DESCRIBE YOUR PAIN:
A HEURISTIC EXPLORATION OF THE ROLE OF ART IN COMMUNICATING THE EXPERIENCE OF CHRONIC PAIN

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ABSTRACT

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The condition of chronic pain, like other chronic illness, is a phenomena that begs further investigation because of its significant physical and psychological impacts. Additionally, it is an affliction that is difficult to treat, understand and overcome. Traditionally, diagnosis and treatment of this condition has depended on retrospective recall of symptoms, which are often subjected to bias. Current research in medical art therapy has shown promising potential in the treatment of both the psychological, physiological and sociological impacts of chronic pain. However, there is limited arts-based research that steps outside of a medical model. In this research I have used my own experience to deepen the understanding of chronic pain by addressing the following question: How might a daily art practice describe the lived experience of a training art therapist experiencing chronic pain?

This was explored using a heuristic, arts-informed methodology. Data was collected through a daily art exercise that responded to the prompt, "Describe your pain today" as well as reflective journaling. The discussion of these images utilizes Jungian theory in order to gain insight into the more intangible meanings produced by the imagery.

Key Terms: Art therapy, Chronic pain, Chronic Illness, Daily Art Practice

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Chapter 1. Introduction

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

-Susan Sontag

The condition of chronic pain is a phenomena that begs for further investigation because of the massive impact it has on individuals' live. Research has shown that chronic pain can disrupt social functioning, cause excessive health concerns and lead to depression (Kelley and Clifford, 1997). Additionally, chronic pain is a condition that is difficult to explain, treat and overcome, because it is not well understood.

I was driven to this topic by my own experience with chronic pain and illness caused by an autoimmune condition. I have sought to enrich the understanding of chronic pain by employing an arts-informed heuristic inquiry. Chronic pain and illness can be differentiated from disease, as *disease* implies a medical and biological lens. Whereas, *illness* encompasses the subjective experience of unwellness (Kleinman, 2007). In other words, "Disease is what happens to the body, illness is what happens to the person (Lelwica, 2017)". Thus, the subject of this research will be in regard to my illness, rather than my disease.

Chapter 2. BACKGROUND LITERATURE

The following literature review provides a context for this research and will explicate the current landscape of chronic pain research in regard to art therapy and expound upon the relevance of Jungian art therapy to this topic. Additionally, I have included literature that examines the underling paradigms and societal attitudes surrounding chronic pain. These sources are paramount because the conversations and thoughts that surround chronic pain influence the way people who experience chronic pain, make meaning of their own condition.

Defining the Problem of Chronic Pain

Chronic Pain and its Impact. The phenomena of chronic pain is not easily definable. Thus, it is unsurprisingly difficult to understand, treat and overcome. At times, chronic pain is discussed in terms of arbitrary time limits, whereby pain exists for longer than a period of 6 months (Angheluta and Lee, 2011). According to one study, it is defined as "persistent or recurrent pain for at least three months that arises as part of a disease process, such as inflammation secondary to infection, autoimmune disease or metabolic aetiology, or direct structural changes affecting bone, joints, muscle or soft tissue." (Cheng and Cheng, 2019) Other sources defines chronic pain as maintenance of a danger signal from the brain. This signal can be malignant, caused by life threatening illness or benign, occurring without significant physical cause (Angheluta and Lee, 2011).

Chronic pain can be a symptom of or cooccurring with other chronic illness such as autoimmune disease, cancer, epilepsy and many others. It could also stem from an injury or traumatic event. The common thread of this condition is that it is largely considered "treatable but not curable", a devastating prospect (Lelwica, 2017). More recently, the term *recurrent pain* has been proposed because it is more descriptive of the temporal and physiological changes that occur, as well as the episodic nature of chronic pain (Angheluta and Lee, 2011). However, for the sake of this research project, the term chronic pain will be used because of its prominence in the literature on the topic.

The physical, psychological and social impacts of chronic pain cannot be overstated. On a individual level, the condition can lead to social isolation, the disruption of job and family, depression and excessive health concerns. Often times people suffering with chronic pain have problem saturated life stories where the symptomology takes over and other aspects of life are ignored (Kelly and Clifford, 1997). A guide to primary care of chronic pain by Dr. Dawn Marcus (2014) explains the problem on larger scale. She posits that only 15% of primary care physicians felt comfortable working with chronic pain patients. This is in spite of the fact that, "pain is a common chief complaint for patients in primary care, with approximately 10 to 20% reporting chronic pain" (p. 3).

Psychological Components of Chronic Pain. The complexity of the problem of chronic pain may also be understood when considering chronic pain as a phenomenological condition that is dependent on an interaction of physiological, psychological, cultural and societal factors. Authors Angheluta and Lee (2011), explain:

> How people experience their pain is influenced by cultural ideas of pain, gender expectations of how one must cope with pain, the quality of personal relations with family or society at large, personal coping capacity, and the presence of other stressors, such as job loss (p. 113).

In *The Challenge of Pain*, by Melzack and Wall (2008), the authors write that the body's processing of pain involves three events that happen simultaneously. First is the sensory processing of pain, the second is the emotional-cognitive processing of pain and the third is the cognitive-affective top down modulation of pain. This explanation fits with another model of pain processing, Gate Control theory. Gate Control theory posits that pain signals are sent from the site of injury to the spinal cord and then messages are sent bidirectionally from the spinal cord to the brain so that the brain modulates the perception of pain (Camic, 1999).

The neuroscience behind pain allows for links to be made to other psychological phenomena. The brains structures that are involved in pain processes, such as the anterior cingulate cortex, the insular lobe and limbic amygdala also play an important role in affect regulation, reaction to threat to stimuli and conflict resolution. Early attachment experiences are also highly associated with these brains' structures. However, it should be noted that short term, acute pain and chronic pain are processed differently (Hass-Cohen and Findlay, 2009).

The experiences of short-term pain and chronic pain diverge in the resulting nervous system response. The threat of pain creates a fear response that activates the autonomic nervous system in a flight or fight response. However, under the threat of chronic and unremitting pain, the body loses control is more likely to activate a passive shutdown coping process, whereby the body attempts to store resources and wait out the pain. This process is called freeze and is activated by the parasympathetic nervous system, specifically the hypothalmic-pituitary-adrenal (HPA) axis. In the long term, over activation of the HPA axis overloads the body's stress

response system and causes nervous system dysregulation, resulting in negative health outcomes (Hass-Cohen and Findlay, 2009).

In a narrative review on stress and chronic pain, researchers found acute stress can exacerbate both acute and chronic pain. In the study, it was proposed that threat learning is the main mechanism that modulates this dynamic. The authors explain that factors, such as a stress response, can bias the body's systems to perceive a potentially harmful situation as highly threatening. Additionally, the threat of pain and stress compromises goal directed behaviour that may lead to recovery and is replaced by more inflexible and habit like behaviour such as avoidance that focuses on controlling pain (Timmers et al, 2019).

How do we look at chronic pain?

Interdisciplinary Communication. While chronic pain is traditionally treated through a biomedical lens, the topic of chronic pain is the subject of study for many disciplines such as religion, shamanism, neuroscience, and many more. However, the cross talk and shared knowledge between these fields has been quite limited. For example, it is widely accepted within the field of immunology that chronic pain is a result of a miscommunication between the immune system and nervous system. However, scientists in the field of immunology and neuroscientists have had very little dialogue amongst themselves and most studies on chronic pain are designed by neuroscientists (Hore & Denk, 2019). This is a testament to how the understanding of chronic pain is so compartmentalized, even two fields of medical inquiry have difficulty in collaborating.

This lack of cross talk is paralleled in the relationship between neuroscience and psychotherapy in the treatment of both the physiological and psychological symptoms. Hardin (2004) explains,

> Pain is both a physiological and psychological experience. Yet putting this realization into practice in treatment has not been simple, given the relative separation of traditional western medicine and psychotherapy. The two fields have developed on separate tracts largely due to the pervasive influence of the work of Descartes, the 17th century philosopher who proposed a distinction between the mind and the body, known as dualism. This concept is an important one, since the modern biomedical model is still

> heavily weighted toward classifying problems as either "medical" or "psychological" (or "psychogenic"). The tendency to ignore psychological issues in the investigation and treatment of pain has in many ways added to the types of problems faced by people suffering with pain (p. 75-76).

We can see that the long-standing paradigms in medicine may run counter to the ideals of comprehensive and holistic treatment of pain.

Assessment Approaches. Another problematic paradigm in the study of chronic pain is how pain is measured. In both clinical and research settings, assessment of chronic pain largely relies on patients' retrospective self-reporting (Brunton, 2004). However, the means by which clinicians collect these self-reports, either verbally, through questionnaires or through a series of liker scales, leaves one questioning their validity. Patient recall of symptoms is subjected to bias such as peak and end effects noted by authors in The Journal of Pain. Peak and end effects describes the phenomenon of patients mostly measuring their somatic symptoms by the most intense episode of symptom presentation or the most recent experience of symptoms (Schneider et al, 2011).

Complimentary Medicine and CBT. While there are a vast number of treatment options for chronic pain, there is little research being done to assess the efficacy of these interventions. Most pharmacological treatments have shown adverse effects and minimal efficacy. Currently, CBT and regular exercise are offered as best practice for non-pharmacological, complimentary medicine. In a meta-analysis, researchers found a small effect for exercise and CBT in treating the intensity of pain. However, it showed a redundancy in the effect size, meaning that CBT and exercise together, was not shown to be more effective than exercise alone. Additionally, the meta-analysis pointed out that there was very little investigation done on how these non-pharmacological treatments could address the psychological impacts of chronic pain, rather than the intensity of pain (Cheng and Cheng, 2019).

While searching for efficacy of treatments that met the psychological needs of people with chronic pain, narrative therapy showed promising evidence. In a study of group narrative therapy and fibromyalgia, researchers found that this modality of therapy was useful to patients, particularly in being able to describe their needs. In-group discussions led participants to be able

to find new inner resources to meet the challenges of chronic pain. Additionally, "the group approach allowed them the opportunity to re-examine and re-story their lives, to not get stuck in repeating the story of helplessness, and to harness their own resources" (p. 276). While these results are favourable, the study did not show significant changes in the group on the CES depression scale or the Pain Experience scale (Kelly and Clifford, 1997).

The Power of Art

When one looks outside of western paradigms of health and medicine, the importance of the image in healing can be revealed. In his exploration of shamanism and medicine, Jeanne Achterberg (2002) explains,

> Imagery has always played a key role in medicine. What is imagery? Imagery is the thought process that invokes and uses the senses: vision, audition, smell, taste, the senses of movement, position and touch. It is the communication mechanism between perception, emotion and bodily change. A major cause of both health and sickness, the image is the world's oldest and greatest healing resource.
>
> Imagery, or the stuff of the imagination, affects the body intimately on both seemingly mundane and profound levels…Because of this pronounced effect the image has on the body, it yields power over life and death, and plays a key role in the less dramatic aspects of living as well (p.3).

This embodied approach to healing is a major departure in paradigm from the cartesian understanding of pain described earlier. When the body is understood as holding knowledge of its own, the body movement in making art can be a transformational process where internal experiences can be discovered. When an embodiment approach is used therapeutically, somato-emotional knowledge can be gleaned from an image (Gabel & Robb, 2017).

The power that the symbolic content in an image holds is championed in Jungian art therapy, whereby images are "to be played with and listened to but not defined" (Swan-Foster, 2018, p. 489). Carl Jung parted from Freud in his understanding of sublimation of unconscious material through tasks like art making. Jung (1973) wrote that sublimation was, "not a *voluntary and forcible* channeling of instinct into a spurious field of application, but an *alchemical* transformation for which fire and the black *prima materia* are needed" (p. 171). Thus, Jungian art therapy looks at the creative process as a collaboration between the ego and the true self, a source of symbolic wholeness (Swan-Foster, 2018). Jung regarded images made by his patients

in a non-reductive way, as expressions of the unconscious and a way of making the contents of the unconscious accessible (Schaverien, 1999). Furth (2002) posits that in this way, symbols that arise in imagery can be used as a healing agent, because on an unconscious level, art reveals what the body knows.

Art Therapy and Chronic Pain

Current State of Research. The prospect of using art therapy as a complimentary treatment for people who experience chronic pain is compelling because of art therapy's potential for addressing both the physiological and psychological symptoms of chronic pain. The creative arts therapies as a whole has traditionally rejected the separation of body and mind and has valued phenomenological and subjective lived experiences as a way of knowing (Koch, 2006). Art therapy has been used in many different therapeutic approaches, to supplement CBT, narrative therapy, attachment based, community based and psychodynamic approaches to chronic pain.

Unfortunately, the current research is both geographically and chronologically disparate. In a study on the potential to use art therapy as a sensory intervention for pain management, Crawford et al (2014) write,

> The practical feasibility of sensory art therapies is appealing, and the ability of aesthetically moving stimuli to engage a patient physically, mentally, and/or spiritually is unique. The clinical research regarding the use of sensory art therapies as self-care interventions for chronic pain patients is limited in quantity and quality (p. 73)

It is clear that there is an intuitive sense from many researchers on the topic, that art holds a powerful tool for working with chronic pain, though the research is scant. In a review of art therapy approaches to chronic pain, Anguleta and Lee (2011) found that "the existing state of art therapy and other art-based modalities for chronic pain treatment appears to be primarily exploratory with a large proportion of anecdotal case studies, case illustrations, and program evaluations" (p. 116). The main contribution of these studies is providing a basis and suggestion for further research, and proposed areas of further inquiry.

Emergent Themes. One of the findings that came from the current research, that requires more inquiry, is the power of art to better explain the experience of living with chronic pain. In a case study explored by Hass-Cohen and Findlay (2009), the clients' artistic response to the therapeutic prompt of "Draw the problem," where one is encouraged to, "tell the story of the

pain: the sensory impact, the medical history, how stress, fear, and emotion may be involved, and insights as to how the problem is perceived" (p. 182). The authors found that the creation of imagery allowed clients suffering with chronic pain to explore their identity outside of their condition. Another area of further inquiry is whether the art making needs to take place in a traditional clinical setting in order for healing to take place. Crawford asks if one of the benefits of sensorial art making as treatment is that it can be self-administered (2014). Additionally, in a study on community art therapy with patients with chronic pain, the authors found that making art in a supportive environment outside of a clinical setting was more conducive to creativity (O'Neill and Moss, 2015).

When the research on the problem of chronic pain and how it is addressed by art therapy is taken together, it becomes clear that further inquiry is needed. Not only is there a call to deepen the understanding of the experience of chronic pain, more insight is needed into how to facilitate the communication of that lived experience. The methods of retrospective recall and liker scales are subject to bias and are reductive. In my search I have found no heuristic exploration of the topic and very little research that has been art informed. This is a gap that needs to be filled because arts-based heuristic inquiry brings forth new ways of knowing and deepens understanding (Kapitan, 2018). It is with this awareness that I asked, does a daily art practice have the potential to describe the lived experience of a person with chronic pain?

Chapter 3. METHODOLOGY

Heuristic Arts-Informed Research

In this culminating research project, I have used an arts-informed heuristic mode of inquiry in order to answer this question, using my own experience with chronic pain. Kapitan (2018), describes the strength of an arts-based research methodology in that it "emphasizes the making of artistic forms and their expressive qualities (images, sound, movement, poetics) in order to call forth, understand, and examine experience that cannot be articulated through conventional means" (p. 212).

Heuristic research comes out of postmodernist, post-colonialist and post-positivist thought that challenges previous notions of social science research. This wave of thinking challenged the assumption of neutrality and the way that research has silenced many marginalized and oppressed groups by making them passive objects of study (Marshall and

Rossman, 2016). This is put well by Luker (2008) when he describes the role bias plays into reflexivity in research.

> Whether we know it or not, we are guided by our taken-for-granted assumptions about what constitutes "good," "rigorous" methods whenever we undertake to do research. How could we not be? The studying of the social order is itself a social process, so how could the process of doing it not be surrounded by assumptions, fetishes, beliefs, and values that are not simply mirror reflections of objective reality, if there is such a thing? … we are fish studying water, and our very fishiness shapes how we think about it. (p.31)

In reaction to modernist modes of inquiry, heuristic research centres findings around the researcher's perspective, using experiential self-knowing (Kapitan, 2018). Since, art plays a crucial role in the way that people make sense of the world, arts-based research and arts informed research is an incredibly powerful tool in informing the contexts that shape human experience. Although his type of research is only recently been recognized in formal academic literature, proponents of arts-informed research view the distinction between arts and sciences as an artificial division between an interdependent process of arts and research. Marshall and Rossman (2016) explain,

> Theorists and practitioners of arts-based and arts- informed research view the distinction between arts and sciences as an artificial and bifurcation of formerly interrelated and intertwined thought processes and activities; viewing the "arts" and "research" as separate processes may, in some ways, harm both fields (p. 20)

In this way, qualitative research can utilize artistic expression in many ways. "Arts-based or arts-informed research means that artistic processes or artistic pieces are incorporated in the development, data collection, and/or analysis of the project, or that they are being used to represent findings" (Marshall & Rossman, 2016 p. 20-21). This process is necessary to answer my research question because this topic concerns the unpacking of meanings, impacts and self-examination.

Rationale for Methodology

While deciding upon the methodology I would use to answer my research question, I was drawn to the idea of using the creation of art as a means of exploring the experience of my illness. Since I had gotten ill, I began to create art less and less. In this way, I felt that I began to trade in my identity as an artist and was overly identifying with the chronic pain I was

experiencing. I was inspired by reading Pat Allen's words about the potential of creation as personal way of working through. She writes, "Our images reveal that we are holographic creatures, living multiple stories. We often get stuck in one view of self and lose the richness of our multiplicity" (1995, p. 10). Allen explains that the creation of art and the reflective process surrounding the resulting images, opens up new possibilities and creates flexibility.

In order to understand the subjective experience of chronic pain, a post-modernist mode of inquiry was necessary. Additionally, I was compelled by the idea of rejecting the modernist divide between art and science in a way that mirrored art therapy's rejection of the cartesian divide between mind and body, in the understanding of chronic pain.

Moustakas Six Steps

Clark Moustakas (1990) describes heuristic inquiry as a relational process, whereby one commits to intensely and fully examining a question until new discoveries are illuminated. In order to partake in a process of self-discovery through a disciplined and engaged process, I have utilized Moustakas' six step process of heuristic inquiry. To fully address my research question, namely the role that art plays in the experience of chronic pain, I have incorporated art making into the data collection, analysis as well as in my findings.

Step one of Moustakas' six steps is initial engagement. It can be described as an "invitation" to the question of research. The second step involves the process of immersion or indwelling, where the researcher extends comprehension by diving deep into a facet of experience. In Moustakas' third and fourth steps of heuristic inquiry, incubation and illumination, the researcher is given a chance for the information that came forth while indwelling to be processed by the unconscious and brought into conscious awareness. This is done by taking a step back from the process of immersion and returning to everyday life. Doing so, allows the knowledge gained to be pushed into a deeper level of the subconscious. New and hidden meaning may come forth in moments of receptiveness but not attempted in an active way (Kapitan, 2018).

Moustakas' fifth step, explication is a deep and concentrated analysis of the discoveries that were made in the earlier steps. This step brings logic to the findings and attempts to discern patterns. The last step is the transformation of the new discoveries made, into a clear and evident form using creative synthesis. Heuristic inquiry allows for the process of investigation to be intuited. By allowing for freedom and curiosity during the process, the project might bring

forward more meaningful and deeply felt discovery. This can be described in arts-based research as intuitive reflexivity. Moreover, the steps that I have previously described are not discrete or linear, in fact they may be cycled through again and again. This practice of revisiting the data enhances the validity of the investigation through exhaustive self-searching (Kapitan, 2018).

Method of Data Collection and Analysis

Data Collection Procedure. As mentioned earlier, one of the main hindrances in research and treatment of chronic pain, is that it relies on retrospective recall (Brunton, 2004). To avoid this, I engaged in a daily art practice over several months. Kapitan (2018), describes this level of engagement as "living in the question" and became my principle mode of data collection.

The daily art practice was restrained by the following procedure. Each morning, I set aside at least fifteen minutes to create a piece of art work, reflecting upon the prompt: "Describe your pain today". This prompt was inspired by an art therapy intervention described in the case study by Hass-Cohen and Findlay (2009). The creative process was followed by a period of fifteen minutes that I used for a journal reflection. Because of the debilitating nature of chronic illness, part of the procedure allowed for a "tap out" option on days in which the sustained attention required for art making, was too arduous due to symptom presentation. On "tap out" days, I would make a single mark, brush stroke or line on a canvas paper, resulting in a simple image to serve as documentation.

Although my initial intention was to adhere to this practice every day for three months, I instead followed this process over a duration of five months with three, 3-4 week breaks. This allowed for a cycling through between immersion, incubation and insight as described by Kapitan (2018). Taken together, the resulting images, the "tap out" images as well as the journal entries, serve as the raw data in this exploration.

Data Analysis Procedure. During my investigation I used the data collected in the form of journal entries, daily art products and "tap out" images to connect related ideas and understand major themes. To do this, I arranged the artwork visually in a way that was determined by themes, similar colours and subject matter. The art was also "interviewed" through the lens of focal points, a Jungian approach to investigating art work in art therapy, proposed by Furth (2002). The interview of the artwork centered around the initial impressions while viewing the images. The use of materials, space, movement, distortion and symbolic

content of the images was considered. Additionally, the images were searched for anomalies, barriers and missing and repeating elements. The artworks were examined individually in this manner and then collectively to scrutinize when and why these elements presented themselves.

The reflective journals were coded using analytic memos, or reflexive free writing. In doing so I was able to use in vivo coding to recognize repeating patterns and major themes present in the journals. In vivo codes use words and phrases present in the data that stand out as significant or summarizing (Saldana, 2011). In accordance with heuristic analytic methods, the analysis from the images and journals were taken together using inductive reasoning to come up with the findings outlined in this paper.

Validity and Reliability

As Kapitan (2018) describes, the main threat to validity in heuristic inquiry is the tendency toward self-immersion or solipsistic reflections on artworks that easily "spiral into labyrinths of personal feelings" (p. 195). In order to combat this, I have employed reflexivity and transparency throughout my investigation, as well as the context for my creation and the findings it provides. Additionally, I have anchored my analysis in Jungian theory by using the external guidelines of focal points described by Furth (2002), to investigate the latent meaning of my artwork. To increase the reliability of my research, the data was triangulated by using the art products of the daily excise, the reflective journaling and the "tap out" images as three separate sources of information.

The time frame for this project was also a concern for validity and reliability. Moustakas (1990) notes,

> The heuristic research process is not one that can be hurried or timed by the clock or calendar. It demands the total presence, honesty, maturity, and integrity of a researcher who not only strongly desires to know and understand but is willing to commit endless hours of sustained immersion and focused concentration on one central question, to risk the opening of wounds and passionate concerns, and to undergo the personal transformation that exists as a possibility in every heuristic journey (p. 14)

Although the quest to take all the time that is needed to fully understand a topic is admirable and ideal, the completion of this research is a requirement for the art therapy master's program. Therefore, pressure to finish within a time constraint is a reality. The endless cycling

through Moustakas six steps is not possible for this reason. It will be important to be open in my analysis about how and why this exploratory process was closed.

Ethical Considerations

While this research is not participatory, there are important ethical implications in research that is centered around a researcher's own lived experience. In this heuristic process, I hold multiple roles. I hold the dual role of both researcher and participant, thus my identity is revealed, and I cannot conceal my vulnerable experiences and my medical history through anonymity. Additionally, since I am engaging in arts informed research, I hold another role as artist. When art is incorporated in research, the aesthetic quality of the work is part of the criteria of assessing the caliber of the research (Marshall and Rossman, 2016). However, it would be unethical to obscure findings to uphold aesthetic quality or out of fear of revealing myself. At the same time, it is important to maintain a level of safety, as I work through sensitive internal experiences. To address these issues, I will explicate the tension that arises between these three roles as I move through Moustakas' six steps.

The use of my own subjective experience in this research is important to me because in my search, I have found very little in terms of academic literature that is written from the perspective of someone who lives with chronic pain. However, it is crucial to note that the experiences I have outlined in my findings are not generalizable to all people who experience chronic pain or illness.

Position of the Researcher

The perception and experience of pain is dependent on many factors such as physiology, psychology, external stressors, gender and cultural attitudes (Angheluta and Lee, 2011). For this reason, as well as to acknowledge my own biases and privilege, I feel it is responsible to be transparent about my own social locators. I am a white cis-gendered, queer woman in my twenties. I was raised in an upper middle-class household in the Mid-Atlantic Region of the United States. Therefore, I grew up in and continue to live within a capitalist social and economic system. English is my first language and the primary language I use to interact with the world. I have always had access to healthcare and have never faced the challenges of food or housing insecurity. Additionally, I was raised within modern-orthodox Jewish tradition and I still consider Jewish culture and spirituality to be an important part of my identity. I now live in Montreal, Quebec where I study at Concordia University, create and perform art and music, and

am training as an art therapist. These identities, experiences and systems of thinking influence my perspective on the world, on pain, on myself and my body.

Chapter 4. DATA COLLECTION AND ANALYSIS

With the knowledge I gained in reviewing the background literature for this topic, I began to embark on a month's long creative practice to address the question that emerged: How might a daily art practice be used as ritual to describe the lived experience of a training art therapist experiencing chronic illness? The process of exploration was not linear or discrete, so I will utilize Moustakas' six steps to guide the reader through the knowledge I gained.

Initial Engagement

The initial invitation to this method of inquiry was the tacit awareness that art holds powerful information, that is not readily available in the verbal or explicit realm. I experienced this myself through the creation and examination of my own artwork. I also witnessed the transformational power of art in my role as a training art therapist. I do not use the word transformational in the sense that the creation of art changes a person, although I certainly believe it can. Instead, transformation is descriptive of the process of using the body to externalize knowledge into a realm that can be witnessed and explored through the creation of art (Gabel & Robb, 2017).

Furthermore, I felt called to this exploration by the immense suffering I was experiencing, while coping with my chronic illness, particularly the pain and discomfort I was experiencing on an almost daily basis. It is now more than four years ago that I began to experience a dull aching pain throughout my joints and an intense and unrelenting fatigue. As time went on, these symptoms worsened and began to be compounded by new symptoms. I dismissed them as a reaction to stress, a temporary state that would resolve itself, or a natural fact of life. This meaning making process has been found to be typical in women. Authors Diane Hoffman and Anita Tarzian (2003) write,

> The types of pain that men and women experience tend to be different. Women more often experience pain that is part of their normal biological processes (e.g.,menstruation and childbirth), in addition to pain that may be a sign of injury or disease. Women may thus learn to attend to mild or moderate pain in order to sort normal biological pain out

from potentially pathological pain, whereas men do not need to go through this sorting process (p.16).

It wasn't until I heard the news of my mother's diagnosis of cancer, a new proliferation of her underlying autoimmune disease, that I began to take my symptoms more seriously.

It was at this time that I began a journey of navigating the medical system to find an answer to my pain, to get a diagnosis and "fix it". When I started out, I did not anticipate how harrowing this process would be. I was referred to many different doctors, waiting weeks sometimes months to meet with them, only for my symptoms to be dismissed as too vague, not aligning with any one diagnosis or completely psychogenic. It took several meetings to even get the proper tests to determine if something was going on biologically, despite my family history of autoimmune disease. I found that I was not alone in this experience. Studies have shown that, "Women who seek help are less likely than men to be taken seriously when they report pain and are less likely to have their pain adequately treated" (Hoffamn & Tarzian, 2003 p. 19).

During this period, I sought a diagnosis as a holy grail. The belief that a diagnosis would hold the key to me returning to my life before I began feeling sick, gave me hope. Additionally, I wanted so desperately for my experience to be validated by a medical explanation. Once I did obtain a diagnosis, I felt that I gained a kind of currency, allowing me to give a concrete explanation to people when illness disrupted my life. However, the conviction that once I held, that a diagnosis, would enable me to rid myself of pain, rang false. The reality of a chronic condition, one that is "treatable but not curable", began to set in (Lelwica, 2017). This realization, that I might never feel "normal" again sent me into a state of grief. This grief manifested as a depression that severely worsened my symptoms.

It is important to say, that as I entered this creative process, I was disillusioned by medicine and mainstream intervention for chronic pain. I felt shame and guilt that I had "given up" on my health. It was difficult to talk about this experience at the time, out of fear of judgement and the burdensome feeling of not being able to find the words or that if I did, they wouldn't be understood. Thus, I had isolated myself in many ways and wondered if art had the capacity to help me communicate this experience.

Immersion

Space. The first step I took on when engaging with a daily art practice, was to secure a place dedicated to art making. I was sharing a home with a partner and therefore did not have a

space that was truly my own, one where I could feel free to make a mess and explore intimate experience in solitude. Instead I rented a space in a shared art studio that was a short walk from my apartment and worked amongst other creatives. This environment provided advantages and challenges to my daily art practice. Being amongst other creatives and witnessing their art was deeply inspiring and facilitated an atmosphere where my imagination was sparked. Taping into creativity came easy. However, the presence of other artists also produced some self-consciousness and inhibition. It took me some time to feel settled enough in the studio to focus on my own work and not compare my art on an aesthetic level.

Once I began to inhabit this space more regularly, I would display my work on the wall next to my desk. As Pat Allen (1995) notes, having my images up in my visual field allowed me to keep the creative process alive and focused me upon entering the space. However, having my creative space outside my home did create a barrier. On days that I felt too ill to leave my house, I had little incentive in creating art. Some of these days became "tap out" days and on others, I would use the limited materials I had available at home and commence my daily art practice at the kitchen table. Figures 1 and 2 are examples of work created under these conditions. I was often less committed to the daily practice on these occasions and had a hard time sustaining my attention for art making beyond the fifteen minutes I had set out for myself.

Figure 1

Figure 2

As I quickly realized, setting aside space for creation also included making emotional space for me to explore the prompt, “Describe your pain today”. In order to get myself into a state of openness, I engaged in a ritual of closing my eyes and conducting a body scan, starting from my toes and working up. This wasn't a meditative process, rather I would ask questions of my body to bring attention to where I was holding tension. On many days, I found this process difficult. I noted in several journal entries that I felt fearful of connecting to my body in this way. I had put in so much effort into disconnecting myself from the pain signals my body was giving me, as a means of survival. Tapping into that level of awareness was unfamiliar. *Would the pain consume me?*

The creation of the art would often be a container for this fear. While my experience of pain felt threatening, I had trust that the images that would result would not be dangerous (Allen, 1995). The process of first going to art before have to put words to my experience, allowed me to circumvent of my defences.

Materials. In approaching the creative process, I leaned heavily upon spontaneity for the source of the images. I very rarely referenced photos or objects, instead, I allowed the material I chose to guide the image. In fact, my choice of material often seemed to be the only conscious choice I made within the art practice. While I had a plethora of materials to choose from in my studio I was often attracted to watercolour, pencil, ink, hard pastel and acrylic paint. I was particularly drawn to watercolour and pencil on days that I was in the most pain. I engaged with these materials on a sensorial level as described by the Expressive Therapies Continuum (Hinz, 2015). This level of engagement was useful in self- soothing and helped overcome some of the numbing and avoidance defences I had accumulated.

I noticed that in response to the prompt, I was hesitant to use media that would leave mess on my hands or body. I avoided chalk pastel and oil paint, materials that I enjoy, but often end up all over my body when I use them. The prospect of so much sensory input from these materials felt overwhelming. Additionally, there was a sense of safety in media that required less clean up because it allowed me to leave the art making as soon as I felt I needed to.

Attention. Perhaps unsurprisingly, my ability to hold sustained attention in art making and journaling was directly impacted by the level of pain I was experiencing. The duration of time I would dedicate to art making would be much longer on days that I had the inner resources to do so. Additionally, on these days, I was able to hold a global awareness as I was creating.

This was not possible on days when pain was more present. This process of engagement and disengagement from the art practice was mirrored in other aspects of my life. In my journals, I would lament the inability to stay within a present moment. I reflected upon the impact that had upon my relationships, on my school work and on my art. The sustained attention required for creating often allowed me to move past the avoidance coping strategies I had developed to live. However, some days this did not feel possible. It was on these days that I allowed myself to tap out. When I next returned to my studio, I would use black acrylic paint to make a mark on canvas paper. This served as documentation of what I began to call my "lost days."

Intention. In her work on *Art is a Way of Knowing*, Allen (1995) notes that in reflexive art making, intention is as important as space and materials. The act of visiting my studio, set a clear intention for me that it was time to create. In my initial approach to the prompt, my intention was to communicate the feeling of pain and convey the emotional impact of living with pain for a sustained period. I believe this approach resulted in important insights. However, it was an overwhelming task to approach and often elicited a reaction where I would identify with my pain. A shift in intention occurred halfway through the creative process as a result of an insight that came from journaling. On this particular day I was driven to write a poem (Appendix A) instead of the stream of consciousness journaling that was typical. This piece of writing created a large shift in my intention towards the daily practice. I began to externalize and anthropomorphize my pain and do my best to listen to it. My artwork began to depict pain as a character and my intention in approaching the work was to try and listen to what pain had to say.

Incubation and Illumination

My initial intent when designing the methodology of this inquiry, was to engage in the daily art practice for three months consecutively and the allow for a period of incubation afterwards. However, heuristic research allows for flexibility and emergent methods to exist (Kapitan, 2018). It became my experience that after some time of intense immersion, there were moments I needed to step back and reflect. This was crucial to my mental health. Also, the cycling between immersion, incubation and illumination, allowed for a deepening in understanding.

During the weeks where I stepped outside of my daily art practice, I was able to give more focus to other aspects of my life. This balance was a necessary condition in order to recognize the zealous over-identification I had with chronic illness. Spending every morning

focusing on this aspect of my experience obscured the other aspects of self. In creating distance from the art process, I was able to view my experience with a broader and less personal lens.

I spent this time reading *Shameful Bodies, Religion and the Culture of Physical Improvement* by Michelle Mary Lelwica (2017). This text provided impactful insight into how I had internalized societal attitudes towards my body, particularly surrounding the idea of physical improvement and the obtainment of bodily perfection. This book was consequential to my research because it helped me come to identify how the connection between pain and punishment took root in my psyche. In doing so, I began to shift my understanding of how I was coping with chronic pain. The feeling of having "given up", was no longer viewed as defeat or capitulation. I was beginning to reframe it as an act of resilience, a radical welcoming of my own experience and a rejection of the judgment I placed upon my illness. I hope to disambiguate this process further as I explain the analysis of my images and journal.

Explication

Over the course of my art practice I produced sixty-one images, sixty journal entries and ten "tap out images". Although I engaged with all of these images with the focal point "interview" I described earlier, I will be highlighting seventeen images that led to significant moments of discovery. These images felt particularly relevant to discuss because of their relation to each other and the themes that were identified in the journal.

In Gregg Furth's (2002), *The Secret World of Drawing,* the author describes the process of discovering an image using "focal points" as a therapeutic and diagnostic tool. He notes that he, "prefers the term 'focal point' to 'guideline' because it is literally *what* our attention focuses on in the picture that gives us an indication as to how to approach the patients psyche" (Furth, 2002 p. 32). I have applied this assessment technique as an analytical method for discovering the latent meaning of the images I created. Furth notes the importance of first approaching an artwork, not to analyze, but instead to touch down on the initial feeling that it conveys. I have grouped several images together based on similarities from the initial impression I noted upon reflecting on them. I will be discussing these groups collectively to investigate the pattern of knowledge they hold.

In the initial images I created early on in the processes of immersion, figures 3 and 4, similar forms of abstraction can be observed. Furth notes that the use of abstraction may be an expression of something that is difficult to understand. He suggests that reproduction of abstract

images may indicate avoidance of problem than needs to be examined. Figure 3 and 4 are just a couple of examples of similar abstractions I created in the first two weeks of immersion. The abstraction began to take a recognizable form in an image I created of a cave (figure 5). It seemed that as I worked through abstraction again and again, I came closer to symbolic representation. This is worth discussing because, as Furth notes, associations made to abstractions can reveal difficult subject matter.

Figure 3

Figure 4

Figure 5

A cave is a common image across mythology and legend. As a symbol, it has been associated with the heart, or a place where the self and ego unite. For Jung, the cave represents the security and impregnability of the unconscious (Biedermann, 1994). The abstraction of this symbol seems to reveal an avoidance of unconscious material. Additionally, the cave resonates with me as a personal symbol. I often refer to my bedroom as a cave, especially at times when I have spent a long time tucked away from the world. It represents a place of safety and containment but also a place to hide. Upon pondering these images, I began to understand them as a reflection the way chronic pain has led me to, withdraw.

In other abstract images, I included text such as in figure 6. Including text often indicates that there is a fear of an image being misunderstood. It displays a lack of trust in the image to convey meaning (Furth, 2002). I remember that while creating this particular image I was dissatisfied with the aesthetic quality. The emptiness within the image seemed to reflect upon my level of energy. Resorting to text seems to be an expression of the impatience I felt towards my lack of stamina and the frustration I had toward the task. In figure 7, another rather empty image is shown. However, the feeling it covers is completely different. The energetic shading within the image may connote anxiety and fixation. In the image the boy holds a faint life force in his hands, but sharp fragments hang over him. I understood this image depicting the threat and unpredictability of pain and the anticipation it created, with the burden of illness always hanging over head.

Figure 6

Figure 7

Surprisingly, there were more than a few instances where an image was unknowingly recreated weeks apart, as was the case with figures 8 and 9. While the two images echo each other in form, however they differ slightly in perspective. Also, the departures in colour and symbolic content are compelling to ponder. Both images feature a similar red tone, one that elicits the quality of irritation or inflammation. However, in the first image, the red is mostly covered up by the muted tones of the chaotic pile of chairs and the shadowed walls. In the second image, the red is present and stable, taking the shape of an unmovable boulder, the shadow underlines the object adding a sense of being ungrounded (Furth, 2002)

Figure 8

Figure 9

The repetition phenomenon is exhibited again in figures 10 and 11, however these two images, when taken together almost read as a narrative. In the first image, the two characters are engaged in a struggle with their gaze meeting one another. The next image shows one of these characters holding the others head and the gaze of the character is now directed towards the

viewer as if communicating. Both images display distortion and fragmentation, however more distance exists in the second image. I came to understand this shift to have taken place around the time that my journals started reflecting the externalization of pain rather that the identifying that was occurring previously. This process allowed for an intellectualization of illness where I began to break down some of the societal attitudes I had internalized around pain.

Figure 10

Figure 11

As I began my intention to try and listen to my pain, I anthropomorphized the pain and depicted it as a series of characters (figures 12, 13 and 14).

Figure 12

Figure 13

Figure 14

As I reflected on this period of making, I was stuck by the oddness of these faces and the fact that many of them had tongues protruding out of their mouths. A tongue may come to symbolize a serpent or a divine voice. However, in Christian and Oriental Art, a protruding tongue can be a sign of a demon (Biedermann, 1994). Upon learning this, the image of the serpent tempting eve in the Garden of Eden was evoked in me and the passage from genesis "To the woman he said, I will make your pains in childbearing very severe; with painful labor you will give birth to children. Your desire will be for your husband, and he will rule over you. (Genesis 3:16)" rang inside me.

In this foundational story I learned at the age of five, Eve accepted the apple from the tree of knowledge and god punishes her by inflicting pain during childbirth. It came to me so clearly that from an early age I was taught that pain was a punishment for wrong doing. In dissecting this, I was able to identify this point as the source of shame and guilt I was facing. As I understood this, I was able to let go of some of that burden.

In the last phase of art making I began to depict bodies in their entirety that came to represent images of self rather than pain. Many of these images featured extensions (figures 15 and 16). Furth (2002) describes extensions as a depiction of something held in the hand, an addition that expand the control of the figure towards their environment. He notes that the extension could imply someone seeing themselves as having control or wishing for control. In figure 15, it seems as though the extension of the right hand is providing a blanket of protection overhead. In figure 16, the extension is a microphone that amplifies the voice of the figure. In both these areas, I seemed to have gained some mastery and control while engaging in the daily art exploration.

I also want to bring attention the mask like appearance on both faces in these images. This called forth a theme that was discussed in the reflective journals. The incongruence of being unwell but appearing healthy created a sense of invisibility. This experience has forced me to remind people of my unseen needs and boundaries an experience that can be alienating and isolating. This sense of alienation began as an alienation from myself, an avoidance of my own experience and extended into an alienation from others.

Figure 15

Figure 16

Figure 17

The final image I created as part of the daily art making practice is shown in figure 17. I decided to create a self-portrait in naturalistic pose with the frame of the door encapsulating me. Furth discusses that enclosure like this could suggest the putting up of boundaries. It felt appropriate to end the exploration on this note as I was closing a period of self-disclosure and reclaiming privacy. I believe this last image reflects the wholeness I began to discover through opening myself up to the knowledge that my body head.

Creative Synthesis

"Tap Out" Images. One of the most surprising outcomes that came from this inquiry was the importance of the single mark images made to document the days in which I could not participate in the daily art practice. My initial intention in doing so was to hold myself accountable to the process of immersion on days that I was unwell. However, as I collected the "tap out" images (figure 18), I began to view them as a memorial for days I lost to illness. They did not appear static as I had predicted them to be, considering they represented a pause, stillness. Instead, they had movement, direction and energy. They reminded me that even on days when I didn't have the energy to leave my bed, cook for myself, check my phone or engage in my life, I was still existing. The images made meaning from the grief I had been experiencing. By memorializing these losses through images, I was able mourn the lost days and let go of the guilt and shame that surrounded them.

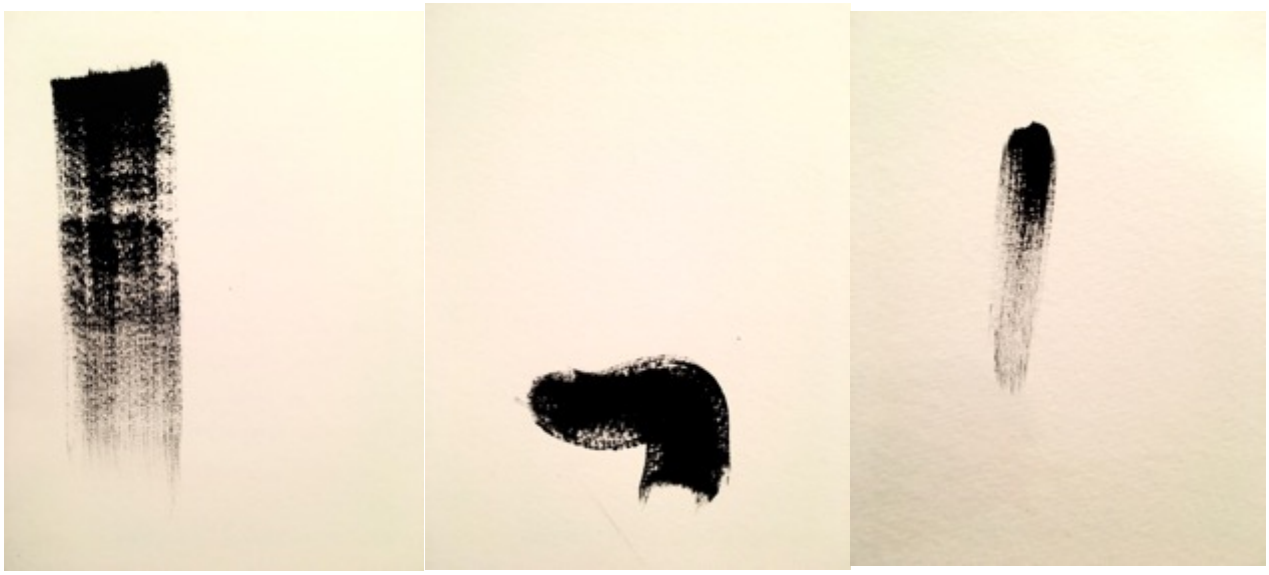

Figure 18

Animation. Out of reverence for these images, I decided to bring them to life through a short stop motion animation (Appendix B). While doing so, I enlisted the help of a dear friend to contribute the score. Collaborating in this way, offered a connection and sharing of experience, an appropriate salve to the isolation that produced these images. The result of the animation is a shrinking and growing, undulating line. In many ways it represents the transformational quality of this art exploration.

Chapter 5. DISCUSSION

Limitations

This exploration allowed for a deeper understanding of the knowledge that is held in one's body. I do believe however, that a major topic was left out of the discussion. Trauma plays an enormous role in chronic pain and the memory of trauma often lives inside the body (Gray, 2001). I avoided the topic of trauma in order to set a healthy boundary around my own level of disclosure. Additionally, the connection between trauma and pain is so deep, I believe it fell outside the scope of this narrow research project. However, I believe that a similar research design could facilitate a deeper understanding of the relationship between pain and trauma.

Additionally, this research might have benefitted if the art was being made in the context of the therapeutic relationship. My methodology relied heavily on my own capacity for self-reflexivity and perhaps would have looked different had I been held to account by an art therapist. Also, the transformational quality of embodied art making relies on being witness (Gabel & Robb, 2017). In a way, I served as my own witness by revisit the images I created and of course, the audience of this research serve as my witness as well.

Future Directions

That being said, the creation of art outside of the context of therapy provided some new perspectives. As described by O'Neill and Moss (2015), creativity may be more easily accessed for some outside of a clinical environment. This has interesting implications on art therapy with individual with chronic pain, for whom their illness might be a barrier to seeking regular therapy outside of their home. This is relevant now, more than ever, considering the expansion of tele-therapy in the context of a pandemic.

Although my intention in pursuing this line of research was to contribute to a base of knowledge that would help in the advancement of treatment practices, I have found through this

process a greater need for inclusivity and normalization of chronic pain and discomfort in our understanding of human experience. This is not to say that the field of art therapy should not look for ways to alleviate suffering in this regard. However, it is crucial to recognize the importance of sitting with pain as part of the human condition, rather than perpetually seeking to fix it. The process of creating and reflecting upon the art made during this period undoubtedly helped me form a voice of self-advocacy and brought meaning to this experience.

Conclusion

As I reflect upon this research, I feel immense gratitude for the opportunity it provided me to make sense of my own experience. I entered this process isolated and fearful that I would not be understood. I asked the question; how might a daily art practice describe the lived experience of a training art therapist experiencing chronic pain? By answering this question, I was able to tap into knowledge, previously inaccessible. In doing so, I was able to understand pain as a shared human experience for which one can relate rather than a condition of my existence.

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Appendix A

Thoughts on Pain

Pain is part of the human experience, it is not to be pacified or overcome

Pain is part of living—not the only part because living without joy or gratitude or adventure would be no life at all

but pain belongs there too

And when pain comes, greet it like an old friend, listen to what pain has to say and take in the meaning deeply

Because pain does not doddle without purpose. He walks dutifully to bring us a message.

To feel pain is understand others

To feel pain is to sense the world

To feel pain is to remember its absence

To feel pain is to be reminded to seek connection, to be gentle, to handle one's self with tenderness

To feel pain is also to feel love

Appendix B

Mourning the Lost Days

(Animation)