drawing, with the option for young people to write text instead. Drawing was selected as an elicitation strategy to promote children’s active engagement in the process of knowledge construction through her research, maximize their ability to share their views, and because of the appropriateness of drawing for her research aims and questions (Mah et al., 2019). The ways that drawing and interview methods were theorized and combined in this study to elicit data with young people,

including the rationales for doing so, was informed by both Guillemin and Mah's research described above.

Chapter 3

Study overview

In this chapter I provide an overview of the methodology and methods used in this study. I begin by overviewing my constructivist paradigmatic stance that informed the planning and actualization of this research. I then provide an overview and rationale of the combination of arts-based and interview methods used to engage children. Then, details of my participant sample are provided along with a detailed overview of the study procedures, prior to concluding with the approach used in analyzing and interpreting the preliminary data generated with the young participants.

Research Paradigm

Prior to engaging in qualitative inquiry, the qualitative researcher must be clear on their orienting paradigm, which is defined as one's set of basic beliefs about the world and the nature of knowledge (Guba & Lincoln, 1994). Research paradigms are meant to inform the methodology and methods used to examine a particular research question and are based on both ontological and epistemological assumptions. Ontology asks questions pertaining to the form and nature of reality, and therefore, what can be definitively known about it (Guba & Lincoln, 1994). Epistemology, in research, concerns itself with questions of what can be uncovered by the relationship between the participant ("knower") and the researcher ("would-be knower") (Ponterotto, 2005). These important questions shape and inform the researcher's methodological choices and guides their process of uncovering what they believe can be known about the world through research (Guba & Lincoln, 1994).

This research, including all methodological and procedural decisions, is guided by a constructivist paradigm. Constructivism is characterized by a relativist ontology and a subjective and transactional epistemology (Ponterotto, 2005). A relativist ontology, or relativism, contends that multiple, equally valid, perceptions of reality can exist depending on that given individual's perception of the world as shaped by their society and culture. Thus, constructivism rejects the notion that a single objective truth can exist,

and instead understands reality to be fluid and influenced by one's lived experience and relationships with others. Thus, relativism opposes realism, which argues for the existence of a single objective, and identifiable, reality. Constructivism is also transactional and subjectivist, emphasizing knowledge as a co-construction arising through researcher and participant interaction and deep discussion (Guba & Lincoln, 1994; Ponterotto, 2005). The knowledge generated through constructivist research is said to be hermeneutic, meaning that knowledge claims are emergent and open to multiple different, and perhaps conflicting, interpretations (Guba & Lincoln, 1994).

As explained earlier, my lived experience of chronic pain has an influence on how I understand pain and coping, and how data is co-generated and analyzed. Constructivism embraces one's past experiences and identity as part of the research process and inherently influencing the knowledge generated. In other words, researcher presuppositions or 'biases' are not anticipated to be separate from the research process, rather, the qualitative researcher is anticipated to make these biases 'known' through independent and group reflexivity, in order to recognize when and how their experiences shape all stages of their research. Accordingly, in line with constructivism, knowledge generated in this research is said to be co-constructed with participants and is thought to represent one possible interpretation of what was shared throughout engaging with participants. The meanings and interpretations displayed and explicated in Chapters 4 and 5 of this dissertation are thus not meant to represent any single universal truth about pain, but rather one possible way of interpreting the pain experiences of the young children who participated in this pilot study.

It is worth noting how the visual art (drawings and paintings) produced by participants through this research were theorized. As explained in the literature review section of this thesis, both Guillemin and Mah's methods of theorizing visual data were drawn upon in this research. It was understood that each participant's process of creating their visual art involved a unique process of meaning-making (Guillemin 2004a; 2004b). Furthermore, the drawings were understood to represent the young person's understandings at that particular time and place. For instance, what children decided to represent in their visual art were unlikely to remain fixed in time, and it is understood to be unlikely that they

would represent the same thing(s) after a period has passed. Accordingly, the drawings, and co-interpretations of them by myself and each participant, are dynamic as opposed to static representations of each young person's understandings of pain.

Methods

This qualitative study piloted the use of semi-structured interviewing methods combined with arts-based methods to generate data with primary-aged children aged 6, 9, and 13 years with lived experience of chronic pain. After expressing interest in participating in this research and acquiring assent and consent, participants engaged in a rapport-building interview. At the end of this first interview, participants were given the option to complete a drawing task or a photography task (or both), in the two weeks that followed. Participants were then invited to engage in a second semi-structured interview to discuss the visual representations that they created and shared with me. See Figure 1 for an outline of the study sequence. The reasons why drawing and photography were chosen for this research along with why they were combined with semi-structured interviews will be explained in Section 3.4 of this dissertation where the Study Procedures are presented in more detail.

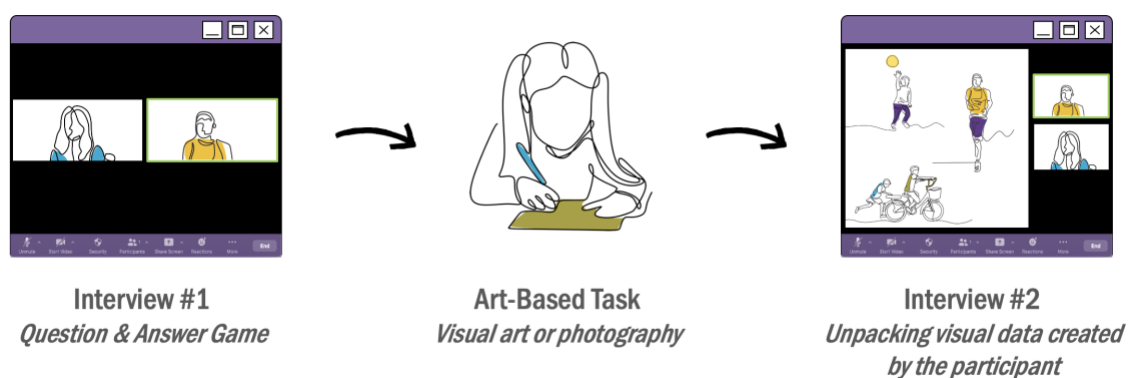


Figure 1: Overview of the study sequence

In past qualitative research with young people, such as with youth of primary-school age or youth who use AAC to communicate, combining art-based methods (including drawing, photo-elicitation, or vignettes) with interviewing methods has successfully yielded rich data (Teachman & Gibson, 2018). Drawing as a methodological tool has

been gaining attention in the qualitative research sphere for a number of reasons, including its diverse potential for use in different settings and groups. For example, Jongudomkarn et al. (2006) described using drawing with participants to build rapport and reduce participant boredom when discussing topics that might be only minimally interesting or engaging. They further justified their use of drawing methods with children stating that “it comes naturally to most children (as part of their “being”) and helps them convey their thoughts and feelings and speak more than they would in an interview” (Jongudomkarn et al., 2006, p. 158). Pate and colleagues (2019) leveraged drawing methods to triangulate findings with other sources of data, namely face-to-face interviews, and vignette data. Mah and colleagues (2019) acknowledge that these are both cited reasons for using drawing methods with children and argue that drawing is more than just a methodological add-on well-suited to children, but a powerful elicitation technique for groups of all ages. For one, children are not a homogeneous group, and their desire to engage in drawing cannot be attributed to their chronological age. Rather, the act of reflecting on the act of producing the drawing, engaging in the drawing, and finally reflecting and sharing about the drawing during the interview is thought to “enable a level of co-construction beyond that possible through interview methods alone” (Mah et al., 2019, p. 2972).

In the field of childhood pain, drawing is becoming increasingly used as a means of examining and unpacking the meanings young people ascribe to pain (Jongudomkarn et al., 2006; Pate et al., 2019). The value of integrating drawing methods to examine an abstract illness experience such as pain, has also been observed outside of the pain research sphere. The Canadian Pain Society’s Art Awards, for example, calls upon individuals with lived experience, clinicians, researchers, and trainees to leverage diverse art techniques to display what pain represents to them. This event was inaugurated in November 2021, and because of its great success in its first year, was brought back for a second time this year. Beyond its advantages as a methodological tool, the popularity of this event lends support to the way art resonates with individuals in the chronic pain sphere as a relevant medium for expression.

In what follows as the methodological contributions of this thesis, the advantages, limitations, and considerations of using art-based methods in combination with virtual interviews to engage young people in discussion about pain will be unpacked. To my knowledge, this is currently absent from the literature in this area of inquiry.

Participants and Sampling

After obtaining Ethics approval for all aspects of the study concerning human subjects through Western University's Health Science Research Ethics Board (Appendix A), the recruitment process began. Recruitment infographics instructed potential participants to reach out to myself, Kristina, via email if they were eligible for inclusion and interested in participating in the study. The inclusion and exclusion criteria are outlined in Table 1.

Table 1: Inclusion and Exclusion Criteria

Inclusion Criteria
<ul style="list-style-type: none"> • Aged between 6 and 13 years • Minimum one year lived experience of chronic pain • Past or current recipient of pain-related health services • Resident of Canada • Able to understand, communicate, and respond in English or French • Capable of providing free and informed consent/assent to participate in the study • Access to a computer with a stable and reliable internet connection, microphone, and camera • Comfortable with participating in the study's art-based task (drawing and/or photography) and sharing stories related to one's experiences of chronic pain and ways of coping

Rationales for the above criteria were as follows. The age range of 6-13 years represents the approximate ages of primary school aged children in Canada. This was taken into consideration when selecting the age of inclusion as it contributed a level of homogeneity to the participant group. The lower limit of 6 years of age was selected as children of this age can be considered to have experienced chronic pain and chronic pain flare-ups over a sufficiently long period of time, allowing them the opportunity to reflect on their experiences prior to and within the research setting. A minimum of one year of 'pain experience' was required to participate as it was considered a sufficient length of time for participants to have formed perspectives and understandings about chronic pain.

Recruitment posters were shared on Twitter, Instagram, and Email with patient-partner groups in both of Canada's official languages (i.e., English and French), as I am bilingual in both languages.

Participants were recruited through social media and communication platforms run by Solutions for Kids in Pain (SKIP) using a purposive sampling method (Abrams, 2010; Palinkas et al., 2015). SKIP is a national knowledge mobilization network based at Dalhousie University and co-led by Children's Healthcare Canada with 5 regional hubs across the country (Halifax, Montreal, Ottawa, Toronto, and Edmonton). SKIP's network connects clinicians and researchers to children and youth with pain and their families to support knowledge translation and communication between these parties. I connected directly with SKIP's media team to share virtual recruitment information.

Study Procedures

The procedures used for this study aimed to optimize the quality and quantity of data generated in a way that would not be overly taxing for young people experiencing chronic pain. As someone who experiences chronic pain, this was an important consideration maintained throughout the planning process. This section outlines the study procedures including rationales for the decisions that were made when designing this study. The methodological design was intentionally selected to align with the research aims, study questions, and research paradigm.

Study Enrolment, Consent, and Assent Processes

After confirming eligibility through the email correspondence initiated by the participant's substitute decision maker (SDM), participants and SDMs were sent Letter of Information (LOI) and Consent, and Assent Letter of Information forms. Consent and assent procedures were modified to accommodate for the virtual format of the interviews; participants and SDMs signed and scanned over their signed documentation without meeting with me in person to collect the forms. Consent was obtained from each participant's SDM, and assent was obtained from each child participant, in line with ethical guidelines provided by Western University's Health Science Research Ethics Board. Within the SDM's LOI and Consent was a one-page questionnaire to collect

participant demographic information to be completed by the parent or guardian prior to the first interview (see Appendix B). This demographic questionnaire was thought to be useful to guide purposive sampling, however, due to the challenges of recruitment, the questionnaire was not used for this purpose. The questionnaire results served primarily as a way of describing the sample for analysis.

After initial consent and assent were acquired, an ethics-as-process approach was adopted (Cutcliffe & Ramcharan, 2002) to ensure participants' ongoing assent. This process included ongoing check-ins prior to beginning each interview, reminding participants they could choose not to answer specific questions, defer questions for discussion later in the interview, or stop the interview and withdraw from the study at any point.

Once consent and assent were obtained, two interviews (ranging from 30 to 60 minutes each) were conducted with each participant approximately two-weeks apart. The decision to meet with participants on two separate occasions was intentional. In past research with children using arts-based elicitation methods, using a combination of two-interviews along with an elicitation tool such as drawing or photography, has proven to be effective in generating rich data with young people (Teachman & Gibson 2013; Teachman & Gibson 2018). Further, it was important that participants were not engaged for too long in the interviews, which eliminated an initial option we considered where participants would produce their visual data on Zoom with me, after an initial ice-breaking session and before formally engaging in an interview about their visual art. This setup was also decided against because it did not give participants sufficient time to reflect on what they wanted to represent in their visual art, which undermines the benefits of art-based methods to promote reflection and meaning-making through the act of creating the visual data.

Interviews were conducted on Zoom, at a time convenient to the participant, and took place in the participant's home. Interviews were audio- and video-recorded for later transcription and reference during analysis. After each interview, I drafted extensive reflective notes which included descriptions of who was present at the time of the interview, my observations and initial analytic thoughts, reflections on what was said and

not said, any concerns or reflections I had regarding the interview process, and new topics and questions to be incorporated into the interview guide for subsequent interviews (with the participant and other participants). These reflexive notes served as a way for me to unpack my initial reflections on the dialogue that took place and begin to theorize the data based on the literature, as well as my own experiences of living and coping with chronic pain.

Interview 1

Information Gathering: The first interview served primarily as a way of building rapport with participants using a question-and-answer game. As described above, following a model of ethics-as-process, consent and assent were revisited prior to beginning the interview. This interview took place over Zoom either following a meeting to discuss eligibility and study procedures, or at mutually agreed upon date. The scheduling of this initial interview was decided upon by participants and their families depending on their desire to engage in an interview after the first meeting and scheduling constraints. As the primary interviewer, I conceptualized this initial interview as a way of getting to know the participant and gather information that would prove helpful to subsequent interviews. Additionally, I saw this as an opportunity to attempt to minimize the power differentials that inherently exist when a young person interacts with an individual perceived as ‘adult’. To minimize discomfort and power differentials, I began each interview by affirming to participants that they have a choice in terms of how the interview proceeded. For example, I explained that the participant was allowed to skip, postpone, or decline to answer any question, and permitted and encouraged to take breaks or pause the interview at any time. I was also intentional in making this first interview ‘fun’, by asking participants about their interests and prompting them to elaborate and tell stories about these topics. Learning more about each participants life, including their likes and dislikes became useful when probing them in their second interviews to learn more about what changes (or not) about their lives when experiencing a pain flare, for example.

Question-and-answer game: This initial information-gathering interview was guided by a question-and-answer game. For a two-interview approach to be successful in generating rich data, it is suggested that the first interview incorporates a ‘warm-up activity’, either

at the start of the interview or as the first interview in entirety (Teachman & Gibson 2013). The virtual warm-up activity that was adapted as the first complete interview in this study was inspired by a card game that was used in in-person interviews with young participants in a different study. It was decided that the ‘warm-up’ activity would comprise the entirety of the first interview so that the event would not be overly taxing to children and so that children would be able to meet with me, reflect prior to producing their artwork, and then have the opportunity to meet with me again after building this initial rapport, to discuss the details of their artwork.

For the question-and-answer activity, I used Zoom’s screen-sharing function to share my screen, where a list of prompts labeled 1-10 were visible on one side, and a virtual die on the other (see Appendix C for a guide of Interview 1 which includes the list of questions asked and Appendix D for a view of my screen setup during this interview). In an engaging manner, I ‘rolled the die’ by pressing a button on my screen. The outcome of the dice roll was a number between 1 and 10. The participant was then given the choice to read the prompt and decide who answered the question first (i.e., the interviewer or participant). Building decision-making in at this stage contributed to building rapport, increasing participant confidence, and further reduced power differentials by emphasizing the participant’s ongoing decision-making capacity during the interviews.

Art-based task: Upon completing the Q&A game, time was spent with each participant reviewing what the drawing and photography tasks entailed. Participants were then offered time to reflect on their preferred arts-based task. There were several reasons why an art-based task was built into the methodology for this study. First, it allowed for participants to be reflexive prior to engaging with me in a second interview. When constructing their visual art or taking their photographs, children were anticipated to have reflected on what pain means to them, prior to completing their activities (Teachman & Gibson, 2013; Mah et al., 2020). Further, giving children the opportunity to take the lead in completing their art-based task positioned them as expert knowers, and enabled them to voice their opinions related to their pain that they might previously have been excluded from or not asked about.

Research incorporating arts-based methods with children has highlighted the benefits of selecting methods based on the participant as an individual and not solely on their age (Teachman & Gibson, 2013; Mah et al., 2020). Therefore, this study intentionally built in the flexibility for participants to choose which of the two art-based tasks (i.e., drawing or photography) might be more enjoyable to engage in. As with the other options given to participants in this study, providing this option increases the control they have over their involvement in this study and had the potential to increase their comfort moving forward into the next stage of the study which would involve discussing their experience of pain. Although steps were taken to reduce discomfort in talking about this subject (i.e., supports were provided and options to dismiss certain questions were offered), talking about one's chronic illness has the potential to be distressing and difficult. It was also acknowledged that some children might not feel comfortable drawing as holding a drawing utensil might cause an exacerbation of pain or might be uncomfortable. In this case, children worried about not being able to draw, or worried about drawing and experiencing a pain flare, might feel discouraged to participate despite having valuable insight to share. Further, drawing on its own can present some difficulties when it comes to describing the experience of pain, for those who are passionate about drawing but might not have the skills or capacity to express themselves fully using this method. In these cases, photography was thought to overcome these limitations by allowing children to capture their world as they see and experience it in everyday life.

Each participant in this pilot study chose to create artwork as their arts-based task. Participants were informed that they could use any drawing utensil they had at home and enjoyed drawing with (e.g., wax crayons, markers, pencil crayons) and blank white paper. Participants were asked to draw or write what came to mind in response to the prompts: "On a good pain day I..." (on one page) and "When my pain gets worse I..." (on another page) (Mah et al., 2020). Instructions and sample drawing setup templates were sent to SDMs for participants to review following this initial interview (See Appendix E). Participants were given two weeks to complete their visual art after which their SDM sent me a scanned image of their work.

Although no participant in this study opted to complete the photo-elicitation task, it is outlined here for completeness and to explain the choice that was offered to participants. The photo-elicitation task, called the ‘photography task’ when engaging with participants, required participants to use a smartphone or any other photo-generating device to collect 6-10 photographs that describe them and might tell others how they cope with pain. As a guide, participants were asked to photograph what might represent or show “A good pain day” and “A day when my pain is worse than usual”. As with the visual art task, participants were given two weeks to take their photographs after which their SDM would securely send the photos to me (see Appendix F for the instructions that were prepared to be sent to participants and SDMs).

Interview 2

Each participant’s SDM contacted me by email to send their children’s artwork and schedule a second interview at a time that was convenient for them. As with the first interview, consent and assent were revisited prior to beginning the second interview through Zoom. Importantly, participants were reminded that they were allowed to decline to participate in this second interview, even though they had previously agreed to participate, and no one would be mad or upset with them. This second interview served as a way for me to discuss the details of the artwork produced following our first interaction. This second interview was semi-structured and followed a guide tailored to the artwork created by the young person. This guide took into account the participant’s representations of pain and coping displayed in their artwork. The questions were designed to elicit stories from the participant wherever possible, and contained topics including: a) the participant’s description of a good pain day; b) the participant’s understandings, experiences of, and ways of coping with especially painful days; c) the participant’s understandings of their pain and the meanings they ascribed to their pain; and d) how they shared pain-related knowledge and coping strategies with others (a sample participant interview guide, created for Sarah, is included as Appendix G). As with the first interview, I shared my screen with each participant during their interview to display their visual art and orient them to aspects of it throughout the interview.

Data Analysis

Data analysis in qualitative inquiry is an iterative, ongoing process that occurs concurrently throughout the many stages of the research project (Eakin & Gladstone, 2020). In this study, analysis began with data generation and ‘writing up’ the study. The learnings and analytic insights gained early-on in the research process informed the subsequent study activities, including data generation and analysis (Green & Thorogood, 2013; Eakin & Gladstone, 2020).

The following made up the data set for this study: a) transcripts from semi-structured interviews (i.e., Interview 1, and Interview 2); b) participant-generated visual art; and c) my post-interview fieldnotes and reflexive memos. Importantly, participant-generated visual art was not analyzed in isolation from other data sources. Rather, they were co-analyzed between me and participants in the context of the second interview (Gibson et al., 2013; Drew & Guillemin, 2014). I transcribed the first two semi-structured interviews myself whereas the remainder of the interviews were transcribed by a professionally hired transcriptionist used by the study team for prior research projects. Following transcription, I reviewed all transcripts alongside audiovisual recorded data for accuracy.

All interview transcripts, visual data, post-interview fieldnotes and reflexive memos were imported into the latest version of NVivo (Release 1.6.1). NVivo is a data management software program which allowed for coding and organization of the data superset. Analytic memos were created using Microsoft Word by extracting excerpts from the data in NVivo, pasting excerpts into a labeled Word Document, and using the comment function to attach comments to each excerpt. Although data analysis was primarily conducted by myself, ongoing guidance and group data analysis sessions were carried out with GT, KM and DMW, my co-supervisors and post-doctoral mentor from my research lab at Western University.

Data analysis, specifically coding and memo writing, followed best-practices of ‘value-adding’ analysis as conceptualized and outlined by Eakin and Gladstone (2020). Value-adding analysis aims to ‘penetrate’ qualitative data through analysis practices that

increase the depth, richness, and overall value of the knowledge and findings generated. Importantly, Eakin and Gladstone advocate for researchers to do more than code for content at face value, rather, they emphasize the importance of ‘theorizing’ data; relating concepts to each other and other sources of credible research, in an effort to make findings analytically or theoretically generalizable. Analytic or theoretical generalizability is distinct from statistical generalizability in that the *abstraction* of qualitative data, rather than the categorization of data, allows for researchers in similar and distinct areas of inquiry to judge if findings can be useful to explain different, but theoretically similar phenomena (Becker, 1998; Eakin & Gladstone, 2020).

Content codes and analytic codes were generated following an analytic guide that was built with close attention to the aim and research questions guiding the study (see analytic guide, Appendix H). Both content and analytic codes helped identify where participants shared information that was relevant to the study’s aims and research questions. The coding process was iterative, with codes being refined in name and meaning as more data was read and incorporated into the coding set. Content codes were used to ‘extract the facts’ imbedded in the data, these ‘facts’ were used to draft the participant interpretive narratives which contributed to the research question for this study calling for explanation of the ways children cope with chronic pain. What I mean by ‘extracting facts’ is that participant interpretive narratives aimed to stay as close as possible to what was said and meant by participants. Although still acts of interpretation, the narratives do not include my personal explanations or rationales for what was shared.

Analytic codes were used to theorize data, through a process beginning with reading and re-reading interview transcripts. On each read through, meaning was assigned to different sections of the transcripts either by generating a new code in keeping with the analytic guide, assigning an extant code to the section of transcript, or exporting the data section into a separate word document for memoing and reflexivity. This process of data analysis was repeated for the first and second interview for each participant, then re-visited as part of an across-participant review and analysis.

The analysis of the data for this project leveraged the “creative presence” (Eakin & Gladstone, 2020) of the members of the research team. Incorporating the researchers’ creative presence encourages and appreciates qualitative data analysis as an artistic process, imbued with preunderstandings, interpretation, and reflexivity. In qualitative analysis the creative presence of the researcher is a strength and provides richness and depth to the findings generated. Later, in sharing and discussing the results of this study, my creative presence as the graduate student interpreting and writing up this dissertation will become apparent. Further information will be shared when discussing the study results, regarding how my creative presence influenced this work, specifically paying attention to my past and present experiences living and coping with chronic pain. To document my creative presence throughout this research, a number of ‘analytic devices’ (Eakin & Gladstone, 2020) were used including reflexivity, memo writing, using ‘everything as data’, reading data for anomalies and invisible or absent meanings, in addition to commonalities, both across-participant accounts but also in relation to my own understandings.

Preface to Chapters 4 and 5

In chapters 4 and 5, I outline my interpretations of the data, presented as intersecting threads, as well as passages from my reflexive memos, maintained throughout the research process. As outlined in Chapter 1, this research study was oriented by two, interrelated research questions. The first, *How do young people understand chronic pain and describe the ways they cope with flare-ups of chronic pain?*, was designed to generate preliminary data with this population. The second, *How can we generate knowledge about young people's understandings and ways of coping with chronic pain?* was designed to pilot a methodology to allow researchers to engage young people with chronic pain in research to learn more about their understandings of, and experiences with pain. In Chapter 4, I address the first substantive question, through presenting my narrative interpretations of children's experiences living with chronic pain, and preliminary threads exploring children's understandings of chronic pain and the strategies they describe using to cope. Chapter 5 outlines methodological reflections of piloting this methodology to examine children's experiences of living with chronic pain. The methodology's strengths, limitations, and lessons learned throughout the research process are highlighted along with suggestions to employ when scaling up this study in future research.

Chapter 4

Preliminary Results: learning about children's experiences of chronic pain

In this section, I outline the study results in two sections. First, I share interpretive narratives for each participant and intersecting threads produced through analysis across the participant accounts. Both sections respond to the first study question: *How do young people understand chronic pain and describe the ways they cope with flare-ups of chronic pain?* These results, while modest due to the overall scale of the study, serve to demonstrate the potential of this novel arts-based methodology to generate rich data with children concerning their experiential knowledge of pain and coping.

Participant Interpretive Narratives

Describing the sample

Three participants were recruited for this study, two of whom were siblings living in the same household. All participants identified as female. One participant identified as Mixed Race, one of East Asian and West Asian/Middle Eastern descent, and one as of South Asian descent. All participants lived in urban centers in Ontario, Canada with both parents. Participants were not required to share their clinical diagnosis (if any) with the research team. The type of pain experienced by the sample included headaches, stomach pain and gastro-intestinal upset and pain. Two of the three participants spoke French, however opted to use English to communicate in their interviews. All names used to refer to the participants are pseudonyms.

Of note, we anticipated recruiting six to eight participants for this study. Given the challenges to health and lifestyle brought on by the Covid-19 pandemic, recruitment proved challenging. Young people and their families are spending less time on social media and email, while also navigating last minute changes related to school, work and extracurriculars. The uncertainty of people's routines and schedules understandably made it difficult to accommodate research participation into busy lives. As a result, the study sample was relatively small and limited in diversity, however, is sufficient to support the methodological and substantive claims of this study (Kuzel, 1992). The conclusions

drawn, and the insights shared account for the limitations that result from a small sample size.

Sarah

Sarah, aged 13 at the time of this research, was the eldest of the three girls who participated in this study. Sarah lived at home with her mother, father, and younger brother in a large urban center in Ontario. Sarah shared that, when at home, she draws often, and her passion for drawing is what prompted her mother to respond to the recruitment information by email expressing her daughter's interest in being part of this research. After speaking with both Sarah and her mom, and receiving their assent and consent, Sarah began her first interview.

Sarah talked of facial caricatures being her favourite thing to draw. Most recently, she began drawing what she described as “a random person on Google”. Although she noted it is not the best habit, Sarah often found time to draw during her online school classes. Sarah explained that, at the time of the study, she was in online school because of a shift to online-learning due to public health concerns imposed by the spread of Covid-19. Sarah described often chatting with her friends through her cell phone or her computer between different classes at school or in her spare time. When asked about whether she still socializes with her friends in-person, she explained: “it’s a bit difficult because you have to like, plan to see them in person, because I don’t really go to school—like, one of them goes to a different school, and the other one is in online school, so I can’t really talk to her. So, I’ll like text her during class or, um, talk to her outside of school”. Sarah also explained that she plays virtual multiplayer games with her friends, like Minecraft or Roblox. Sarah described taking advantage of socializing with her friends on a good pain day, she explained: “I don’t like to socialize as much when I am in pain, because it just puts me in a bad mood”.

Sarah’s family described adopting Maxim, their cat, to provide her with some companionship when she was struggling with her pain and in the hospital often. Sarah’s mother explained the cat as being a non-negotiable addition to Sarah’s life when she was struggling: “She needed a cat. Cuz she was in the hospital and had to have a cat. But

she's allergic to cats, so we had to get a cat that was hypoallergenic". Maxim has indeed served his purpose in Sarah's life as she described him as a great companion. Sarah also introduced me to younger brother, aged 11 at the time the study. She and her mom giggled when describing him as smelly, loud, and full-of-energy. Sarah talked of their shared love for their cat, Maxim. "Me and my brother made a whole show about [Maxim's floofy tail], she explained. Sarah's brother has a lot of energy, too much for her to handle when she's overwhelmed by her pain, she said. Luckily, Sarah shared that her brother is a big Pokémon fan, which she said does not really appeal to her, so this passion of his that is not shared with her is something he can occupy himself with when she is not in the mood to play or socialize.



Figure 2: Sarah's Visual Representation of a 'Good Pain Day'

Sarah described her pain as being in her stomach and bowel area. She also explained experiencing occasional headaches, either in combination with her stomach pain or on their own. On a 'good pain day', Sarah shared that she takes advantage of engaging in pleasurable or, what others might describe as 'regular' occupations. When asked to describe why she chose to depict the activities she did in Figure 2 Sarah explained: "[...]

when I'm feeling good, like, I like to draw, so I'll draw. Sometimes with a bad pain day, sometimes walking is difficult, so I that's why I put 'walk' [on a good pain day], also I don't feel like eating at all when it's bad, so, like, my appetite will be more. And 'talk to friends', I don't like to socialize as much when I am in pain, because it just puts me in a bad mood". Sarah described taking advantage of reduced pain days by working on drawing projects, socializing with her friends and family, and appreciating the relative ease of walking around and eating (Figure 2).

When describing her evening routine, Sarah shared that she spends about two hours engaging in "medical stuff" to help prevent an eventual flare-up of her stomach pain. Her medical routine consists of administering an enema, which functions to reduce her pain in the following hours or days. If Sarah were to skip her two-hour medical routine, she explained that she would likely end up at the hospital with severe pain. In the first interview, Sarah avoided using the word 'enema' to describe what she called her medical routine, choosing instead to refer to "medical stuff". She then deferred to her mom to elaborate on what this meant:

Sarah's Mom: It takes two hours, she has two hours of medical stuff a day.

KF: Are they exercises?

Sarah: No...

Sarah's Mom: It's like, um, *Sarah and her mom loom at each other* for her bowels and bladder.

In our second interview, Sarah explained more to me about her "medical stuff" and its purpose, eventually sharing that this routine served to induce a bowel movement. Sarah elaborated by sharing that the process involved a glycerin-based solution, that forced her intestines to contract and cramp, and eventually result in a bowel movement. She explained that this bowel movement helped to reduce her stomach pain and the headache that might come with it, explaining that "during my medical procedure that I have to do, the headache will get worse and so will the stomach pain. If the stomach pain gets worse, then the headache will increase".



Figure 3: Sarah's Visual Representation of a 'Bad Pain Day'

Sarah explained multiple times that bad pain days make it difficult for her to engage in her daily routine. Sarah's visual representation of a bad pain day (see Figure 3) details the occupational changes she described making when her pain is flaring up. For instance, on days where her stomach pain was especially bad, she shared that she would typically experience increased nausea, making eating unappealing because it would further fuel her nausea and make her symptoms worse. Sarah explained that "on a bad pain day I'm nauseous, and just in general I feel really full. So by drinking something it makes me feel, like, not as nauseous, and, it's just easier than like eating a big thing of dinner, I guess." On days when she would experience a flare-up of pain, Sarah described opting for a meal-replacement beverage instead of eating solid meals.

Sarah shared that a pain flare-up might be triggered by a number of different things and in many ways, explaining that "sometimes, cause I'm wearing headphones for like, my class, um, the volume or staticky connection can make me have a headache, or sometimes lights, or if I'm having a bad pain day if like I don't eat as much, that can also contribute to the headache. Um, with the stomach pain, if like I don't get a good [bowel] empty like

yesterday or like the day before, it'll make my stomach pain worse, or if I just like did the enema, it'll make my stomach pain worse". No matter the cause of the flare-up, Sarah described using distraction as a coping strategy, but not in ways that involve socializing because she feels annoyed and easily irritated when experiencing a pain flare.

Socializing, she explained, was just too much work. Sarah also shared that it was difficult for her to be in a good mood when she was experiencing a pain flare-up, which further prevented her from socializing. Sarah expressed discontent at these bad moods, explaining that: "I'm definitely not happy about being in a bad mood. I would like to change it, but I don't really know how. Because like when you're in pain you're gonna be in a bad mood and that's that. But I probably wouldn't want to be in a bad mood, especially since, even when you're not in pain you can be in a bad mood. So, it can be like you're in a bad mood all the time which is not good".

When experiencing a flare-up, Sarah described typically keeping to herself, with the only living thing in her life that she wanted to engage with being Maxim, her cat. Sarah explained that "[Maxim] helps me on any day", especially when in a bad mood, because he did not judge Sarah, run away, or ask too much of her. She could satisfy his need for play in exchange for silent company which seemed a reasonable and manageable trade-off. Sarah described Maxim as "simple" explaining that "[Maxim] is quite simple, like, if you want to give him a treat you can either shake the treat bag or make noise and he'll come over to you. So, I don't know, he's very simple. And if he does want to play, it's usually under a blanket, and you just have to move your hand, so it doesn't take that [much effort]". All it took was some low-key play underneath a blanket and Maxim was happy to keep Sarah company, and unlike human company, his was invited during pain flares.

Sarah shared a number of coping strategies she relied on to address pain flare-ups. She described her first line of defence (as illustrated in Figure 3), as laying down in bed with a heating pad on her stomach. This coping strategy helped her preserve her energy, mainly because of the lying down, she explained. Sarah also described some other coping strategies that she had tried following advice from her mother: "well medicine doesn't really help... We've been trying to eat turmeric. But it doesn't taste very good and they

look like turds [smiles]. Ginger sometimes helps. Just like the smell of it, or just eating ginger. Um, we've tried to do weird relaxation videos, where it tells you to, like, breathe in and breathe out, or something like that... those don't really work—oh meditating, that's what it is". As evidenced by her comments, Sarah engages in a number of diverse coping strategies, yet none of them really work, at least not to the degree that she had hoped.

Simran

Simran, aged 6 years at the time of enrolment in the study, turned 7 between her first and second interview. She was in grade 1. Simran was the youngest member of her household and lived with her parents and sister Kaia (who also participated in this study) in an urban center in Ontario, Canada. Simran described her favourite hobby as playing imaginary games with her imaginary friends, including Harry Potter. Simran shared that she preferred sleeping in over waking up early, primarily because she enjoyed dreaming and would rather finish her dreams before waking up and going to school. Part of our first rapport-building interview included the following question prompt: "If you could have one superpower, what would it be and why?". Simran responded without hesitation, as if she'd already had an answer prepared in advance: "If I had a superpower, I would want to imagine something and make it come true. Why? So that I can make sure that my parents let me sleep in, and make sure that school ends later, and it starts later and ends earlier—No starts later, ends later". If given the option, Simran would have started her days later, opting to sleep-in so she could finish her dreams. Simran expressed that, if she had unlimited wishes, she would have wished for it to be summer year-round because this is when she got to travel and engage in outdoor activities such as visiting her community waterpark. Simran also shared her passion for nature, especially flowers and plants, explaining that "I have two favourite [flowers]. It's a rose and a tulip!"



Figure 4: Simran's Visual Representation of a 'Good Pain Day'

Simran described experiencing chronic stomach pain, and occasionally headaches. On the day of her first interview, Simran described feeling no stomach pain, which made her happy. Typically, Simran's pain levels fluctuated throughout the week and throughout each day. She described her pain as unpredictable and random; it was difficult for her to point out what exactly caused her pain to flare-up or improve as it did not appear to follow a reliable pattern. For example, she described that eating might sometimes make her pain worse, but at other times it might not. Simran described a 'good pain day' as one with very little pain, or if she did have pain, as one where she remained distracted from it for most of the day. On a good pain day, Simran described having "...just a little pain. Just a teeny, teeny bit. Because I'm like not concentrated... And at recess, like when I'm not concentrated and I'm playing, and I concentrate on that, I like may have a little pain. And then when I'm doing work, I need to think hard. I only have a little pain. Like when I'm focused on other things and I concentrate on other things, I think like I only have a...I only feel a little pain."

When asked about her visual representation of a good pain day (Figure 4), Simran shared her decision to depict things in life that bring her joy since this is what she's reminded of on a day where she has relatively little pain or is distracted from her pain. Simran

described reflecting on what to share before painting, choosing to represent a good pain day as a flower with diamonds for petals and soft, welcoming wind. She also added smiling faces to the flower and the wind surrounding the flower, emphasizing that a good pain day reminded her of being happy. Nature, flowers, and a day without pain flares were “happy things” according to Simran, helping her to feel hopeful for a good day at school and, if it lasted, a good week as well.



Figure 5: Simran's Visual Representation of a 'Bad Pain Day'

In Simran’s representation of a day when her pain was worse than usual (see Figure 5), her pain is depicted as a fire burning out of control. The fire she drew was animated with an angry facial expression, breathing hot “cells of fire” which functioned to help the fire grow and become more powerful. Simran stressed the relative size of the fire compared to her representation of herself. The fire Simran painted was larger and more powerful than her, “the fire is a giant...when it grows, my pain grows”. In likening her pain to a growing fire, Simran described her coping strategies as helping to extinguish this fire. One of her strategies involved drinking water, she explained: “...like if... If like I drink water, sometimes it's like water goes on the fire and it runs out”.

Simran’s experience of pain flare-ups was deeply enmeshed with feelings of fear. She explained that the fire could be replaced with any other “scary thing” such as a dinosaur, a dragon, or a monster. Pain and fear were inextricably linked for Simran; in that her pain

brought about thoughts of fear and fear made her pain worse. She explained this when describing why she chose to represent her pain as a fire in her visual representation, sharing “because like, [fires] can make me a little scared. And then my tummy starts hurting when I get scared. But then like if my tummy hurts, I think...I think of being scared.” Simran shared nuanced details regarding her fear of fires, not all fires evoked fear for Simran. A backyard bonfire, for example, did not evoke fear in the way a wildfire would, Simran explained.

When Simran experienced a pain flare, she shared that her strategy was to distract herself from the pain. If she was distracted, she does not notice her pain as much, and therefore it affected her less; both physically and emotionally. She described several tasks that successfully distracted her, including colouring, or playing games, either imaginary or tangible, focusing at school, or moving around. Additionally, Simran described several interventions that she frequently attempted to alleviate a pain flare. She tried to empty her bowels by using the bathroom, drank water, and if neither proved to be successful, positioned herself on her stomach in bed and took Tylenol from her mother. Simran also shared that movement sometimes helped her alleviate her stomach pain; this was something she learned from her grandfather. This movement entailed a walk around the house, or deliberately moving her stomach inwards and outwards repeatedly, she explained.

Kaia

Kaia was 9 years old at the time of enrolment in this study and lived with her younger sister Simran, along with their parents, in an urban center in Ontario. Two of Kaia’s passions were playing the piano and animals; she had always wished her family would adopt a cat or a puppy, but given her mother’s allergy to fur, this was not realistic. Kaia’s favourite hobby was reading, and she especially enjoyed fiction books and comics. She had recently finished reading all seven Harry Potter books by J.K. Rowling and expressed excitement in starting the Fantastic Beasts collection by the same author.

Kaia went to a French-language school and expressed enjoying her time there. When speaking of her favourite subjects at school she shared that they “are math and something”, the “something” changed every once and a while. Kaia was proficient in

both English and French, however expressed a preference towards speaking English throughout the interviews. Kaia explained that she used to attend an English-language school and made the transition to French school in grade two when her teacher suggested she'd do well there. Altogether, Kaia spoke three languages: English, French and Hindi. She practiced Hindi at Saturday school, however, expressed that she finds it boring because she is more advanced than her other classmates. She explained: "It's kind of boring because I know a lot of it. And there's these kids who don't know. But the teacher always asks them. And they don't think much of me because I don't answer because she doesn't choose me."

If Kaia could have any superpower, she would have the ability to control those around her "because then I can get what I want and I can do what I want. And then when I'm not controlling people, if anyone does anything I don't like, I can just control them to say yes. And everyone else will think that they do what I want. And no one would know I could control people", she explained. An extension of this superpower allowed Kaia the option to sleep at school at night, she said, so that she could continue to learn all night.

Although her birthday was in the Spring, Kaia shared that her favourite season was Summer, because of the unlimited potential for outdoor activities. Unlike during the winter in Canada where it was impossible to go swimming or play in outdoor playgrounds, the summer gave Kaia the opportunity to enjoy both these things. Despite her passion for nature and the outdoors, Kaia found it important to share that she is not a fan of mountains, but preferred flowers and other types of botany; another thing she enjoyed about the warmer weather. Kaia expressed that she enjoyed playing games with her cousins but shared a tension regarding the type of game to play. Her sister Simran and cousins preferred to play imaginary games, explained that she does not find these enjoyable and would rather play challenging, board games, or card games; she did not really have a favourite game to share, as long as it was *not* an imaginary one.

Kaia described experiencing pain in her stomach area. She explained that her stomach pain is always different and often accompanied by "nauseousness". Kaia told how her pain fluctuated throughout the day, she noted: "usually in the morning if it's a good day,

throughout the day, it like worsens and gets better. And by the end of the day, it's better than it was in the morning. If my pain is very bad in the morning, it gets better, better, better, and then just a little bit worse. So a little better than what it was in the morning... that's usually how it goes". Kaia said she can sometimes predict the patterns of her pain in general, but not necessarily the times when her pain is likely to improve or worsen. Kaia experienced pain in her stomach for as long as she can remember, she shared that her earliest memory of chronic pain dates back to age three, maybe even before that. The nausea that accompanied her pain, however, was a newer symptom that she noted has only been around for the past six months or so.



Figure 6: Kaia's Visual Representation of a 'Good Pain Day'

Kaia's passion for nature was evident in the visual art she created (Figures 6 & 7). On a good pain day, Kaia described being reminded of a peaceful day out in nature, therefore she "drew a little forest because it makes me feel like I'm out in nature and I'm just having a lot of fun, and I just feel great", she said. Being distracted by nature's sights, smells, and sounds was a large part of what a good pain day means, she noted. Rather than visually representing herself on a good pain day, Kaia used metaphor to explain the feeling she has when she's having a good pain day. On good pain days, Kaia was not necessarily pain-free, rather, she described having very little pain or 'regular pain' that

she can cope with throughout the day. A good pain day also made her think of a calm ocean, with a pleasant smell; the ocean representing her calm, smooth, and stable mood, she explained.

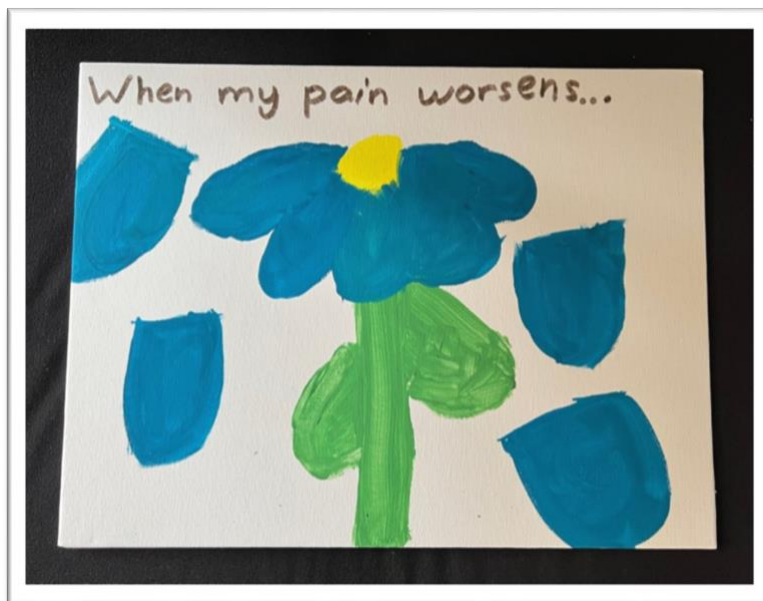


Figure 7: Kaia's Visual Representation of a 'Bad Pain Day'

Kaia's visual representation of a bad pain day was also inspired by nature. Specifically, she noted her understanding of a bad pain day as a blue flower wilting (Figure 7). Wilting flowers were a negative thing, according to Kaia, they made her feel down and unhappy, similar how pain made her feel, she shared. Usually, Kaia perceived pain as a negative phenomenon because it causes suffering. However, she recognized pain as also having positive components: "well, because I think nature represents many different things. It can represent good things and bad things. Like a good thing is that trees give us oxygen. A bad thing is wildfires can hurt us, plants, humans, and animals. So, there's lots of different ups and downs about nature". Kaia then compared this to her understanding of pain sharing that having minor pain or 'cope-able' pain, helps her learn to live with pain flare-ups. In the same vein, pain flare-ups, despite being difficult to manage and cope with while occurring, taught Kaia how to manage "bigger pain next time". Bad pain days help Kaia cope with worse days and appreciate the good ones, she explained.

Kaia understood pain as part of her daily life. She shared that she does not feel too annoyed or angry about a flare-up until around day 3 of a prolonged pain flare, at which point she begins to feel frustrated. She explained: “sometimes when [a pain flare-up] happens a few days in a row, I think to myself, why? Why does it have to be me with the pain, or why do I have to have pain? Why can't I just not have pain? Kaia shared that she tries to distract herself when she is feeling this way about her pain; a technique shared by all three participants in this pilot study. According to Kaia, a distracting task entailed something enjoyable or fun, such as socializing with friends regarding regular things unrelated to pain. Kaia also talked about a home remedy that her grandmother shared with her: warm lemon water with honey. She described consuming this occasionally when her stomach was bothering her along with RestoraLax daily in milk, to prevent a flare-up from occurring. Finally, Kaia described using some massaging techniques as a way of soothing her stomach pain.

This chapter contributed to the first research question: *How do young people understand chronic pain and describe the ways they cope with flare-ups of chronic pain?* by providing a series of interpretive narratives that illuminate the ways young people understand pain and the strategies they employ to cope. The analysis presented herein represents an interpretation of the data co-constructed between me and each participant. The narrative interpretations pay close attention to the ways children expressed their understanding of pain and coping, without branching too much into interpretive analysis and rather, remaining close to the descriptive. There are clear areas of convergence and divergence when it comes to each participant's expressed point of view. The following section will highlight these similarities and differences through an across-participant analysis of young participants' accounts.

Theorizing chronic pain and coping

In the following section, I set out and expand on the intersecting threads produced through my analysis across the participants' accounts of living and coping with chronic pain. The threads serve as modest examples of the type and depth of data about living with pain that can be produced with young people through the data generation strategies

piloted in this study (i.e., arts-based methods coupled with two semi-structured interviews).

Describing chronic pain and pain flares

Pain is like Nature

All three participants compared their experience of pain metaphorically with aspects of nature. During their interviews, each participant referenced nature in explaining how they understood pain on a good day versus a day when they were experiencing pain flare-ups. In addition, Simran and Kaia both included nature in some capacity in their visual art. For example, Simran drew “a flower with petals that are diamonds” and soft, gentle wind to represent a good pain day. To emphasize an emotional connection to pain, she included a smiling face on the flower and the wind (see Figure 4). When asked why a good pain day reminded her of nature in this way, Simran explained “I really like nature, and it makes me think of happy things”. Both nature and a day with reduced pain, and no pain flare-ups, were positive things for Simran, and reminded her of a calm, peaceful spring, or summer day.

In her visual art depicting a good pain day, Sarah drew many small pictures, one of which showed her walking outside (see Figure 2). When asked about this particular drawing, and whether nature was meaningful to her understanding of a good pain day, she explained that it meant to show that she is able to walk more on good pain days, whether inside or outside her home. Conversely, she likened the sun’s hot rays to the way she felt when she heard the word ‘pain’. Sarah used the annotation feature on Zoom to visualize what she comes to mind when she thinks of a pain flare-up, explaining:

Sarah: The colour red. [...] But it kind of looks like the sun, and it has, like, can I annotate on this thing? Just imagine that’s full, like a full circle, and it goes like that [draws a circle] and then the background is black and it kind of looks like a ball of light, like that [colours in the circle red] and its orange as well... here [adds some orange to the red circle]. And then the background is blue, like darker blue than this, like here [fills in the space surrounding the red circle with blue], and when it goes further away its black... except it’s a background.

KF: Okay. So, it's kind of like a red blob with all these different extending red arms. And then the background all fills in to be a dark blue and black.

Sarah: Yeah... kind of like the sun.

For Sarah, pain was like a bright, hot, red and orange sun on a dark blue-black backdrop.

Pain as both good and bad

Each young participant in this study expressed understandings of pain being at once 'good' and 'bad'. For example, during our second interview, Kaia used metaphors to explain how she understands pain this way:

KF: I'm curious to know why you drew nature for a good pain day and a bad pain day...

Kaia: Well because I think nature represents many different things. It can represent good things and bad things. [...] Like a good thing is that trees give us oxygen. A bad thing is wildfires can hurt us, plants, humans, [and] animals. So, there's lots of different ups and downs about nature.

KF: And do you believe that that's very similar to pain?

Kaia: Yeah...pain can sometimes be good when it hurts...because like when it's bad...it helps you to learn how to cope with it. And the next time, if you get something bigger, it'll be easier than last time.

Kaia described pain and nature similarly, as both containing aspects of good and bad. From her point of view, pain flare-ups could be considered good in some ways because they teach her how to cope with pain in the long term.

Simran also talked about pain as being both good and bad. When I asked her what came to mind when she heard the word pain, Simran explained "I think about good... I feel like I see something split in half with something good and nice, and then something bad and horrible". When asked her to clarify what she meant by "split in half", Simran did not expand. She said simply. "Good and bad. Nothing specific". Though I probed these meanings at a later point in our interview, Simran did not share any further views about how or why she understood pain this way.

Pain that never departs: present even when absent

Young people in the study shared other metaphors when describing their experiences of pain. For example, Sarah alluded to embodied experiences of pain describing it was always “there”, even on good days. She explained:

Like if you just touch a chair, and you take your hand off of it, you can still kind of feel like it was just there? ...that’s where the pain is supposed to be, so it doesn’t necessarily hurt, you can just feel that [the] pain is there, but it doesn’t necessarily hurt at the moment. [...] Or like an elastic has been on your wrist for a really long time and when you take it off you can still kind of feel like it’s there?

Pain, mood, and emotions

A relationship between pain, mood, and emotion was discerned in the ways participants described and represented their pain. In the context of a ‘bad pain day’, young people shared that flare-ups altered their moods and emotional states. For example, to illustrate a bad pain day, Sarah drew and labeled a caricature of herself in a bad mood (see Figure 3). When asked about this part of her drawing, she explained “I mostly feel just irritated very easily. Like, if there’s a repetitive noise, that makes me annoyed really quickly, or I just don’t want to socialize or be around people”. For Sarah, bad pain days meant feeling irritable and annoyed, and preferring to be alone or with her cat rather than her family and friends.

Kaia also explained how pain flare-ups affected her mood. She spoke about anger when explaining how she felt after a prolonged pain flare:

“But sometimes when [a flare-up] happens a few days in a row, I think to myself, why? Why does it have to be me with the pain, or why do I have to have pain? Why can't I just not have pain? [...] I feel angry. Only after a few days, though.”

The relationship between pain and mood was also present in Simran’s description of her pain, where pain was associated with feelings of fear. For Simran, it was unclear in her account if her pain was the cause of fear or if she experienced pain following fear. In fact, it appeared a reciprocal relationship between fear and pain had developed for Simran as

she said pain flare-ups brought about feelings of fear, but also fear could sometimes induce pain flare-ups. When asked about her drawing of a bad pain day (see Figure 5), Simran described the relationship in this way:

KF: All these things - the fire, the dragon, or the monster - are they meant to represent pain?

Simran: Yes. Because like they can make me a little scared. And then my tummy starts hurting when I get scared. But then like if my tummy hurts, I think...I think of being scared.

KF: What are you scared about? ...

Simran: Like at night, I'm scared of darkness. And when I'm in small spaces or small rooms, I get scared that like something's hiding.

So, while pain and fear appeared to be intimately related for Simran, pain did exist without fear, fear did exist without pain, but fear tended to make already-existing pain worse.

Pain and fear were related for Kaia as well, but in a different way. When asked how she might visualize or picture pain in her mind, Kaia explained that “sometimes I picture [pain] as a monster, something that's scaring my insides”. Fear was less related to evoking pain or resulting because of pain, but rather more related to how pain was understood by Kaia. The emotion of fear did not necessarily give rise to pain for Kaia, nor did her pain cause her to be fearful. For Kaia, pain represented a scary entity that was inside her.

Coping with pain

In this section, I begin with a discussion of threads resulting from my analysis where I report and theorize the ways that young people cope with pain and pain flare-ups: by using distraction or by using their imagination to escape.

Distraction as a coping strategy

Each of the three young girls that participated in this study described employing distraction strategies to avoid concentrating on their pain, when describing how they managed and coped with a flare-up. These discussions of seeking distraction a range of activities. For example, Simran explained how she used distraction as a strategy to cope:

KF: And on a good pain day, for example, how would you describe the way your pain feels? Is it gone completely?

Simran: No. Like just a little pain. Just a teeny, teeny bit. Because I'm like not concentrated... And at recess, like when I'm not concentrated and I'm playing, and I concentrate on that, I like, may have a little pain. And then when I'm doing work, I need to think hard. I only have a little pain. Like when I'm focused on other things and I concentrate on other things, I think like I only have a...I only feel a little pain.

In this exchange, Simran later noted that not all activities are equally helpful when it comes to distracting herself from pain. She said that watching television, for example, was not as effective as colouring, playing with friends at school, or being involved in learning at school.

While screen use was not an effective distraction strategy for Simran, Sarah described using her iPad to distract herself when experiencing a pain flare-up, explaining that “I use like, an iPad for like distractions if the pain is really bad, so, I will play Minecraft on my own”. She emphasized how virtual games are her primary form of distraction on days when she is experiencing a flare-up and noted she prefers to opt for single-player modes instead of multiplayer, so that she does not have to interact with others at these times.

Kaia considered a day in which she could distract herself from pain to be a good day. When discussing her painting of a good pain day (see Figure 6), Kaia noted initially that she depicted nature “because flowers smell great”, then expanded on this, explaining that “really it’s just seeing and smelling and hearing, and just being distracted.” She explained

that she painted nature as representative of a good day because of the feelings nature evoked for her, and similarly brought up the concept of being distracted. When asked to elaborate on her comment about distraction, she explained:

Kaia: So when my pain is very bad, and I just do something I really like that makes me happy, I kind of forget about my pain and I focus on the thing I like, and I just don't feel it very much.

KF: So on a good pain day, does that mean that you don't have any pain, or does that mean to you like you still have pain but you're able to do the things that you like to do?

Kaia: Yeah, so good pain days, either I have very little pain or that I have regular pain and I can just cope with it.

Kaia described using distraction to cope, no matter if she was experiencing “little” pain, “regular” pain, or a pain flare-up.

Imagination as a coping strategy

In addition to trying to distract themselves from their pain, participants described using their imagination to take them out of their ‘real life’ worlds. They described regularly engaging in activities that provided a form of escape. Simran, for example, spoke several times about her passion for imaginary games, and the imaginary friends who inhabited those games. She explained that her imaginary friends offered her more than just companionship with playtime, they also consulted with imaginary doctors and delivered advice regarding her pain. Simran expanded on the role of her imaginary friends:

My imaginary friends, they don't make mean comments about anything, and they always listen. [...] Usually they tell me, they'll try their best to find a way to help me. ...sometimes they talk...they call the doctor so I can talk to them – the imaginary doctors, [...] [and the doctors] tell me to play more or draw more and try and make myself distracted from the pain.

Simran went on to say she preferred to share details about pain with her imaginary friends over her friends at school, explaining that her friends at school did not have pain like her, and so would not be able to understand or help her much.

Chapter 5

Methodological Reflections: what worked well, and lessons learned

As explained in the earlier sections of this thesis, there exists very little research examining children's own perspectives of chronic pain. As such, I developed a methodology, combining arts-based elicitation methods and semi-structured interviews, to engage children in producing knowledge concerning their lived experience of chronic pain and coping. This section outlines results related to the second study question: *How can we generate knowledge about young people's understandings and ways of coping with chronic pain?* through expanding on the methodological approach I adopted in this study. Drawing on my reflexive memos, I outline my learnings related to implementing my methodological design, including insights pertaining to what worked well and lessons learned.

Researchers, especially novice trainees new to the field of qualitative inquiry, could benefit from published accounts of the obstacles, questions, and difficulties of carrying out qualitative research combining arts-based elicitation methods and semi-structured interviews through a virtual platform. The kinds of insights contained in this chapter seldom make it into published literature, but present useful insights for individuals who might scale-up this methodology in future research.

Insights pertaining to what worked well

The study methodology combining arts-based elicitation methods and semi-structured interviews was successful in prompting participants to be reflexive about their pain experiences while engaging in the process of creating their visual art. I noticed this as participants mostly had stories, explanations, and rationales for why they included particular things in their visual art, as if they paid a significant amount of time and attention to creating and perfecting them.

Further, Simran described taking the time to reflect on her experiences of chronic pain, both her good pain days and bad pain days, prior to crafting her visual art for this study. When I asked when she produced her paintings, Simran explained that she produced them both on a day she had little pain. This prompted me to ask if she would have represented things differently if she had produced them on a bad pain day, to which she quickly responded, “No. Because I already thought of what to do like before... On both of them”. For Simran, and the other young people in this study, the act of creating their visual art was deliberate and purposeful.

Another celebration of the methodology relates to the opportunities for young people to exercise their ability to make choices. Choice was intentionally built into the methodology and study protocol at various points. First, if participants were bilingual (English/French speakers), as were Simran and Kaia, they had the opportunity to participate in the study, receiving correspondence and conducting the interviews, in their language of choice. Second, participants were given the choice of completing one of two art-based tasks based on their preference: either drawing or photography. Finally, flexibility was built into the protocol, so if young people expressed an interest in completing both arts-based tasks, this could be arranged.

Upon reflection on the research practices used, there were several other opportunities for ‘micro-choices’. These micro-choices were not those purposefully built into the protocol for this study, nor did I anticipate them in preparing to engage with the young participants. For example, when engaging with participants in their first rapport-building interview, I gave participants the choice of who would read the prompt aloud for the two of us, and who would answer the question prompt first (myself or the participant). Participants mostly opted to answer the questions first, and all of them chose to read the questions out loud for us. If a participant ever appeared to have difficulty answering a question or responded with something along the lines of “I don’t know the answer”, I would jump in with a response to get the conversation started. In every case this helped initiate a conversation.

One final celebration of the methodology relates to the sequence and time-course of data generation. Recall that the first interview served primarily as a rapport building interview, and the second served as an opportunity to discuss the visual art produced by each participant in the time interval between their first and second interviews. The initial ‘rapport-building interview’, aimed at getting to know the participant’s likes, dislikes, and lifestyle, was successful in providing me and each participant ample time to co-produce the rich data without the need for further interviews or participant observation. To illustrate how this sequence, and the passage of time between interviews, enabled the co-construction of rich and detailed data, I turn to Sarah. Sarah first mentioned her cat, Maxim, in our first interview together, although ‘mention’ does not really do justice to the amount she spoke about him, or the meaningful place he occupied in her life. Sarah spent a large portion of her first interview talking about her cat; his favourite spot, his likes and dislikes, his breed, and the reason he was selected to join her family. After reviewing her drawings of a good pain day and a bad pain day, I was surprised to notice that Maxim was absent. Even when explaining her drawings, Sarah did not mention Maxim much, that is, until I asked why:

KF: I noticed how you didn’t put Maxim anywhere in your drawings...

Sarah: *pauses* [in a shocked tone] ...cuz I forgot about him.

KF: Where would you put him?!

Sarah: I’d put him... in both. Cuz on a good pain day I’d pet my cat, and on a bad pain day I’d pet my cat.

In preparing for the second interview where Sarah’s artwork was discussed, I re-read our initial interview transcript, reviewed her artwork, and made notes to myself about important aspects of Sarah’s life as she had described them to me. I did this to be able to keep our discussion rolling and so I would be able to refer to our first interview if the conversation took us that way. If Sarah and I did not have an initial rapport-building interview prior to her sharing her visual art, I might not have been prepared to prompt her about her cat Maxim.

Insights pertaining to methodological lessons learned

Part of learning to interview participants for qualitative research involves learning to be comfortable with pausing and appreciating silence. Especially during my interview with the first participant, I struggled to pause and invite silence after asking a question or making a statement. If the participant did not immediately respond, or at least begin to respond, I took this as a sign that I should jump in and lend a hand. For example, the following exchange took place between me and Kaia:

Kaia: No. But sometimes when it happens a few days in a row, I think to myself, why? Why does it have to be me with the pain, or why do I have to have pain? Why can't I just not have pain?

KF: And would you...

Kaia: I feel angry. Only after a few days, though.

I jumped in prematurely with the “And would you...” after Kaia paused to think about her next response. I was uncomfortable with the silence after she shared such an intimate detail about her pain experience. My intention was to help her along with elaborating on her answer. It is clear, however, that Kaia was just thinking about her next thoughts, as she jumped right back in before I had the chance to probe once more.

After practicing being comfortable with silence on multiple occasions throughout the interviews with the three participants in this study, I began feeling comfortable with the idea of pausing after asking questions; and remaining silent until the participant had the opportunity to, what seemed to be, gather their thoughts. I noticed when a participant needed clarification or guidance, that they would then ask for it after having the chance to think about a response either by saying “I don't know” or “I'm not sure exactly what you're asking”, which are two ways participants in this study sought clarity from me. The intention when being open and building rapport with participants is to be able to build a relationship that would allow participants to ask for clarification, if needed. In my experience with the interviews I conducted for this study, the more I paused and leveraged silence before jumping in to guide participants, the more I would get out of

their responses. Although it is the role of the interviewer to guide the interviewee, inviting silence for reflection during the interviews, in my experience, increased the depth and richness of the data co-generated.

Another learning gathered related to the importance of recognizing the implications of the words chosen when responding to participants. To illustrate, I turn to the following exchange with Simran describing the colours she used in her drawing of a good pain day:

Simran: I like green because it's like nature. I like pink because it's my favourite colour. And the blue because it's like water. And diamonds are sometimes light blue.

KF: Very true. Okay, great. Yeah, that makes a lot of sense.

During the interview, my intention when uttering this phrase to Simran was to affirm her statement; to assure her that she was 'making sense' and that I understood her and even approved of the decisions she made when choosing the colour scheme of her drawing. It was my hope that responding very positively would encourage Simran to share again and perhaps further, as I began to ask her more about her experiences of pain. Upon reflection, it might have been useful to leverage silence and pause after Simran responded to me; allowing them to elaborate, retract, or clarify anything that they said. In my response, I may have inadvertently communicated to Simran that what was shared was sufficient, and that no follow up or elaboration was needed. Moreover, I might also have implied that all Simran had shared before this statement might *not* have made sense, or that I might not have agreed with it or approved of it. This is especially relevant if the young person is elaborating for a while, over the course of several exchanges; the exchange directly preceding this response is the one that is rewarded and enforced by this praise, thus shaping future responses by the participant.

Overall, while this methodology will benefit from continued elaboration, I argue that it was effective in producing rich and nuanced data and allowed young people to contribute to the research in ways that go beyond 'talk' alone.

Chapter 6

Discussion

The first section of this chapter contains a reflexive introduction where I share my own reflections on what coping with pain means, and what the word ‘coping’ might have come to replace. Next I discuss my preliminary findings related to the first research question: *How do young people understand chronic pain and describe the ways they cope with flare-ups of chronic pain?* keeping in mind that these are preliminary insights that are gathered from this pilot study piloting a novel methodology. This section is followed by a discussion of the insights shared related to the second research question: *How can we generate knowledge about young people’s understandings and ways of coping with chronic pain?* which asks about the potential of combining arts-based methods and two semi-structured interviews to generate rich data regarding chronic pain and coping. In the final sections of this chapter, I discuss the limitations and contributions of this research.

The process of generating data with participants in this study prompted me to be reflexive around my current understandings of what it means to live and cope with chronic pain, and my engagement in the research process. These reflexive memos are also incorporated throughout this chapter.

Reflexive Introduction

In conceptualizing this master’s study, I was inspired by a recent study by Dr. Birnie and colleagues (2019) entitled ‘Partnering for Pain’, that collaborated with patient partners to identify a number of priority areas for future pediatric chronic pain research. When reading the publication that came out of this research, two of the identified priority areas stood out to me: “What interventions are effective for managing acute pain flares in children and adolescents with chronic pain?” and “What physical and psychological treatments are effective for improving pain and function in children and adolescents with chronic pain (for example, functional outcomes including quality of life, depression, fatigue, sleep, acceptance, concentration, resilience, coping, self-management)? (Birnie et al., 2019, p. E660). These priority areas resonated with my past and present hopes

regarding the potential of pain research to improve my own pain symptoms. I thus decided to focus my master's thesis around contributing knowledge that might support future research in these areas. Although the word 'coping' is not directly used in these two identified priority areas, the lack of research done with children about their own experiences with pain and their coping strategies, motivated me to include a focus on how children described the ways they cope with pain flare-ups. I see this focus as a necessary first step in research that might one day address the priorities identified in the above mentioned Partnering for Pain study.

Accordingly, in my work, coping was conceptualized as any remedy, intervention, or strategy described or represented by young people, either physical or psychological, to reduce or manage their pain. In the process of conducting the interviews and analyzing the data generated with participants, I found myself reflecting upon the meaning of the words 'coping strategy' and 'intervention'. I began to consider why the term 'interventions' was more often used in reporting on pain research, rather than discussing 'coping strategies'; a term that is so loosely defined in the pain research sphere. Was it considered better to aim to identify interventions instead of merely 'coping'? Moreover, I realized that goals of aiming to 'eliminate' or 'cure' pain were largely missing from discussions, and in my experience, these words are rarely, if ever, brought up in relation to chronic pain as potential or realistic outcomes. In retrospect, I see that prior to conceptualizing and carrying out this research project, my own understandings of the words 'intervention' and 'coping' influenced my choices in designing this study. For me, pain interventions, pain management, and pain treatments were all the same as what I thought of as coping strategies. I had learned through experience that regardless of steps I had taken involving pain interventions, management or treatment always led me back where I started: coping with chronic pain. Thus, my lived experience of chronic pain has informed my perspective that coping, management and intervention are all ways to, at best, 'improve' but not 'eliminate' pain.

As a teenager, my greatest wish was to rid myself of my pain; to return to a time in my life that I took for granted. During appointments with members of my care team, especially in formal biomedical settings such as hospitals and pain clinics, I would avoid

expressing this wish, and instead asked for better, more effective ways to cope with my pain. I learned to avoid asking for a ‘cure’ or solution to eliminate my pain because it had been made clear over time that this was not the goal of my pain treatments. Asking for medical help to eliminate chronic pain, especially when it is idiosyncratic, unidentifiable, or otherwise difficult to diagnose, felt like breaching a taboo and, in my experience, was dismissed as unrealistic. Thus, I learned from a young age that the only reasonable thing to ask of pain specialists was for help with ways of coping with or managing pain; but certainly not ways of getting rid of it altogether.

These reflections are pertinent to this study in that they call attention to what can and cannot be said by children, and arguably adults, living with chronic pain. It is notable that none of the participants in this pilot study shared that they would like their pain to be ‘gone’, nor that they try to get rid of it through interventions or coping strategies explicitly. Rather, they explained how they try to distract themselves, and otherwise learn to live with pain, intervening with coping strategies when experiencing a flare-up. This absence of mention by participants of curing pain across the data prompted me to ask myself some difficult questions about what living and coping with chronic pain really mean. For example, when a young person asks for help with chronic pain intervention strategies, what exactly are they asking for? Are they looking for help with finding coping or management strategies, or are they tacitly asking for a cure? I began to wonder if the words ‘intervention’ and ‘coping strategy’ are used instead of asking for a cure, as they are more socially accepted ways of asking for help.

Preliminary analysis of chronic pain and coping

“The word ‘pain’ refers to an endless variety of qualities that are categorized under a single linguistic label, not to a specific, single sensation that varies only in intensity.

Each pain has unique qualities” -Melzak (1975)

The experience of pain is strongly subjective and understood to be mediated by numerous intersecting factors, both internal and external to the young person in pain (Melzak, 1975; 1999; 2001). In this study, participants used metaphor to explain the ways they have come to understand their chronic pain, and the ways they have learned to cope, both with

flare-ups but also with the persistent/recurring nature of their pain. In this study, participants described their pain in relation to nature, as containing both aspects of ‘good’ and ‘bad’, as absent yet somehow present, and as affecting mood and emotions. In relation to coping, participants shared the specific strategies they employed, which were shared in the interpretive narratives in Chapter 4. Theorizing the concept of coping throughout this study motivated me to take a closer look at what children described doing and feeling when coping with pain, revealing how distraction and imagination were used as cognitive strategies.

In this study, participants consistently used metaphor to express their understandings of pain. The Māori people of New Zealand are said to often express their pain experiences using metaphor (Henare, Hocking & Smythe, 2003), perhaps because of the inherent difficulties of expressing one’s experience of pain, as it is subjective, personal, and constantly changing (Melzack & Wall 1996, Strong et al., 2002). Using metaphor can thus make sharing information about one’s pain more effective and productive. Guillemin (2004a; 2004b) notes the presence of metaphor in the artwork participants produce in art-based research. She points out that the artwork produced by participants about their chronic pain is influenced by diverse and numerous sources, including the cultural metaphors that they might have been exposed to in their daily lives (Guillemin 2004b).

The participants in my study represented nature in their artwork in the form of flowers, sun, wind, and trees. Also, Sarah used metaphor to explain her pain as a ‘red blob’ that is at once red and orange, big, bright, and sun-like. In Western culture, a bright blazing sun might represent emotions such as discomfort, pain, and an overall desire to ‘escape’ or eliminate exposure to the intense heat and light. Simran, who painted nature to explain how her pain is like on a good day, explained her love for nature and flowers with me on several occasions. This context, coupled with the smiling faces she painted on the flowers and wind in her artwork, supports the idea that a good pain day brings her joy, reminds her of the things in life that she enjoys, and makes her feel calm and happy.

A study in New Zealand used a drawing exercise to examine what pain means to a group of adults with chronic pain participating in a pain-management programme (Henare,

Hocking & Smythe, 2003). Aspects of nature permeated the data they presented in their publication where they outlined their study results. One participant added the word ‘wilderness’ to her drawing, another drew rainbows, and a third drew a storm cloud, rain, and a sun with an animated face. Interpretations of the aspects of nature regarding understandings of pain were not provided by the authors, and are largely missing from the illness literature, especially with populations of children and youth with chronic pain.

Each participant in this study expressed, at one point, the understanding that pain contained aspects of both good and bad. Notions of pain are historically imbued with negative perceptions (Cassell, 1998). Pain can bring about suffering, especially when it is chronic or recurring. However, understanding pain as a positive or ‘good’ experience does not negate the possibility that it might also be difficult, uncomfortable, or unpleasant, as evidenced by Kaia and Simran’s statements positioning pain as both good and bad. Understanding pain as a ‘good’ experience can have beneficial effects, which might help explain why this thread came forward in this data (Leknes & Bastian, 2014). Picture a sizzling hot and spicy dish of traditional Indian curry. In this scenario, the curry is objectively painful to eat because of its exceedingly high temperature and overwhelming quantity of spice. A reframing of the painful experience from a threat to a challenge, looking forward to the possibility of redemption from pain, enhancing one’s attention to pleasant signals in the body, and the ability of pain to distract from other noxious stimuli such as itch or worse pain are all ways of re-framing pain as something enjoyable... something ‘good’ (Leknes & Bastian, 2014). Elsewhere this idea of reframing pain as ‘good’ has highlighted its benefits, outlining how a positive outlook on pain has been linked with successful coping (Abdulcadir & Catania, 2020). Research examining children’s experience of arm fracture pain also reported that children described both negative and positive aspects to pain (Hanson & Drendel, 2017). For example, pain was framed negatively when it created difficulties for children to engage in aspects of their daily routines that they enjoyed. However, children described their pain positively when it prevented them from having to do their homework and meant that they were “spoiled with treats” (Hanson & Drendel, 2017, p. 209).

Sarah described to me her understanding of pain as never quite leaving, describing how her pain was always “there”, even on good days. From a biomedical perspective, what Sarah described might be interpreted as resulting from a disturbed body schema, affecting the way pain and other endogenous and exogenous signals are perceived and interpreted by the body (Martínez et al., 2018). Chronic pain changes the way neural pathways operate which might explain this lasting perception of pain that Sarah described (Melzack, 1990; 2001). As someone who lives in a painful body, I understand what Sarah is describing through my lived experience. Pain, once chronic or recurring, becomes something that one learns to ignore; like how we learn to ignore the clothes on our back or the rings on our fingers. This becomes commonplace when pain is always there, and a baseline level of discomfort becomes what used to be a ‘nothing-ness’ prior to the beginnings of chronic pain. Yet, if asked to focus in on the painful area, and this is something that is usually done when a clinician asks about our pain, we can, with patience, bring back that uncomfortable feeling, and notice it as if it were new.

It is not unusual that the participants in this study described the emotional implications of pain and pain flare-ups. Both Sarah and Kaia explained how their chronic pain affected their mood and emotions. For example, Sarah drew her negative mood in her representation of a ‘bad pain day’ and Kaia described being feeling angry about flare-ups of her pain when they persist for a few days. Other research with children defining what pain is and the function it serves in the body noted that children with persistent pain were more likely to draw on the emotional aspect of pain to describe their pain experience (Pate et al., 2019). For example, children with persistent pain drew elements such as broken hearts, frowning faces, and tears when asked to draw what ‘pain’ makes them think of. These children expressed confusion when asked about the emotional aspects of their artwork and were unsure of why they drew them as part of their pain experience (Pate et al., 2019).

Of all three participants, Simran elaborated the most on the relationship that exists between her pain and fear. She used the metaphor of a large burning fire to share this understanding with me, explaining that fires that are large, unintentional, and difficult to control brought about feelings of fear, which is also how she feels about her chronic pain.

A possible way of interpreting the relationship that Simran described is that it is not the fire nor the pain itself that cause fear, but rather the unpredictability and lack of control over these two phenomena. This experience of ‘being afraid of being in pain’ is one that I can relate to. For instance, in my early years of learning to live and cope with pain, I would become afraid of having a flare-up of my symptoms on an ‘important’ day; say a day where I had a final exam at school or exciting plans that evening. The fear of feeling sick at these events would often, it seems, contribute to this fear becoming a reality. I tried noticing and journaling when and why my fear turned into pain. It appeared to me that my fear of having a pain flare-up increased my stress levels, ultimately causing me to clench my muscles and initiate the flare-up that I feared. I quickly learned the relationship that existed between pain and fear was only contributing to a viscous loop where each fed the other simultaneously.

The role of fear in promoting the onset and persistence of pain is an area of growing research interest (Asmundson et al., 2004; Turk & Wilson, 2010). Investigators have noted that fear of pain brought about by the fear of increased pain or injury, reinforces particular behaviours. Typically, these behaviours motivate people to avoid what they perceive to be a potential pain trigger, eventually leading to an avoidance of this event or activity altogether. If this behaviour persists without intervention, pain-related fear has the potential to lead to functional disability and emotional distress (Turk & Wilson, 2010; Pate et al., 2019). Quantitative disability studies scholars researched a tool to assess the avoidance and fear associated with childhood chronic pain patients. The questionnaire was built to clinically assess pain-related fear, as it “plays an important role in relation to emotional distress and pain-related disability among children and adolescents with chronic pain” (Simons et al., 2011).

Participants in this study described two cognitive strategies, theorized in this study as coping strategies, namely: using distraction and imagination. The finding that young people use distraction as a means of coping with pain is supported by other pain literature. For example, two of the few studies exploring how children understand and conceptualize pain found that children experiencing persistent pain commonly reported using distraction as a coping strategy (Hanson & Drendel, 2017; Pate et al., 2019). For

example, children described using their iPad to read or watching TV to take their mind off their pain (Hanson & Drendel, 2017), which is similar to the types of distractions shared by participants in this study. The concept of pain-related distraction appears to be something that is self-taught; that comes with time and experience of living and coping with chronic pain. The use of distraction as a coping or management strategy thus merits more attention, paying particular attention to different ‘types’ of distraction, and why they are effective, or not.

Imagination has many definitions including the “ability to confront and deal with a problem”, “a creation of the mind”, or “the act or power of forming a mental image of something not present to the senses or never before wholly perceived in reality” (Merriam-Webster, n.d.). ‘Access’ to one’s imagination is often considered to be innately ‘child-like’. Although this research concerns itself with understandings of childhood pain, the idea that imagination can be used as a coping strategy is not outlined because of its ‘child-like essence’, but rather because it presents a way to learn from children who use their imagination as a way of coping with chronic pain.

The literature investigating imagination in relation to pain is scarce but fascinating. Some authors contend that the concept of imagination directly opposes the concept of physical pain in that pain necessitates an ‘object’ (i.e., the body) to exist whereas imagination can exist entirely without ‘object’ (Anderson, 2015). According to Scarry (1985) imagination can offer potential analgesic effects if mobilized properly, being able to act as “the ultimate painkiller” (Scarry, 1985, as quoted in Anderson, 2015). Nonetheless, ideas shared by children in this study about imagination’s potential to serve as a way of coping with (or, potentially eliminating) chronic pain are intriguing, and present an interesting avenue for future research. Such research might include questions related to: what is it about imagination that motivates young people to describe its use when asked of their experiences with chronic pain and coping? In what ways do young people describe using imagination to cope with pain? And, are children intentional about using imagination to cope with pain?

Discussing methodological insights

I begin this section with a review and discussion of the methodological celebrations outlined in the previous chapter, namely: the ability of the methodology to successfully promote participant reflexivity, success in purposefully building in participant choice, and the benefits of the selected sequence of data generation. I end this section with a discussion of the methodological insights regarding lessons learned while piloting the use of arts-based methods in combination with semi-structured interviews with children. Specifically, I discuss the considerations of leaving space for silent pauses during interviews and the implications of responding to participants in particular ways.

Discussing methodological celebrations

One of the arguments for engaging research participants in an art-based task during a study is due to its potential to prompt participants and researchers to think reflexively (Guillemin 2004a; 2004b; Teachman & Gibson, 2018; Mah et al., 2019). In this way, participants' visual art represents the output of their intentional reflection, where meanings and understandings are being co-produced through the very act of creating the artwork. Research participants who have reflected on their experiences prior to engaging in an interview discussing them is anticipated to elevate the richness and depth of data generated. Both my personal observations and my exchange with Simran, where she explained having thought for a while about what she was going to represent in her visual art, reinforced the importance and value of building time for reflection into a study. This is especially important when aiming to generate rich data in as little as two interviews; any opportunity to engage children in thinking about their experiences prior to asking about them can elevate the output of the research. The analysis of preliminary findings provided in this dissertation lends support to the depth and nature of data that can be generated using art-based methods as a means of prompting participant reflection and meaning-making, prior to engaging them in a second interview.

The second celebration of the methodology relates to its attentiveness to promoting children's participation by building in choices. Options were intentionally built into this research, in order to avoid making assumptions about the preferences and abilities of the

children participating. For example, children were encouraged to select which art-based task they preferred doing (either visual art or photography), reminded of their ability to drop out of the study if they wished, and reminded of their ability to decline to answer or defer questions. Other choices, hereafter called ‘micro-choices’ came about organically while I conducted this research and were noted and reflected upon in order to be carried forward in future iterations of this work. Micro-choices acknowledged and enabled children’s agency at multiple stages of the research process, beyond the larger formal decisions outlined above. These micro-choices involved respecting participants’ stated preference for engaging in the research in English or French (if bilingual), and asking participants if they desired, or not, to read the question prompts for the question-and-answer game. Children are not a homogeneous group, and their preferences and desires cannot be spoken for them nor considered to be universal across all members (Mah et al., 2019). For instance, it would be inappropriate to assume that each participant in this study was able or comfortable with reading out loud to strangers. Instead of making this assumption and using language such as: “Let’s take turns reading the questions on the screen. You go first.”, the researcher should ensure that expectations about participants’ age, preferences, and abilities are not taken for granted and assumed. It is important that this aspect of doing research with children is carried forward in future iterations of this research methodology for several reasons. Above making the participant feel comfortable, it avoids a potentially uncomfortable situation, and contributes to the success in the rapport building stage by empowering young participants. It thus acts to reduce the power dynamics that conventionally exist between young children and someone they perceive as ‘adult’.

Recall that this research used the following sequence of data generation: Interview 1 (question-and-answer exercise), 2-weeks to complete art-based task, and Interview 2 (unpacking visual data in relation to pain) (see Figure 1). The sequence of data generation in this study was successful in allowing for rich data to be generated when unpacking visual data with participants in their second interview. To prepare for each second interview, I revisited the transcript and my post-interview field-notes from that participant’s first interview alongside visual data. I then prepared a semi-structured

interview guide tailored to that participant, paying attention to details that might be important to recall or revisit during this second interview.

The initial rapport building interview provided me with the opportunity learn about meaningful aspects of each participant's life. I drew upon this insight when theorizing each participant's visual art; questioning why certain aspects were included or not and making note of areas that I wanted to know more about. Without access to information about each participant's life before our second interview, it is likely that the quality and depth of data generated would not be the same. Many of the insights generated from participants' visual art built off my prior knowledge of the participant's life.

The chosen methodological sequence used in this study also reduced the burden placed on tailoring each second semi-structured interview to each participant 'in the moment'. I had time to prepare questions, think of potential probes, and otherwise anticipate the direction the interview might go, based on each first interview and preliminary review of visual art. This reduced my stress level in the second interview; I felt prepared and confident in my interview guide as I carefully ensured it would make sense for the participant I was engaging with. Overall, the sequence of research events in this study allowed for each participant to receive a research experience that was specifically tailored to them, which increased my confidence as a novice researcher and bolstered the quality of the data generated.

Discussion of lessons learned

The occurrence of silent intervals in childhood speech are well researched in childhood speech literature (Esposito, 2005; Esposito et al., 2007). Silent intervals are empty pauses in the speech generated by children and are thought to occur for a number of different reasons. For example, cognitive psychologists suggest that children sometimes use pausing strategies as a way of thinking though expectations about their response or to assist them in understanding what the speaker has just communicated. Pauses allow for complex neural processing to take place that cannot occur during speech generation. Of note, pauses in verbal speech are not anticipated to be uniform in length, as the length of

a given pause is understood to represent the cognitive load of processing and generating verbal information (Esposito, 2005).

Leaving space for silence is thus imperative when it comes to prompting complex thought with children. Being comfortable with silence, or what I initially conceptualized as ‘that awkward pause in between the question I asked, and the participant’s response’ was essential, as this research called for children to reflect and express responses to abstract and likely, unordinary questions. Thus, leaving space for participants to anticipate a pause after most, if not all, of my verbal utterances, likely would have improved the depth the data generated early-on in this research. Further, if a participant expects a pause to occur, they might be more likely to reflect on a response instead of responding with an utterance to the extent of ‘I don’t know’, because they aren’t used to the silent pause that comes after a question.

As someone with difficulty accepting silent pauses in conversation with new people, in a research setting or otherwise, it was important that I reminded myself that pausing is beneficial for participants and necessary to generate rich data. I did two things to remind and teach myself to be comfortable with silent pauses. First, I wrote myself a note that read “Don’t forget to pause!” and pasted it above my computer desktop where it would be visible to me throughout my interviews with participants. Although I had a hard time reading the written words when focusing on engaging participants during interviews, the paper that I used to write this reminder was bright pink, and the pink hue in my peripherals was enough of a reminder to invite silence throughout the interview process. Second, I informed my family, friends, and partner that I was making an effort to invite pauses during conversation and asked them to remind me if ever I jumped in prematurely after they uttered something or tried to help them along after I asked them a question. The people in my life thus held me accountable and helped me ‘unlearn’ verbal behaviours that actively eliminated any potential pauses during verbal speech. Through reflection, I noticed these were largely unconscious behaviours that I often performed in my daily life before beginning this research. Both these techniques were invaluable in helping me invite more silent pauses thought my research interviews with participants, which I

noticed improved with time, and likely also improved the depth and quality of the data generated.

My final reflection in the previous chapter (5) outlined an example of how I responded to participants after they shared details about their lives with me. I often used phrases to the extent of “that makes sense” or “now I understand”, or “that’s great” and “I one-hundred percent agree”. When responding to participants in this way, my intention was to affirm that they were doing a good job in sharing intimate details about their lives with me, hoping that my kindness and ability to relate would motivate them to share further. My lived experience of chronic pain taught me how difficult it can be to talk about your experiences living with pain, especially when asked to recall moments related to ‘bad pain days’, when I might have struggled to cope or was emotionally distraught from a prolonged pain flare-up. Despite my intentions to comfort participants, my reflections and discussions with my co-supervisor, GT, shed light on the unintended implications of responding to participants this way. For example, comments to the extent of “*now I understand*” might unintentionally hint that participant were not ‘making sense’, in my perspective, prior to their last utterance. Signifying that their previous attempts to explain their perspective were not sufficient, but this final attempt was successful, and ‘finally made sense’. My reflections on this method of responding to participants have revealed the unintended harm of responding in this way. One possible interpretation of my response by participants is saying that their way of understanding or making sense of their pain, as they ‘first’ explained it to me, did not fit with my way of making sense of their, or my, pain. In other words, in suggesting that further clarification is needed I might be implying that their initial perspective was somehow not ‘good enough’ because I did not understand it right away. They might also feel that they weren’t doing a good job before, but now that I said I understand, they might feel relieved that they finally gave me the ‘right answer’. Instead, it is sufficient when interviewing to move forward with the next question or prompt, without affirming to participants whether I understand them or not in the present moment. If I wanted to invite further reflection or clarification, I might leverage silence or pauses, as explained above, to see if the participant has more detail to add without feeling like they must do so to be doing a good job and be contributing ‘successfully’ to this research.

Limitations

Most of the limitations of this study are related to the small sample size of three participants. Although considered sufficient for a pilot study, this sample size limits the types of claims that can be made from the substantive data generated through this study (i.e., data related to the ways children understand chronic pain and coping). As explained throughout this thesis, the analytic insights related to chronic pain and coping are not considered to be analytically generalizable. Rather, these results present modest examples of the type and depth of data that can be generated from the combination of arts-based methods and semi-structured interviews piloted in this study. Moreover, limitations of a small sample size include a lack of diversity with respect to participant demographics. For instance, this study sample only contained biologically female participants, all of whom self-identified as girls and as either South-Asian or East-Asian/Caucasian (mixed) descent. A larger study with a more diverse, heterogenous sample might produce results that confirm some aspects of the pilot results but would likely provide far greater and more varied patterns and insights related to children's experiences and understanding of chronic pain.

Second, data was generated for this study throughout the COVID-19 pandemic, a time where children's experiences of chronic pain and their means of coping were likely to be in flux and rapidly changing. For example, my own lived experience of pain and coping during the pandemic changed drastically, as I no longer had reliable access to in-person supports that I would traditionally use to cope. Thus, experiences of chronic pain, including coping and seeking care for pain, were taken in a specific (and unique) time and place, in this case throughout the COVID-19 pandemic.

Contributions

This study adds to the literature by demonstrating the utility and benefits of a new arts-based methodology and providing preliminary insights about children's experiences with chronic pain and coping. This preliminary research should be built upon and scaled up in future studies now that its potential to generate rich knowledge with young people has

been established. Thus, a logical next step to this study involves a repetition of this methodology, with a larger, more diverse sample, such that insights gathered in relation to chronic pain and coping can contribute analytic generalizability.

The methodological insights from this pilot study, including both the celebrations and the lessons learned, contribute unique value to graduate trainees and novice researchers. Reflexive insights pertaining to the planning and delivery of qualitative research seldom make it into published literature. It is my hope that my reflections resonate and aid researchers who are in a similar position that I was in when beginning my graduate journey. Lessons are meant to be learned throughout research, however having access to anticipated areas of attention or concern can be helpful. Given the creative presence of the qualitative researcher, it is anticipated that different researchers engaging in qualitative research examining similar areas of inquiry will have different reflections on what went well and areas of concern. In this case, my reflections and examples provide a way of approaching and learning from lessons learned throughout the research process, to then be carried forward in with future interviews with subsequent participants and in future iterations of research with young people. Overall, this methodology combining arts-based methods and semi-structured interviews has the potential to generate rich data with young participants regarding their experiences of chronic pain and coping, and, I argue, might be equally as helpful to unpack children's understandings of other chronic conditions.

Finally, this study reinforced that the concept of 'coping' warrants future attention. Both because of its ambiguousness and lack of a clear definition, and because of the potential to generate knowledge of how to improve the quality of life of children living in painful bodies. The two cognitive coping strategies shared by children in this study, which involved distraction and imagination, are only discussed in the extant literature at a superficial and theoretic level, respectively, and thus warrant further research attention.

Conclusion

This study piloted a promising methodology combining arts-based elicitation methods with semi-structured interviews to generate data with children experiencing chronic pain.

To provide supporting evidence of the quality and richness of the potential data that can be generated using this novel methodology, my analysis of children's understandings and experiences of pain and coping with pain flare-ups has been presented and discussed in terms of implications and relevance to the little that is known concerning children's views on their own pain experiences. The preliminary analytic and methodological insights and reflections shared in this thesis support the potential of this methodology to contribute to knowledge production in the area of childhood pain research. Although growing in attention, the area of childhood pain research is still an area of scant empirical research, with even less attention paid to children's lived experiences as they understand them. This dissertation outlined a promising new methodology and provided modest results that contribute important first-hand knowledge of children's own experiences of living and coping with chronic pain.

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Appendices

Appendix A: Non-Medical Ethics Approval



Date: 25 October 2021

To: Dr Gail Teachman

Project ID: 118661

Study Title: Exploring children's understandings of chronic pain and coping with acute flare-ups of chronic pain

Application Type: HSREB Initial Application

Review Type: Delegated

Meeting Date / Full Board Reporting Date: 02/Nov/2021

Date Approval Issued: 25/Oct/2021

REB Approval Expiry Date: 25/Oct/2022

Dear Dr Gail Teachman

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.**

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Interview Guide – Interview #2_Jun28_2021	Interview Guide	28/Jun/2021	Version 1
Interview Guide – Interview #1_Jun28_2021	Interview Guide	28/Jun/2021	Version 1
Drawing Task Instruction Script_June28_2021	Other Data Collection Instruments	28/Jun/2021	Version 1
RecruitmentScript_Jun28_2021	Recruitment Materials	28/Jun/2021	Version 1
RecruitmentPoster_June28_2021	Recruitment Materials	29/Jun/2021	Version 1
Email Recruitment Script_June29_2021	Email Script	02/Jul/2021	Version 1
Follow-Up Email Recruitment Script_June29_2021	Email Script	02/Jul/2021	Version 1
SocialMediaGraphic_Jul21_2021	Recruitment Materials	21/Jul/2021	Version 2
Photo-Elicitation Task Instruction Script_Sep22_2021	Other Data Collection Instruments	22/Sep/2021	Version 2
Assent Letter of Information_Sep22_2021	Assent Form	22/Sep/2021	Version 2
RecruitmentScript_Oct13_2021_FR	Translated Documents	13/Oct/2021	Version 1
Follow-Up Email Recruitment Script_October13_2021_FR	Translated Documents	13/Oct/2021	version 1
Email Recruitment Script_Oct13_2021_FR	Translated Documents	13/Oct/2021	version 1
Assent Letter of Information_Oct13_2021_FR	Translated Documents	13/Oct/2021	version 1
Drawing Task Instruction Script_October13_2021_FR	Translated Documents	13/Oct/2021	version 1
Interview Guide – Interview #1_Oct13_2021_FR	Translated Documents	13/Oct/2021	version 1
Photo-Elicitation Task Instruction Script_October13_2021_FR	Translated Documents	13/Oct/2021	version 1
Interview Guide – Interview #2_Oct13_2021_FR	Translated Documents	13/Oct/2021	version 1
LOI and Consent Form (SDM)_October14_2021_FR	Translated Documents	14/Oct/2021	version 1
K.Ferreira_Master'sProtocol_Oct14_2021	Protocol	14/Oct/2021	Version 2
LOI and Consent Form (SDM)_October23_2021	Written Consent/Assent	23/Oct/2021	Version 3

Documents Acknowledged:

Document Name	Document Type	Document Date	Document Version
StudyRationale_References_Mar22_2021	References	22/Mar/2021	
StudyBudget_June28_2021	Study budget	28/Jun/2021	Version 1
DELFB2_Ferreira_Oct21_2021	Translation Certificate	21/Oct/2021	
AttestationLetter_Ferreira_Oct23_2021	Translation Certificate	23/Oct/2021	

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB , except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions. Sincerely,

Patricia Sargeant, Ethics Officer (psargean@uwo.ca) on behalf of Dr. Emma Duerden, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B: Participant Demographic Information

The following questions will help us describe the participant in general terms. They will also be used to help us recruit participants from diverse backgrounds. If you are not comfortable responding to an item, you are welcome to skip the question.

(1) What is the participant's age: _____

(2) Which option(s) best describe the participant's race? Select all options that apply:

- Black (e.g., African ancestry, Afro-Caribbean, African American, African Canadian, etc.)
- East Asian (e.g., Chinese, Japanese, Korean, etc.)
- Indigenous Global (e.g., Maori, Australian Aboriginal, South American Indigenous, etc.)
- Latino/a or Latinx (e.g., South Central American, Caribbean, etc.)
- South Asian (e.g., Bangladeshi, Pakistani, Indian, Sri Lankan, etc.)
- South East Asian (e.g., Vietnamese, Thai, Cambodian, Malaysian, Filipino/a, etc.)
- West Asian or Middle Eastern (e.g., Iranian, Afghan, Lebanese, Iraqi, Armenian, Israeli, Palestinian, etc.)
- White (e.g., Caucasian, European ancestry, etc.)
- I prefer not to answer
- If you would like to identify the participant further, please do here:

(3) Which option(s) best describe the participant's gender identity? Select all options that apply:

- Gender Non-conforming, Gender Fluid, Non-binary, Genderqueer, Gender Variant, X, Agender, Queer
- Boy (includes Transboy)
- Two-Spirit
- Trans
- Girl (includes Transgirl)
- I prefer not to answer
- Additional: _____

Do you have any other questions related to the study that I can answer before we start the interview?

Appendix C: Interview Guide for Interview #1 - Getting to know each other...

1. Begin with brief introduction to myself and an explanation of the project in simple terms.
2. Introduce the ‘interview ground rules’
 - This interview is not a test like what they might be used to at school but rather a discussion about pain and your experience of pain.
 - There are no right, or wrong answers and I want you to feel comfortable telling me if you don’t feel like answering a question or if you would like to skip it and come back later. You are the leader of this game!
 - If at any point you would like to take a break or end the discussion, please let me know and I will be happy to make that happen.
3. Explain and begin the dice game

* KF will begin by sharing her screen with a dice web application

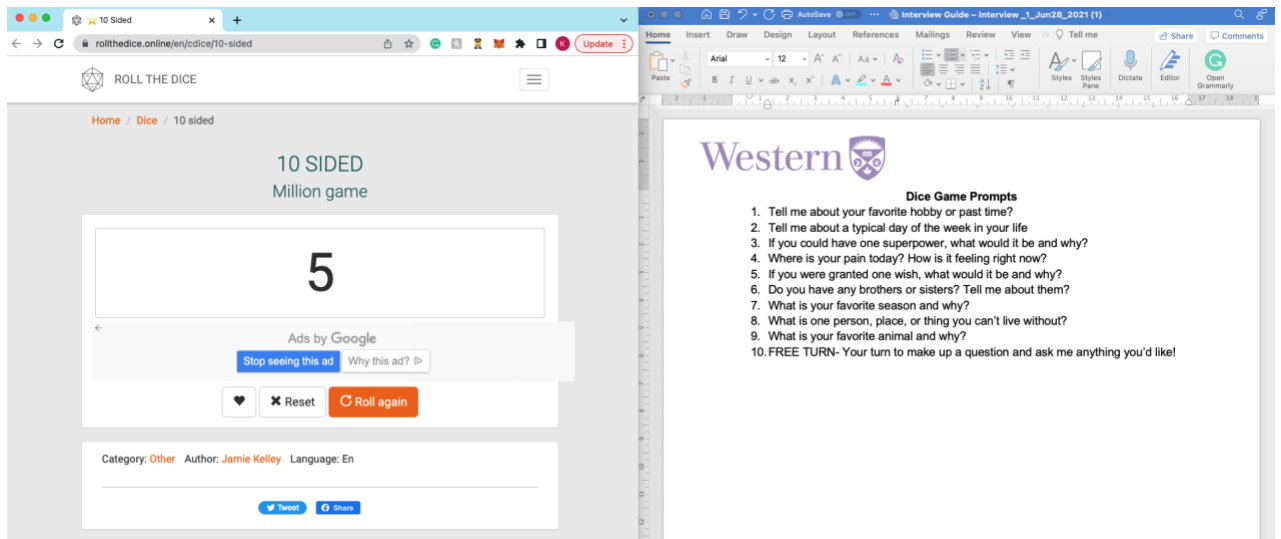
(<https://rollthedice.online/en/cdice/10-sided>) on the left-hand side of her screen and the list of prompts numbered 1-10 on the right-hand side (See below)

- Here on my screen, I have an electronic dice with 10 sides labeled 1 to 10 and a list of 10 questions. When we start the game, I will press the button on the screen that says, “Roll Again”. This will roll the dice and whichever number it lands on corresponds to a topic that we can talk about. How does that sound?

Dice Game Prompts

1. Tell me about your favorite hobby or past time?
2. Tell me about a typical day of the week in your life
3. If you could have one superpower, what would it be and why?
4. Where is your pain today? How is it feeling right now?
5. If you were granted one wish, what would it be and why?
6. Do you have any brothers or sisters? Tell me about them?
7. What is your favorite season and why?
8. What is one person, place, or thing you can’t live without?
9. What is your favorite animal and why?
10. FREE TURN- Your turn to make up a question and ask me anything you’d like!

Appendix D: Screenshot of Shared Screen for Interview 1



Appendix E: Instructions for Drawing Task

Instructions:

- Please print or recreate the template below.
- You will need two sheets of paper (minimum) and any drawing utensil. Following the formatting below, page one should contain the prompt: “On a good pain day, I” and page two should contain the prompt “When my pain gets worse, I”.
- Participants should draw or write what comes to mind when they hear the two phrases. There are NO wrong answers or limitations on what the drawings should look like!

On a good pain day, I ...

When my pain gets worse I...

Appendix F: Photo-Elicitation Task Email Instruction Script

This script will be sent to SDMs after the participant completes Interview #1 should they have chosen to complete the drawing task.

Dear *participant name and SDM name*,

Thank you again for your participation in today's interview. As I had mentioned, here are the instructions on how to complete the photography activity for the study attached to this email. *Participant name* has two weeks to take 6-10 photographs that describe them and might show/tell others how they cope with pain. The photographs could represent or show "A good pain day" and "A day when my pain is worse than usual". Once *participant name* is finished with their photography, I kindly ask that you scan or send over their photographs to me by email (mailto: kferre6@uwo.ca). Once you have sent over the photographs, we will schedule a second follow-up interview. If *participant name* needs more time to complete the activity, we will be happy to accommodate this so do not hesitate to contact me. Please feel free to reach out with any questions or concerns should they arise in the coming days.

I look forward to chatting with *participant name* soon,

Kristina

Appendix G: Participant Interview Guide for Sarah

- **Remind Sarah:**

- About her right to withdraw from this study and stop the interview at any time (either for breaks or a pause, or altogether).
- She is also welcome to not respond to anything you don't want to respond to- or come back to it later.

- **General probes:**

- Can you tell me more about that?
- Do you have any stories that come to mind about drawing, walking, eating, and talking to friends?

1. Would you like to explain a good pain day to me?

Probe: Here it says “On a good pain day I...”. Can you explain to me what you drew here?

- Where do you take walks?
- When and where do you talk with your friends? What else do you do with your friends? Tell me a story!

Probe: When you hear the word pain, what do you think?

Probe: When you hear the word pain, what do you feel?

Probe: How would you describe your pain on a ‘good pain day’?

- How does a good pain day feel?

Probe: How does that make you feel?

Probe: Can you tell me a bit more about this part of your drawing?

2. How do you cope with especially difficult or painful days?

Probe: Here it says, “When my pain gets worse, I...”. Can you explain to me what you drew here?

- I notice you don't have any other people or friends in your drawings of a bad pain day. Can you tell me more about that?

Probe: You show me here that you feel like you're in a bad mood on a bad pain day. Can you tell me a bit more about how the person in your drawing might **feel** when their pain gets worse? **Pause and see how they interpret this question**

Probe: What are they thinking when they feel this way?

Probe: What sorts of things help you when your pain is worse than usual?

- I see you have lay down here – does that help you? What about laying down helps your pain?
- I see you don't like to eat when you don't feel well. Does not eating help alleviate your pain?
- What other activities or actions help you when you're in pain? Does your medical stuff help?

Probe: How did you learn about this way of feeling better?

Probe: Was it something someone taught you? Who taught you about this?

Probe: Can you tell me a bit more about this part of your drawing?

3. If you could show your drawing to anyone, who would you show it to?

Probe: Why would you show that person?

Probe: Who do you think should see this drawing?

Probe: What would you tell that person about your drawing?

Appendix H: Analytic Guide for Data Analysis

1. **Pain fact or descriptor**; used when a young person describes their pain type, pain location, or pain characteristic.
2. **Pain pattern**; used as a description of the frequency, pattern, or severity of pain at different points in time.
3. **Locating pain**; used when young people talk about how pain is experienced in their bodies. Different from pain fact/descriptor in that it can be considered a subjective interpretation of their pain experience, rather than a fact (i.e., I have stomach pain).
4. **Cultural ways of coping and understanding pain**; used when young people leverage culture to explain pain or coping.
5. **Pain as a positive experience**; used when pain is described or explained using positive descriptors or in a positive light.
6. **Pain as a negative experience**; used when pain is described or explained using negative descriptors or in a positive light.
7. **Pain as a mixed experience (good/bad)**; used when pain is described or explained as having both positive and negative components.
8. **Pain coping strategy**; used when a young person displays or explains anything that can be considered a pain coping mechanism (either physical or mental) – i.e., a strategy to reduce or illuminate the unwanted sensation or experience of pain.
9. **Specific child-based understanding of pain**; used to describe an understanding of pain that might be different or specific to children in pain (rather than an adult with pain).
10. **Pain and mental health/psychological well-being**; used when a young person relates pain to a mental or psychological state.
11. **Pain metaphor**; used when a young person uses metaphor too describe their experience or understanding of pain.

Curriculum Vitae

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2020-2022

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2021-2022

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Publications:
Teachman, G., *Ferreira, K., Hamdani, Y, Eglison, S, (in progress; lit. review completed and data analysis underway). Childhood out of time: Examining childhood disability and the effects of normative conceptions of time. Target Journal: Disability and Rehabilitation.

Presentations:

Teachman, G., ***Ferreira, K.**, Hamdani, Y., Egilson, S. T. (2022, Aug). *Reflections on 'normal' time and its disabling effects for children and their occupational possibilities.* Presentation at 2022 World Federation of Occupational Therapists International Congress, Paris, France.

***Ferreira, K.**, Birnie, K., Walton, D., Teachman, G. (2022, Feb). *Using arts-based methods to examine children's understandings of chronic pain and coping.* Oral presentation at the 2022 Health and Rehabilitation Graduate Research Conference, Western University, London, Canada.

***Ferreira, K.**, Birnie, K., Walton, D., Teachman, G. (2021, May). *Designing a study to examine children's understandings of chronic pain and coping.* Poster presented at the 2021 Child Health Symposium, London, Canada.

***Ferreira, K.**, (2021, March). MedScien 3900G Schulich School of Medicine and Dentistry, Western University. *Becoming a qualitative health researcher: my MSc journey.* Invited/Guest Lecturer.