An investigation of how chronic pain has affected individuals' personally significant activities

by

John W. Murray

MDiv., Faith Evangelical College and Seminary, 2010

B.A., Pacific Lutheran University, 2001

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF

THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

in

THE FACULTY OF GRADUATE AND POSTDOCTORAL STUDIES

(Counselling Psychology)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

July 2018

The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, a thesis/dissertation entitled:

An investigation of how chronic pain has affected individuals' personally significant activities

submitted by   John W. Murray   in partial fulfillment of the requirements for

the degree of   Master of Arts

in   Counselling Psychology

Examining Committee:

F. Ishu Ishiyama, Counselling Psychology

Supervisor

Norman Amundson, Counselling Psychology

Supervisory Committee Member

Joseph M. Lucyshyn, Special Education

Supervisory Committee Member

Abstract

The emergence of chronic pain is often a disruptive event across multiple dimensions of individuals' lives. Several models have been suggested in efforts to identify mediating factors between pain and disability, as well as helpful psychological interventions. Much of this recent research has examined the efficacy of acceptance and commitment therapy (ACT).

The current study used inductive thematic analysis to examine participant narratives of the effects of chronic pain on the personally significant activities of individuals living with chronic pain. Eight participants (5 female, 3 male) were interviewed using a combination of autobiographical lifelines and qualitative narrative interviews.

Results of the analysis showed two main themes: Activity Loss and Interruption, and Activity Gain and Maintenance. There were 18 sub-themes gathered under Activity Loss and Interruption, and 17 sub-themes gathered under Activity Gain and Maintenance. These themes exhibited that participants experienced the effects of chronic pain across somatic, psychological, interpersonal, behavioural, and environmental domains. In turn, these effects either contributed directly or indirectly to the loss or interruption of their personally significant activities, or the participants expressed adaptive responses or facilitating environmental factors that helped them gain activities or maintain their current activity levels.

The findings of this study subsumed the constructs of Psychological Flexibility (PF) and Psychological Inflexibility, pain catastrophizing, and self-efficacy, all of which were present in the lives of the participants in the context of living with chronic pain and experiencing its effects on their personally significant activities. Additionally, the findings showed how participants

were able to engage behaviourally with activities even while expressing statements reflective of Psychological Inflexibility. Finally, the findings also highlighted the importance of facilitating and inhibiting environmental factors, which are not currently accounted for in the ACT model of treatment for chronic pain. The clinical and research implication of these findings are discussed.

Lay Summary

Living with chronic pain is an experience that affects multiple dimensions of a person's life. One important dimension is in that person's ability to be active in their own lives. While literature shows the effectiveness of therapy for individuals with chronic pain, much of it does not explore how individuals with chronic pain experience the effects of chronic pain in their own lives. The present study interviewed eight individuals to explore their experience with chronic pain and how it affected their personally significant activities. Their experiences were gathered in two themes: Activity Loss and Interruption, which contains sub-themes related to the way pain directly or indirectly caused loss of activity in their lives; Activity Gain and Maintenance, which contains sub-themes related to the way individuals and their activities adapted or were helped by external factors. These results add narrative voice to experiences that therapists may work with.

Preface

This thesis is the original work of the author, John Murray, and was supervised by Dr. F. I. Ishiyama. All data and subsequent analysis was conducted by the author and approved by the University of British Columbia's Behavioural Research Ethics Board, certificate number H17-01601, titled "An investigation of how chronic pain has affected individuals' personally significant activities." The research was supported in part by funding through the University of British Columbia Faculty of Education and Counselling Psychology and Special Education Graduate Student Research Grant.

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List of Abbreviations

ACT – Acceptance and Commitment Therapy

BDI – the Beck Depression Inventory

BPI – the Brief Pain Inventory Short Form Interference subscale

CAQDAS – Computer Assisted Qualitative Data Analysis Software

CBT – Cognitive Behavioural Therapy

CPAQ – the Chronic Pain Acceptance Questionnaire

CSQ – the Coping Strategies Questionnaire

EF – Environmental Factors

FABQ – the Fear-Avoidance Beliefs Questionnaire

ICF – the International Classification of Functioning, Disability, and Health

MBCBT – Mindfulness-Based Cognitive Behavioural Therapy

MPI – the West Haven-Yale Multidimensional Pain Inventory

MS – Multiple Sclerosis

NEO-PI-R – NEO-Personality Inventory-Revised

PASS – the Pain Anxiety Symptoms Scale

PBPI – the Pain Beliefs and Perceptions Inventory

PBQ – the Pain Behaviour Questionnaire

PDQ – the Physical Disability Questionnaire

PF – Psychological Flexibility

PLC – the Pain Locus of Control Questionnaire

PSEQ – the Pain Self-Efficacy Questionnaire

SF-12 – the Medical Outcomes Study 12-item Short Form Health Survey

SIP – the Sickness Impact Profile

SOPA – the Survey of Pain Attitudes

RA – Rheumatoid Arthritis

UBC – The University of British Columbia

WHO – World Health Organization

Glossary

Acute Pain: Pain with a duration lasting less than three months.

Chronic Pain: Pain that lasts, or recurs, over a duration lasting longer than three months and in excess of expected healing time if resulting from surgery or injury.

Chronicity: The permanence of a disease or condition.

Disease: The pathophysiology of a given condition.

Environmental Factors: As defined by the ICF, these are contextual factors in a person's life that can either be facilitators or barriers to being active. These can include laws, transportation options, building access, etc.

Illness: The lived, individual experience of, perception of, and response to symptoms and suffering of each person.

Acknowledgements

I wish to thank certain persons who have been instrumental in helping me put together this proposal. I thank Dr. F. Ishu Ishiyama, who has encouraged me and helped me grow as a thinker and a researcher, to help me develop my project and to ensure that it was accurate and reflective of the individuals who shared their stories with me. I also thank him for challenging me and supporting me under his tutelage.

I thank Dr. Masahiro Minami for his wisdom, guidance, and encouragement. I have gained much through the many impromptu discussions in which he has graciously participated. I thank Dr. Norm Amundson for his guidance and for modelling creativity in approaching the helping profession of counselling. I also thank Dr. Joe Lucyshyn, who offered his wisdom and support in the development and refinement of this project.

I want to thank my fellow students at UBC, who have continuously encouraged and supported me as I have worked my way through this process. I wish to thank my many professors as well who have helped guide me and opened my mind to the many different possibilities I hope to explore, as well as the many unknown possibilities I have yet to see or encounter. I wish to thank my colleagues, who have shared their wisdom and their time with me.

I thank my parents for their love, help, and support as I struggled through my own trials of disability and suffering due to Rheumatoid Arthritis.

I thank the participants who were part of this study. They trusted me with their stories of living with chronic pain and honoured me with their honesty and openness. I am hopeful that this project repays that trust in some small part.

Finally, I thank my wife, Samantha, who accepted what I had to offer and opened my mind up to so much more, and who daily strengthens me and supports me. This current project would not be possible without her.

To My Wife

Chapter 1: Introduction

1.1 Introduction

I have rheumatoid arthritis. I still vividly remember the day when this diagnosis was made, when I could put a label to the chronic pain that had plagued me without identified source at that time in my life. It changed in my mind what I experienced from pain that could go away to pain that may never go away. I felt freed and defeated at the same time. As time marched forward, I found that I had to find new ways to approach my life that respected the effects rheumatoid arthritis (RA) was having and could have on my body. It could be random or predictable, acute or constant. The ways that RA and the resulting chronic pain impacted my life, activity levels, and activity choices, was profound and far-reaching. Yet my story also shows how, while I had chronic pain, I was not defining it as chronic pain without a firm diagnosis.

Chronic pain is a multi-etiological, far-reaching condition that affects multiple dimensions in a person's life (Falvo, 2014). Disruptions can be experienced in one's self-identify, the amount and types of previously engaged activities and behaviours, one's self-efficacy, the type and amount of employment one engages in, as well as the development of psychological comorbidities such as depression and anxiety (Beatty & Joffe, 2006; Charmaz, 1983; Charmaz, 1991; Dahan, Velzen, & Niesters, 2014; Falvo, 2014; Larsen, Engel, & Prentice, 2014; Wells, 1998; Yalcin & Barrot, 2014; Zautra et al., 2008). It is also the largest self-reported cause of disability amongst surveyed Canadians, affecting some 2,664,240 persons, or 9.7% of (Social and Aboriginal Statistics Division, 2013).

Acceptance and commitment therapy (ACT) is increasingly being shown as an effective intervention for persons with chronic pain (Dahl, Wilson, & Nilsson, 2004; Gutiérrez, Luciano,

Rodríguez, & Fink, 2004; McCracken & Eccleston, 2003; Veehof, Oskam, Schreurs, & Bohlmeijer, 2011; Vowles, McCracken, & O'Brien, 2011; Scott, Hann, & McCracken, 2016; Wetherall et al., 2011; Zautra et al., 2008). The aim of ACT is to help an individual's psychological flexibility (PF), or their ability to be in contact with their present-moment thoughts and feelings without judgement as a way to move forward toward their goals through commitment to values-based action (Flaxman, Blackledge, & Bond, 2010; Hayes, Levin, Plumb-Vilardaga, Villatte, & Pistorello, 2013; Hayes, Luoma, Bond, Masuda, & Lillis, 2006; McCracken & Morley, 2014). However, limited research exists that identifies how people experience chronic pain with relation to their activity level and activity choices. Without paying attention to what a counsellor is implicitly asking a client to work on being active through and accepting of in their lives with chronic pain, ACT interventions may be used without compassionate insight.

1.2   Statement of Problem

While extensive research exists into the efficacy of various psychological interventions such as cognitive behavioural therapy (CBT) (Boschen et al., 2016; Kaiser, Mooreville, & Kannan, 2015; Pike, Hearn, & Williams, 2016), ACT (Hann & McCracken, 2014; Hughes, Clark, Colclough, Dale, & McMillan, 2017; Vowles, Sowden, & Ashworth, 2014), and mindfulness-based cognitive therapy (MBCT) (Bawa et al., 2015; Chiesa & Serretti, 2011; Hilton et al., 2017), less research exists into the effect people express as having experienced of chronic pain on their activity level and activity choices. Persons with chronic pain face a number of physical and psychological challenges in their daily lives. Comorbidities with psychological disorders such as depression and anxiety are common (Dahan et al., 2014; Yalcin & Barrot, 2014; Zautra et al., 2008). They also come to face the many physical challenges of having

limited activity as well as often developing avoidance behaviors as protective measures against making their pain worse (Asmundson, Norton, & Vlaeyen, 2004; de Moraes Vieira, de Góes Salvetti, Damiani, & de Mattos Pimenta, 2014). A decrease in self-efficacy and an increase in fear-avoidance behaviors contribute to a withdrawal from both social and work-life activities, can often itself contribute to a worsening of experienced pain levels (Kroska, 2016), and can lead to ever decreasing levels of social interaction (Dueñas, Ojeda, Salazar, Mico, & Failde, 2016).

At the same time there is a very real economic impact from having persons out of work or at a decreased level of work. Statistics show that for the income brackets of $10,000 to $14,999, $15,000 to $19,999, and $20,000 to $29,999, persons with disabilities have a significantly higher percentage of their population represented (difference > 5) when compared with persons without disabilities, while their representation shrinks by comparison in income brackets about $40,000 (Statistics Canada, 2012). Younger persons with disability who obtain college educations may have similar likelihood as their compatriots without disability in finding work, but they are less likely to find employment at the management level and beyond. For those in the same age group with only a secondary-level education, or less, the opportunity to find employment is quite decreased. Persons with disability are also overrepresented in the number of persons who are not taking part in the workforce, even among those of working age (15-64-years old; Turcotte, 2014).

1.3   Significance of Study

Chronic pain is a condition that can cause people to lose previously taken-for-granted capabilities, life styles, and employment. What was an invested part of one's identity as a worker and contributor (both at the familial and social levels) can become disrupted and damaged. Further damage may result from having to choose completely new forms of

employment for which one holds no skill or education. Yet chronic pain need not be a prohibitive condition. The work currently showing the effectiveness of acceptance-based therapies shows promise in helping persons with chronic pain learn to live productively without trying to alter the presence or experience of chronic pain.

1.4   Research Question

This project investigated the experience of persons with chronic pain to understand how said persons expressed the effect that their chronic pain has had on their personally significant activities. The research will be conducted using inductive thematic analysis to address the following question: How does chronic pain affect the personally significant activities of those individuals with chronic pain?

This question will be addressed using semi-structured interviews that are guided by a narrative lifeline (see Chapter 3: Method). A guiding statement will be used to help facilitate the completion of the lifeline. Following this, open-ended statements and questions will be used to investigate the entire lifeline drawn by the participant, focusing on smaller portions.

1.5   Rationale

For helping professionals, measures such as the Chronic Pain Acceptance Questionnaire and models for mediating factors between pain and disability, or pain and mood disorders such as depression, provide quick and accessible insight into potential mitigating or blocking factors for persons with chronic pain from more fully engaging with the world around them. However, these measures and models do not include individual perspectives on the *why* that exists for each individual with chronic pain. Fear and subsequent avoidant behaviour is not understood more completely until the individual can speak to what was lost or gained, what is feared, and what is desired. Accessing the inner world, the lived context, of persons with chronic pain provides a

larger picture of the experience of chronic pain. Understanding the inner world of the

participants involved and seeing the ways in which they experience these blocks, thoughts,

emotions, etc., can only be provided by the participants themselves. Approaching this from a

Social Constructivist epistemological perspective sees the participants in constant

communication with the myriad social, political, and economic forces around them as they

construct their own opinions of what they can and cannot do, how much or how little they can

do, and what they can and cannot accomplish (Charmaz, 1983; Charmaz, 1991; Charmaz, 2014).

1.6   Literature Review

In Chapter 2 below, I will examine the literature with respect to a number of different

topics. I will begin by examining the definitions around chronic disease and illness, with further

argument for why this study focuses on persons with chronic pain. I will then briefly discuss the

definitions of disability before exploring some of the psychological constructs identified as part

of the process of experiencing disability for individuals with chronic pain. I will also explore the

literature with respect to ACT, PF, and its intervention model for chronic pain.

1.7   Method

In Chapter 3 I will provide a robust discussion of my methodological approach to this

project. I will first define my epistemological and theoretical viewpoint. I will then describe in

detail the participants I recruited, the setting I used, and how the interviews were conducted. I

will then describe the data produced through these interviews and the ways I analysed the data.

1.8   Results

In Chapter 4 I will look at the results that were constructed from the analysis of the data

produced by the interviews. I will look at the themes and sub-themes that were found present

through the exhaustive and iterative data analysis process. Participant quotes will be included to

provide support for these themes. The themes will be those found as relating to the participant's experiences of the effects of chronic pain on their personally significant activities. Attention will be given at the end of the Chapter 4 to two themes that arose not related to chronic pain's effects on participants' activities but still warranted exploration.

1.9 Discussion

In Chapter 5 I discussed the themes described in chapter 4 as they relate to the literature. I will also explore any gaps identified by the findings of the current study. I will then discuss the clinical and research implications of the findings, the strengths and limitations of this study, and then end with my conclusion.

1.10 Personal Reflection

In Chapter 6 I will reflect on this project, its impact on me, my possible impact on clients, and other thoughts that felt relevant to this study. I will explore ways I felt the study could have improved upon itself. I will also discuss insights into how I think parts of the study could be used within the counselling setting as a tool within the context of working with clients with chronic pain.

Chapter 2: Literature Review

2.1 Defining Illness and Disease

One of the many ways that a person can come to experience chronic pain is through the development of a chronic illness. I use the phrase *chronic illness* here purposefully. If one does a search using google to see what organizations such as the World Health Organization or the Public Health Agency of Canada define as chronic disease, the returned websites point primarily to conditions such as chronic heart disease, chronic respiratory diseases such as asthma and chronic obstructive pulmonary disease (COPD), diabetes, stroke, and cancer. Changing the search term to "chronic illness" still sees these same websites as the primary results. These chronic conditions certainly have not only high mortality rates across the world but also have large impacts on the daily lives of the individuals living with them and their families. They are however not the only source of chronic conditions that affect people. Falvo (2014) has 29 chapters dedicated to different kinds of chronic conditions which, as well as the above, include Rheumatoid Arthritis, Multiple Sclerosis (MS), Traumatic Spinal Cord Injury, Traumatic Brain Injury (TBI), and Human Immunodeficiency Virus (HIV) Infection, among others.

Regardless of similarity in returned searches, the phrases "chronic disease" and "chronic illness" should be seen with quite separate operational definitions. Larsen et al. (2014) write that disease "refers to the pathophysiology of the condition, such as an alteration in structure and function. Illness, on the other hand, is the human experience of symptoms and suffering, and refers to how the disease is perceived, lived with, and responded to by individuals, their families, and their healthcare providers" (p. 5). This project focuses on the impact on the individual, the "human experience of symptoms and suffering," which is more appropriately the domain of the

word "illness." When necessary, in order to describe disease pathology, "chronic disease" will be used. When appropriate, the phrase "chronic illness" will be chosen.

2.2 Narrowing to Chronic Pain, Defining Chronic Pain

However, for the purposes of this study, the focus itself will narrow even further from chronic illness to chronic pain. There are many different conditions that may cause chronic pain (Apkarian, Baliki, & Geha, 2009). These may be resultant from diagnosable medical conditions arising biologically (e.g., Rheumatoid Arthritis, Multiple Sclerosis, Fibromyalgia Syndrome, Shingles), from injury (e.g., traumatic spinal cord injury, low back injury), or chronic widespread pain with unknown cause. This variability of the cause of pain is not itself a limiting factor for this study, nor does it make the study too broad. As with chronic illness and disability, the individual experience of chronic pain is rarely the same, even when illness or cause of pain is from the same condition (Charmaz, 1983; Charmaz, 1991; Falvo, 2014).

The following distinction is necessary. *Acute* conditions and diseases are usually typified by "sudden onset, with signs and symptoms related to the disease process itself, [which] end in a relatively short time" (Larsen et al., 2014, p. 6). *Chronic* conditions on the other hand can have periods of vacillating symptomatology, rarely fully resolve, often include periods of relapse and remission, can include visible as well as invisible effects on the individual, and rarely display a simple progression from a singular cause to a conclusion of cure (Beatty, 2012; Charmaz, 1991; Falvo, 2014; Larsen, Engel, & Prentice, 2014; Wells, 1998). *Chronicity* refers not just to the above components of the experience of a chronic condition, but also includes the extent to which the chronic condition affects the individual, which may or may not include disability, as well as the long-term effects resulting from either the treatment for the condition

itself (e.g., chemotherapy and radiation for cancer) or from the extension of life with what once were terminal conditions (such as HIV) (Dowrick, Dixon-Woods, Holman, & Weinman, 2005).

Noteworthy is that this also allows the viewpoint that not all experiences of chronic illness or chronic pain lead to disability (Leeuw et al., 2006). Pain intensity, pain catastrophizing, and fear-avoidance of pain have all been shown to mediate the relationship between chronic pain and disability. Indeed, since not all illness experiences, perceptions, and responses are the same (Larsen & Kramer-Kile, 2014; Larsen, Hummer, & Osuji, 2014), it should follow that not all chronic illnesses will lead to the same level of disability (Larsen et al., 2014). It is important that responses to chronic illness explore client perceptions, supports, and current strengths on which the client can draw.

2.3   The Individual Impact of Chronic Pain

With the understanding that the impact of chronic illness on the individual is quite varied (Beatty & Joffe, 2006; Charmaz, 1983; Charmaz, 1991; Larsen et al., 2014; Falvo, 2014; Wells, 1998), attention can narrow to the many ways that the individual can be impacted by chronic pain. Disruption of one's self identity, limitation of previously engaged in behaviors, avoidance of previously performed activities and behaviors, loss of self-efficacy, loss of employment, development of psychological distress (e.g., depression or anxiety), and perceptions and beliefs about the disease are all potential effects of chronic pain. Additionally, environmental barriers may also pose a block to the ability of those with chronic pain to gain activity or remain active, including accessibility and the lack of understanding from others (WHO, 2013).

How these aspects of an individual's life are affected, and how addressing them can help not only with the re-engagement of certain behaviors but also the development of a healthy (even if altered) sense of self, has been the source of much research. Some concepts that will be

further highlighted here include self-efficacy, fear-avoidance beliefs, development of co-morbid psychological distress, and social beliefs and barriers.

2.3.1   Self-Efficacy

One of the concepts that is showing great promise in recent research is the inclusion of self-efficacy among the mechanisms addressed to help individuals re-engage with the world around them.   Self-efficacy is the belief one has, before beginning a task, that she or he will be able to successfully perform that task (Bandura, 1977).   This is different from outcome expectations, which Bandura described as the belief that one's performance of a task would produce certain results.   The more positive one's outcome expectations, the more likely one was to believe that engaging in an activity would produce the desired outcome.   The stronger one's self-efficacy beliefs, the more likely one would engage in that activity to begin with.   Self-efficacy has been shown to play a role in career change, career development, job seeking, and career maintenance (Betz & Luzzo, 1996).   Bandura also argued that self-efficacy has an effect on health-related outcomes as well.   Beatty (2012) showed that chronic illness difficulties, due either to illness symptomatology or reaction of others to one's illness, can lead to a decrease in the self-efficacy of persons with chronic conditions.

Self-efficacy has been shown to mediate the relationship between pain intensity and pain-related disability in persons with chronic pain.   In their study, Arnstein, Caudill, Mandle, Norris, and Beasley (1999) examined data obtained from a group of chronic pain patients (N=126) on four different assessments: Pain Intensity on a visual analog scale (VAS), chronic pain self-efficacy scale, pain disability index, and the center for epidemiological study-depression scale (CES-D).   Results obtained showed that self-efficacy was a mediator of the pain intensity, disability relationship, and "accounted for 44% of the explained variance in disability" (p. 486).

These results suggest that helping persons with pain-related disability increase their self-efficacy could lead to a decrease in their perceived levels of disability.

Similarly, Asghari and Nicholas (2001) studied 183 chronic pain patients to explore any potential links between pain self-efficacy beliefs and pain behaviour.   Pain behaviour includes "limping, avoidance of certain activities, complaining about pain, resting and taking analgesic medication" (pp. 85-86).   The measures used were a numerical rating scale (NRS) of 0-10 for pain intensity, the NEO-Personality Inventory-Revised (NEO-PI-R) for personality, three self-report measures for pain-related beliefs, the pain self-efficacy questionnaire (PSEQ), the pain beliefs and perceptions inventory (PBPI), the pain locus of control questionnaire (PLC), the catastrophizing subscale of the coping strategies questionnaire (CSQ), a modified version of the physical disability questionnaire (PDQ) (the term 'back' in the questionnaire was changed to 'pain'), the revised version of the Beck depression inventory (BDI), and the pain behaviour questionnaire (PBQ).   Measurements using these tools were taken on four occasions, with 145 participants completing all measurements across all occasions.   The results from their study showed that pain self-efficacy beliefs were "highly, but negatively, correlated with total pain behaviour, avoidance and complaint behaviours across all occasions" (p. 91).   This suggests that being able to help increase a person-with-chronic-pain's pain self-efficacy beliefs will lead to a decrease in pain behaviour, avoidance behaviour, and complaint behaviours.

Recent efforts have built on research regarding self-efficacy, chronic pain, and disability in order to develop tools to help identify self-efficacy beliefs of patients with chronic pain in different measures (Anderson, Dowds, Pelletz, Edwards, & Peeters-Asdourian, 1995) as well as to develop measures that can gauge the job-seeking self-efficacy belief levels of unemployed persons with chronic pain (Barlow, Wright, & Cullen, 2002; Hergenrather, Turner, Rhodes, &

Barlow, 2008; Strauser & Berven, 2006).   These efforts have built upon prior work that showed

the predictive value of self-efficacy with job-seeking behaviours (Betz & Hacket, 1986).

2.3.2   Fear-avoidance beliefs

It is not surprising, given the strength with which self-efficacy beliefs are tied into

healthy and adaptive behaviors in persons with chronic pain, that avoidance of activities due to

fear of pain has been shown to be one of the more maladaptive behavior patterns (Falvo, 2014;

Iles, Davidson, & Taylor, 2008; McCracken & Keogh, 2009).   One of the more researched

models of chronic pain is the fear-avoidance model, which was first suggested by Lethem, Slade,

Troup, and Bentley (1983) to explain development of disabling behaviours with chronic low

back pain.   Two primary responses to fear of pain were suggested: "confrontation" and

"avoidance." A confrontation response "typically leads to a reduction (or total abolition) of fear

with time," while an avoidant response "usually leads to maintenance and exacerbation of fear,

the end stage being a full-blown phobic state" (p. 404).   Vlaeyen and Linton (2000) expanded

this model to explain how fear of pain leads to physical disuse, distress, and pain-related

disability.

In the fear-avoidance model of pain behaviour, fear and anxiety are seen to interact in

ways that lead to the development or worsening of chronic pain problems and disability.   As

Leeuw et al. (2006) define the two concepts, fear is "the emotional reaction to a specific,

identifiable and immediate threat" (p. 77), while anxiety is "a future-oriented affective state and

the source of threat is more elusive without a clear focus" (p. 78; see also Carleton &

Asmundson, 2009).   Anxiety also can lead to a state of hypervigilance, wherein the person

attends to threat-related stimuli while ignoring other stimuli.   Thus, one's attention can become

fixated on potential causes of (worse) pain, leading to avoidance of those potential threats

altogether.   Asmundson et al. (2004) suggest that the link between fear and avoidance is not correct because pain is always present and therefore cannot technically be avoided in the present. Instead, they described an anxiety (anticipation) pathway and a fear (presence) pathway.

Whatever the distinction in definition, studies show that fear-avoidance beliefs can lead to reduced activity and disability (e.g., Crombez, Vlaeyen, Heuts, & Lysens, 1999).   These beliefs are oftentimes affected by pain severity (Gay, Horn, Bishop, Robinson, & Bialosky, 2015), pain catastrophizing and the attention one gives to the presence of pain (Leeuw et al., 2006), rest advice (Fujii, Matsudaira, & Oka, 2013), and even gender, income level, depression, and level of disability (de Moraes Vieira et al., 2014; Lööf, 2014).   This leads to avoidant behaviours, which are efforts by the individual to delay any undesirable actions or situations (Asmundson et al, Norton, & Norton, 1999).

Ayre and Tyson (2001) conducted a study that found a large degree of overlap between two assessment tools used to measure pain self-efficacy beliefs and fear-avoidance beliefs, the PSEQ and the Fear Avoidance Beliefs questionnaire (FABQ).   The study participants (n=121) completed both assessment tools, and a multiple regression analysis was performed to see if these two questionnaires were measuring the same construct.   With disability scores as the criterion, pain, the PSEQ, and then the FABQ were all entered into the equation.   The results showed that pain accounted for the highest variability in disability scores (31%), followed by pain self-efficacy (24%) and then fear avoidance beliefs (3%).   The authors note that this is not surprising given a high amount of overlap in the development of the PSEQ and the FABQ.   That there is overlap in the constructs but not necessarily the everyday usage of the terms by persons with chronic pain makes it more important to understand the internal world of the individuals who exhibit behaviours consistent with these constructs.

Kroska (2016) conducted a meta-analysis of the available literature to examine the relationship between fear-avoidance and pain intensity. The author examined 18 studies produced between 1989 and 2015. The results from this study indicated that "fear-avoidance and pain intensity are positively associated, and this link is of small-to-moderate magnitude" (p. 50). Additionally, the meta-analysis showed that this positive association worked in both directions: i.e., persons with higher fear-avoidance beliefs reported higher pain intensity, and persons with higher pain intensity reported higher fear-avoidance beliefs.

2.3.3 Pain Catastrophizing

Pain catastrophizing is an important part of the Fear-Avoidance model discussed above (Neblett, 207), as well as an independent construct in the study of how people respond to chronic pain. It is "an exaggerated negative 'mental state' brought to bear during actual or anticipated pain experience" (Sullivan, 2001, p. 53). According to the subscales identified in the development of the 13-item self-report Pain Catastrophizing Scale (Sullivan, Bishop, & Pivik, 1995), pain catastrophizing is a comprised of three domains: helplessness, rumination, and magnification. While pain-related catastrophizing may either be a disposition (stable characteristic of personality, such as hypochondriasis) or situational response (Leung, 2012; Turner & Aaron, 2001), studies have shown mediation from mindfulness and acceptance on pain-related catastrophizing (Craner, Sperry, Koball, Morrison, & Gilliam, 2017; de Boer, Steinhagen, Versteegen, Struys, & Sanderman, 2014), suggesting that pain-related catastrophizing can be addressed through therapeutic means. In fact, Richardson et al. (2009) showed that pain-related catastrophizing may be more significantly related to maladaptive affect states such as depression and anxiety than pain acceptance, which further highlights the importance of investigating pain-related catastrophizing in individuals with chronic pain.

2.3.4   Self-Identity

Charmaz (1983) argued that one of the broader experiences of suffering felt by persons with chronic illness was the loss of identity, which she more broadly termed "loss of self." This loss is experienced through the erosion of the old senses of self "without simultaneous development of equally valid new ones" (p. 168).   Chronic illness threatens not only internalized notions of self, but also senses of the self as a whole and healthy body (Charmaz, 1995; Larsen et al., 2014; Vick & Lightman, 2010).   People who develop chronic illness may go through a number of various responses, though ultimately most of these responses present some struggle against the present reality of the illness.   Charmaz (1995) argues that adaptation to the new reality reunifies the body and self and subsequently "shades into acceptance" (p. 657).   Beatty and Joffe (2006) contribute to this understanding of the change of identity due to chronic illness by arguing that the experience of identity change by persons with chronic illness can be both sudden and gradual, and that the experience of chronic illness will also affect how a person experiences all other aspects of his or her current life-stage.   The effect on the sense of self can be with regard to the sense of body health (biological), future expectations, self-esteem, career goals, even the sense of self as "strong, competent, 'can-do' individuals" (Wells, 1998, p. 134).

2.3.5   Chronic Pain and Co-Morbidity

Co-morbid psychological disorders, such as anxiety and depression, have been shown to have high rates of occurrence in individuals with chronic pain (Burri, Ogata, Vehof, & Williams, 2015; McWilliams, Cox, & Enns, 2003).   Depression especially has been shown to increase rates of disability for those who also have chronic pain (Arnow et al., 2006).   Chronic pain has also been shown to increase the duration of depression and anxiety (Gerrits, van Oppen, Marwijk, Penninx, & van der Horst, 2014; Gerrits et al., 2012).   Individuals with chronic pain

have also been shown to have rates of suicidal ideation higher than that found in the general

population (Fisher, Haythornthwaite, Heinberg, Clark, & Reed, 2001; Smith, Edwards,

Robinson, & Dworkin, 2004). In a study looking at a convenience sample of 1512 patients at a

university hospital, Edwards, Smith, Kudel, & Haythornthwaite (2006) were able to show that

pain catastrophizing in patients with chronic pain predicted both the presence and severity of

suicidal ideation. Furthermore, the presence of co-morbid somatic symptoms, psychological

distress, and fatigue has also been shown to increase the persistence of symptoms of pain (Arnow

et al., 2006; McBeth, Macfarlane, Hunt, & Silman, 2001).

2.3.6   Environmental Factors

Environmental factors (EF) are defined by the International Classification of Functioning,

Disability, and Health (ICF) as contextual factors that are external to the individual (WHO,

2013). These factors can be either barriers or facilitators. When barriers, they can include lack

of ramps into buildings, lack of elevators inside buildings, doorways that are too narrow for

wheelchairs and/or walkers, lack of transportation options, lack of money, and lack of

understanding from others (Allen, Murphy, Kiselbach, VandenBerg, & Wiebe, 2015; Jerant, von

Friederichs-Fitzwater, & Moor, 2004). In a study to explore what affects the perception and

impact of EF, Ravesloot, Berendts, and Schiwal (2017), the authors found that more income was

associated with fewer problems with environmental factors. They also found individuals who

catastrophize their pain also extended this outlook "to perception of EF" (p. 71). While noting

that individual pain perspectives can impact the experience of EF, adapting and/or modifying

thoughts and behaviours cannot always overcome these social barriers. This can be especially

compounded in marginalized and impoverished populations, as Allen et al. (2015) found, where

participants described barriers (associated with poverty and the effect of low-income and

inadequate housing on managing a chronic condition" (p. 4). This important dimension of

social human functioning is important because paying it attention "makes it possible to articulate

clearly whether the needs of the individual require environmental changes or the provision of

personal support" (WHO, 2013, p. 11).

2.4   Acceptance and Commitment Therapy

While cognitive-behavioural therapy (CBT) has been the "'gold standard' of behavioural

approaches" when working with persons with chronic pain (Zautra et al., 2008, p. 408),

Acceptance and Commitment Therapy (ACT) for chronic pain psychotherapy is showing

positive outcomes as well (Dahl et al., 2004; McCracken & Eccleston, 2005; Vowles et al., 2011;

Wetherell et al., 2011). This is significant because CBT attempts to "change maladaptive ways

of thinking and feeling in response to illness" (Zautra et al., 2008, p. 408), an approach that,

while effective for some, has not been effective for others (Wetherell et al., 2011). ACT, on the

other hand, works with clients to help them gain "awareness and non-judgmental acceptance of

all experiences, both negative and positive" (Wetherell et al., 2011, p. 2098; see also McCracken

& Eccleston, 2003). The purpose of this is to "increase valued action in the presence of pain

and bring about behavioral change and improvements to functioning" (Hughes et al., 2017, p.

552). The approach to this awareness is through acceptance of chronic pain and chronicity,

which McCracken and Vowles (2006) see more as a process of being (pain willingness) and

doing (activity engagement) while pain is present and not simply a belief about the permanence

or uncontrollability of pain: "A behavior pattern that happens with awareness of pain but is not

directed at changing pain or otherwise influenced by pain demonstrates acceptance" (p. 91).

In a study of 118 participants attending a pain management unit in the UK, McCracken

and Eccleston (2005) were able to use the Chronic Pain Acceptance Questionnaire (CPAQ),

taken at two times, to study the relationship between acceptance and other constructs through the use of assessment tools commonly used with individuals with chronic pain. These measures included measures of overall patient functioning (0-10 pain scale, ratings of average daily rest and uptime, use of analgesic medications, and a dichotomous measure of work affected by pain), the BDI, the Pain Anxiety Symptoms Scale (PASS), and the Sickness Impact Profile (SIP). Their results showed that acceptance played a much larger role than that of pain in the measured aspects of patient functioning at time 2. This highly suggests that working with patient acceptance levels of chronic pain can have potentially powerful impacts on patient functioning. This conclusion is further supported by studies of acceptance-based therapies for persons with chronic pain (Dahl et al., 2004; McCracken, Vowles, & Eccleston, 2004; Vowles et al., 2011; Wetherell et al., 2011; Wicksell et al., 2013). All of these studies showed positive impacts of acceptance and acceptance-based interventions on patient functioning and affective well-being.

Particularly of note is the study conducted by Wetherell et al. (2011). In this study participants were randomly assigned to eight weekly group sessions of either ACT (n = 57) or CBT (n = 57). Primary outcomes were measured using the Brief Pain Inventory Short Form Interference subscale (BPI), which measures interference in daily life activities due to pain and includes a four-item subscale for pain severity. Secondary outcomes were measured using the Medical Outcomes Study 12-item Short Form Health Survey (SF-12), which measures mental and physical health-related quality of life; also used was the West Haven-Yale Multidimensional Pain Inventory (MPI) to assess disability, functioning, and pain outcomes. Finally, the CPAQ was used to measure pain acceptance and the Survey of Pain Attitudes (SOPA) Control subscale was used to assess client beliefs in their personal control over their pain, which were viewed as mediators. Their results showed that the outcomes from each group were equivalent, though

they highlight one finding as important: "The finding that ACT was rated more satisfactory than was CBT is important; patients are more likely to remain engaged in a treatment they find enjoyable" (Wetherell et al., 2011, p. 2104).

ACT focuses on an individual's way of living that develop into maladaptive ways of living. ACT's approach to changing these maladaptive ways of living depends on "not a set of techniques, but rather an orientation guided by the PF [psychological flexibility] model" (Yu & McCracken, 2016, p. 2). Psychological flexibility (PF) is the "ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends" (Hayes et al., 2006, p. 7). PF is at the centre of six intersecting psychological processes: acceptance, cognitive defusion, present-focused attention, self-as-context, values, and committed action (Flaxman et al., 2010; Hayes et al., 2013; Hayes et al., 2006; Scott et al., 2016). Acceptance involves mindful engagement of parts of the self without attempts to change them. Cognitive defusion involves working to change the way one relates to their own thoughts and any resulting unhelpful interactions. Present-focused attention involves working to bring the attentive awareness of an individual into non-judgmental contact with the present context, both internal and external. Self-as-context helps individuals to "be aware of one's own flow of experiences without attachment to them or an investment in which particular experiences occur" (Hayes et al., 2006, p. 9). Values-based actions involve individuals based on enabling values in their lives, rather than through disabling values such as avoidance. Finally, committed action involves growing these values into actions (Flaxman et al., 2010; Hayes et al., 2013; Hayes et al., 2006).

ACT defines thoughts, feelings, and behaviours that are rigid and not present centred as psychological inflexibility (Hayes et al., 2013; Hayes et al., 2006). The six constructs of PF are

present here as well but seen in ways wherein the individual is not living in a present-focused, non-judgmental way. The constructs for psychological inflexibility are cognitive fusion, experiential avoidance, loss of flexible contact with the present, attachment to a conceptualized self, values problems, and inaction, impulsivity, or avoidant persistence (Hayes et al., 2013). Interventions are employed in ACT aim to help individuals remove rigid and judgmental appraisals of situations, experiences, and themselves to under-take values-orientated actions with present-centred non-judgement. (Hayes et al., 2006). By working to increase an individual with chronic pain's PF, therapists aim to reduce the distress caused by the experience of chronic pain and increase attention paid to constructive and adaptive ways of living (Scott et al., 2016; Vowles et al., 2011; Vowles, Wetherell, & Sorrell, 2009; Yu & McCracken, 2016). By attending to the constructs making up PF, individuals with chronic pain may be able to develop or modify their ways of living in order to return meaning to an existence that includes the presence of persistent and disruptive pain.

2.5 Morita Therapy

As the definition of acceptance discussed above from McCracken and Vowles (2006) defines acceptance in a behavioural manner, working with individuals who have chronic pain in a form of therapy that engages with behaviour to build such acceptance may prove efficacious. Morita therapy is one such form of therapy. It was developed in Japan in the 1920s by Shōma Morita (Morita, 1928/1998; Ogawa, 2013; Spates, Tateno, Nakamura, Seim, & Sheerin, 2011) and is model of therapy with which ACT has much in common (Hofmann, 2008; Ogawa, 2013).

The original model of Morita therapy was developed to treat a condition Morita called *shinkeishitsu* (anxiety disorders with hypochondriasis) and was specific to an inpatient context. Clients went through four stages of therapy, with each stage focusing on specific goals (see

Table 2.1). Stage 1, which consisted of isolation and bed rest, was focused on having the client fully immersed in experiencing the distressing emotional state in order to experience moving through complete distress to relief without the aid of distraction or attempts at modification. Stage 2, which allowed very light work as well as diary keeping, was focused on having the client experience mental and physical boredom, which in turn prompted spontaneous activities and desires for action; i.e., the desire for life. Stage 3 allowed an increased amount of work by the patient in order to get the patient to experience repeated success and develop increased self-confidence. Finally, patients in stage 4 were allowed to leave the facility for the purpose of running errands, but otherwise patients were focused on work as well as adding in reading for the purpose of reading without attachment. The focus of this final stage was to help patients break attachments, including to their own interests, and to learn to adapt to changing external circumstances.

Not only has this inpatient process of Morita therapy evolved over time (Ohara and Reynolds, 1968), it has also evolved to fit different outpatient contexts (Kitanishi & Mori, 1995; Reynolds & Kiefer, 1977). These include career counselling (Chen, 1998; France, 1989), emotional or cognitive stagnation (Ishiyama, 1990), shyness (Ishiyama, 1987), communication apprehension (Ogrisseg, 1998), Bulimia Nervosa (LeVine, 1993), as well as fibromyalgia syndrome (Nagata et al., 2006). Nevertheless, what the above all have in common are the foci on central aspects of Morita therapy that find applicability within specific client-lived experiences. These include the desire for life, spontaneous action, *arugamama* (accepting reality as it is), attitudinal fixation, ideational contradictions, perfectionistic expectations, and constructive action-taking (Chen, 1998; Chen, 2010; Ishiyama, 1986a; Ishiyama, 1986b; Ishiyama, 1987; Ishiyama, 1990a; Ishiyama, 1990b; Ishiyama, 2003; Morita, 1928/1998; Ogawa,

2013; Spates et al., 2011).

Table 2.1

Original Morita therapy inpatient structure

Stage	Length*	Goals	Allowed Activities
Stage 1	4 – 7 Days	• Dismantle client suffering and pain • Experience liberation through symptom confrontation • Boredom	• Maintain resting or prone state • Toilet • Bath
Stage 2	1 – 2 Weeks	• Calmly enduring distressing symptoms • Stimulate spontaneous activity • Stimulate desire for action • Experiencing mental and physical boredom • Cease client evaluation of symptoms and treatments • Break down anticipatory fears	• Light repetitious work done in silence (not even sweeping for first two days) • No resting in room except for sleep • Diary writing after evening meal • Reading from beginnings of books – engaging of mental faculties • No tasks assigned by therapist
Stage 3	1 – 2 Weeks	• Acquire patience and endure work • Engender self-confidence • Empower subjective experience • Encouragement through repeated successes	• Anything "that they think normal people do" (p. 48) • More labour-intensive tasks assigned
Stage 4	5 – 7 Days	• Break all attachments • Break fixation on one's own interests • Learn to adjust to changes in external circumstances • Learn to accomplish purposeful objectives in the real world without anticipatory fear	• Reading books – not alone in rooms – opening to random pages and reading "without any special effort to understand or remember the content" (p. 51) • Allowed to leave hospital grounds in order to accomplish purposeful tasks; no leisurely tasks allowed

* Lengths for stages 1 – 3 are approximates according to Morita's statements in Chapter 2 of his book (Morita, 1928/1998). In the editor's introduction, LeVine says that all stages were approximately 5 – 7 days. This figure was used for the length of stage 4.

Source: Morita (1928/1998).

A central concept that is at the heart of Morita Therapy is the concept of *desire for life*, or *sei-no-yokubo* in Japanese. For every fear of death, there is an accompanying desire for life (Morita, 1928/1998), akin to a two-sided coin (Chen, 1998). Using the concept in this manner has proven useful with cancer patients using Meaningful Life Therapy (MTL; see below) (Ishiyama, 1990c; Reynolds, 1989). This is also used to recognize the desire that accompanies anxiety (Ishiyama, 2003). Helping clients to positively reframe their anxieties and fears as the accompanying desires in order to promote client focus on concrete behaviours (Ishiyama, 1986a; Ishiyama, 1986b). With pain-related catastrophizing and anxiety being parts of what is seen to lead to loss of activity, depression, and disability (as discussed above), helping individuals turn their focus to their desires could prove beneficial.

Different client attitudes and behaviours may block this desire for life and lead to focus on fearful and anxious emotional and psychological states. These include *shisō-no-mujun* (contradiction between ideas and reality), perfectionistic thinking, rejecting reality, imposing dogmatisms, and negotiating with the unnegotiable (Ishiyama, 2003). In each of these, the client develops an unrealistic expectation that what is (reality) is somehow not sufficient in order for the client to perform the desired behaviour. For instance, a client may perceive that a certain emotional or physical state is undesirable and thus become excessively focused on the presence of that emotional state (i.e., *toraware*; Morita, 1928/1998). The client will believe that the undesirable state itself must be conquered and changed before what is desired can be done. In other words, a client may come to believe that the presence of pain inhibits being able to be active, and thus the pain itself must be removed before engaging with any activity. However, because the pain will not necessarily go away, this fixation leads to a stagnation of action and an unhealthy use of energy in obsessively focusing on the pain itself.

Part of the path of positive reframing efforts include helping clients achieve *arugamama*, or accepting reality as it is, as well as helping clients develop an attitude of *obedience to nature* (Chen, 1998; Chen, 2010; Ishikawa, 2011; Ishiyama, 2003; Morita, 1928/1998). For individuals living with chronic pain, accepting reality would mean accepting that the presence of pain is a prolonged and perhaps permanent fixture of one's life. The presence of pain would thus become a reality to be lived with and through, not a conditional to be fought against. This concept very closely aligns with that of obedience to nature, wherein the individual would learn to move with the way their natural world now moves.

Helping to engage a client with this new reality is not a task the therapist should undertake lightly, because the client will often need to express the full range of emotions associated with developing acceptance of this new reality. The therapist should be careful while doing this to avoid reinforcing a dichotomous state of emotions as positive (to be enjoyed) and negative (to be avoided) (Ishiyama, 2003). At the same time, helping the client to develop a positive attitude and engage in positive reframing can be accomplished through allowing the client to express her or his full range of emotions with regard to said client's new reality, new identity, and her or his new relationship with their own body (Chen, 1998; Ishiyama, 1986b).

True obedience to nature cannot occur through intellectual simulation. Rather, it is helping clients to develop attitudes and methods of constructive action-taking that reinforce the idea of being able to perform desired behaviours while the pain is present. Morita also argued that such performance of action is not something that can be achieved through obsessive planning, but must be developed through spontaneous activity (Morita, 1928/1998). Helping clients to perceive their own ability to act spontaneously while in pain can also lead to the development of stronger self-efficacy toward implementation of larger plans of action, such as

job-seeking, which by its nature requires some planning. In this Chen (1998) was clear that obedience to nature did not mean one would have a ready-made excuse for giving up due to factors outside of one's control. Instead, constructive action-taking that is in line with obedience to nature means that a client with chronic pain will learn to be creative in how they engage with life given the limitations that can come with chronic pain.

The concept of *seishin-kogō-sayō* in Morita therapy, or "psychic interaction" (Morita, 1928/1998; Ogawa, 2013) is reflective of much discussed above in the fear-avoidance model of pain behaviour. This is the "vicious cycle of the interaction between one's felt sensation and one's focus of attention on the sensation" (Morita, 1928/1998, pp. 1-2). In other words, the client associates an experience (such as the presence of pain) with the inability to perform an action. This association leads to a greater focus on the pain, which itself intensifies the experience of the pain. With the pain thus intensified, the client perceives reality as one where action cannot occur because of the present pain. Instead, the client must be helped to change attention, the controllable factor, and leave the presence of pain as something that simply is.

One form of therapy influenced by these concepts from Morita Therapy is Meaningful Life Therapy (MLT) (Ishiyama, 1990c; Reynolds, 1989). MLT is a therapy that was developed by Dr. Jinro Itami in Japan around 1981 for working with patients with cancer or other incurable diseases. It seeks to help patients and clients with terminal and incurable forms of cancer and other diseases to turn attention away from the disease itself toward helping activate behaviours that return a sense of meaning to the remainder of life. These actions, following Moritian principles, are what brings purpose and meaning—meaning and purpose are not first created through reflection before action is commenced (Reynolds, 1989). Through the many activities

that are a part of MLT, participants are "guided to find fulfillment in the present by doing and living to the best of their ability" (Ishiyama, 1990c, p. 83).

While ACT and Morita Therapy share some commonality, such as learning to perform constructive behaviours while experiencing discomforting emotions and/or bodily sensations, Ogawa (2013) highlights what he sees as notable, though subtle, differences. Whereas ACT seeks to help clients accept their feelings and emotions in order to be able to take action while they are present, Morita therapy seeks to initiate action whether or not acceptance of emotion or feeling has taken place. The acceptance of ACT also subtly implies a judging of the emotional state, that it is ok to feel a certain way. Morita therapy, instead, seeks to allow the emotional or physical state to simply exist without judgment. In other words, anxiety is neither good nor bad, it simply is, and by my doing I might come to acceptance of being able to act while feeling anxious.

This subtle difference can be described as one of direction and cognition. ACT, coming from its CBT roots as shown above, still anticipates that people will actively and cognitively accept some negative emotion or state in order to take action. Morita therapy, on the other hand, ascribes no such cognitive efforts. In fact, efforts to first reach cognitive acceptance are seen as ineffectual. It is only through repeated and increasing levels of activity that one comes to a state of acceptance. In this way Morita Therapy seeks to capitalize on the belief that enlightenment, which should be seen more as an "embodied knowing," comes through experience, and thus knowing "I can act while anxious" comes through "acting while anxious" (Chen, 1998; France, 1989; Morita, 1928/1998). Through repeated action-taking with positive outcomes one learns and confirms that one is capable of performing the intended action successfully. This concept

was equally important to Bandura (1977), who wrote that improved self-efficacy came through

experiential learning of capability.

Chapter 3: Method

This research was framed by a Social Constructivist epistemological perspective, which sees that all knowledge each individual has of the world around them is the result of a variety of interactions between that individual and the larger world (Berger & Luckman, 1966). As with Charmaz (1991) and Thorne, McCormick, and Carty (1997), the research here approached the world of each individual as one that arises through interaction with forces both internal and external, and through that person's subjective perception of social, economic, gender, and personal barriers, through which both the illness experience and disability are defined. Additionally, this also acknowledges that researcher and participant interacted in a place and time and together co-created knowledge about participant experiences.

Furthermore, this research project was firmly rooted in the symbolic interactionist theoretical perspective; that is, people interact with one another and the world around them through the meanings that they associate with those other persons, objects, environments, or social structures (Schwandt, 2015). The perspective I took here was additionally tempered by feminist theoretical perspectives that acknowledge that certain social structures are constructed in such a way that disadvantage individuals based on their not belonging to the male, Western European, and able-bodied hegemonic group. In this way, social structures could be analyzed not only for the meaning participants assigned to them, but also acknowledged for any potentially discriminatory aspects. This is in keeping with Arduser (2014), who warns that approaches to the illness narrative tend to put the sources of agency and identity solely within the individual, thereby neglecting social, economic, and institutional forces exerted on these constructs. It is also in line with the biopsychosocial model of disability and the social constructivist view of the individual and social context.

3.1   Participants

Participants were recruited using a combination of physical and electronic flyer. Physical flyers were distributed at a local counselling agency, Brookswood Counselling, in Langley, British Columbia, as well as the Multiple Sclerosis clinic at the UBC Hospital. Additionally, pain clinics in British Columbia and PainBC, a province-wide chronic pain agency, were contacted with a copy of the recruitment flyer to request distribution. Finally, an electronic version of the recruitment flyer was distributed via Facebook.

Participant inclusion criteria for this project were that individuals were (a) between the ages of 19 and 65 years old and (b) had chronic pain. Chronic pain, as discussed within Chapter 2 above, was any pain that had persisted in excess of 3-6 months. Eight participants, five female and three male, who had met the inclusion criteria were included in this study (see Table 3.1 for demographic information). Participants were between the ages of 29 and 54 years old ($M = 41.38$ years old). Participants reported the presence of chronic pain, with little to no interruption in experienced pain, from between 5 and 41 years ($M = 21$ years). Participants reported between zero and 7 medical diagnoses ($M = 3.38$ diagnoses) given by either general practitioners or specialist doctors. Two participants reported their doctors had suspected they had had additional conditions, with one reporting one suspected medical condition and the other reporting three suspected medical conditions (see Table 3.2 for diagnoses and suspected conditions). Each participant was provided with a $10 Canadian stipend for their participation. Six participants reported that they were currently employed and two reported they were not.

Table 3.1

Participant Profile

Participant	1	2	3	4	5	6	7	8	Means
Gender	F	M	F	F	F	M	M	F	
Age	31	53	32	29	47	54	41	44	41.38
Born in Canada?	Y	Y	Y	Y	Y	Y	Y	Y	
Employed?	Y	Y	N	Y	Y	N	Y	Y	
Number of Diagnoses	1	6	0	6	7	5	1	1	3.38
Number of Suspected Conditions	1	0	3	0	0	0	0	0	0.5
Years with Chronic Pain	13	27	14	5	27	31	41	10	21
Activities Engagement Subscale*	49	42	29	34	33	24	47	39	37.13
Pain Willingness Subscale**	35	22	30	28	22	16	22	26	25.13
CPAQ Total Score***	84	64	59	62	55	40	69	65	62.25

*Activities Engagement Subscale scored on a possible range of 0 to 66

**Pain Willingness Subscale scored on a possible range of 0 to 54

***Chronic Pain Acceptance Questionnaire (McCracken, Vowles, & Eccleston, 2004) score from adding together Activities Engagement and Pain Willingness Subscales, for a total score of 0 to 120.

Table 3.2

Participant Medical Diagnoses and Suspected Conditions

Participant	Medical Conditions Diagnosed by Doctor	Medication Conditions Suspected by Doctor
1	Post-Traumatic Stress Disorder	Fibromyalgia
2	Arthritis, Restless Leg Syndrome, Coronary Heart Disease, Gout, Type II Diabetes, Sleep Apnea	
3	None	Fibromyalgia, Irritable Bowel Syndrome, Restless Leg Syndrome
4	Fibromyalgia, Anxiety, Depression, Temporomandibular Joint Disorder, Irritable Bowel Syndrome, Dysmenorrhea	
5	Hypothyroidism, Cerebellum Stroke, Spondyloarthritis, Raynaud's Syndrome, Sjogren's Syndrome, Pancreatitis, Central Sensitivity Syndrome	
6	Herniated Disc L5/S1, Back Failed Fusion with Instrumentations, Spinal Column Cut, Screw Pressing on Nerve, Neck Herniation C1-C5	
7	Migraines	
8	Multiple Sclerosis	

3.2   Setting

Three interviews were conducted in office space at Brookswood Counselling in Langley, BC. Five interviews were conducted in the residences of the participating individuals. Two interviews that were conducted in these residences had family members present in part or total for the interview, with the consent of the participant. One interview was conducted with a roommate present in the residence, but in another room behind closed door. Five interviews were conducted with only the researcher and the participant present for the whole interview.

3.3   Measures

One measure, the Chronic Pain Acceptance Questionnaire (CPAQ) was included in the research project as a point of demographic information (see Table 3.1).   The Chronic Pain Acceptance Questionnaire (CPAQ) was developed by McCracken, Vowles, and Eccleston (2004). It is a two-factor, 20-item inventory, that is scored on a 7-point Likert-type rating scale from 0 (never true) to 6 (always true) (see Appendix B). The two factors are activity engagement, which measures a respondent's "pursuit of life activities regardless of pain," and pain willingness, which measures a respondent's "recognition that avoidance and control are often unworkable methods of adapting to chronic pain" (p. 161). The 11 activity engagement subscale items are scored to give a subscale score between 0 and 66. The 9 pain willingness subscale items are reversed scored and the items for each subscale are added to give a subscale score between 0 and 54. The two subscales are then totalled to provide an overall score between 0 and 120. A higher score indicates a higher level of pain acceptance. Vowles, McCracken, McLeod, & Eccleston (2008) conducted exploratory and confirmatory factor analyses that confirmed the two-factor, 20-item questionnaire was most appropriate and had the best overall fit. Additional studies have since provided further evidence in support of the psychometric properties and internal consistency of the CPAQ (Fish et al., 2010; Reneman, Dijkstra, Dijkstra, & Geertzen, 2010; Vowles et al., 2011).

Participants were asked to complete this questionnaire immediately prior to the conducting of the interview. Participant scores on the activity engagement subscale were between 24 and 49 ($M = 37.13$, $SD = 8.71$). Participant scores on the pain willingness subscale were between 16 and 35 ($M = 25.13$, $SD = 5.89$). The totaled scores for the participants on the questionnaire were between 40 and 84 ($M = 62.25$, $SD = 12.46$). These questionnaires were not

scored until after the completion of the data analysis to avoid influence on the interpretation of the narrative interviews. Scores were gathered to help identify how accepting the study population was of their chronic pain for assistance in further understanding the participants of this study. No further statistical analyses were conducted.

3.4   Data collection

Data collection took place using two methods: (a) an autobiographical lifeline and (b) semi-structured interview using open-ended questions. Participants were asked to provide on a lifeline (see Figure 3.1) graphical depiction of losses and gains in activity level and involvement throughout their life from the point that they first experienced the emergence of their chronic pain. Lifelines can assist participants in their recall of life-history events (van der Vaart & Glasner, 2007). The usefulness of the lifeline activity as a method to supplement and triangulate narrative interviews has been shown in many different studies, including those on health equity and homelessness (Patterson, Markey, and Somers, 2012), developmental transitions for young women (Gramling and Carr, 2004), meaning-making for cancer patients (r, 2010), weight gain

Figure 3.1 Lifeline used with participants

and loss (Sheridan, Chamberlain, and Dupuis, 2011), and for interviewing those who have

attempted suicide (Rimkeviciene, O'Gorman, Hawgood, De Leo, 2016). In all instances,

lifelines were not used as a primary source of data, but were instead used to help ground, direct,

and supplement narrative interviews and subsequent analyses.

Similarly, this research study used the lifeline activity to help provide a chronological

structure for participant recall within the interview. Rimkeviciene et al. (2016) noted that

timeliness help provide memory cues that "aid recall of more detailed information" (p. 233).

Time itself is an important component of narrative recall (Belli, 1998), as "time and narrative are

inextricably woven together, in that narrative almost always involves time and requires a

temporal component to be meaningful" (Sheridan et al., 2011, p. 554).

The lifeline for this project was structured in the following way: the line at the x-axis represented a median level of activity at the point of chronic pain emergence, with peaks representing increases in activity level and involvement, and valleys representing decreases. The lifeline also helped provide an anchor to which the narrative portion of the interview could return when necessary, as well as chronological guidance. As Sheridan et al. (2011) note, "Time is organized through narrative and narrative humanizes time" (p. 554).

The interview itself utilized an initial direction to the participant for plotting on the lifeline, as well as questions to focus in on the periods of time graphed on the lifeline to prompt participant narratives (See Appendix C for the interview guide). The initial direction given to the participants was as follows: "On this lifeline you will notice two lines. Where they intersect should be the time when chronic pain first began for you, and the horizontal line will represent the activity level you had at that time. With that in mind, please draw a continuous line from that point in your life until now, indicating whether your activity levels decreased (indicated by the line going down) or increased (indicated by the line going up)." Participants were also encouraged to label the starting point with the age or year during which they first experienced chronic pain, as well as any other graphical details they wished to include. The completion of the lifeline activity was audio recorded in order to capture any narrating done by the participants while visually capturing their experience of the way chronic pain affected their activity levels. The audio recording was then stopped to create separate files for both parts of the interview.

Following this, the audio recording resumed, and participants were asked to provide description of the time in and around the starting point they provided for their lifeline. Participants were then prompted with questions to further explore experience or provide further detail of their descriptions. As descriptions of periods of time were completed, follow-up

prompting questions were asked, such as, "Please tell me more about this time," or "What can you tell me about this period here?" Participants then continued their narrative descriptions of these times, while the researcher asked few, if any, investigative questions.

On completion of the first interview, a copy of the transcript of both parts of the interview were sent to the research supervisor, Dr. Ishiyama, who read over the interview to ensure that it appropriately followed the study protocol. A phone conversation was then held to discuss the transcript, after which further interviews continued. In total, 16 audio recordings were produced from the eight interviews. Interview times for the first part of the interview were between 4 minutes, 34 seconds and 18 minutes, 8 seconds ($M = 9$ minutes, 11 seconds; $SD = 4$ minutes, 55 seconds). Interview times for the second part of the interview were between 40 minutes, 22 seconds, and 1 hour, 28 minutes, 32 seconds ($M = 1$ hour, 5 minutes, 21 seconds; $SD = 14$ minutes, 33 seconds). Total interview time from both interviews per participant was between 58 minutes, 30 seconds and 1 hour, 33 minutes, 6 seconds ($M = 1$ hour, 14 minutes, 32 seconds; $SD = 11$ minutes, 9 seconds).

3.5   Data Analysis

Analysis of the interviews was a multi-step process that followed Braun and Clarke's (2006) guide for conducting inductive thematic analysis for both latent and semantic themes. This multistep process followed their process for inductive thematic analysis, an analytic process that is data-driven and thus derived codes and themes primarily from the data themselves. Table 3.3 provides a brief synopsis of the phases they outlined in their article.

Following the completion of each interview, verbatim transcriptions of both parts of a participant's interview were completed by the researcher. Each transcript was then read through in full to increase familiarity with the data. The transcripts were then uploaded into Atlas.ti, a

Table 3.3

Process of thematic analysis

Phase number and name	Steps involved in the phase
1. Becoming familiar with the data	Transcribing the interviews verbatim; repeated and active reading; making notes
2. Generating initial codes	Coding for either latent or semantic content, theory-driven or data-driven; work systematically through all of the data; coding extensively, inclusively, and exhaustively; include surrounding context relevant to the code; include codes that differ from any perceived emerging primary narrative
3. Searching for themes	Begin to identify themes and sub-themes from among codes; collate codes into relevant themes; place ungrouped codes into a category for later review
4. Reviewing themes	Check to see if collated data are consistent and coherent with the theme; check themes for whether they retain validity in relation to the data set; generate a thematic map
5. Defining and naming themes	Being able to define each theme for its "essence" and seeing the emerging narrative produced by the themes; naming themes
6. Producing the report	Clearly relate the narrative that the themes tell of the analysed data, providing clear, strong, and relevant extracts from the data for each theme

Note. Summarized from Braun & Clarke, 2006, pp. 87-93.

qualitative data analysis software (QDAS). Within-interview data analysis was then conducted

for each interview before proceeding to the next. Initially, all coding was done using Atlas.ti's

"open coding" function, allowing the researcher to enter either verbatim, literal, or interpretive

descriptive phrases for each quote. These quotes ranged from sentence fragments to entire

paragraphs, depending on identified content within each. As more interviews were transcribed,

Atlas.ti's "list coding" function was also used as patterns began to emerge between transcripts. An iterative process between analysed transcripts also occurred as participant statements were analyzed for similarities to ensure appropriate coding. In total, 16 transcripts (two per participant) totaling 126 single-spaced pages were analysed, which produced a cumulative total of 1386 codes.

While the coding was taking place within transcripts, participants were contacted through email with a copy of the transcripts from their interviews and a summary description of the codes along with the researcher's perceived meaning of those codes. Participants were asked to review the transcripts and the codes and then respond to the interviewer by indicating whether they agreed with the codes and interpretation or not, and to include any desired corrections or clarifications if there was disagreement. Some of the codes were themselves adjusted at this step as well, though no new codes were added. This was primarily due to clarification within the researcher as codes and their descriptions were written out for the participants. As all participants responded with their agreement with the coding of their interview, the participant check was considered completed at this point and the next part of the analysis began.

The next step involved collating similar codes into groups using Atlas.ti's "code group" function. Groups were generated using language relevant to the descriptive nature of the code and its quotes, or directly from code names. Codes were also individually analysed to ensure attributed quotes bore similarity with each other. Many codes were however connected to only one quote. As the list of codes was analysed for placement in existing groups or placement in new groups, many codes were either deleted or merged. Deleted codes were those that restated what another code attributed to the same quote already captured; e.g., one quote with multiple and similar codes that were defined as "Fear" and "Fear of Pain," which resulted in the deletion

of "Fear." Merged codes were either those with similar spelling or phrasing (e.g., "Activity loss" and "Loss of activity") or codes that were similar in meaning but different in phrasing (e.g., "Angry at pain" and "Upset") when the attributed quotes bore enough similarity. At the end of this process, 1178 codes remained, and 125 code groups had been created.

The next step in the analysis involved going back into each code group. First, some codes that had been placed into code groups due to user error were removed (click-and-drag placement of codes into the wrong groups). Next, analysis against the research question for this project began. The codes that were relevant to interactions between chronic pain and participant activity levels were marked, and those that were not relevant were moved to a unique category group. Next, each code group was analysed for intra-group agreement amongst all grouped codes and their quotes. Further merging and pruning of codes at this stage took place.

The third phase in this process involved the generating of themes from codes. This step "involves sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes" (Braun & Clarke, 2006, p. 89). Codes and groups were analysed specifically for what they were "saying" about chronic pain and activity. Many themes that emerged at this stage were themselves then gathered into higher order themes. This was further refined in phase four. Multiple discussions, both in person and by phone, were held with the research supervisor to ensure clarity of meaning in the themes as well as clarity of the thematic schema. An initial outline and thematic map were both created and further refined through this process. These steps helped to further refine the themes and sub-themes.

The fifth phase, defining and refining themes, "means identifying the 'essence' of what each them is about (as well as the themes overall), and determining what aspect of data each theme captures" (Braun & Clarke, 2006, p. 92). In this phase, I wrote my interpretive

description for the themes in order to tell the story that each presented. I also thought through how the broader story about the whole data set was being told. I worked to make sure there was little to no overlap between themes, further cementing which of the themes have their own sub-themes. Each theme was then named and defined. Once these definitions and names were made, the research supervisor was provided with the list of names and definitions, along with an initial version of a diagram of the thematic schema. Further discussion with the research supervisor until the production of the written report led to the final diagram (see Figure 4.1).

The sixth and final phase was the production of the written report (Braun and Clarke, 2006), which is captured in this and the following chapters, as well as the previous chapters. Every effort was made to not only share the meaning of what the participants shared, but also to return to the literature where appropriate. The purpose here is to "tell the complicated story of your data in a way which convinces the reader of the merit and validity of your analysis" (p. 93).

3.6   Qualitative Validity

The first step undertaken in this process has been to work on bracketing myself as a researcher, counsellor, white male, and person with chronic pain. Bracketing is the undertaking of the researcher in qualitative research to "mitigate the potential deleterious effects of unacknowledged preconceptions related to the research and thereby to increase the rigor of the project" (Tufford & Newman, 2010, p. 81). By acknowledging these preconceptions, the researcher aims to acknowledge positions, beliefs (both positive and negative), biases, and viewpoints that may affect the findings of the research project. This is especially important as the "researcher is the primary instrument for data collection and analysis in qualitative research. The findings are mediated through this human instrument" (Chan, Fung, & Chien, 2013, p. 3).

Furthermore, as Chan et al. (2013) argue, bracketing is an exercise that the researcher should undertake before posing the research question, not only once data collection and analysis begins. Adapting the questions they posed and expanding upon them, I have asked and will continue to ask myself the following throughout this project: "Am I humble enough to learn about the experiences of other persons with chronic pain?" "Can I equip myself to adopt an attitude of conscious ignorance about this issue" (adapted from Chan et al., 2013, p. 4)? "Does this question/activity leave sufficient space for the participant to tell the narrative in their way?" "Does this honour the perspective of the participant?"

It was in answering this final question that the lifeline portion of the qualitative interview was revisited and adapted. I initially included points on the x-axis of the timeline to indicate 10-year periods, where the participant would mark the start of their line at the approximate age when their chronic pain began. As I sat with and questioned this process, where it arose from within me, and how it would be perceived by participants, I realized that it could graphically be dishonouring of a participant's experience if they had not had much chronological experience living with chronic pain relative to their total years lived. Participants who have experienced chronic pain from an earlier age, or over a longer period of time, would have greater graphical representation of their experience. Whether consciously or not, I realized that I could very well be giving more credence to persons who have experienced chronic pain longer. I thus removed the age-related component of the timeline and used the current version. Without reflexive efforts at bracketing, this question may not have been asked and answered, and the subsequent change to the lifeline may not have been made.

This has also meant bracketing myself during the interviews themselves to ensure that questions that arose were relevant to the data gathering process. As a social constructivist, I

recognize that the person of the researcher is integral and ultimately undivorceable from the research process. I have worked to ensure that this served the research itself and that the narratives of the participants and their meanings are at the forefront of this interpretive effort.

Further validity of the study in question included two different methods of self-check detailed by Braun and Clarke (2006): (a) maintaining awareness of potential pitfalls that are common when conducting thematic analysis (Table 3.4 below), and (b) following the procedures that they detail (Table 3.5 below), many of which involved rigorously adhering to the six phases of their process for thematic analysis (as detailed above). Outlining these steps to be followed here, as well as the detailed outlining of the phases and how they will be followed above, helped to establish the quality of this research. "As thematic analysis is a flexible method, you also need to be clear and explicit about what you are doing, and what you say you are doing needs to match up with what you actually do" (Braun & Clarke, 2006, p. 96).

Table 3.4

Pitfalls to avoid when conducting thematic analysis

No.	Description
1	Not actually conducting analysis but simply stringing together codes, no deeper interpretative efforts made
2	Not developing themes through interpretative analysis but using data-gathering questions as the themes
3	Producing a "weak or unconvincing argument"
4	Making analytic claims that are not support by the data
5	Theory and analytic claims made are not in alignment, or researcher using a form of thematic analysis that is not in alignment with the research questions

Note. Summarized from Braun & Clarke, 2006, pp. 94-5.

The five pitfalls summarized above were not an exhaustive list of the necessary awareness kept throughout conducting the study. Rather, they were important points to keep

awareness of as progression was made through the research process. In concert with the 15-point

checklist shown below in table 3.5, these were important to keep as part of my constant internal

dialogue in order to apply a rigorous and consistent effort to remain as true as possible to my

methodology, theory, and to the data themselves as well.

Table 3.5

A 15-point checklist of criteria for good thematic analysis

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written Report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done – ie (sic), described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as active in the research process; themes do not just 'emerge'.

Note. Reprinted from Braun & Clarke (2006), p. 97.

Importantly, there was no standard used for a specific rate of occurrence of codes across data to establish a theme's trustworthiness or validity. Braun and Clarke (2006) argue that "the 'keyness' of a theme is not necessarily dependent on quantifiable measures – but rather on whether it captures something important in relation to the overall research question" (p. 82). This differs from methods such as content analysis, where "it is possible to reach a theme based on the frequency of its occurrence in the text" (Vaismoradi, Turunen, & Bondas, 2013, p. 403). This project relied not on the number of participants who made statements that supported a theme, but whether a theme had unique relevance with respect to the research question, supported by the theoretical and methodological underpinnings of the research.

Nevertheless, certain checks were made with others in efforts to ensure the open-ended nature of the interview remained intact, and that the themes identified were as "accurate" as can be claimed in a constructive and interpretative research project. Thus, following the first interview, the transcription of the interview was shared with the research supervisor for this project for his review. The interview was then reviewed both for relevance of gathered data and to ensure that the follow-up questions were open-ended, non-directive, and appropriate.

Codes were also checked by sharing them with each participant to ensure agreement with my own interpretation, as my interpretation should be one that is nevertheless a telling of their perspectives. I also maintained the use of a researcher journal throughout the research and analysis process, which helped provide insight and evidence that themes identified were respectful to the data. Themes and definitions were also discussed with the research supervisor to ensure their relevance and appropriateness. This does not provide "proof" of the objectivity of codes and themes, but rather that I and another reviewer were able to view the text through the same lens (Loffe & Yardley, 2004). "However, because of the pure qualitative nature of

thematic analysis, peer checking of intercoder reliability is not always possible since there is

scepticism about the value of such testing" (Vaismoradi et al., 2013, p. 403).

Chapter 4: Results

This chapter focuses on the results of the analysis of the eight qualitative interviews conducted for this study. As this study comes out of a social constructivist epistemological perspective, it is argued that "Constructions" or "Constructed Knowledge" would be a better title for this chapter as it more fully expresses that the data emerged as the result of a constructive effort between researcher and participants. As discussed above in Chapter 3: Method, the themes discussed below emerged from an inductive, iterative, and exhaustive process of working between the participant transcripts, codes, and themes. This process was inductive in that all segments of the transcripts were coded to allow for the codes to emerge from the data themselves. The process then examined all codes and the applicable coded segments to see which answered the research question for the current study, "How does chronic pain affect the personally significant activities of those individuals with chronic pain?" These codes were then grouped into larger code groups. As an investigative and interpretive lens was applied to these groups, themes began to emerge as to how the participants experienced impact on their activities from their chronic pain. At each step in the process, codes and themes were discussed and reviewed with the research supervisor for this study to ensure accurate interpretation and knowledge transmission.

While the themes do suggest internal agreement among included codes, they should also not be taken to be exclusive. Participants would speak of more than one idea in a single statement and, where applicable, codes did express ideas across themes.

4.1   Lifeline

The lifelines were consistently a work in progress by all participants, which can be seen in the additions and changes captured in each lifeline shown in Appendix D. Participants used

the lifeline to structure their timeline and some would mark out ages or years ahead of time before drawing their line, as participant 3 showed: "So, 2003, I need to, like, date it, so I know what the heck I'm doing with…" For others, the lifeline helped them structure thoughts that had not been connected in this way before, as was the case with participant 1:

"Ok. I feel like I need to see it in my head before I can draw it, 'cause I haven't… I think what I'm just already aware of is that I've reflected on specific parts of my life where there's been a lot of loss, but I don't have a sense of the, the way that they're all interconnected."

Thus, the lifeline helped serve the purpose of chronologically ordering the participant's sense of loss and gain.

At the same time, all participants expressed, and were granted, opportunity to make corrections and additions to their lifelines throughout the interview as their own narrative restructured what they had first graphically depicted.

P8: I think, I think f, I think ok. Um, you know, it's always interesting when you do something, then you start to unpack it a bit. If, if this was going to change at all, it, that 2009 to about 2014, 15, here, this line would still be the same frequency, but down here.

R: And feel free to put that in if you'd like as well.

P8: Yeah, so, I would, I would move it down here, because this was pain and, bring it up, bring it up a bit, so more like again, like this. Sorry, I know. Like that. Yeah.

This process of constantly unpacking their narrative recall while interacting with their lifeline both directly and figuratively allowed the participants the freedom to not just tell their recall but craft and update their recall as details became firmer in their memory. It also allowed participants to address gaps in their memory as well, as participant 7 expressed:

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"So, maybe I can do like a dotted line to indicate I was probably doing more, but, but don't know. And then, I don't know where it goes up and where it goes down. Like, you know, if we, like I don't know if it goes all the way up here, or if it just goes a little bit up here."

Participants were granted freedom to tell their story both in their narrative recall and in their graphical recall. While many inquired about starting a fresh lifeline during the narrative interview, only participant 6 felt it essential to correct his before moving forward.

Three participants drew their lifelines such that their activity level never rose above nor returned to pre-chronic pain levels (the x-axis) of chronic pain. For participants 1 and 8, both lines were drawn to be approaching the x-axis at the end of the line. For participant 4, her lifeline was drawn such that the line met with the x-axis at the end. Participant 2 stated that his median level was the same pre-and post-chronic pain, representing being employed in one job and, at the end, preparing to return to work. Participant 7, who stated that he had lived with chronic pain his whole life, stated that his median level remained constant through most of his life. He drew a line as a reference point, choosing to place that line just under the provided line of the graph. Participant 6 drew his line with peaks that rose above the x-axis at two points but remained under otherwise. Participant 3 drew her line with multiple peaks and valleys; two of these peaks rose above the x-axis, four of them met the x-axis briefly, but otherwise her line stayed at or below the x-axis. Participant 5 drew her line with one peak that rose above the x-axis with both a gentle rise and fall, with her line ending below the x-axis and continuing slowly downward. On visual inspection, six of the participants drew their lines in such a way that the majority of their lifeline was below the x-axis, indicating most of their life with chronic pain was

at activity levels below their perceived average activity level before chronic pain began in their lives.

4.2 Activities

Participant losses, interruptions, and gains are best first understood through exploring what they perceived to be their activities. Activities were not predefined for the participants. For one participant, her statement was that she was graphically depicting losses and gains of physical activity:

P1: "Ok, ok. So, it was like, I went down to basically not doing anything physical (sighs)… Activity. All activity."

R: "What would be all activity for you?"

P1: "Um, I'm defining activity in my head as physical activity."

R: "Ok"

P1: "Which is what I lost. Um, but I was sti, I kept going to school, and I had jobs and I was active in my community, but physical activity when chooo [sound to signify drawing decrease]."

What became evident throughout the narratives, including the interview for this participant, is that activities were far more than physical activity. Various kinds of activity arose, including physical activity, social activity, activities of daily living, employment activity, and academic activity. Participant 4 described her own definition of activity as "In terms of my activity. Yeah, I mean, like when I think about the activity, it's not just like physical activity, like I think it's more for me like how much I was even able to emotionally engage. Yeah, and like spiritually engage." Participant 7, who said that his pain had been a part of his life since his

earliest memories as a young child and likely before, said that activities were "basically the main ones for me are just, you know, really it's just living life."

Activities were thus more than just physical activities, but physical activities were among those described. Physical activities described by the participants included roller-skating, bowling, golfing, going to the gym, walking, riding a bicycle, sex, travelling, and even participating in the interview. Social activities described by the participants included dating, choir, watching tv or movies with friends or family, attending social engagements, and other activities involving friends, family, or both. Activities of daily living including eating, cooking, and sleeping. Employment activities were activities specifically related to working. Academic activities were those activities specific to school, including attending school and completing schoolwork: one participant described completing her thesis while struggling with chronic pain and the impact of pain on that activity. For another participant, pain had specifically extended the period of time he has spent in completing his doctoral work. It is thus important to understand this variety of activities when exploring chronic pain's impact more closely.

4.3   Effect of Chronic Pain

Participants described a variety of effects that chronic pain had in their lives that were collected under two main themes: (1) Activity Loss and Interruption, and (2) Activity Gain and Maintenance.   Each of these two were built from sub-themes that helped capture meaning specific to participants' statements. While some quotes carried within them multiple codes relating to more than one theme, the themes themselves do not overlap to an unnecessary degree in meaning. See Figure 4.1 for a diagram of the thematic breakdown.

Activity Loss and Interruption

- Direct Impact
  - Pain Limits the Body
  - Pain Increased by Activity
- Indirect Impact
  - Somatic Impact
    - Exhaustion/Fatigue
    - Medication Side-Effects
    - Negative Outcome from Medical Procedures
  - Psychological Impact
    - Fear/Anxiety
    - Emotional Impact
  - Interpersonal Impact
    - Social Losses Compound
    - Lack of Understanding from Others
  - Encountering Structural and Social Barriers
    - Lack of Accessibility
    - Lacck of Accommodation
    - Lack of Money

Activity Gain and Maintenance

- Adaptive Responses
  - Psychological Responses
    - Cognitive Adaptation
    - Emotional Responses
    - Heightened Vigilance
  - Interpersonal Communication of Pain and Needs
  - Behavioural Responses
    - Pushing Through Pain
    - Modifying Behaviour
    - Accessing Services
    - Managing Pain with Physical Instruments
    - Activity-Based Coping Strategies
- Facilitating Environmental Factors
  - Understanding from Others
  - Positive Outcome from Medical Intervention
  - Money Opens Doors
  - Pain Managed by Medication

Figure 4.1 Themes and Sub-Themes

4.3.1 Activity Loss and Interruption

This theme and its sub-themes captured experienced moments of activity loss or activity interruption in the participant's lives around chronic pain. Some moments of activity loss that were not relevant to a participant's pain experience were excluded, such as completing school, wherein a perceived activity loss would be the natural ending of school itself (i.e., graduation). Activity losses were those activities that were lost over an extended period of time, usually at least months if not permanently through the conducting of the interview. Activity interruptions were those times experienced by the participant where pain resulted in the cancellation or abrupt-ending to an activity in progress (such as travelling), or where the participant experienced a delay in activity completion that was either completed prior to the conducting of the interview or for which progress had or would be resumed.

Two main sub-themes emerged under this theme: (1) Direct Impact and (2) Indirect Impact. Direct Impact captured those moments described by participants where the pain experience itself, the somatic experience of pain, was directly responsible for activity loss or interruption. Indirect Impact captured those experiences described by participants wherein pain affected some aspect of their internal world or environmental context that then in-turn resulted in activity loss or interruption. Visually, Direct Impact would be PAIN → Activity Loss or Activity Interruption, while Indirect Impact would be PAIN → Impact on Internal World or Environment → Activity Loss or Activity Interruption.

4.3.1.1   Direct Impact

This theme captured two main sub-themes: Pain Limits the Body, and Pain Increased by Activity.

Pain Limits the Body. For every participant, the pain itself created new limitations that meant that activities could no longer be engaged. Pain's presence was one that was expressed as directly causing or contributing to limited, interrupted, or lost activity. Participant 2, who stated his only activity was work, described the limitation of pain in his life:

> "'cause all I did was work and even when my pain level got to ridiculous levels I'd hobble to work and, 'cause I'd work my day job and I'd go work my night job, and literally I'd be hobbling when I'd come home and [Partner] would put ice packs on my knees and rub my feet, go to sleep for six hours, go back and do it again."

For this participant, activities lost were the ability to do anything outside of work other than recuperate from the effects of pain on his body as he pushed through this pain to continue working.

For participant 7, who had chronic migraines, the pain level would be too great for participation in activities, meaning he would lose out on an activity and the impact would also be felt by others as well:

"My, my wife and I, there was a party that, um, we got invited to. It was a games night, locally. And, and with some new friends that she wants to develop a friendship with. But I hadn't met them yet. The day of, I got a brutal migraine. And she ended up having to go on, on her own. And she was ultimately fine with it, although I think she was a bit annoyed. You know? But, it, it's sort of like, it's hard for them, and it's hard for me. Right? 'Cause I feel like I'm letting people down and disappointing them."

This was reflected by other participants as well, who expressed constant or rising pain prior to activities that precluded their involvement in those activities. Participant 6 stated, "Like, our sexual life was [noise completely lose]. There just wasn't one. Between the pain and the medication, I mean there were some, you know, obviously you can be intimate in different ways. But, yeah, that was, that's, uh, that was one of the big ones." For participant 8, pain from her MS would at times occur at the start of an activity and remove the ability to engage in that activity:

"Like, the other day, not the other day it was a few weeks ago, and I was gonna go get on the horse, and all of the sudden, this right side of me the pain just shot up and my leg gave and I was on the ground. And I'm looking up at the horse, the horse is looking at me like, 'Whatcha doin', what are you doing down there?' And uh, you know, I'm just like, 'Ok, give me a second. I'll get up in a minute.'"

The pain for some participants would become so great that they were relegated to their bed, as was the case with participant 3: "So, this, this is, this little dip right here happened in

about August, and I would say, like, now that is the worst flair up I've ever had in my life, and this was like, it's st, like there was two months of, um, like ag, like being, being bed-ridden." In these times of isolation in bed, this was not a welcome change for the participants, which participant 2 expressed by seeing his bed as jail: "So it was like, I'm stuck in this bed, I hated my bed, I didn't want to get, and it was like I would pay anything. It was like being in a jail. Queen-size jail cell."

Pain Increased by Activity. Participants also described the ways in which pain would be increased by their attempts at being or remaining active. For participant 1, her dancing had been an important part of her life and she would make attempts to resume that activity. "I would miss dance so desperately that I would go for a class and I would feel amazing, and I would dance my heart out, and… And then it would knock me out, and it would take me like two weeks to get back on my feet." For participant 5, efforts to remain active resulted in dramatically increase pain, "'cause every time I went to skate, as soon as I pushed myself really hard the pain would be so intense I'd have tears in my eyes." Participant 4 described her experience with pain's increase doing activities and how that conflicted with what she had been taught to value:

> "Um, and, yeah, I was home for 2 and a half weeks and, I was having quite a bit of pain at that time, and like my dad's always like, 'If you start something you finish it.' You know? And so, with the dishes, right? I would be like almost done with the dishes, and I'm like, 'I actually can't stand on this floor anymore, like, I need to just like go lay down 'cause my body hurts.' I think that's where I, that's the time that I started kind of realizing the extent of my pain."

These increases from pain due to a participant's efforts to gain or regain activities captured by this sub-theme reflect how the pain increase from these efforts was disruptive.

4.3.1.2   Indirect Impact

This theme and its sub-themes reflect the ways that chronic pain indirectly caused activity loss or interruption. This meant that pain itself was not the primary cause of activity loss or disruption, but rather than some other factor arising because of the chronic pain resulted in activity loss or interruption.

Somatic Impact. For many of the participants, different somatic experiences that were a result of their chronic pain or attempts to manage their chronic pain resulted in disruption of their activities. These were seen as specific to three main themes: Exhaustion/Fatigue, Medication Side-Effects, and Negative Outcomes from Medical Procedures.

One of the primary factors that resulted in exhaustion or fatigue was the result of living in pain or attempting to be active through pain. Participant 8 said, "I was getting, um, tired of even thinking about it anymore, it was a, I'm, I'm ex, I'm exhausted by it. Uh, and pain is exhausting." Even if the pain itself has decreased by the next day, participant 7 found that the next day would be filled with the feeling of exhaustion. "But yeah, you know, like it, the day, you know, if the day before is a, is a bad migraine day, the next day might not be a migraine day, but it might be a, I'm wiped from the day before. Like, just wiped." At the same time, the activities participant 5 needed to manage her pain were themselves exhausting:

> Um, but when you're trying to get well, and you're going to doctors all the time, and pain clinic classes and trying to learn about that, and then you're supposed to eat healthy every day, that's a lot of work and a lot of prep. Especially when you go meet with the nutritionist that I was meeting with, and it's like vegan this and that and my brain's

breaking and I'm just like, this is too much to even understand. And then there was also, um, just like, ok, you're supposed to exercise and meditate and nap and not overdo it. How do you do that and work? It's really hard! 'Cause by the time I've finished work I'm exhausted!

Participant 1 described the impact this fatigue had in her life, saying, "I missed a fair number of classes, often more for fatigue than pain, but the pain fatigued me. Um, so like if I'm just in pain I can get up and go, but then I use more gas. My, I don't burn as efficiently and so I just get drained faster."

Medication side-effects could also produce results that some expressed as disruptive. For participant 8, the medication she took to help manage her MS was a challenge for her, in part, "because I had to spend two days a week with flu-like symptoms. So, I would retreat." For participant 7, the medications taken for migraines could have lasting effects into the next day. "And the next day it's like migraine's gone but the effects of the meds are still there." For these participants, the effects that the medications themselves required for managing their chronic pain and chronic conditions had side-effects that also disrupted their ability to be active.

Finally, other participants experience negative outcomes from medically necessary procedures and surgeries that were connected to their chronic pain that resulted in disruption of their activities. These outcomes are defined here as being different from extended recovery times considered expected from surgery. Instead, these outcomes were considered not expected, or even among minor risks that resulted in activity disruption. This is also different than those times participants sought out treatments that were not beneficial; instead, these interventions had effects that resulted in increased pain. Participant 5 stated, "So, every time they do something to help me it puts me back in the hospital. Yeah. So, that pretty much, yeah. It's down here now,

it's not a lot of activity, I've worked half days, if that." Participant 6's surgeries had complications that result in increased life-long chronic pain as well as immediate activity loss. "Um, and then the '07 surgery occurred and that was it. Like, I was done."

Psychological Impact. Chronic pain could also result in a number of different psychological impacts and responses that would themselves then lead to activity loss or interruption. These psychological impacts fell into two main themes: Fear/Anxiety and Emotional Impact.

Fear and anxiety was one of the most expressed emotional responses to chronic pain, often resulting in new or continued activity loss. For many participants, trying to take part in activities in ways that caused pain also contributed to this; as participant 1 said, "I would try something and then I would feel terrible, and so then I became, like I became increasingly scared of physical activity in particular… I would feel so awful after. So I became really like fearful and avoidant of physical activity." For participant 5, the fear of pain because of previous painful episodes from eating meant eating less: "I remember not feeling well and going in to see my internist, he said, 'You have to eat. Like, you have to eat.' But when you're not, you're scared to eat, 'cause everything hurts when you're eating, it's hard to [eat]." The fear of causing more pain, especially when based on having had pain caused by previously being active, at times meant that participants thus avoided activities in order to avoid causing or increasing their pain.

Fear was not necessarily something that happened when activity wasn't engaged in but could be occurring during a moment when a participant was experiencing psychological impact (anxiety) from chronic pain while also experiencing a moment where limitations were actively being imposed on their body from their chronic pain. When this happened during a moment where they were also showing an adaptive behavioural response, activity interruption and

activity maintenance may appear together but also out of alignment. For example, participant 5 expressed a moment where she was active but also actively experiencing a limitation, along with the thoughts and emotions that were present:

> Like it was, like, yeah. I mean, we went for a, a bike ride in March of 2016, and at that time I wasn't allowed to get my heart rate over 118 or something like that. You can't, you can't do anything without, I couldn't carry bags over 20 pounds, you couldn't, like it was ridiculous. I remember doing this bike ride and I cried the whole time. Like, I'm never going to be able to do anything for the rest of my life.

For participant 5, limitations on activity were equivalent to "never" being able to do anything, an example of catastrophizing anxiety that some of the participants could experience. She made statements showing that pain limited her body ("I wasn't allowed") and that she experienced psychological impact ("I'm never going to be able to do anything"). At the same time, she expressed activity engagement that displayed the behavioural response Pushing Through Pain.

Emotional impact resulting from the pain, or from loss because of pain, also meant further activity interruption or loss for participants. Depression was experienced by different participants who expressed the way that depression would cause or contribute to their loss, an example of which Participant 3 showed when she said, "This goes along more with like how depressed I feel than, like, I guess, yeah, your mood and your pain tolerance totally go hand-in-hand. And, like, this is a chart for like my mood and my pain tolerance just kind of goes with it." Feeling hopeless could also contribute to activity loss and interruption, as could feeling overwhelmed by the pain itself, such as when participant 1 said, "I, um… felt like I, felt like I was drowning, um, like trying to come up for air, and I just kept getting sort of knocked over by wave and pushed back under."

Interpersonal Impact. The sub-themes under this theme capture the ways that pain and initial activity interruption and loss impacted the participant's social lives and social activities, which then resulted in further loss. Captured here are also those moments when the participant was unable to communicate to others their experience and/or needs. The two sub-themes here are Social Losses Compound and Lack of Understanding from Others.

For many participants, losing access to social groups would result in continued activity interruption or loss. For participant 3, losing friends meant losing ways to remain active, because "when you have friends, or, friends who were like calling you up and like, 'come on!' Like, "get out of the house!" Um, uh, it, you kind of stops you from like, yeah, from wallowing in it." When pain made activity more difficult, it affected her mood as well, decreasing her access to and tolerance of people. As participant 4 described, "with the pain, with the increase in pain, there's decrease in access to peer and community."

Lack of understanding from others was another sub-theme present, which was described as impacting all of the participants' activities in some way. Individuals who were not understanding could be friends, professors, romantic partners, employers, parents, etc. These impacts were at times experienced when the participants needed to cancel activities or end activities early and did not received understanding from others. For participant 1, the people in her life may have responded in ways that seemed respectful of the her needs but resulted instead in further loss: "Some saw that I was really struggling and didn't know what to do and thought it was best to give me the space that I was repeatedly taking. But looking back, what would have been really nice is, like, 'you don't have to get out of bed, I'll come over with a movie.'" This could also impact a participant's willingness to engage in any future-oriented planning with others, as with participant 7, who said, "I can never, a hundred percent, confirm with anybody,

that I'm gonna be able to do something with them. And that has, I don't know if it's cost me friendships, but it has certainly made it, people have had a hard time, some people have had a hard time understanding that."

Encountering Structural and Social Barriers. The sub-themes under this theme all represent factors in the participants' contextual environments that affected their abilities to be active or participate in activities. The three sub-themes are Lack of Accessibility, Lack of Accommodation, and Lack of Money.

Lack of accessibility represents times participants described not being able to take part in activities due to accessibility not being available to them at the time of attempted activity. This was especially evident in many instances for participant 6. In particular, during the vacation for his 25th wedding anniversary he found he could not go to some places:

I couldn't go on our trip to Location, um, Location, Location, from Location, it's a real rough road. But I guess the fall, there's falls that are beautiful, and there's a ton of stuff that's just great to see. Couldn't do it. None of the vans would take the wheelchair. It was like, "Is there not a van that takes wheelchairs?" There might be now, but at the time there wasn't, or we couldn't find anything to do it. So it was something we couldn't do.

Having locations without accessibility options provided a structural barrier that could not be crossed due to the participant's dependence on a wheelchair for his mobility. Even when he was more able to move, some locations required too much walking and meant passing on those plans as well. "But I gave tickets away because I knew I couldn't go to the ski hill, or I couldn't go to the luge, because it meant a lot of walking and climbing and I just couldn't do any of that. So I even missed out on stuff with the Olympics." While this did mean missing out on those activities, he still expressed that what he was able to participate in was pleasurable and ended

this part of his narrative by saying, "But, I still got out to socialize." Nevertheless, while the participant could be active, there were activities missed out on because they weren't accessible.

Lack of accommodation encompasses those times where individuals, whether friends or employers, were not accommodating of new needs the participants had. For some participants, this meant that plans friends were making did not accommodate what they were capable of while living in chronic pain, as participant 1 said, "And, and so, so many of the plans were going out in ways that would have been really exerting." This meant participants would miss out on those physical and social activities. For others, this lack of accommodation was from employers resulted even in lack of upward mobility, such as for participant 6: "So really, I should have been the next [warehouse manager], before they ever got it I should have got the warehouse, if you're going on time and seniority and capability and so on. But, sometimes, obviously, um, other issues come into that. But I knew that the writing was on the wall that I wasn't going to get it."

Lack of money also presented a barrier for some participants to be able to participate in activities, especially social activities. For participant 3, not having money meant there was "no money to go out." Lack of money also impacted the ability to participants to manage their pain so that they could engage in activities. It also meant being left in a position of discomfort in daily life that further affected their pain and activity levels, as with participant 4 who said, "but I didn't have any money and my roommate that moved out took all the furniture in the living room, so I literally lived with no furniture for six months." For her, this meant that a decrease in activity and increase in pain because "I didn't have anywhere to sit that was comfortable." Without financial ability to replace these things, or provide means to be socially active, participants experienced further activity loss.

4.3.2   Activity Gain and Maintenance

The second main thematic category was Activity Gain and Maintenance. This category represented how individuals were able to gain or regain activity, or remain active while living with chronic pain. Activities were often impacted by chronic pain's presence for the participants, but they were able to either develop adaptive responses to chronic pain or experience positive assistance from factors in their contextual environments. There are two sub-themes under this theme: Adaptive Responses and Facilitating Environmental Factors.

4.3.2.1   Adaptive Responses

Adaptive responses displayed by the participants included three sub-theme categories: Psychological Responses, Interpersonal Responses, and Behavioural Responses. These were responses to the presence of chronic pain made by the participants themselves, allowing them to adapt their psychological appraisal of and response to pain, develop ways of communicating pain to create understanding in others, or develop behavioural responses to chronic pain.

4.3.2.1.1   Psychological Responses

Cognitive Adaptation. This psychological response consisted of expressed efforts by the participants around cognitive acceptance and cognitive reframing of their pain experience. Participants expressed several ways that they were able to adjust their thinking and feeling around the meaning and presence of chronic pain. Some expressed ways of accepting that chronic pain would be a part of their lives and that they needed to adjust their appraisal of it. Making such adjustments were not always easy for the participants. For example, Participant 8 stated,

> "And it was also part of me recognizing, and I guess also accepting, that I do have this
>
> thing called MS that, you know what, your body is, um, in a fight. It's attacking you.

Um, and if you're resting or dealing with this pain you have, and all these, mmm, you

know, you have a right to rest and regroup so you can, um, resume. And that was a really

hard place for me to get to."

Another part of accepting involved also recognizing that certain ways of being active were no

longer good for their body. Participant 1 displayed this recognition when she stated, "Like, yes,

I was hurting more after the activity, but it wasn't because the activity was bad for me. It was

that I wasn't going about it the right way." Acceptance for participant 7 also meant taking on a

new identity:

"I never, I never, like, um, like, I had to decide to take on the label of, uh, 'disabled

student' or 'person' or whatever, right? And, um, which is fine and there's nothing wrong

with that and, and I, I don't know what the PC term is now, but since I'm, since I'm listed

as on it doesn't matter, I can, I can call it what I want. (laughs) Right? But like, but that,

you know, I had to sort of at some point say, "Oh, you know what? I've never sort of

thought of myself this way. And yet, with all the issues I've had and the problem I've

had, of course I am!" You know. Like, of course I, I'm, I can't live a normal life that

other people live."

However, cognitive acceptance was not always a process that was easy or quick for some

participants. Participant 5 expressed this struggle: "But yeah, no, it's been my, this huge life

shift. And, uh, they, again letting go of derby took me a year, year and a half, to let go of the fact

that, 'Ok, I probably can't play anymore. Well, maybe I can. Uh, no, mmm, ok.'" Once

accepted, participants were able to move forward in search of activities they could physically and

psychologically enjoy, a shift participant 5 also expressed: "But it's finding, again, like, I

believe you need to find something that fills you back up. For 30 years that was sports. And I

can't have that anymore. So now, it's trying to move into that next thing, which right now is the painting."

While cognitive acceptance meant accepting the presence of a persistent and often limiting chronic pain, reframing involved arriving at a new understanding of who they were as persons in chronic pain. Participant 8 discussed this, saying,

"I think here in North America we have a very, we sort of have this framework of, for, you know, mental health and, and many other constructs that what well-adjusted looks and feels like. And I think the same thing applies to pain. There's, there's always a way to fix everything. And that, and I had to start and consider that I don't have to adopt those constructs or frameworks because they may not apply to me."

Reframing also involved adjusting perspectives of what being active looks like, as well as what successful activity looks like, such as for participant 6:

"And it, there were a lot of things that I didn't do in the business, in running a business, because, but then I wasn't in the right mindset. Right? It was more a, it gave me a purpose, I was making other people happy, that made me happy knowing that a bouncy castle that I picked out for some boy or girl, and now they were having a blast with their kid, with their friends, and then, you know, it just, I had a self-fulfil, a self-fulfillment from doing it."

In instances where participants expressed ways of reframing themselves and their experiences, they also expressed needing to adjust their own definition of "normal," which participant 3 expressed when she stated

"In my mind, you know you convince yourself that like all of these, I think I'm just in that stage of like you convince yourself that maybe this will make you better, or maybe

that will make you better, but I'm like at that stage where I'm convinced that like maybe, um, healing myself like psychologically, um, or putting myself in like a better frame of mind will make me better. At least not, not better as in, what everybody else would consider, like, better, but like at a baseline where I can just be like, have a somewhat normal life.

Emotional Responses. Participants also expressed emotional responses to their chronic pain and their current or past circumstances. While the majority of emotional responses centered around feelings like depression, anxiety, and unhelpful expressions of frustration and anger, participants did express moments where emotions were helpful. These emotional responses that were expressive of adaptive responses often came from more difficult experiences. Emotions such as desire, hope, frustration, and anger could prove motivating for the participants, as was the case for participant 3: "Like, I work from home, I'm stuck at home, I'm, nobody's at home most of the time. So it's just like, I don't know, I'm just so fed up. I'm so fed up, with this condition, and my body, um, and I'm just like, fuck it." Hope would also help participants to plan for future activities even with uncertainty about whether they would be able to participate at that time. This was reflected in participant 7's statement, "So, like, I buy tickets to a concert coming up in a few months or whatever. I have no idea if I'll actually be able to go. I'm, I'm hoping I will, and I know that there's a good chance I'll go."

Heightened Vigilance. One final Psychological Response that provided assistance to especially participant 7 was Heightened Vigilance. While the participant did express this in terms including "hypervigilance," because there is a maladaptive understanding attached to hypervigilance in much of the literature around fear and avoidance in chronic pain (Leeuw et al., 2007), the phrase Heightened Vigilance was chosen. Heightened vigilance meant being on

constant alert for changes in both pain and environment. "So it's, it's, it's like just this constant, like, state of emergency preparedness." Participant 7 acknowledged that such heightened vigilance was tiring but also found it reassuring. "And so, on the one hand like it takes a lot out of me, on the other hand there's some reassurance at being able to say, 'I've got medications here, there, in that bag, in this drawer.'… It's like I can be self-sufficient."

4.3.2.1.2   Interpersonal Communication of Pain and Needs

Interpersonal responses that aided the participants were those where participants developed and utilized communication skills to communicate their pain, limitations, and needs, as for participant 8 who said, "I mean, I'm up front with everybody. Instructors and that. 'Cause it wouldn't be fair. 'I do have MS.' Uh, and, there's certain things that will take me longer or I just, 'No, that's too sharp of a pain.'" Communicating with others in this way allowed participants to create ways of being active in which they could participate with others, with work, and with school. In one instance, participant 7 reflected this when he said,

> "You know, I've had to have accommodations. I'm registered with the, they changed the name, but used to be the disability centre. You know, I'm registered there so that I could get accommodations for migraines and, and stuff. And, and, and everyone has been very understanding and very good."

These interpersonal responses allowed participants not only to communicate with others, but also to ask for help. With participant 5, this request for help came during the interview itself, "Um, this is my daughter, Name. Name, this is Researcher. Can you do me a super big favor, Name? My heating pad, bit the dust, can you go to store and buy me a new one before you go?" For this participant, the heating pad itself was something of importance to help manage the pain, helping

her to work from home or do other activities there, and asking for this help meant getting a replacement heating pad to help her continue with what activities she was able.

Finally, being able to communicate pain also opened the possibility of releasing shame that came for participants when missing activities scheduled with others. Participant 1 said, "I also had language at that point. I was saying, 'I live with chronic pain, I'm in pain today, I can't come.' Um, so, I was, I was also apologizing I supposed, which opens the door to forgiveness and understanding. Um, yeah, having language for it was really significant." Having ways to communicate inability to participate in certain activities, the need to cancel other activities, or requests to adapt activities was not a guarantee that others would respond favorably. It was a difficult process learning and being open to communicating pain to others in ways the participants felt were healthy, as was reflected when participant 8 said, "But then, this, these relationships, the fine line, the balance of the give and take, and when you have something like chronic pain, how do you do that without, um, burning them out as well?"

4.3.2.1.3   Behavioural Responses

Participants expressed different ways that they responded behaviourally to their chronic pain in ways that were adaptive. These included Pushing Through Pain, Modifying Behaviour, Accessing Services, Managing Pain with Physical Instruments, and Activity-Based Coping Strategies.

Pushing Through Pain. Pushing Through Pain were responses where the participant participated in activities in spite of pain being present and even at times overwhelming. For some, the motivation to push through the pain came because of fear of how they would be perceived by others, which was the case for participant 2: "Because I don't want people to realize I'm in pain, like, sort of be the weak, the weak, the weak of the herd. Right? You gotta

stand up and look tough, right? You gotta be ready to go, kind of thing." While the argument

can be made that this response does not display adaptive psychological adjustment to pain, it also

highlights the fear of social judgement due to chronic pain that is present for many individuals

with chronic pain. Pushing through his pain was necessary because of environmental factors,

especially financial necessity: "Work, work, work, I mean we're, have financial issues and that

sort of stuff… So, I mean it just, you just suck it up!"

However, pushing through pain also coupled behaviour with the cognitive acceptance

discussed above. It was also motivated by the desire to get healthier, both physically and

especially mentally, such as for participant 8:

> "And then I made a decision, those years ago, um, "Ok. There's, uh, you've gotta get
>
> active again." And, uh, so what's that gonna look like? And it's going to, it's not going to
>
> be comfortable in the beginning. And what's one of the easiest, low-cost things you can
>
> do? It's go walk. So, and I needed it. And at that point it wasn't necessarily to resolve
>
> pain, I needed it more for my men, my mental, um, health. And so I, I just started
>
> walking."

Pushing through pain became a way for participants to find healthy ways of being active without

causing themselves harm. For participant 1, this meant finding appropriate activities for her

body: "And climbing is actually really, for my, for my body, is really, really good. It's the, it's

the stability and strengthening that I need, where dancing was really inflaming. It was, like, it

was the wrong kind of movement, so I found the right kind of movement." For participant 2, it

was the recognition that getting healthier wouldn't come without such efforts:

> "So, but, at the end, where you've got the arrow going through the roof basically the idea
>
> is, I started going to the gym. And even though my pain level is like at a ridiculous level,

I do the treadmill, force myself to walk, literally it's because I have to do it, it's like a

work ethic. If I don't go to the gym, I'm not gonna get better."

Nevertheless, pushing through pain was not something that could be done without resulting in

harm without being done with body-attunement, as participant 4 noted that

"I actually think I did a lot of damage by like not paying a lot of attention to my pain.

And like went and did a bunch of hikes and, you know, was just pushing through it. Um,

which, because my body wasn't strong enough, I was actually causing harm going to do

all those things."

Modifying Behaviour. Modifying behaviour represents participant expressions of times

that they changed how they engaged with activities in order to maintain an activity level they

experienced as appropriate for their pain level, or in order to persevere through the pain.

Accessing Services. Some participants described times that they utilized services that

provided ways for them to continue to be active. This may have been even just ordering takeout

dinners as participant 5 did, "because we were so tired at the end of the day, I was just ordering

out every couple of nights." This also includes those services that served as replacements in

ways that participants could no longer be active. Participants used online services to purchase

their groceries, which participant 5 also stated: "so I would order them online and I would pick

them up, 'cause grocery shopping when you have chronic pain is one of the worst things to do."

For her, there was still a lot of difficulty cooking due to her pain and exhaustion from other

activities, so she also began using a service called Eat Your Cake that she found out about

through a pain clinic, which delivers fully prepared lunches and dinners for her and her partner,

which she said is also "making things nicer for him, I've got the bigger size now for his lunches

and he doesn't have to worry about, 'cause I haven't cooked since I got home from the hospital in the summer."

Participant 6 found a service called Chef's Plate that allowed him to participate in a new activity (cooking) that he also found meaningful:

"But, um, again, with the um, with the crocheting, it was, 'What can I do to give me some other purpose and fill some of my time?' And so, it was like, 'Well, this is kind of good. I don't actually have to go shopping to get the stuff. It's all brought to me, and I get a recipe, and I can make mistakes, and whatever.' Right? So, we started doing it."

From this he expressed plans to use online ordering from grocery stores so that he can continue cooking using recipe books instead. These helpful services, and ones like them, allowed participants to engage with activities they had not previously or no longer could.

Managing Pain with Physical Instruments. Participants also made use of a large number of different physical instruments that provided pain management so that they could remain active. This included clothing worn, bed purchased, car purchased, topical ointments, heating pads, orthotic inserts for shoes, and more. Participant 7 expressed the importance of one of these tools to his life, saying,

"to me it's so relieving. To the point that if I had to be on, like a desert island and they're like, 'Do you want your pain medication, or do you want your,' we call it lenço, it's a Portuguese word, 'do you want your cloth thing? For the rest of your life, take one or the other.' I would take the cloth thing every time."

He also used a number of other items, which he described as essential to his pain management and ability to engage as much as he was currently able. Other participants would also mention these items, whether in passing like participant 5 who asked her daughter to get a replacement

heating pad, or more directly. These tools didn't necessarily decrease their pain. At the least,

participants expressed that their ability to engage with the activities they did depended on the use

of these tools, as when participant 2 said, "so, you force yourself, you'll be gritting your teeth,

and, like, I mean I'd had, in my boots I'd have 3 sets of insoles, 'cause my feet hurt so bad… but

I had to work!"

Activity-Based Coping Strategies. Participants also expressed making use of activity-

based coping strategies to help them with both their pain management and pain evaluation. This

included meditation, naps, walks, and other activities that participants expressed were useful for

their mental wellbeing and/or physical coping with pain. For some participants, these activities

were specifically pain coping strategies, as the case with participant 5 who took some classes that

she found "really helpful, especially the breathing, meditation, and thoughts and emotions, that

was my favourite course." Sometimes this also meant choosing one activity over another

because the former would provide greater satisfaction with life. This was evident for participant

3, who said, "I'm at that point where it's like, 'What does life, like, what is it if I have enough

money to survive if I'm not really living?' Um, and if I'm just like unhappy?" Being active

could itself be coping strategies for some of the participants.

4.3.2.2   Facilitating Environmental Factors

Facilitating Environmental Factors were those that participants expressed came from

outside themselves. These were factors over which the participants expressed little to no control

over the outcome and where the assistance of these factors appeared essential to their continued

activity.

Understanding from Others. Understanding from others came from a number of

different sources. Participants reported this understanding as originating from parents,

organizations, medical professionals, academic professionals, and employers. Where this

understanding translated into facilitating factors that helped participants engage with activity

were moments that others could meet participants in the participant's own context, as was the

case for participant 1.

> "Um, and I was living with a, a roommate that really understood me, and also had some
>
> physical struggles, so we're often kind of knocked out together. And also, he was just
>
> enormously an introvert, so I had a lot of social connection at that same time that I'd been
>
> really missing, we spent a lot of time together."

This helpful and often accommodating understanding provided participants who had this

experience with missing social activity. Also, as participant 3 said, "I just felt like a little bit

protected from everything that was going on. It was like a bit of an escape every time she came."

Positive Outcomes from Medical Intervention. While some of the participants

described negative outcomes from medical procedures (as described above), they and others also

described positive outcomes from medical interventions that enabled them to be active. More

than one participant expressed that they found therapy helpful. Participant 1 stated, "the big one

being that I started getting neuro-feedback treatments, and this thing that I never thought

possible, is actually treating my pain. So, I have less pain now." Participant 7 expressed his

suspicion around seeing a chiropractor, but that "over time, it started to lessen. It'd go away for a

bit and come back. But it was one of the most brilliant moves, I saw this guy for, I don't know, a

couple of years before I moved away."

Money Opens Doors. The doors that money opened was apparent in a few of the

narratives provided by these participants. Money enabled this in multiple ways, including

providing access to medical interventions that had positive outcomes, tools that assisted with

pain management, or even ways of being active that cost money. This acknowledgement of money's importance could be overt, such as with participant 5 who stated that the service she accesses for their meals is "not cheap and thankfully, I think I make enough money to pay for it." Oftentimes, however, the statements around money were more acknowledgements of the cost of treatments or items in their lives that allowed them greater mobility or pain management, such as in the following statement from participant 8:

"Everything from, uh, I mean from the car I drive. I spent a lot of money on my vehicle, 'cause I had to find one ergonomically that didn't cause me pain, more pain. Didn't aggravate what I already had. Um, so that was, that was one big thing I had to, I had to get rid of my car, my old car, get a new one, um, and, uh, um, even, even too, my, my mattress, I spent like 5 grand on my mattress and, uh, just so I could get sleep, some sleep. Uh, and that, I mean, money well spent."

Another aspect of being active, of coping with pain, was the access that money provided to certain treatments. Participants remarked on the cost of certain medical services, especially when paid out of pocket. Participant 1 noted the particular importance of having these financial means: "I have had the immense fortune of having my grad school paid for, so I literally spent my student loan money on treatment while I was in school, but I can't think of any other way that I could have done any of this."

Pain Managed by Medication. Some participants also described how some medications were able to moderate or even reduce their pain levels in such a way that they were able to continue with their activities. Participant 7 stated, "And then with, later on with the Maxalt a few years ago, and the Botox, it's just more weapons in my arsenal. But all of this has remained as key components to how I live my life." However, this did not mean that medications were

always successful, including for participant 8 who said that when the pain was bad enough she tried "taking some anti-inflammatories, which I always hope will work but they don't." However, it was still expressed by some participants as, at times, one of the only things that allowed them to remain active, such as for participant 2 who said, "But even though, at night time I'm loading myself up with Percocet and then Tylenol and hydromorphone and then… It's like, but I still did it, just to get me through."

4.4   Activity loss not related to chronic pain

It is important to note that not all activity interruption or loss described by these participants was due to chronic pain as discussed above. Sometimes, the activity loss experienced by the participant was due to changing life circumstances. For instance, multiple participants described loss of school activity, but this was because of graduation from university. While these losses were themselves losses anyone might experience across the lifespan, the ability for these participants to find replacement activities was compounded by the many factors described above in the Activity Loss and Interruption Theme. For others, the losses were more acute and persisted across some months, whether due to injuries or from heart attacks. These reported losses from heart attack and injury were especially particular to participant 2, whose drive to continue working through pain levels he at times described as "out of this world" was nevertheless interrupted by these the injuries and heart attacks he experienced.

4.5   Identity Impact

A factor that emerged throughout all of the interviews, though not necessarily impacting activity levels, was the impact participants experienced on their identity. All participants expressed some degree of both identity loss and identity reconstruction in their interviews. Participant 3 stated, "Yeah, I feel like I'm a hyperactive person that can't allow me to be, um,

like hyper anymore." Participant 1 commented, "there were all of these things that I had defined myself by, that I was no longer doing, so I didn't know who I was anymore." Identity loss meant participants were uncertain of who they were and who they could still be when no longer able to be what they had once been. And this loss was across multiple parts of their identities: worker, partner, friend, parent, lover, active person. Often these identities were replaced with only one identity that assumed prominence in the minds of some participants: someone who will always suffer.

Encountering such a possible identity was a distressing concept for the participants. Participant 2 stated, "And honest to God, I can tell ya, that was, that was probably miniscules away from, from taking my life. 'Cause the pain levels were absolutely out of control." The impact across multiple identities created pessimistic perspectives around possible futures that gave rise to suicidal thoughts, such as for participant 6:

"I definitely thought about ending my life. Um, I wondered how I could be of use to anyone. Um, I worried about even intimacy and how that would impact me sexually. Um, employment, like, they were releasing me in, into what? Dead end job? Like, you know, like, it just, yeah, the whole, my whole fell apart."

Who he could be and how he could live appeared distressingly limited: "I mean, why would you want to live? Just to eat, eat, shit, and sleep."

For the participants who expressed the highest level of suicidality, their reasons for continuing to live were rooted in their families.

R: I'm curious then, what was the reason you didn't?

P2: Um, probably Partner and my daughter. That's the only reason that I stuck around. Um, and that was quite, quite the challenge. 'Cause I mean, it was like, I want to see her get married, I want to see her have, I want to see grandkids and that kind of thing.

Their desire to be around for their families, the impact suicide would have on their families, and the support of their families appeared to be strong mitigating factors in the choices to keep living, as was reflected by participant 6: "Um, thankfully, I mean, I was, I was, at the time, had started dating Partner, and she's, she was the type of woman that looked past all that."

Identity reconstruction was a major part of most of the participant narratives. Each told a history of a person who struggled to come to terms with this new way of being, with their new reality, and at times this new way of being meant infringing on important values. Participant 3 expressed this when she said, "I'm like this hardcore environmentalist, and I just, my fridge is full of frozen vegetables in plastic bags because I'm just like, I'm doing everything so that my, like, life activities are less so that my like fun activities can be more." This displayed a level of resilience within participants to find new ways of being and living that did not define them simply in terms of suffering, but also in terms of who they could now be. It also meant reconciling their identity with their pain, as with participant 8 who said, "I mean, the years have marched by, so when you start to get towards this, 'No, that's my new normal.' I don't remember life before that." This meant finding new ways of interacting with life that brought them meaningful experience, as with participant 5: "But it's finding, again, like, I believe you need to find something that fills you back up. For 30 years that was sports. And I can't have that anymore. So now, it's trying to move into that next thing, which right now is the painting."

It was in finding this new way of meaningfully existing, and finding new purpose, that participants were able to resiliently reconstruct an identity that helped them participate more

fully with life. This full participation was never a return to previous activity levels, but rather a redefined normal, as participant 3 expressed:

> "I'm like at that stage where I'm convinced that like maybe, um, healing myself like psychologically, um, or putting myself in like a better frame of mind will make me better. At least not, not better as in, what everybody else would consider like better, but like at a baseline where I can just be like, have a somewhat normal life."

For these participants, reconstructing their identity meant arriving at an understanding of themselves and their chronic pain as likely inseparable, a resilient exercise that was shown to not have been easy and one they expressed that was an ongoing process.

Chapter 5: Discussion

Because to me, chronic pain is often a story of loss.
And I'm also sort of realizing this past year, redemption,
but those are often not the stories that I think of.
Study Participant

5.1.1   Summary of Research Findings

This study was conducted to explore the experiences of individuals living with chronic pain in the context of its effects on their personally significant activities. With the assistance of a lifeline exercise as a visual contextualizing tool, eight participants (5 female, 3 male) told their experiences of the loss and gain of activity while living with chronic pain. Participants reported effects across psychological, somatic, behavioural, interpersonal, and environmental domains in their lives that were identified as fitting into two main themes: (a) Activity Loss and Interruption, and (b) Activity Gain and Maintenance. Under these themes were gathered 35 total thematic categories: 18 under Activity Loss and Interruption, and 17 under Activity Gain and Maintenance.

Thematically, Activity Loss and Interruption gathered participant experiences where chronic pain either had a direct or indirect impact that led to the loss or interruption of their personally significant activities. Activity Gain and Maintenance gathered both participant responses to their chronic pain and any facilitating environmental factors that helped participants maintain their personally significant activities or gain new ones.

"Personally significant activities" were left open to the definition provided by participants. For participant 2, this was primarily work. For other participants, activities included school, sleep, social interaction, and physical activities such as biking, dancing, bouldering, and walking. Participant 4 also expressed that, for her, activities consisted of four types: physical, social, spiritual, and emotional. It was through my own interaction and

reflection with this participant during and following the interview that I recognized that sleep can often be its own activity that is affected by chronic pain. Additionally, not all activity loss expressed by participants was the direct or indirect result of their chronic pain. The participants also experienced anticipated activity loss due to standard life transitions, such as the ending of school due to graduation.

Outside of its effects on their activities, participants also discussed the effect that their chronic pain had on their identity. This loss of identity was often relative to the losses they had experienced from their chronic pain. Participants reflected experiences of identity loss due to lost activity, including no longer being a skater or being a dancer, as well as loss of identity related to their social or familial function, such as effects on identity as a father.

5.1.2   Relationship of Findings to Existing Literature

The model suggested by this study shows how the experience of chronic pain can be a disruptive presence in being or remaining active. These disruptions occur either through direct pain experiences, or through how pain impacts a person's somatic, psychological, interpersonal, or environmental contexts. Participants in this study often experienced these impacts from chronic pain across more than one of these domains, either concurrently or with one leading to the next, such as Direct Impact of pain leading to a Somatic or Psychological Impact, which in turn led to further loss of activity. Participant experiences align with the fear-avoidance model, pain catastrophizing, environmental factors as barriers and facilitators, and self-efficacy models as applied to chronic pain and disability.

The way in which chronic pain impacted the lives across participants in multiple ways closely aligns with the fear-avoidance model of chronic pain, which shows that pain-related fear can be adaptive to painful stimulus but, in the context of chronic pain, can lead to withdrawal

from activity and subsequent pain-related disability (Vlaeyen & Linton, 2012). Participants expressed multiple psychological impacts of pain that were specifically related to their fear and anxiety of causing worse pain, increasing current pain, causing injury, and impacting their ability to participate in other activities. This fear of pain is itself often an adaptive response as it "informs the individual that there is the imminent or actual threat of body damage" (Vlaeyen & Linton, 2012, p. 1144). For persons with chronic pain, however, this painful stimulus shifts from the instructive stimulus acute pains provide for behaviours to avoid, to an unhelpful stimulus. When fear of pain is given maladaptive attentional fixation, individuals with chronic pain develop disabling and avoidant patterns of behaviour and cognitions about activity (e.g., Crombez et al., 1999; Westman et al., 2011), all which showed under the direct and indirect impacts of chronic pain on activity loss and interruption in the lives of the participants.

Research is showing greater evidence for cognitive and behavioural acceptance (e.g., Ravn, Vang, Vaegter, Andersen, 2017; Vowles & McCracken, 2008; Vowles et al., 2007) and possessing psychological flexibility (PF) (e.g., Vowles & McCracken, 2009) as mediating factors in the relationship between pain-related fear and pain-related disability. Participants in this study showed diverse ways that they had arrived at perspectives reflective of this acceptance in response to their chronic pain and active losses. Two participants expressly stated the need to see their chronic pain as different from the traditional perspective that pain identifies a danger to personal well-being and thus is an experience to be avoided. Further shifts were shared by other participants as well, though more subtly indicating a shift toward such acceptance either in their cognitive framing of the need to be active while in pain, or in their behavioural adaptations of being active while in pain.

Theoretically, PF is at the core of the treatment model for ACT (Vowles et al., 2014). The thematic categories developed from this study show how the constructs comprising PF are subsumed under many of the sub-themes comprising the Adaptive Responses sub-theme. However, PF fails to address the many facilitating environmental factors (EFs) that participants expressed were helpful, if not essential, for them to gain activity and/or remain active. Figure 5.1 helps illustrate these alignments and gaps.
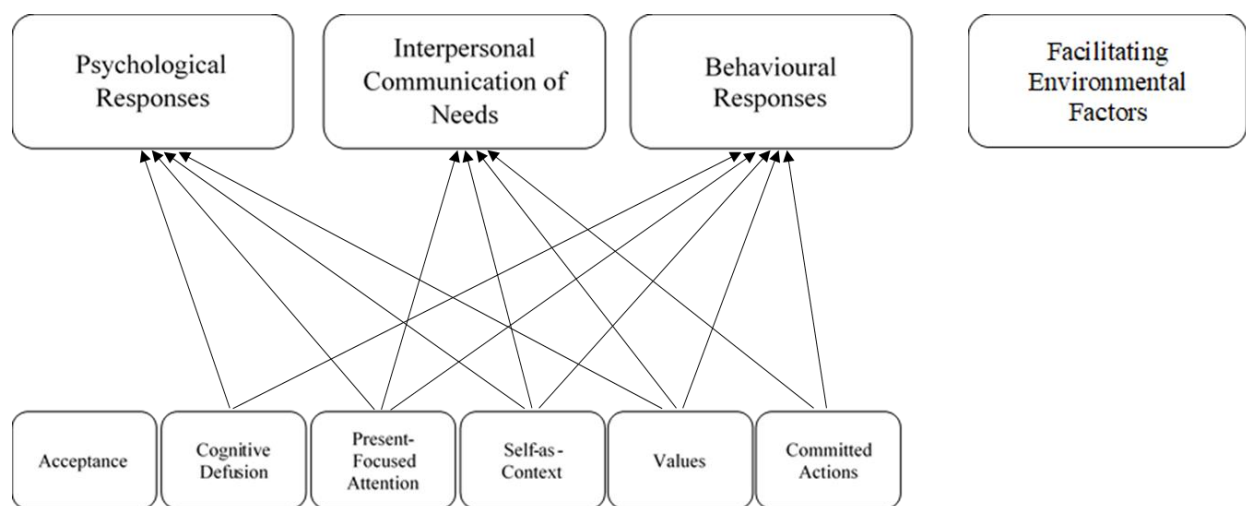
Figure 5.1 Psychological flexibility subsumed under research findings

Thus pain-related acceptance, the behavioural and psychological presentation of having PF, is subsumed under the adaptive responses that participants expressed as contributing to their ability to gain activity and remain active. However, PF does not account for the EFs that the participants found facilitated their ability to gain activity or remain active.

In addition to fear-avoidance and acceptance, pain catastrophizing, a maladaptive psychological response to painful stimulus, often also contributes to functional disability for persons with chronic pain. This response of "exaggerated worrying, helpless, and distress-

amplifying thoughts in response to pain" (Vowels et al., 2008, p. S136) showed up in participants in this study, primarily in their thoughts around what they would no longer be able to take part in due to their pain. This is model supports the links found between pain catastrophizing and the fear-avoidance models of chronic pain (Neblett, 2017), such as the experience quoted from participant 5 in Chapter 4 (section 3.2), where she expresses her anxiety during a bike ride due to experiencing and ruminating on the limitations that were present in her life at the time. Furthermore, Ravesloot, Berendts, and Schiwal (2017) showed in a study how both pain level and pain catastrophizing can contribute to the evaluation and impact of environmental factors. This is supported by the current study, where participant expressions of lack of accessibility or lack of accommodation were often tied to the evaluation of their own pain.

Self-efficacy is another predictor of avoidant behaviour for individuals with chronic pain (Ashgari & Nicholas, 2001). Losses in confidence can in turn lead to loss in activity. Conversely, gains in confidence can lead to gains in activity, a cycle that can then build on itself, as Bandura's (1977) original model of self-efficacy argued (Jackson, Wang, Wang, & Fan, 2014). Participant expressions of confidence in their ability to engage in activity also emerged in this study. These expressions were often a result of experiences with how their pain had previously impacted them, which were captured under both (a) Pain Limits the Body and (b) Pain Increased by Activity.

The model suggested by this study shows that these distinct theoretical perspectives of chronic pain are important aspects of the chronic pain experience but are not complete on their own. All of these appeared in the narratives of clients but were not wholly representative of their experiences. Catastrophizing may better mediate the relationship between symptoms of

depression and evaluations of pain than acceptance of pain (Richardson et al., 2009), while

acceptance may help moderate the relationship between functioning with chronic pain and pain

catastrophizing (Vowels et al., 2008). Catastrophizing may also affect how persons with chronic

pain evaluate EFs (Ravesloot et al., 2017). This model supports these broader theoretical

perspectives of how chronic pain affects individuals.

5.1.3 Implications

Focus on behaviour. CBT and ACT have received a large amount of attention in

research into clinical interventions for chronic pain and have shown a large degree of efficacy in

working with individuals with chronic pain (Kaiser et al., 2015). These two therapeutic styles

achieve these goals through differing means. CBT addresses thoughts and emotions about pain

and attempts to help individuals change and restructure these thoughts, improve self-efficacy,

reduce pain catastrophizing, and develop self-management approaches to chronic pain (Turner,

Holtzman, & Mancl, 2007). ACT, rather than focusing on changing thoughts, works to help

individuals experience thoughts, feelings, and the presence of chronic pain itself in ways that are

non-judgmental and look to refocus behavioural and cognitive energies on the present here-and-

now moment where values can become the driving force for committed action (Vowles et al.,

2014). This is done through interventions aimed at changing psychological inflexibility into

psychological flexibility (PF).

Participants described experiencing a number of internal effects of pain that were limiting

to their ability to engage or remain engaged in activities. These effects were often experienced

concurrently, such that a participant might express experiencing effects like both pain and fatigue

together and express feeling limited by both. Such inter-woven connections between dimensions

affected by chronic pain seems well-suited to interventions seated in ACT, which sees that the

six dimensions of psychological flexibility are "understood more fully in the context of the others… Acceptance seems to depend upon defusion, for example, because it is hard to embrace private events fully if they are as we evaluate them to be" (Hayes et al., 2013, p. 187).

What the model developed in this study also shows is that participants expressed ways that they remained active while also expressing forms of psychological inflexibility (see figure 5.2). Thus, a participant could experience psychological impact (anxiety) from chronic pain while also experiencing a moment where limitations are actively being imposed on their body from their chronic pain. When this happens during a moment where they are also showing an adaptive behavioural response, activity interruption and activity maintenance may appear together but also out of alignment.
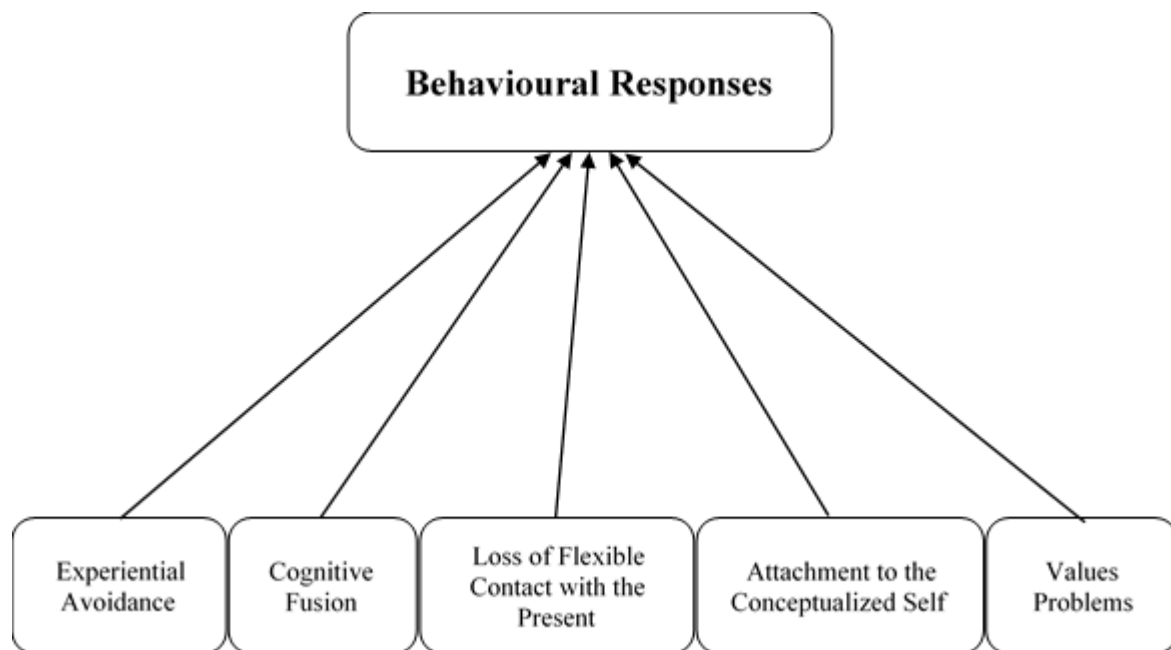
Figure 5.2 Psychological inflexibility subsumed under adaptive behavioural responses

For one participant, limitations on activity were equivalent to "never" being able to do anything, an example of catastrophizing anxiety that some of the participants could experience. These statements were captured in the Fear/Anxiety sub-theme of Psychological Impacts of chronic pain. At the same time, the participant expressed activity engagement that displayed the behavioural response Pushing Through Pain. This helps illustrate that participants could enter into activities in limited ways while exhibiting elements of what ACT would define as psychological inflexibility.

Behavioural Responses expressed by participants showed the greatest variety of participant engagement with activity alongside experiences of chronic pain. This, along with what may be classified as unhelpful thoughts and expressions of pain-related anxiety, suggest that participant engagement with activities does not need to first be experienced in their pain-related cognitions and emotions, but can happen in behavioral domains first. The findings of this study suggest that using behaviorally-focused therapeutic interventions, such as Morita therapy (Morita, 1928/1998), could be helpful in working with individuals with chronic pain to improve their functioning.

Participants expressed experiences reflective of the Moritian concept of *arugamama*, highlighted especially where Behavioural Responses precipitated Cognitive Adaptation. The act of engaging in the activity itself was shown for participant 8 to precipitate any cognitive adaptation in her decision to begin walking. She also recognized that it did not resolve the pain but still engaged with the activity while still in pain. In this way, Morita therapy corresponds to the adaptive behavioural response that she made that occurred prior to any cognitive adaptation. Morita therapy would also not depend on such cognitive adaptation, but would simply focus on

activity engagement and, through repeated engagement, the experienced understanding that engaging in activity is possible.

Addressing environmental factors. The results of this study further show that environmental factors operate both as barriers to and enablers of activity. The ICF (WHO, 2013) captures this in its inclusion of environmental factors (EFs) as contributors to the functioning or performance of an individual. As Bostan, Oberhauser, Stucki, Bickenbach, and Cieza (2014) write, "Performance is the outcome of the interaction between the intrinsic capacity of the person with both the environmental and personal factors" (p. 806). Environmental factors stand outside of intervention when seeing how the components of psychological inflexibility and PF are subsumed under the themes generated by this study. ACT interventions address psychological and behavioural components of the individual (Flaxman et al., 2010). Morita therapy, with its focus on behavioural engagement with life, also does not possess interventional mechanisms with which to address environmental barriers to activity. While these interventions may address the evaluations of structural and social barriers, as well as the willingness of the individual to engage with certain environmental factors, these interventions cannot necessarily create change within any external reality for the clients.

Where these environmental factors are addressed in currently existing programs include rehabilitation programs that provide mechanisms to enable individual engagement. Social workers are also well-suited to addressing EFs, as they "operate from a position of social justice, possess a global view based on an appreciation of a 'person in environment' perspective, and follow an engagement process that 'starts where the client is'" (Hruschak & Cochran, 2017, p. 575). The implication for the psychological clinician that is suggested by this model is the limitation of counselling interventions and the need to help the client with chronic pain to engage

with resources that will address EFs in ways that address the fullness of the lived context with which the individual is trying to remain engaged or re-engage.

Addressing identity. This study provides further support around the impact that chronic pain has on individual identity. Previous studies have shown impact on identity as worker (Beatty, 2012; Beatty & Joffe, 2006), as a person able to complete goals (Charmaz, 1995), and of their social identities (Bailly, Foltz, Rozenburg, Fautrel, & Gossec, 2015). While studies have shown that family identities may not be as affected (Bailly et al., 2015; Harris, Morley, & Barton, 2003), this study showed that at least one participant, participant 6, found his identity as husband and father heavily affected by his chronic pain. This finding suggests that counsellors pay careful attention to a client's identity by identifying aspects of their identity and helping them to develop new identities.

There are many avenues for exploration of identity with clients with chronic pain. One is through the use of the validationgram developed by Ishiyama (1995), which is based on Ishiyama's (1989) earlier self-validation model. This activity would help individuals direct their energy on areas where validation is lacking or has been lost through graphical and narrative activities. An additional avenue of exploration would be through the use of narrative interventions aimed at identity reconstruction (Holloway, Sofaer, & Walker, 2000; Phillips, 2017).

5.1.4   Strengths and Limitations

The different methods used with this study helped provide guidance and flexibility for participants in their recall and narration of their experience with chronic pain. The lifeline activity itself helped participants situate their narratives within periods of their life that they defined in a variety of ways. Each of the participants used marks they drew on the lifeline to

define years, either calendar years or (in the case of participant 7) their age. These then provided ways for them to produce a graphical representation of their level of activity during those periods of time as they were able to initially recall. Participants also often used descriptive phrases to capture experiences or branching points for both their recall and to aid my own understanding.

As they provided descriptive narratives during the second portion of the recorded interviews, participants often also adjusted these lifelines by adjusting the line itself or by adding further descriptive words and phrases. These adjustments helped to highlight the fluid nature of the memory recall of the participants. As they recalled specific memories seated within the chronological structure provided by the lifeline, they realized that either the lifeline didn't accurately reflect the narrative as it was being recalled, or that the lifeline had not accounted for a specific memory not initially recalled during the drawing phase of the interview.

This supports the purposes of the lifeline as outlined in Chapter 3: Method. The lifeline was a chronologic tool that aided in the structuring and ordering of participant memory. Without the use of the lifeline, participants may have skipped around in their narrative and produced a disjointed recall. Additionally, using the lifeline helped participants to see whether what they were telling in narrative form was reflected in the peaks and valleys as drawn on the lifeline. If the story did not match the lifeline, then adjustments could be made that helped participants feel more secure in their narrative construction. The results of this study suggest that using a lifeline structured for narrative interviews that have chronological elements focused on memory recall can help produce a product about which participants will feel more securely represents their lived experience.

In conducting the analysis of the interviews and producing this report, I closely followed Braun and Clarke's (2006) guidelines for pitfalls to avoid and conducting good thematic analysis

as referenced in tables 3.4 and 3.5 above. Points 1 through 5 in Table 3.4 in Chapter 3: Method were followed to ensure that the analysis was not poor. The analysis provided has been interpretive and goes beyond the literal content of the statements. The themes were generated from the data and not restating the research questions as themes. The analysis is strong, coherent, and each theme is unique enough to warrant standing on its own while also cohering "around a central idea or concept" (p. 94). The analytic claims have been supported by the participant statements and their agreement with the coding; and that the analysis and claims used in this research study were in alignment with each other and with the research question. These 5 steps were also part of ensuring that Braun and Clarke's 15-point checklist for good thematic analysis was adhered to throughout the study from transcription to the creation of this written report (see Table 3.5 in Chapter 3: Method).

There are limitations for this study that are important to recognize. The sample size was small, and sampling was primarily from a convenience population. All participants were professionals and had at least completed high school (with the majority have a four-year university degree or higher), thus they were also able to articulate their experiences quite well. Therefore, there may be limited applicability of the results themselves beyond this population. Finally, all the participants were able to host me in their home or could travel to my office for their interview. Including participants from less accessible or more vulnerable populations would be important for any future continuations of this study.

5.1.5   Conclusion

This study helped show that individuals can experience the effects of chronic pain across multiple domains in their lives, whether in the ways they adapted or the ways they saw themselves and their activities as interrupted or lost. The rich narratives provided insight that is

often not gained without qualitative methodologies that allow for individuals to provide robust accounts of their lived experiences. The use of the lifeline helped provide a chronological structure for these narratives, which helped guide and expand both narration and recall. Participant experiences described throughout the interviews displayed a range of the effects that chronic pain can have in the lived contexts of those individuals with chronic pain. These effects were at times limiting and isolating. However, participants also displayed adaptive responses. They expressed interaction with barriers and facilitators from their environmental context, which also contributed to either loss and interruption of activity or gains and maintenance of activity. These losses and gains provide insight into how individuals can display either maladaptive or adaptive responses to chronic pain *in vivo*. This study shows the importance of attending to the full scope of impact that chronic pain has, as well as the broad range of adaptive responses necessary for individuals to be active and find value and meaning in living with chronic pain.

Chapter 6: Personal Reflection

This project has been one both personal and professional. Personally, I have struggled with chronic pain to varying degrees throughout most of my adult life. I struggled to find new definitions of self and new ways of being as old identities and activities became distressing losses. Even today, thoughts of the impact an activity could have on my pain raise internal concern and struggle around the thought of engaging in that activity.

At the same time, very real limitations and struggles occur. Transcription time in this project was increased due to increased hand and wrist pain. Stress from the rigors of schoolwork would also lead to increased pain. At times the pain disrupted my sleeping, mood, and eating. There were moments where the thought, "perhaps this thesis is too much and I should switch my program to a non-thesis degree" were cognitively entertained.

What kept me going through this were a number of factors. One, I willingly began to stretch out the time that I spent typing, which was accomplished through multiple factors. One, I acknowledged that my not completing a transcript in time that I thought I "should" did not signify either "failure" of the activity, nor define me as a "failure." Two, I focused on the value that I found in doing this thesis and seeing it through to completion. I also experienced a way to be accepting of pain's presence while typing and a mindfulness to the intensity of my pain. I focused on the work I could accomplish, used what I had accomplished as "truth" that I could do more when pain was within my own tolerable limits, and set my sights on the value that I had in the completion of this project. I developed a self-as-context around the present moment, while not adopting a self-as-content that would highlight breaks as incompletions and negative self-descriptors.

Nevertheless, I sit weighed down by the knowledge that my research methodology limited what I could do with the data produced by these interviews. The narratives told by participants are stories full of loss, suffering, anger, dismissal, despair, gains, hope, and a spirt of strength and fortitude that was inspiring to me to both hear and read through. Chronic pain, arising from a variety of causes for these participants, was a story about losing oneself and gaining a new self. Those new selves are still in progress, activities of self-creation and co-creation that will continue forward in each of their lives. What it means to be a father, a mother, a partner, a lover, a worker, a contributor, and more are all concepts that they have struggled with to find new meaning within themselves.

As a person who also has chronic pain, as well as a counsellor, I found my greatest difficulty during the interviews themselves to be avoiding diving into empathy and relationship of understanding. It was inviting to my own spirit to feel connected in ways that are not possible with those who do not have chronic pain. The fear of judgement, the responses of "have you tried this?", and the deeply felt longing for connection and understanding are something I know all-too-well.

I was asked more than once by participants, "Why are you doing this study?" It was a question that I wrestled with as I developed this second thesis project. I believe deeply that finding new ways of being that display a lived acceptance of chronic pain are important for individuals to gain in their identity and their fulfillment from life. The literature, as discussed above, shows great potential benefits for therapeutic interventions from ACT. I found as I reflected on this further that I knew that I didn't know what we as counsellors would be asking persons with chronic pain to learn to give up, to try, to live with, to be with. As I went through these interviews, I became thankful for the question I asked, the willingness to share displayed

by each participant, and I also developed a newer appreciation for each of these participants and the many people in the population from which they come: people with chronic pain. If this thesis can provide the reader with a fraction of that appreciation, hope, and understanding, this project will have been worth it. In that moment of positive impact on the reader I will have found my answer and be able to say, "This is why I did this project."

References

Aldous, J. L. (1994). Cross-cultural counselling and cross-cultural meanings: An exploration of Morita psychotherapy. *Canadian Journal of Counselling*, *28*(3), 238-249. Retrieved from http://cjcp.journalhosting.ucalgary.ca/cjc/index.php/rcc/article/view/18

Allen, C., Murphy, A., Kiselbach, S., VandenBerg, S., & Wiebe, E. (2015). Exploring the experience of chronic pain among female survival sex workers: A qualitative study. *BMC Family Practice, 16*, 182. doi: 10.1186/s12875-015-0395-6

Anderson, K. O., Dowds, B. N., Pelletz, R. E., Edwards, W. T., & Peeters-Asdourian, C. (1995). Development and initial validation of a scale to measure self-efficacy beliefs in patients with chronic pain. *Pain*, *63*(1), 77-83. https://doi.org/10.1016/0304-3959(95)00021-J

Apkarian, A. V., Baliki, M. N., & Geha, P. Y. (2009). Towards a theory of chronic pain. *Progress in Neurobiology, 87*, 81-97. doi: 10.1016/j.pneurobio.2008.09.018

Arduser, L. (2014). Agency in illness narratives: A pluralistic analysis. *Narrative Inquiry, 24*(1), 1-27. doi: 10.1075/ni.24.1.01ard

Arnstein, P., Caudill, M., Mandle, C. L., Norris, A., & Beasley, R. (1999). Self-efficacy as a mediator of the relationship between pain intensity, disability and depression in chronic pain patients: *Pain*, *80*(3), 483–491. http://doi.org/10.1016/S0304-3959(98)00220-6

Asghari, A., & Nicholas, M. K. (2001). Pain self-efficacy beliefs and pain behaviour. A prospective study: *Pain*, *94*(1), 85–100. http://doi.org/10.1016/S0304-3959(01)00344-X

Asmundson, G. J. G., Norton, P. J., & Norton, G. R. (1999). Beyond pain: The role of fear and avoidance in chronicity. *Clinical Psychology Review*, *19*(1), 97-119. doi:10.1016/S0272-7358(98)00034-8

Asmundson, G. J., Norton, P. J., & Vlaeyen, J. W. S. (2004). Fear-avoidance models in chronic

pain: An overview. In G. J. Asmundson, J. W. S. Vlaeyen, & G. Crombez (Eds.),

    Understanding and treating fear of pain (pp. 3-24). Oxford: Oxford University Press

Ayre, M., & Tyson, G. A. (2001). The Role of Self-Efficacy and Fear-Avoidance Beliefs in the

    Prediction of Disability. *Australian Psychologist*, *36*(3), 250-253. https://doi.org/10.1080/

    00050060108259663

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change.

    Psychological Review, *84*(2), 191-215. doi: 10.1037/0033-295X.84.2.191

Barlow, J., Wright, C., & Cullen, L. (2002). A job-seeking self-efficacy scale for people with

    physical disabilities: Preliminary development and psychometric testing. *British Journal*

    of Guidance and Counselling, *30*(1), 37-53. https://doi.org/10.1080/

    030698880220106500

Bawa, F. L. M., Mercer, S. W., Atherton, R. J., Clague, F., Keen, A., Scott, N. W., & Bond, C.

    M. (2015). Does mindfulness improve outcomes in patients with chronic pain?

    systematic review and meta-analysis. *The British Journal of General Practice, 65*(635),

    e387-e400. doi:10.3399/bjgp15X685297

Beatty, J. E. (2012). Career barriers experienced by people with chronic illness: A U.S. study.

    Employee Responsibility and Rights Journal, *24*(2), 91-110. doi: 10.1007/s10672-011-

    9177-z

Beatty, J. E., & Joffe, R. (2006). An overlooked dimension of diversity: The career effects of

    chronic illness. *Organizational Dynamics*, *35*(2), 182-195. doi: 10.1016/j.orgdyn.

    2006.03.006

Belli, R. F. (1998). The structure of autobiographical memory and the event history calendar: Potential improvements in the quality of retrospective reports in surveys. *Memory, 6*(4), 383-406. doi: 10.1080/741942610

Berger, P. L., & Luckman, T. (1967). The social construction of reality: A treatise in the sociology of knowledge [Kindle version].

Betz, N. E., & Hackett, G. (1986). Applications of self-efficacy theory to understanding career choice behavior. *Journal of social and clinical psychology*, *4*(3), 279-289. doi: 10.1521/jscp.1986.4.3.279

Betz, N. E., & Luzzo, D. A. (1996). Career assessment and the career decision-making self-efficacy scale. *Journal of Career Assessment*, *4*(4), 413-428. https://doi.org/10.1177/106907279600400405

Boschen, K. A., Robinson, E., Campbell, K. A., Muir, S., Oey, E., Janes, K., … Katz, J. (2016). Results from 10 years of a CBT pain self-management outpatient program for complex chronic conditions. *Pain Research and Management, 2016*, 1-10. doi:10.1155/2016/4678083

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi: 10.1191/1478088706qp063oa

Burri, A., Ogata, S., Vehof, J., & Williams, F. (2015). Chronic widespread pain: Clinical comorbidities and psychological correlates. *Pain, 156*(8), 1458-1464. doi: 10.1097/j.pain.0000000000000182

Carleton, R. N. & Asmundson, G. J. G. (2009). The multidimensionality of fear of pain: Construct independence for the fear of pain questionnaire-short form and the pain anxiety symptoms scale-20. *The Journal of Pain*, *10*(1), 29-37. doi: 10.1016/j.jpain.2008.06.007

Chan, Z. C. Y., Fung, Y., & Chien, W. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process? *The Qualitative Report, 18*(30), 1-9.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, *5*(2), 168-195. doi: 10.1111/1467-9566.ep10491512

Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time.* New Brunswick, NJ: Rutgers University Press.

Charmaz, K. (1995). The body, identity, and self: Adapting to impairment. *Sociological Quarterly*, *36*(4). Retrieved from http://www.jstor.org.ezproxy.library.ubc.ca/stable/4121346

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.) [Kindle for Mac version]. Thousand Oaks, CA: Sage Publications Inc. Retrieved from Amazon.com

Chen, C. P. (1998). A holistic approach to worklife dynamics: Morita philosophy-based career counselling. *Counselling Psychology Quarterly*, *11*(3), 239-256. doi:10.108/09515079808254058

Chen, C. P. (2010). Morita therapy and its counseling implications for social anxiety. *Counselling Psychology Quarterly, 23*(1), 67-82. doi: 10.1080/09515071003629805

Chiesa, A., & Serretti, A. (2011). Mindfulness-based interventions for chronic pain: A systematic review of the evidence. *The Journal of Alternative and Complementary Medicine, 17*(1), 83-93. doi:10.1089/acm.2009.0546

Craner, J. R., Sperry, J. A., Koball, A. M., Morrison, E. J., & Gilliam, W. P. (2017). Unique contributions of acceptance and catastrophizing on chronic pain adaptation. *International Journal of Behavioral Medicine, 24*(4), 542-551. doi: 10.1007/s12529-017-9646-3

Crombez, G., Vlaeyen, J. W. S., Heuts, P. H. T. G., & Lysens, R. (1999). Pain-related fear is more disabling than pain itself: evidence on the role of pain-related fear in chronic back pain disability. *Pain*, *80*(1), 329-339. doi: 10.1016/S0304-3959(98)00229-2

Dahan, A., van Velzen, M., & Niesters, M. (2014). Comorbidities and the complexities of chronic pain. *Anesthesiology, 121*(4), 675-677. doi: 10.1097/ALN.0000000000000402

Dahl, J., Wilson, K., & Nilsson, A. (2004). Acceptance and commitment therapy and the treatment of persons at risk for long-term disability resulting from stress and pain symptoms: A preliminary randomized trial. *Behavior Therapy*, *35*(4), 785–801. http://doi.org/10.1016/S0005-7894(04)80020-0

de Boer, M. J., Steinhagen, H. E., Versteegen, G. J., Struys, M. M. R. F, & Sanderman, R. (2014). Mindfulness, acceptance and catastrophizing in chronic pain. *PLoS One, 9*(1), e87445. doi: 10.1371/journal.pone.0087445

de Moraes Vieira, É. B., de Góes Salvetti, M., Damiani, L. P., & de Mattos Pimenta, C. A. (2014). Self-Efficacy and Fear Avoidance Beliefs in Chronic Low Back Pain Patients: Coexistence and Associated Factors. *Pain Management Nursing*, *15*(3), 593–602. http://doi.org/10.1016/j.pmn.2013.04.004

Dowrick, C., Dixon-Woods, M., Holman, H., & Weinman, J. (2005). What is chronic illness? *Chronic Illness, 1*(1), 1-6. 10.1177/17423953050010010801

Dueñas, M., Ojeda, B., Salazar, A., Mico, J. A., & Failde, I. (2016). A review of chronic pain impacts on patients, their social environment and the health care system. *Journal of Pain Research, 9*, 457-467. doi: 10.2147/JPR.S105892

Falvo, D. R. (2014). *Medical and psychosocial aspects of chronic illness and disability*. Burlington, MA: Jones & Bartlett Learning, LLC.

Fish, R. A., McGuire, B., Hogan, M., Morrison, T. G., & Stewart, I. (2010). Validation of the

    Chronic Pain Acceptance Questionnaire (CPAQ) in an Internet sample and development

    and preliminary validation of the CPAQ-8. *Pain*, *149*(3), 435–443. http://doi.org/10.

    1016/j.pain.2009.12.016

Fisher, B. J., Haythornthwaite, J. A., Heinberg, L. J., Clark, M., & Reed, J. (2001). Suicidal

    intent in patients with chronic pain. *Pain, 89*(2), 199-206. 10.1016/S0304-

    3959(00)00363-8

Flaxman, P. E., Blackledge, J., & Bond, F. W. (2010). *Acceptance and commitment therapy:*

    distinctive features. Retrieved from https://ebookcentral.proquest.com

France, M. H. (1989). A Morita therapy approach to career issues. *International Bulletin of*

    Morita Therapy, *2*(2), 40-46

Fujii, T., Matsudaira, K., & Oka, H. (2013). Factors associated with fear-avoidance beliefs about

    low back pain. *Journal of Orthopaedic Science, 18*, 909-915. doi: 10.1007/s00776-013-

    0448-4

Gay, C. W., Horn, M. E., Bishop, M. D., Robinson, M. E., & Bialosky, J. E. (2015).

    Investigating dynamic pain sensitivity in the context of the fear-avoidance model.

    European Journal of Pain, 19, 45-58. doi:10.1002/ejp.519

Gerrits, M. M. J. G., van Oppen, P., Marwijk, H. W. J., Penninx, B. W. J. H., & van der Horst,

    H. E. (2014). Pain and the onset of depressive and anxiety disorders. *Pain, 155*, 53-59.

    http://dx.doi.org/10.1016/j.pain.2013.09.005

Gerrits, M. M. J. G., Vogelzangs, N., van Oppen, P., van Marwijk, H. W. J., van der Horst, H., &

    Penninx, B. W. J. H. (2012). Impact of pain on the course of depressive and anxiety

    disorders. *Pain, 153*, 429-436. doi: 10.1016/j.pain.2011.11.001

Gramling, L. F., & Carr, R. L. (2004). Lifelines: A life history methodology. *Nursing Research, 53*(3), 207-210. doi: 10.1097/00006199-200405000-00008

Gutiérrez, O., Luciano, C., Rodriguez, M., & Fink, B. (2004). Comparison between an acceptance-based and a cognitive-control-based protocol for coping with pain. *Behavior Therapy*, *35*(4), 767–783. http://doi.org/10.1016/S0005-7894(04)80019-4

Hann, K. E. J., & McCracken, L. M. (2014). A systematic review of randomized controlled trials of acceptance and commitment therapy for adults with chronic pain: Outcome domains, design quality, and efficacy. *Journal of Contextual Behavioral Science, 3*(4), 217-227. doi: 10.1016/j.jcbs.2014.10.001

Harris, S., Morley, S., & Barton, S. B. (2003). Role loss and emotional adjustment in chronic pain. *Pain*, *105*, 363-370. doi: 10.1016/S0304-3959(03)00251-3

Hayes, S. C., Levin, M. E., Plumb-Vilardaga, J., Villatte, J. L., & Pistorello, J. (2013). Acceptance and Commitment Therapy and contextual behavioral science: Examining the progress of a distinctive model of Behavioral and Cognitive Therapy. *Behavior Therapy, 44*(2), 180-198. doi: 10.1016/j.beth.2009.08.002

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy, 44*(1), 1-25. doi: 10.1016/j.brat.2005.06.006

Hergenrather, K. C., Rhodes, S. D., Turner, A. P., & Barlow, J. (2008). Persons with disabilities and employment: Application of the self-efficacy of job-seeking skills scale. *Journal of rehabilitation*, *74*(3), 34. Retrieved from http://link.galegroup.com.ezproxy.library. ubc.ca/apps/doc/A186950681/HRCA?u=ubcolumbia&sid=HRCA&xid=5685a9cd

Hilton, L., Hempel, S., Ewing, B. A., Apaydin, E., Xenakis, L., Newberry, S., … Maglione,

M. A. (2017). Mindfulness meditation for chronic pain: Systematic review and meta-analysis. *Annals of Behavioral Medicine, 51*(2), 199-213. doi: 10.1007/s12160-016-9844-2

Hofmann, S. G. (2008). Acceptance and commitment therapy: New wave or Morita therapy? *Clinical Psychology: Science and Practice*, *15*(4), 280-285. doi:10.1111/j.1468-2850.2008.00138.x

Holloway, I., Sofaer, B., & Walker, J. (2000). The transition from well person to "pain afflicted" patient: The career of people with chronic back pain. *Illness, Crisis & Loss, 8*(4), 373-387. doi:10.1177/105413730000800403

Hughes, L. S., Clark, J., Colclough, J. A., Dale, E., & McMillan, D. (2017). Acceptance and commitment therapy (ACT) for chronic pain: A systematic review and meta-analyses. *The Clinical Journal of Pain, 33*(6), 552-568. doi:10.1097/AJP.0000000000000425

Iles, R. A., Davidson, M., & Taylor, N. F. (2008). Psychosocial predictors of failure to return to work in non-chronic non-specific low back pain: A systematic review. *Occupational and Environmental Medicine*, *65*(8), 507-517. doi:10.1136/oem.2007.036046

Ishikawa, Y. (2010). Philosophy of accepting as it is (ARUGAMAMA) in Japanese psychotherapy, Morita therapy. *The Journal of Sagami Women's University*, *74*, 1–5. Retrieved from http://ci.nii.ac.jp/naid/110008454378/en

Ishiyama, F. I. (1986a). Morita therapy: Its basic features and cognitive intervention for anxiety treatment. *Psychotherapy: Theory, Research, Practice, Training*, *23*(3), 375-381. doi: 10.1037/h0085626

Ishiyama, F. I. (1986b). Positive reinterpretation of fear of death: A Japanese (Morita)

psychotherapy approach to anxiety treatment. *Psychotherapy: Theory, Research, Practice, Training*, *23*(4), 556-562. http://dx.doi.org/10.1037/h0085657

Ishiyama, F. I. (1987). Use of Morita therapy in shyness counselling in the West: Promoting clients' self-acceptance and action taking. *Journal of Counseling and Development*, *65*(10), 547-551. doi: 10.1002/j.1556-6676-1987-tn.00705.x

Ishiyama, F. I. (1990a). A Japanese perspective on client inaction: Removing attitudinal blocks through Morita therapy. *Journal of Counseling and Development*, *68*(5), 566-570.

Ishiyama, F. I. (1990b). Japanese perspective on client inaction and procrastination: Morita therapy. *International Journal for the Advancement of Counselling*, *13*(2), 119-128. doi: 10.1007/BF00115707

Ishiyama, F. I. (1990c). Meaningful Life Therapy: Use of Morita therapy principles in treating patients with cancer and intractable diseases. *International Bulletin of Morita Therapy*, *3*(2), 77-84.

Ishiyama, F. I. (1995). Use of validationgram in counselling: Exploring sources of self-validation and impact of personal transition. *Canadian Journal of Counselling*, *29*(2), 134-136.

Ishiyama, F. I. (2003). A bending willow tree: A Japanese (Morita therapy) model of human nature and client change. *Canadian Journal of Counseling*, *37*(3), 216-231.

Iwai, H., & Reynolds, D. K. (1970). Morita psychotherapy: The views from the West. *American Journal of Psychiatry*, *126*(7), 1031-1036. http://dx.doi.org/10.1176.ajp.126.7.1031

Jerant, A.F., von Friederichs-Fitzwater, M. M., & Moore, M. (2004). Patients' perceived barriers to active self-management of chronic conditions. *Patient Education and Counseling, 57*, 300-307. doi: 10.1016/j.pec.2004.08.004

Jeong, S., & Cho, S. (2016). Acceptance and patient functioning in chronic pain: The mediating

role of physical activity. *Quality of Life Research, 26*(4), 903-911. doi: 10.1007/s11136-016-1404-5

Kaiser, R. S., Mooreville, M., & Kannan, K. (2015). Psychological interventions for the management of chronic pain: A review of current evidence. *Current pain and headache reports, 19*(9), 1-8. doi:10.1007/s11916-015-0517-9

Kitanishi, K., & Mori, A. (1995). Morita therapy: 1919 to 1995. *Psychiatry and Clinical Neurosciences*, *49*(5-6), 245-254. doi: 10.1111/j.1440-1819.1995.tb01896.x

Kurokawa, N. (2006). Morita therapy in psychosomatic medicine. *International Congress Series*, 1287, 313-315. doi: 10.1016/j.jcs.2005.12.040

Kroska, E. B. (2016). A meta-analysis of fear-avoidance and pain-intensity: The paradox of chronic pain. *Scandinavian Journal of Pain, 13*, 43-58. doi: 10.1016/j.sjpain.2016.06.011

Larsen, P. D., Engel, J. K., & Prentice, D. (2014). Introduction to Chronicity in Canada. In M. L. Kramer-Kile & J. C. Osuji (Eds.), *Chronic illness in Canada: Impact and intervention* (pp. 45-68). Burlington, MA: Jones & Bartlett Learning, LLC.

Larsen, P. D., Hummel, F. I., & Osuji, J. C. (2014). Adaptation. In M. L. Kramer-Kile & J. C. Osuji (Eds.), *Chronic illness in Canada: Impact and intervention* (pp. 45-68). Burlington, MA: Jones & Bartlett Learning, LLC.

Larsen, P. D., & Kramer-Kile, M. L. (2014). The Illness Experience. In M. L. Kramer-Kile & J. C. Osuji (Eds.), *Chronic illness in Canada: Impact and intervention* (pp. 45-68). Burlington, MA: Jones & Bartlett Learning, LLC.

Leder, D. (2016). The experiential paradoxes of pain. *Journal of Medicine and Philosophy, 41*, 444-460. doi: 10.1093/jmp/jhw020

Leeuw, M., Goossens, M. E. J. B., Linton, S. J., Crombez, G., Boersma, K., & Vlaeyen, J. W. S. (2007). The fear-avoidance model of musculoskeletal pain: Current state of scientific evidence. *Journal of Behavioral Medicine*, *30*(1), 77–94. http://doi.org/10.1007/s10865-006-9085-0

Lethem, J., Slade, P. D., Troup, J. D. G., & Bentley, G. (1983). Outline of a fear-avoidance model of exaggerated pain perception—I. *Behaviour Research and Therapy, 21*(4), 401-408. doi: 10.1016/0005-7967(83)90009-8

Leung, L. (2012). Pain catastrophizing: An updated review. *Indian Journal of Psychological Medicine*, 34(3), 204. doi: 10.4103/0253-7176.106012

Leung, P. P. Y. (2010). Autobiographical timeline: A narrative and life story approach in understanding meaning-making in cancer patients. *Illness, Crisis & Loss, 18*(2), 111-127. doi: 10.2190/IL.18.2.c

LeVine, P. (1993). Morita-based therapy and its use across cultures in the treatment of Bulimia Nervosa. *Journal of Counseling and Development*, *72*(1), 82. Retrieved from http://search.proquest.com.ezproxy.library.ubc.ca/docview/219107409?accountid=14656

Loffe, H., and L. Yardley. (2004). "Content and Thematic Analysis." In *Research Methods for Clinical and Health Psychology*, edited by D. F. Marks and L. Yardley, 56–68. London: Sage. http://dx.doi.org.ezproxy.library.ubc.ca/10.4135/9781849209793

Lööf, H., Demmelmaier, I., Henriksson, E. W., Lindblad, S., Nordgren, B., Opava, C., & Johansson, U.-B. (2014). Fear-avoidance beliefs about physical activity in adults with rheumatoid arthritis. *Scandinavian Journal of Rheumatology*, *44*(2), 93–99. http://doi.org/ 10.3109/03009742.2014.932432

McBeth, J., MacFarlane, G. J., Hunt, I. M., & Silman, A. J. (2001). Risk factors for persistent

chronic widespread pain: a community-based study. *Rheumatology*, *40*(1), 95-101.

https://doi.org/10.1093/rheumatology/40.1.95

McCracken, L. M., DaSilva, P., Skillicorn, B., & Doherty, R. (2014). The Cognitive Fusion

Questionnaire: A preliminary study of psychometric properties and prediction of

functioning in chronic pain. *The Clinical journal of pain*, *30*(10), 894-901. doi:

10.1097/AJP.0000000000000047

McCracken, L. M., & Eccleston, C. (2003). Coping or acceptance: what to do about chronic

pain? *Pain*, *105*(1), 197–204. http://doi.org/10.1016/S0304-3959(03)00202-1

McCracken, L. M., & Eccleston, C. (2005). A prospective study of acceptance of pain and

patient functioning with chronic pain: *Pain*, 118(1), 164–169. http://doi.org/10.1016/

j.pain.2005.08.015

McCracken, L. M., & Keogh, E. (2009). Acceptance, mindfulness, and values-based action

may counteract fear and avoidance of emotions in chronic pain: An analysis of anxiety

sensitivity. *The Journal of Pain*, *10*(4), 408-415. doi: 10.1016/j.jpain.2008.09.015

McCracken, L. M., & Morley, S. (2014). The psychological flexibility model: A basis for

integration and progress in psychological approaches to chronic pain management. *The*

Journal of Pain, 15(3), 221-234. http://dx.doi.org/10.1016/j.jpain.2013.10.014

McCracken, L. M., & Vowles, K. E. (2006). Acceptance of chronic pain. *Current Pain and*

Headache Reports, *10*(2), 90–94. http://doi.org/10.1007/s11916-006-0018-y

McCracken, L. M., Vowles, K. E., & Eccleston, C. (2004). Acceptance of chronic pain:

component analysis and a revised assessment method: *Pain*, *107*(1), 159–166.

http://doi.org/10.1016/j.pain.2003.10.012

McWilliams, L. A., Cox, B. J., & Enns, M. W. (2003). Mood and anxiety disorders associated

with chronic pain: an examination in a nationally representative sample: *Pain*, *106*(1), 127–133. http://doi.org/10.1016/S0304-3959(03)00301-4

Morita, S. (1928/1998). P. L. Vine (Ed.), *Morita therapy and the true nature of anxiety-based disorders (shinkeishitsu)*. (A. Kondo, Trans.) Albany: State University of New York Press.

Nagata, K., Hasegawa, T., Okano, K., Kiyama, K., Aoyama, Y., Hirokado, Y., & Otsuki, C. (2006). Development and evaluation of Balneo-Morita therapy for the treatment of fibromyalgia syndrome. *International Congress Series*, *1287*, 97-100. doi: 10.1016/j.ics.2005.12.057

Nakamura, K., Kitanishi, K., Maruyama, S., Ishiyama, I., Ito, K., Tatematsu, K., … & Ichikawa, M. (2009/2010). Guidelines for practising outpatient Morita Therapy. (I. Ishiyama, Trans.) Monograph published by Japanese Society for Morita Therapy, 32 pages.

Neblett, R. (2017). Pain catastrophizing: An historical perspective. *Journal of Applied Behavioural Research, 22*(e12086). https://doi.org/10.1111/jabr.12086

Ogawa, B. (2013). *The desire for life: The practitioner's guide to Morita Therapy* [Kindle iOS Reader App version]. Available from http://www.amazon.com/

Patterson, M. L., Markey, M. A., & Somers, J. M. (2012). Multiple paths to just ends: Using narrative interviews and timelines to explore health equity and homelessness. *International Journal of Qualitative Methods, 11*(2), 132-151. doi:10.1177/160940691201100202

Phillips, L. u. (2017). A narrative therapy approach to dealing with chronic pain. International

Journal of Narrative Therapy & Community Work, (1), 21-30. Retrieved from

http://ezproxy.library.ubc.ca/login?url=https://search-proquest-com.ezproxy.library.

ubc.ca/docview/1915853882?accountid=14656

Pike, A., Hearn, L., & Williams, Amanda C de C (2016). Effectiveness of psychological

interventions for chronic pain on health care use and work absence: Systematic review

and meta-analysis. *Pain, 157*(4), 777-785. doi: 10.1097/j.pain.0000000000000434

Ravesloot, C., Berendts, C., and Schiwal A. (2017). Can people catastrophize barriers? An

exploratory analysis of the association between pain catastrophizing and perceptions of

environmental factors. *Disability and Health Journal, 10*, 65-72. doi: 10.1016/

j.dhjo.2016.10.001

Ravn, S. L., Louison, V., Vaegter, H. B., & Andersen, T. E. (2017). Pain-related acceptance as

a mediator in the fear avoidance model of chronic pain: A preliminary study. *Pain

Medicine, 0*(pnx223), 1-8. https://doi.org/10.1093/pm/pnx223

Reneman, M. F., Dijkstra, A., Dijkstra, P. U., & Geertzen, J. H. B. (2010). Psychometric

properties of chronic pain acceptance questionnaires: A systematic review. *European

Journal of Pain, 14*(5), 457-465. doi: 10.1016/j.ejpain.2009.08.003

Reynolds, D. K. (1989). Meaningful life therapy. *Culture, Medicine and Psychiatry*, *13*(4), 457-

463. doi: 10.1007/BF00052052

Richardson, E. J., Ness, T. J., Doleys, D. M., Baños, J. H., Cianfrini, L, & Richards, J. S. (2009).

Depressive symptoms and pain evaluations among persons with chronic pain:

Catastrophizing, but not pain acceptance, shows significant effects. *Pain, 147*, 147-152.

doi: 10.1016/j.pain.2009.08.030

Rimkeviciene, J., O'Gorman, J., Hawgood, J., & De Leo, D. (2016). Timelines for difficult

    times: Use of visual timelines in interviewing suicide attempters. *Qualitative Research in*

    Psychology, 13(3), 231-245. doi: 10.1080/14780887.2016.1170913

Schwandt, T. A. (2015). *The SAGE dictionary of qualitative inquiry* (4th ed.). Thousand Oaks,

    CA: SAGE Publications, Inc.

Scott, W., Hann, K. E. J., & McCracken, L. M. (2016). A comprehensive examination of

    changes in psychological flexibility following acceptance and commitment therapy for

    chronic pain. *Journal of Contemporary Psychotherapy, 46*(3), 139-148. doi: 10.1007/

    s10879-016-9328-5

Sheridan, J., Chamberlain, K., & Dupuis, A. (2011). Timelining: Visualizing experience.

    Qualitative Research, 11(5), 552-569. doi: 10.1177/1468794111413235

Smith, M. T., Edwards, R. R., Robinson, R. C., & Dworkin, R. H. (2004). Suicidal ideation,

    plans, and attempts in chronic pain patients: factors associated with increased risk. *Pain,*

    111(1-2), 201-208. https://doi.org/10.1016/j.pain.2004.06.016

Social and Aboriginal Statistics Division. (2013). *Disability in Canada: Initial findings from the*

    Canadian Survey on Disability. (Statistics Canada catalogue no. 89-654-X-No. 002).

    Retrieved from the Statistics Canada website http://www.statcan.gc.ca/pub/89-654-x/89-

    654-x2013002-eng.htm

Spates, C. R., Tateno, A., Nakamura, K., Seim, R. W., & Sheerin, C. M. (2011). The experiential

    therapy of Shoma Morita. *Annals Of Psychotherapy & Integrative Health*, *14*(1), 14-25.

    Retrieved September 1, 2014 from Academic Search Complete database.

Statistics Canada. (2012). *Table 115-0014 - Total income for adults with and without*

disabilities, by age group and sex, Canada, provinces and territories, occasional

(number unless otherwise noted). CANSIM (database). (accessed: 2015-06-28)

Statistics Canada (December, 2013). *Data tables: Canadian Survey on Disability*. Government

of Canada Publications (Catalogue no. CS89-654/1-2013E-PDF). Retrieved from

http://www.publications.gc.ca/pub?id=9.698643&sl=0

Strauser, D. R., & Berven, N. L. (2006). Construction and field testing of the Job Seeking Self-

Efficacy Scale. *Rehabilitation Counseling Bulletin, 49*(4), 207-218. https://doi.org/

10.1177/00343552060490040201

Sullivan, M. J. L., Bishop, S. R., & Pivik, J. (1995). The pain catastrophizing scale:

Development and validation. *Psychological Assessment, 7*(4), 524-532. doi:

10.1037/1040-3590.7.4.524

Sullivan, M. J. L., Thorn, B., Haythornthwaite, J. A., Keefe, F., Martin, M., Bradley, L. A., &

Lefebvre, J. C. (2001). Theoretical perspectives on the relation between catastrophizing

and pain. *The Clinical Journal of Pain, 17*. 52-64. doi:10.1097/00002508-200103000-

00008

Thorne, S., McCormick, J., & Carty, E. (1997). Deconstructing the gender neutrality of chronic

illness and disability. *Health Care for Women International*, *18*(1), 1–16. http://doi.org/

10.1080/07399339709516255

Tufford, L., & Newman, P. (2010). Bracketing in qualitative research. *Qualitative Social Work,*

11(1), 80-96. doi: 10.1177/1473325010368316

Turcotte, M. (2014). Persons with disabilities and employment. *Insights on Canadian Society.*

December. Statistics Canada Catalogue no. 75-006-X

Turner, J. A. & Aaron, L. A. (2001). Pain-related catastrophizing: What is it? *The Clinical*

Journal of Pain, 17(1), 65-71. doi:10.1097/00002508-200103000-00009

Turner, J. A., Holtzman, S., & Mancl, L. (2007). Mediators, moderators, and predictors of therapeutic change in cognitive-behavioral therapy for chronic pain. *Pain, 127*, 276-286. doi: 10.1016/j.pain.2006.09.005

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis. Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences, 15*(3), 398-405. doi: 10.1111/nhs.12048

van der Vaart, W. & Glasner, T. (2007). Applying a timeline as a recall aid in a telephone survey: a record check study. *Applied Cognitive Psychology, 21*(2), 227–38. doi: 10.1002/acp.1338

Veehof, M. M., Oskam, M.-J., Schreurs, K. M. G., & Bohlmeijer, E. T. (2011). Acceptance-based interventions for the treatment of chronic pain: A systematic review and meta-analysis: *Pain*, *152*(3), 533–542. http://doi.org/10.1016/j.pain.2010.11.002

Vick, A., & Lightman, E. (2010). Barriers to employment among women with complex episodic disabilities. *Journal of Disability Policy Studies*, *21*(2), 70–80. http://doi.org/10.1177/1044207309358588

Vlaeyen, J. W. S. & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: A state of the art. *Pain, 85*(3), 317-332. doi: 10.1016/S0304-3959(99)00242-0

Vowles, K. E., McCracken, L. M., McLeod, C., & Eccleston, C. (2008). The chronic pain acceptance questionnaire: Confirmatory factor analysis and identification of patient subgroups. *Pain, 140*(2), 284-291. doi: 10.1016/j.pain.2008.08.012

Vowles, K. E., McCracken, L. M., & O'Brien, J. Z. (2011). Acceptance and values-based

action in chronic pain: A three-year follow-up analysis of treatment effectiveness and process. *Behaviour Research and Therapy*, *49*(11), 748–755. http://doi.org/10.1016/j.brat.2011.08.002

Vowles, K. E., Sowden, G., & Ashworth, J. (2014). A comprehensive examination of the model underlying acceptance and commitment therapy for chronic pain. *Behavior Therapy, 45*(3), 390-401. doi: 10.1016/j.beth.2013.12.009

Vowles, K. E., Wetherell, J. L., & Sorrell, J. T. (2009). Targeting acceptance, mindfulness, and values-based action in chronic pain: Findings of two preliminary trials of an outpatient group-based intervention. *Cognitive and Behavioral Practice, 16*(1), 49-58. doi: 10.1016/j.cbpra.2008.08.001

Wells, S. M. (1998). *A delicate balance: Living successfully with chronic illness*. New York: Insight Books.

Wetherell, J. L., Afari, N., Rutledge, T., Sorrell, J. T., Stoddard, J. A., Petkus, A. J., … Atkinson, H. J. (2011). A randomized, controlled trial of acceptance and commitment therapy and cognitive-behavioral therapy for chronic pain: *Pain*, *152*(9), 2098–2107. http://doi.org/ 10.1016/j.pain.2011.05.016

Wicksell, R. K., Kemani, M., Jensen, K., Kosek, E., Kadetoff, D., Sorjonen, K., … Olsson, G. L. (2013). Acceptance and commitment therapy for fibromyalgia: A randomized controlled trial: ACT for fibromyalgia: A randomized controlled trial. *European Journal of Pain*, *17*(4), 599–611. http://doi.org/10.1002/j.1532-2149.2012.00224.x

World Health Organization. How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. October, 2013. Geneva: WHO

Yalcin, I., & Barrot, M. (2014). The anxiodepressive comorbidity in chronic pain. *Current Opinion in Anesthesiology*, *27*(5), 520-527. doi:10.1097/ACO.0000000000000116

Yu, L., & McCracken, L. M. (2016). Model and processes of Acceptance and Commitment Therapy (ACT) for chronic pain including a closer look at the self. *Current Pain and Headache Reports, 20*(2), 1-7. doi: 10.1007/s11916-016-0541-4

Yu, L., Norton, S., & McCracken, L. M. (2017). Change in "self-as-context" ("perspective-taking") occurs in Acceptance and Commitment Therapy for people with chronic pain and is associated with improved functioning. *The Journal of Pain, 18*(6), 664-672. http://dx.doi.org/10.1016/j.jpain.2017.01.005

Zautra, A. J., Davis, M. C., Reich, J. W., Nicassario, P., Tennen, H., Finan, P., … Irwin, M. R. (2008). Comparison of cognitive behavioral and mindfulness meditation interventions on adaptation to rheumatoid arthritis for patients with and without history of recurrent depression. *Journal of Consulting and Clinical Psychology*, *76*(3), 408–421. http://doi.org/10.1037/0022-006X.76.3.408

Appendices

Appendix A Telephone Intake Screener

This space is for researcher use only.			
Participant Number:		Date Received	

I would like to thank you for expressing your interest in taking part in this research study. This study is investigating how chronic pain affects an individual's personally significant activities.

Before we begin, I would like to ask you a couple of questions to help determine if you meet the recruitment criteria for this project. This information will remain absolutely confidential. Would that be ok with you? *If participant agrees, ask:*

1. Are you between the ages of 19 and 65 years old? ☐ **YES**   ☐ **NO** (Must be Yes)

    [Select participant's current age]

2. Do you have Chronic Pain?   ☐ **YES**   ☐ **NO** (*Must be Yes*)

If the participant does not meet the recruitment criteria: Thank you for taking the time to speak with me today. Unfortunately, you do not appear to meet the recruitment criteria for this research study. We appreciate your interest.

If the participant does meet the recruitment criteria: Now that I've made sure that you meet the criteria for participation in this study, I would like to take the time to describe what your participation will entail before asking you for more of your information.

You will be asked to join me for an in-person interview at your earliest convenience. Upon meeting, we will discuss the consent form that I will be emailing to you after this interview, I will answer any questions you may have, and I will then ask you to sign it. Once you have signed the consent form, we will start the interview.

The interview will begin with you completing a 20-item questionnaire that assesses your level of acceptance of your chronic pain. I will then ask you to complete a task called a lifeline. In this task, you will draw a line with ups and downs, like waves, in a way you believe best represents times of difficulty or improvement with respect to the activities in your life while you lived with chronic pain. Then, using that lifeline as a guide, I will ask you follow-up questions about this time in your life. Once this interview has been completed, I will ask you to once again complete the 20-item questionnaire.

This process will take between an hour and a half to two hours. Our interview will be audio-recorded, with your consent. You are entirely free to stop and terminate the interview at any time. There will be no repercussion whatsoever and no question will be asked should you

decide to terminate the interview. You will still receive the $10 token of appreciation, regardless of continuing or discontinuing your research involvement.

If this sounds like something you are still interested in, I would like to ask some questions that will provide me with some demographic information. No personally identifying information gathered today will appear in anything made public from this study. Demographic information will be used primarily for generally describing the persons who take part in this study.

Finally, I would like to also state that all the information you provide to me today is for use with this research only and will be kept completely confidential. Only I and my research supervisor, Dr. Ishiyama, will have access to this information. If you end up being a part of this research project, no information that can identify you will be used in any reports that are made from this research project. This remains true for any follow-up articles or presentations generated from this project as well. I have a few more questions to get your contact information so that I can send you the consent form for this study for your review before our interview. I would like to state that your participation in this project is completely voluntary. You are free to end your participation at any time and for any reason.

Name:	[Participant's full name]
Gender:	☐ **Male** ☐ **Female**
(Please indicate the gender the participant identifies with)	
Email:	[Participant's email address here]
Phone:	[Participant's phone number here]

Thank you for taking the time to answer these questions today. I look forward to meeting you in person for our interview.

Name: _____   Date: _____

Chronic Pain Acceptance Questionnaire

Directions: Below you will find a list of statements. Please rate the truth of each statement as it applies to you. Use the following rating scale to make your choices. For instance, if you believe a statement is 'Always True,' you would write a 6 in the blank next to that statement.

0 Never true	1 Very rarely true	2 Seldom true	3 Sometimes true	4 Often true	5 Almost always true	6 Always true

1.	I am getting on with the business of living no matter what my level of pain is…	
2.	My life is going well, even though I have chronic pain…	
3.	It's OK to experience pain…	
4.	I would gladly sacrifice important things in my life to control this pain better…	
5.	It's not necessary for my to control my pain in order to handle my life well…	
6.	Although things have changed, I am living a normal life despite my chronic pain…	
7.	I need to concentrate on getting rid of my pain…	
8.	There are many activities I do when I feel pain…	
9.	I lead a full life even though I have chronic pain…	
10.	Controlling pain is less important than any other goals in my life…	
11.	My thoughts and feelings about pain must change before I can take important steps in my life…	
12.	Despite the pain, I am now sticking to a certain course in my life…	
13.	Keeping my pain level under control takes first priority whenever I'm doing something…	
14.	Before I can make any serious plans, I have to get some controls over my pain…	

15.	When my pain increases, I can still take care of my responsibilities…	
16.	I will have better control over my life if I can control my negative thoughts about pain…	
17.	I avoid putting myself in situations where my pain might increase…	
18.	My worries and fears about what pain will do to me are true…	
19.	It's a relief to realize that I don't have to change my pain to get on with my life…	
20.	I have to struggle to do things when I have pain..	

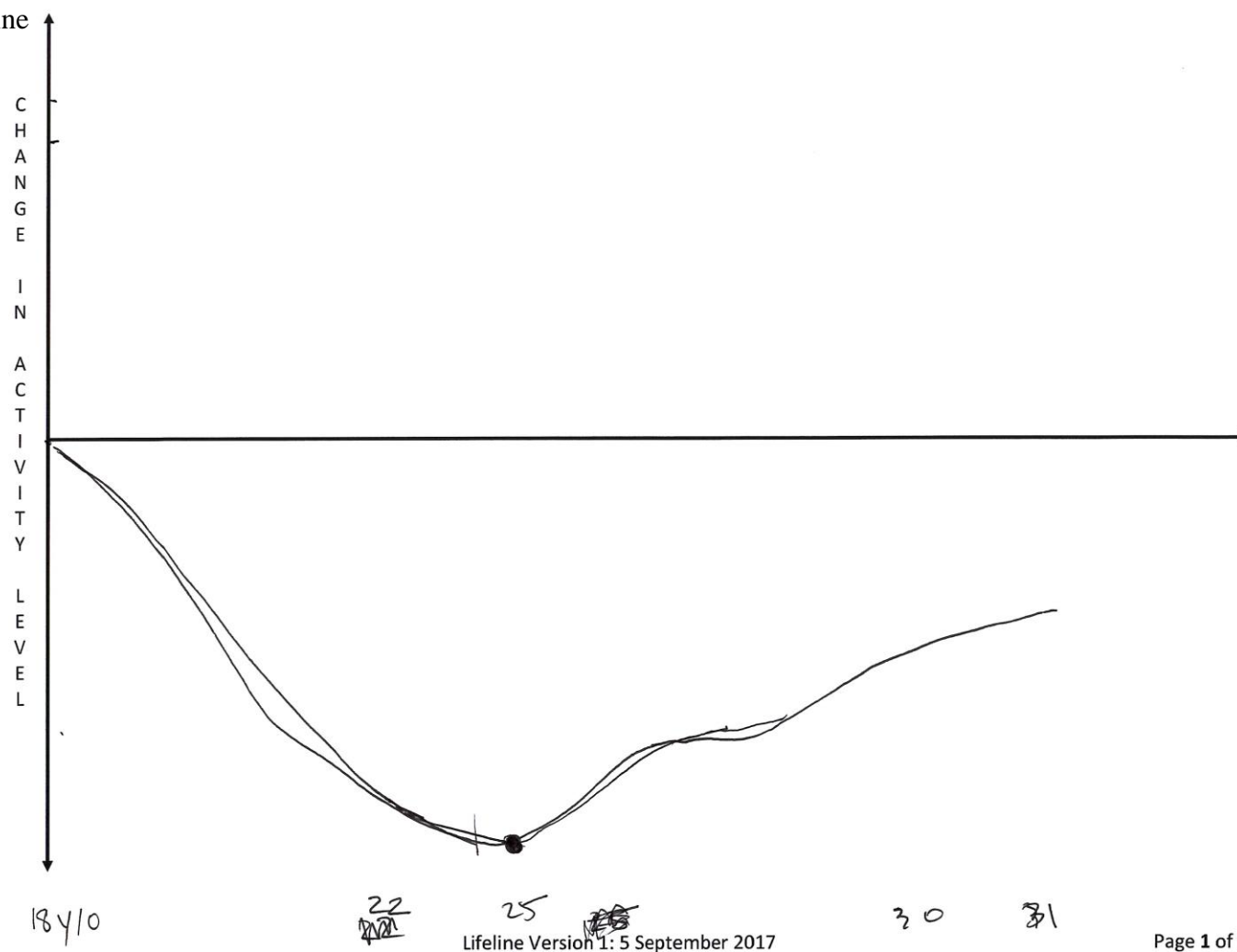| This space for researcher use only.	
Administration Number:	
Subscale Scores:	
Activities Engagement: (Sum 1, 2, 3, 5, 6, 8, 9, 10, 12, 15, 19)	
Pain Willingness: (reverse score 4, 7, 11, 13, 14, 16, 17, 18, 20, and sum)	
Total Score:	

Appendix C Interview Guide
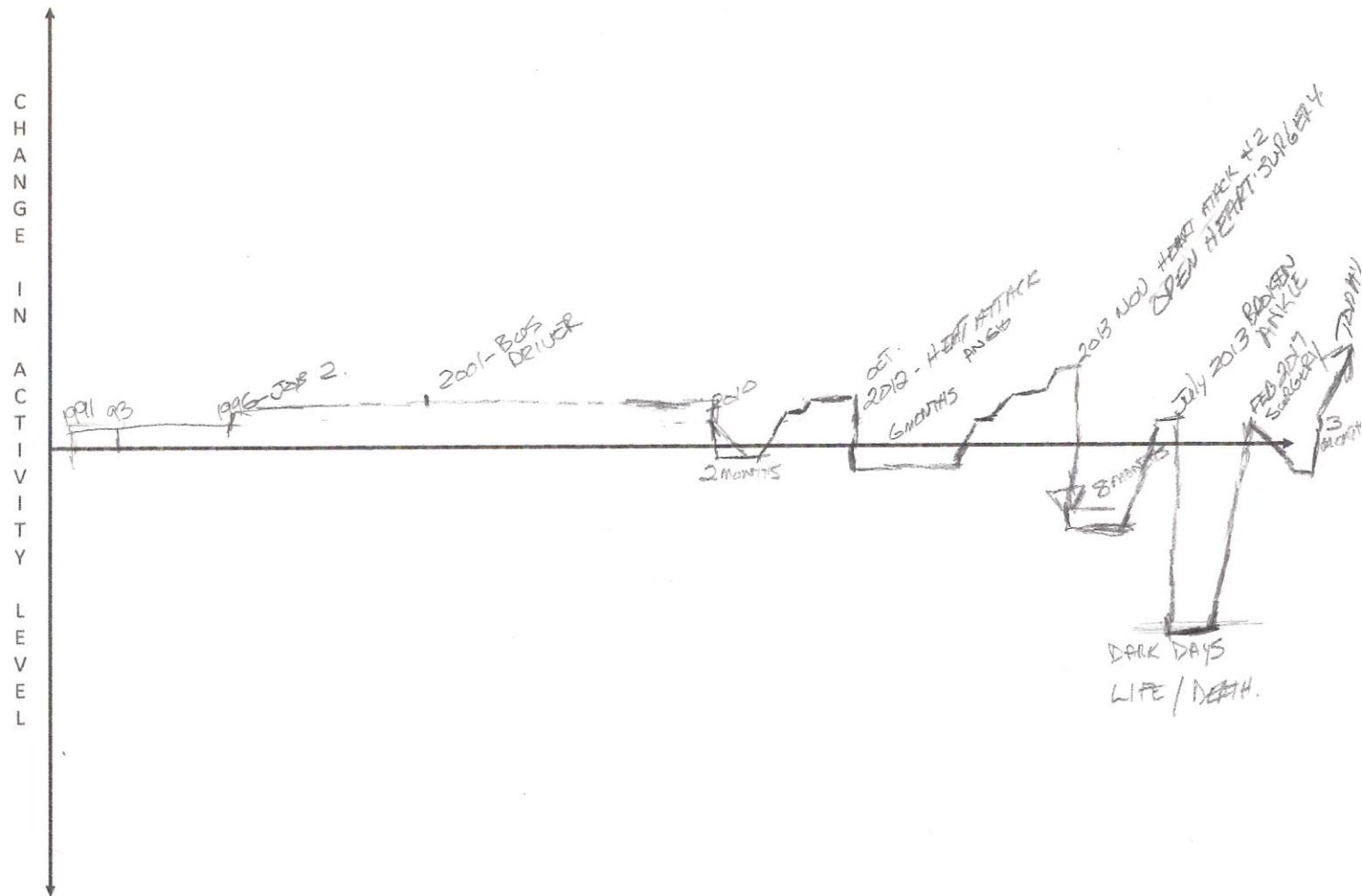
Interview Schedule:

1. Prompting instruction for the lifeline exercise:

    - "On this lifeline, you will notice two lines. Where they intersect should be the time when chronic pain first began for you, and the horizontal line will represent the activity level you had at that time. With that in mind, please draw a continuous line from that   point in your life until now, indicating whether your activity levels decreased (indicated by the line going down) or increased (indicated by the line going up)."

2. Follow-up questions to be used once the lifeline has been completed:

    - "Please tell me more about this time here."

    - "What can you tell me about this period here?"

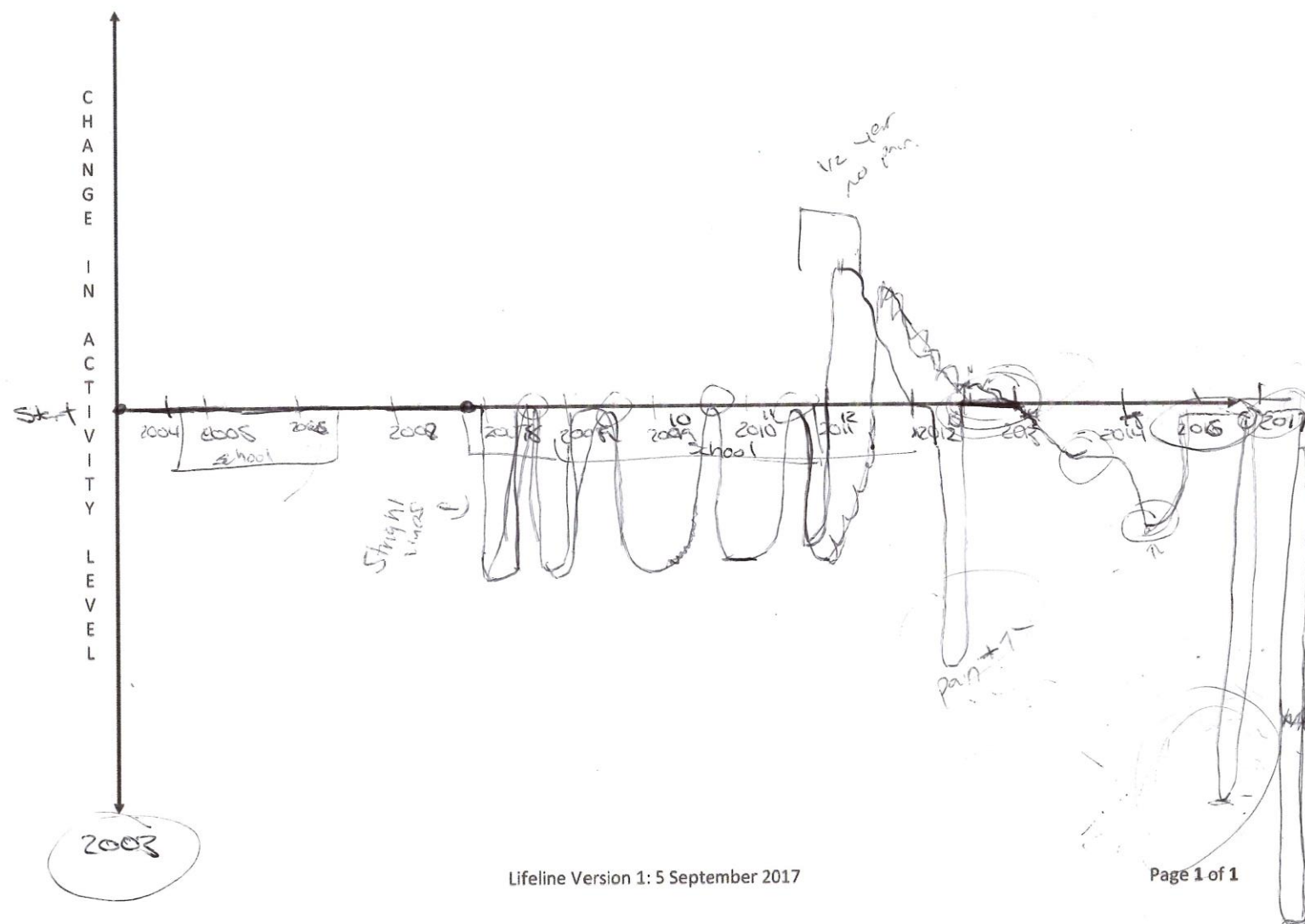**Appendix D Participant Lifelines**

Participant 1 Lifeline

Participant 2 lifeline

The hand-drawn lifeline chart has a vertical axis labelled "CHANGE IN ACTIVITY LEVEL" and a horizontal timeline arrow. Annotations along the line include:

- 1991 Q3
- 1996 – JOB 2
- 2001 – BUS DRIVER
- 2010
- 2 MONTHS
- OCT 2012 – HEART ATTACK AN66
- 6 MONTHS
- 2013 NOV HEART ATTACK #2
- OPEN HEART SURGERY
- 8 MONTHS
- DARK DAYS LIFE / DEATH
- JULY 2013 BROKEN ANKLE
- FEB 2014 SURGERY
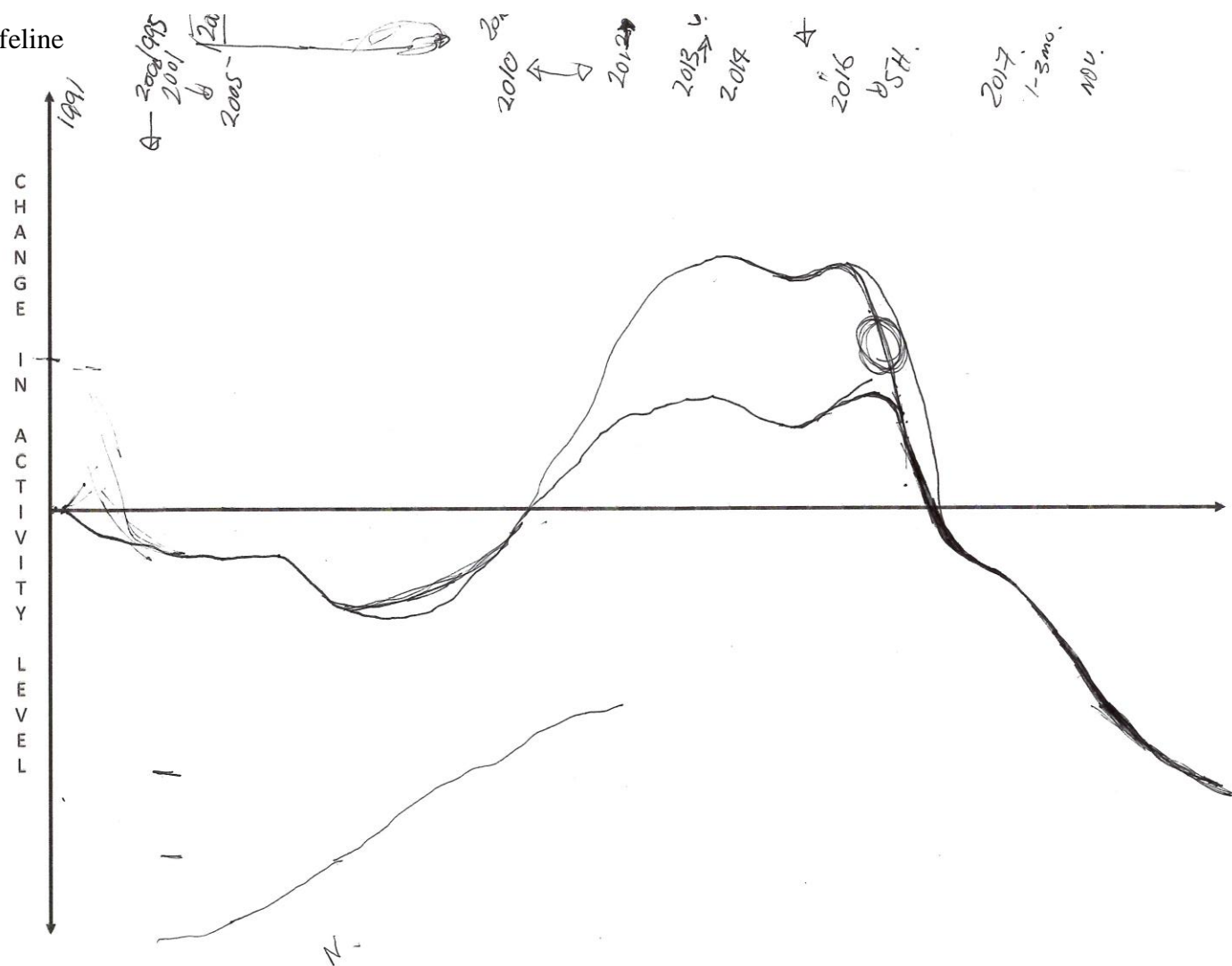- 3 MONTHS
- TROPHY

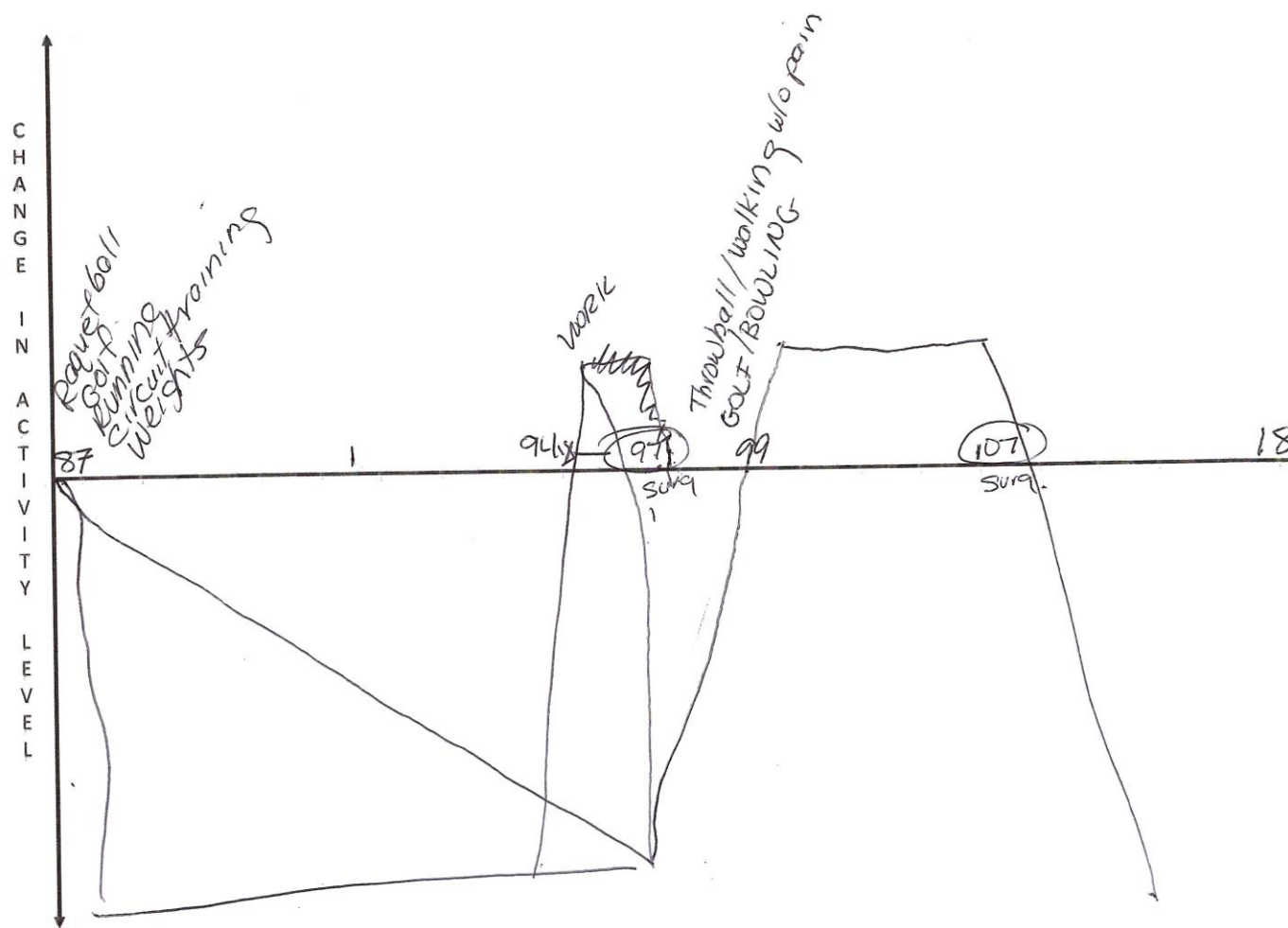Participant 3 Lifeline

Participant 4 Lifeline
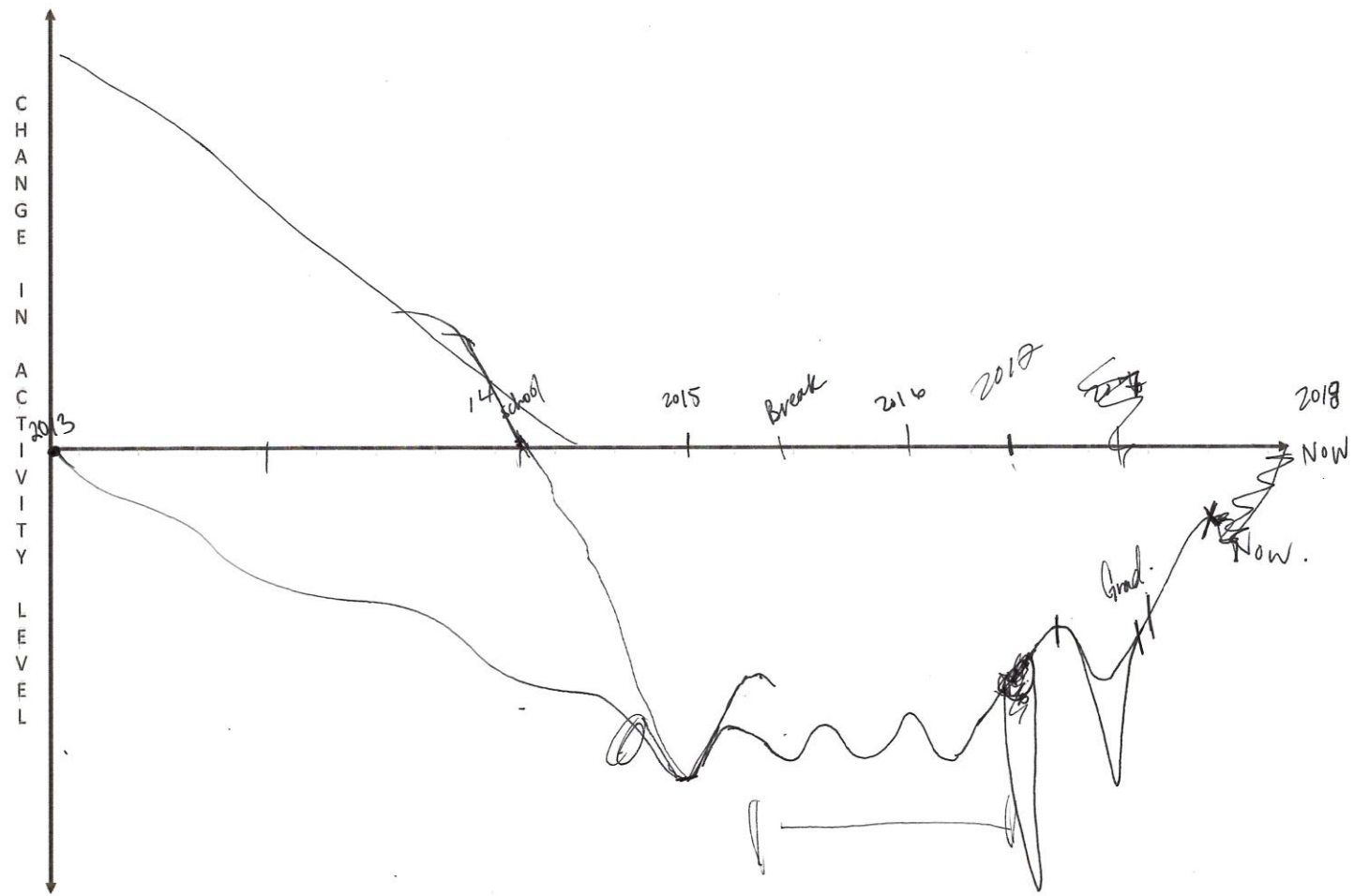
Lifeline Version 1: 5 September 2017
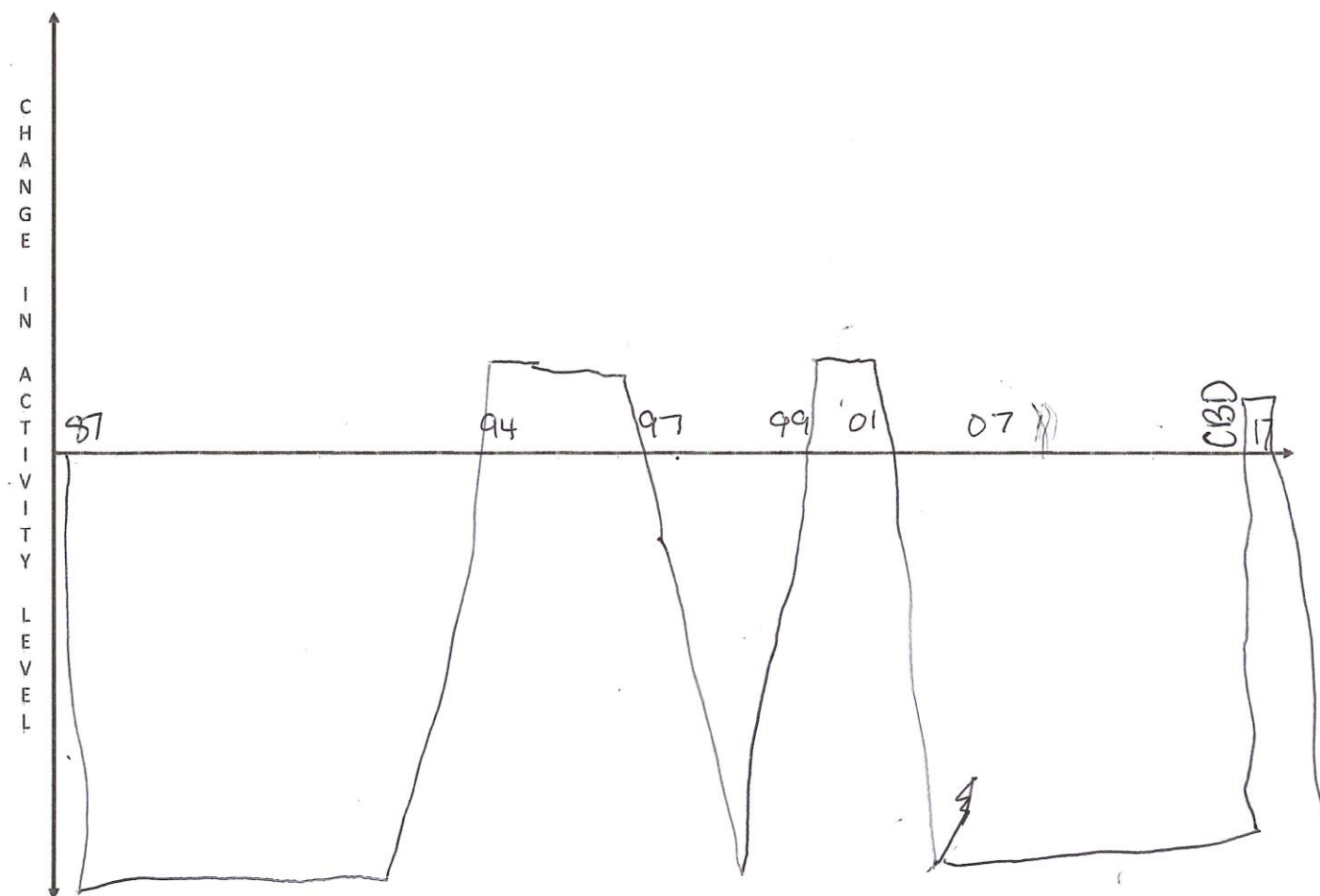
Page **1** of **1**

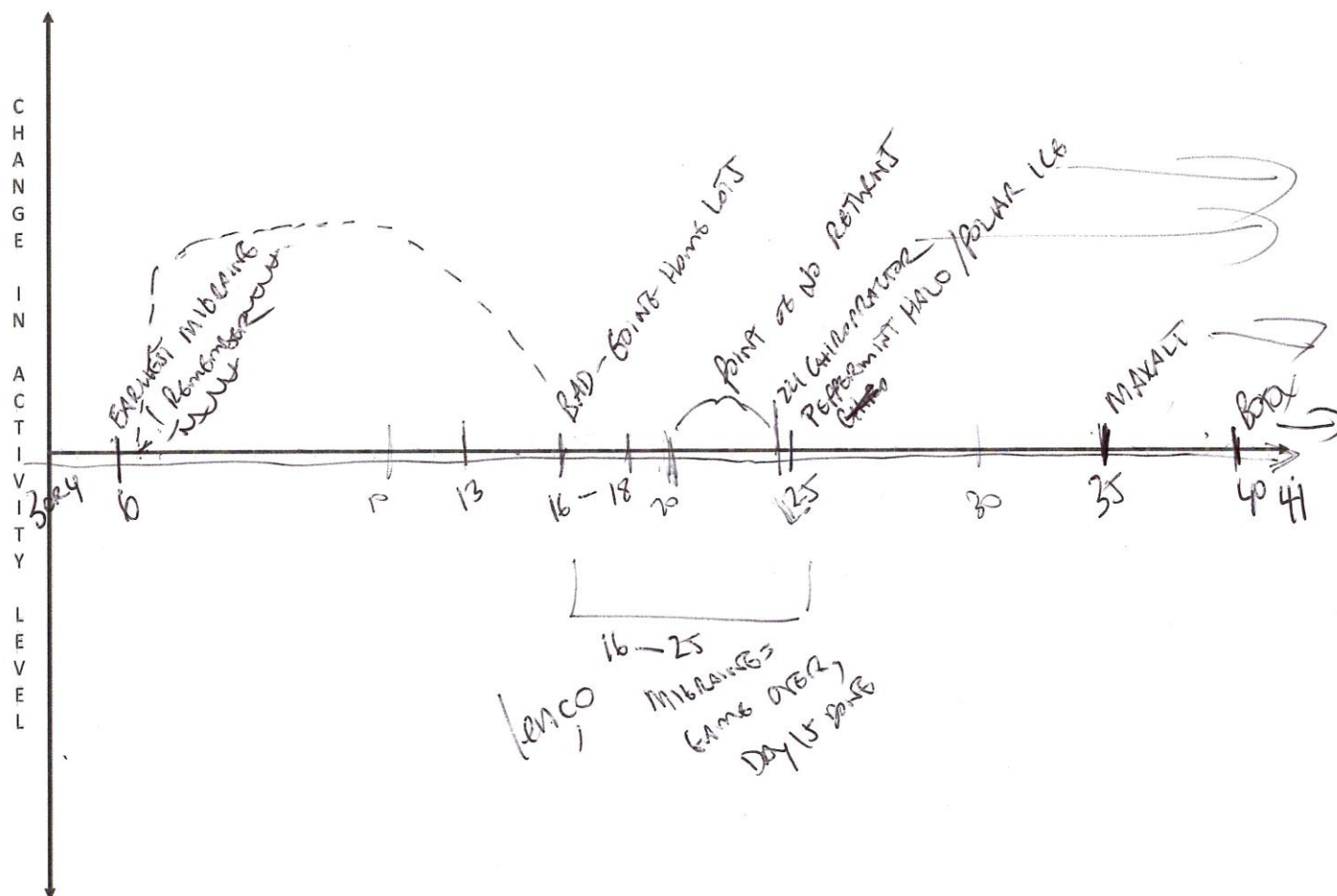Participant 5 Lifeline

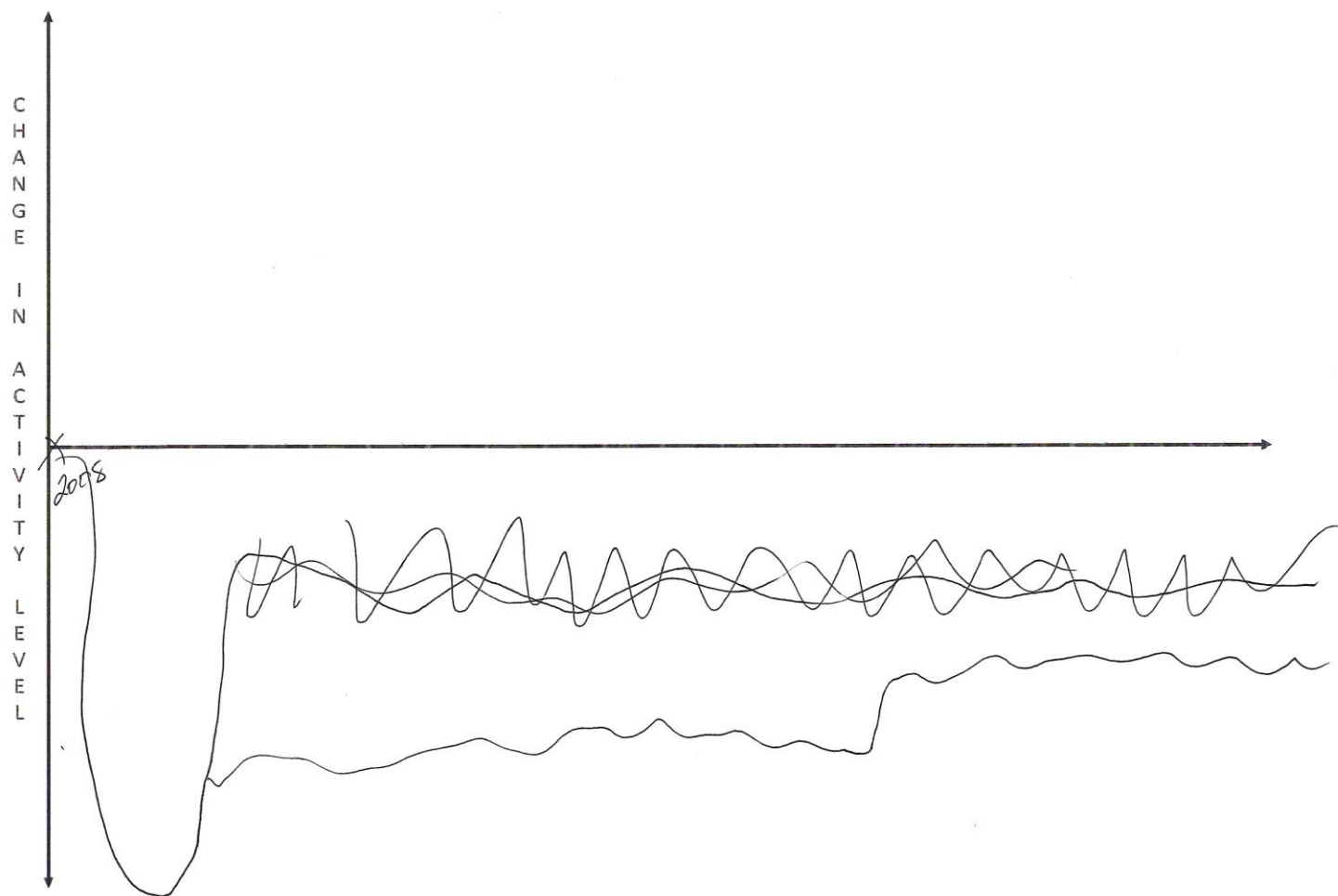Participant 6 Lifeline – First Drawing

Participant 6 Lifeline – Second Drawing

Lifeline Version 1: 5 September 2017   Page **1** of **1**

Participant 7 Lifeline

The handwritten lifeline chart contains the following labels:

Vertical axis: CHANGE IN ACTIVITY LEVEL

Timeline markers: 3ory, 6, 10, 13, 16-18, 20, 25, 30, 35, 40, 41

Handwritten notes along the timeline:
- EARLIEST MIGRAINE... I REMEMBER...
- BAD - POINT HANG LOTS
- POINT OF NO RETURN
- 24 CHIROPRACTOR
- PEPPERMINT HALO / POLAR ICE
- MAXALT
- BOTOX
- 16-25 MIGRAINES SAME OVER, DAYS DONE
- len co

Participant 8 Lifeline

Lifeline Version 1: 5 September 2017   Page 1 of 1