

University of Alberta

The Acceptance of Chronic Pain

by

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ABSTRACT

This study explored acceptance of chronic pain by speaking with ten individuals who had learned to cope and were living with their pain through acceptance. Participants were experiencing nonmalignant chronic pain which had disrupted their lives, were living meaningful lives, had accepted their pain, and desired to reflect on acceptance. None received treatment from a pain management clinic. A naturalistic paradigm based on phenomenological methodology guided the study. Data were collected through in-depth interviews. A reflexive journal documented the research process and evolving interpretations. A data analysis program was employed to code interview transcripts. The constant comparative method was used to further analyze the data until five themes emerged. The *Essence of Acceptance* identifies acceptance as an ongoing process with characteristic attitude and language. *Interpersonal Interactions and Acceptance: Help or Hindrance* underscores qualities and details of interactions and relationships which facilitate or intercept acceptance. *The Journey of Acceptance* focuses on the decision to accept, the steps, and time required for acceptance. *Choices and Changes on the Journey* outlines the many ways participants were positively transformed through acceptance. *Where the Journey has Lead . . . So Far* presents how participants are managing hope, fear, and uncertainty while living meaningfully with pain. Acceptance of pain took months or years of hard work and persistence. Being believed by professionals was critical as was their response to the uncertainty of chronic pain. Realizing choices were available, taking control and responsibility, focusing on the pain in order to learn about its insidious nature, and receiving information from professionals were all essential in order to gradually move the focus from pain to life.

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DEDICATION

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CHAPTER ONE

INTRODUCTION

'Acceptance of Chronic Pain' begins with an anecdote describing one person's, the researchers, experience with chronic pain. This anecdote serves to introduce chronic pain and its' acceptance. Related research literature will be presented which describes important issues relating to chronic pain. Finally, the statement of the problem describes the direction the research took.

A Personal Experience with Chronic Pain

"There is nothing I can do for you. You'll have to learn to live with the pain. You will need to accept nothing more can be done" the orthopedic surgeon said informing me the Magnetic Resonance Imaging (MRI) report for my shoulder had come back 'normal'. He had no explanation for the pain and didn't offer any suggestions as to how I was to "learn to live with the pain" or "accept it". As I hung up the phone I could feel fear rushing my body while thoughts raced through my mind. 'How was I to live with this relentless pain that was ruining my career and interfering with my life, when the previous months of physiotherapy, massage, medication, and exercise had not helped?' My hope had been that the MRI, the 'god' of medicine, would provide an explanation and direction for treatment. In the moment, there seemed to be no options, no hope that the pain could ever be lessened, and nobody to help me through it. My world of pain seemed so large and overwhelming.

This stage of my life began 11 months prior to this phone call when I had been hit by a truck while cycling. On the warm fall day, I was less than two weeks from completing the ultrasound technologist training program. I was looking forward to writing the registration exams and advancing my career in this direction. I was anticipating the freedom of not having to study and resuming normal life activities complete with a steady income, activity, socializing, and nurturing relationships which had been neglected for the past year while I had been in school and living across the country. The moments after being struck by the truck were a blur. I heard sirens and saw people, both regular folk and professionals arriving to help. The ride in the ambulance, arriving at the emergency department of the hospital at which I worked as an x-ray technologist, and then being taken to the x-ray department, where I was the one who took x-rays, seemed surreal. I received the results; "Nothing is broken. You will be sore for six weeks."

With this information off I went with my scraped and bruised body to continue with my life plans. Within hours the soreness predicted by the emergency room physician became apparent. Since I was accustomed to pain from my years of athletic training and exercise, I fully expected the pain caused by the accident to go away. But, within a few days I was perplexed that the shoulder and arm that had taken the force of the truck, were feeling better, but the shoulder which had hit the ground was getting worse. Even so, I continued to hold to the 'six week' rule given by the emergency room doctor, and my belief the pain would go away. I continued to swim and run thinking that maintaining the mobility and strength would help with this injury as it had with previous injuries I had experienced. I wrote the ultrasound registration exams, returned to my x-ray technologist position part time and began an ultrasound job.

Around the six-week mark, at which time the pain was to have disappeared, I visited my general practitioner who promptly referred me to a physiotherapy centre which treated workers compensation and insurance clients. By this point the pain had settled in my shoulder. This referral was to be the beginning of a long journey through the health care system with side trips with the motor vehicle insurance and legal systems. Since I had seen physiotherapists for previous injuries, I thought I knew what to expect. However, I soon realized that this time was different. This time I was an 'insurance case' and with this designation came the words of the physiotherapist "we don't care how much pain you are in as long as you are working." This admonishment came as a surprise considering that I had been taught, and had taught others to respect the pain messages given from their bodies during exercise. And, from my point of view the problem was the pain and not my stopping work since I was working and had no intention of stopping. From my perspective the problem came from the increased pain from having the therapist force my body

beyond what it wanted to do. When I first started going to this physiotherapist, I had pain only in my shoulder. The physiotherapist noticed a decreased range of motion in my neck that I hadn't noticed, and began treating my neck as well as my shoulder.

After a few visits to the physio the pain in my shoulder, and now my neck become intolerable as she stressed the range of motion to "ensure it was maintained," even if it causes pain." I would leave the treatments in tears. Her instructions were to stop massage therapy and to keep swimming to "keep the mobility up." Swimming, a sport I loved was by now causing excruciating pain. The pain I felt in my shoulder was qualitatively different from the pain I felt during exercise. Within a few weeks of starting physiotherapy, I became aware that I was under the watchful eye of the insurance company and this physiotherapist. Because of the presence of being observed and judged, I felt pressured to ignore the message my body was giving and follow her direction. 'And besides', I reasoned to myself, 'I have never had an injury caused by an accident; maybe she is right, maybe keeping the range of motion up will help'.

After a few months of increasing pain I had an appointment with my general practitioner who told me 'the insurance case' that "physiotherapy is expected to hurt and you'll just have to deal with it." When I heard these words it became apparent that the approach of ignoring the pain and doing things which made it worse was not working. Despite my inexperience with accident injuries and my self-doubt as to what was going to help I decided that this physician's and the physiotherapist's approach was not working and I would need to find a different doctor.

At this point, now almost six months after the accident, using connections, I started to make changes to who was helping me recover. I consulted with a fellow triathlete, who gave me suggestions for a general practitioner. I made an appointment with this physician who was understanding, supportive and seemed to have a different approach to pain than the first family practitioner. He, to my surprise told me that I had 'chronic pain'. Because I associated 'chronic pain' with pain that would never go away and something only old people had, I was resistant to this diagnosis. In my mind I simply had an injury that just hadn't healed yet.

I used my connections in diagnostic imaging to get an appointment with an orthopedic surgeon. This connection was helpful as my wait was days rather than months many people wait. The orthopedic surgeon ordered more x-rays and arranged for me to see a different physiotherapist. This physiotherapist worked in the public health system rather than private practice. With these changes I felt more hopeful. The x-ray report came back 'normal' and an MRI ordered. The new physiotherapist slowly began to undo the (what I believed to be) damage caused by the first physio. I was directed to stop swimming which by now was so painful that I was grateful to do. She was gentle with my neck, and over the weeks reduced the pain and increased the range of motion. She educated me on shoulder injuries while encouraging me to do the exercises. I felt I was being treated like a person with a sore shoulder rather than an 'insurance case'. She pointed out how my arm hung partway out of the shoulder socket. Her knowledge and expertise with shoulder injuries enabled her to diagnose my pain within a few appointments. She thought there was a tear in the capsule around the shoulder which would need several months to heal and perhaps surgery. Her diagnosis would be eventually confirmed, not with MRI, but with surgery. I was optimistic for the first time in months.

Despite my optimism the pain persisted and I sensed the physiotherapy was not really helping. The wait for the MRI and the results was filled with uncertainty, physical pain, and emotional distress. During the wait of over six months for the MRI and report, the pain was relentless as I continued working and going to physiotherapy. I began taking pain medication which left me sleepy, anti-inflammatory medication for the swelling, and stomach medication for the nausea and vomiting caused by the other medications. The impact of pain on my life became obvious when I was turned down for a permanent position in ultrasound because of the my shoulder even though I was working full time hours. And, because my employer was unwilling to rearrange the equipment in the ultrasound room so that I could use my left (healthy) arm, working intensified the pain. The decisions by my employer combined with the uncertainty and waiting, left me with a sense that my life was out of control. Since I was not swimming, and not cycling due to fear of being hit again, my participation in triathlon changed. I volunteered and joined teams but this participation did not fill the void, was not what I wanted, and more important, was not something I had chosen. I continued to run because running didn't cause as much pain and it provided a bit of solace.

During the first summer after the accident, while waiting for the MRI, the pain seemed to take on a life. The pain seemed to be escalating, constant, and interfered with both daytime activities and nighttime sleep. The side trip with the insurance company and legal system began unfolding during this time. At times the fear, anger and sadness would surface. Anger at the driver, anger at the health system, and anger at myself for not healing in the way and on the schedule the professionals told me healing was to occur. Sadness and fear were felt for the pain, for the lost opportunities, for the uncertainty, and fear that the pain would continue. I tried not to focus on the feelings. Rather, my focus was on holding onto what I had in terms of employment, activity, and my well-being, as well as my goal of finding something that would help the pain. Despite the negativity, I clung to the hope that the MRI would identify the cause of my pain which would enable the surgeon to fix the damage, and the pain would finally vacate my body.

After months of waiting, the day of the MRI test came and went. A few weeks later came the phone call from the surgeon. In a flash the hope I had been holding, vanished. I didn't understand how he could not put the pieces together that were so clear and obvious in my mind. 'How could he not understand that my arm being partway out of the shoulder socket and my pain were an indication something was wrong with my shoulder?' The shock and fear associated with the phone call soon lead to a resolve to continue the battle and find a solution that would end the pain and allow me to get on with my life. I would later learn that the surgeon believed I was attempting to claim pain and suffering in order to get money from the insurance company.

After the disappointment and shock of the MRI result and the surgeon's withdrawal from my care, the tenacious part of me went into action searching for other steps I could take. From my x-ray job, I learned an orthopedic surgeon with expertise with shoulders recently arrived to work in the region. Coincidentally, on one of my x-ray shifts, I had the opportunity to speak with him. I explained my situation and he arranged an appointment within a few days. After he examined my shoulder and reviewed the MRI films directly (as opposed to simply reading the report), he indicated that perhaps the MRI wasn't normal after all. He thought there was a tear and recommended surgery. I was relieved! Finally someone who could do something about my pain heard me and believed me. He explained the surgery would require me to be off work for six weeks while my arm healed. My name was put on the wait list. The wait and subsequent surgery became a bit complicated when it was realized that the instrument needed for the surgery was not owned by the health region. The instrument needed to be requested, approved, ordered, and received before the surgery could proceed.

With a plan in place to address the medical aspect of my injury I continued to work full-time hours at the ultrasound clinic and part-time at the hospital. In anticipation of being off work I wanted to prepare myself financially so I worked as much as I could despite the pain. Within a month of being on the wait list for surgery, I received a phone call informing me that my operation would be held in one week. Excited with the news I informed my employer at the ultrasound clinic, who admonished me for not informing him sooner. My explanation that I had just found out was not well received. Two days before the operation I was informed that my surgery had been postponed because the required equipment had not been received. The surgeon assured me the instrument would arrive. This change of plans did not go over well with the ultrasound employer. He told me my shifts had been filled and he refused to schedule me anymore because with an unknown surgery date, I was deemed unreliable.

The sense of hopelessness and being out of control returned. To me, neither the situation with the equipment nor the actions of my employer made sense. Although nothing could be done about the equipment, friends suggested I fight the decision of the employer through the Human Rights Commission. I contacted the Commission who informed me that I was indeed being discriminated against due to a 'disability'. While I didn't perceive myself as disabled, I decided a complaint was something I could do to try to get my job back. From the Commission I learned that my employer's unwillingness to accommodate me utilizing my left arm violated my human rights. The complaint and resolution process with the Human Rights Commission turned out to be four years of frustration, letter writing, and waiting.

The one year anniversary of the accident arrived. In one year it seemed my life had done an about face. The anticipation of simply living a normal life had been replaced with waiting for surgery, loss of a job, a legal case, a human rights complaint, and pain. The expectations of resuming my life after being in school for a year, advancing my career, and having financial security had been replaced with pain, uncertainty, and a lack of control.

With the blow from the ultrasound clinic I turned to the hospital for employment. I thought I would be able to work at the hospital in x-ray while waiting for surgery. This hope was soon dashed as I realized the dominance of the radiologists. I knew the hospital radiologists were the same radiologists I worked for, and filed the human rights complaint against, at the ultrasound clinic. It seemed more than a coincidence that the number of shifts I received went down despite my availability and the shortage of technologists. My inquiry to the manager of the department was unsatisfactory. I realized, with sadness, fear, and anger, that my shifts at the hospital would be rare and there was nothing I could do. I started looking for work in my field, but in a small city and in a specialized field, the opportunities were minimal because of the dominance of this group of radiologists. I realized I would need help if I was going to pay the bills and I turned to family, the bank and I sold possessions including my triathlon bike.

The wait for the operation lasted three months. Not a long time in the scheme of things but waiting seemed long when I was not working or participating in activities because of the pain. Even though I had stopped working, the pain continued. Day to day tasks such as carrying groceries, sweeping the floor, getting dressed had, over the months became difficult. My physician and the insurance company suggested I attend a pain management program. Still expecting my pain to be resolved with surgery, I didn't believe pain management was necessary or would be helpful. However, I was aware I was still an 'insurance case' and so I went. I didn't know what to expect except that everyone there would have chronic pain - except me. Me, I just had an injury that hadn't healed - yet.

Unexpectedly the pain program provided information which I found surprisingly interesting. We, the participants learned relaxation skills, and the importance of setting goals and keeping active so that we did not focus on the pain. Each person created a chart of daily tasks to do. I found the chart helpful because it gave me something to do each day and I could see what I had done. In a funny way I felt successful when I could see all I had done in a day. I still did not see the connection to my pain. The pain was still there. I was still waiting and still not doing the things that I wanted to do. I felt like a misfit in the group - the other members complained and were not as active as people I typically spent time with. I remember thinking that I need a group comprising of injured athletes who were unable to participate in their chosen sport. Part-way through the group I had the surgery, but continued with the group anyway, which I did even though I thought I didn't need it. I was glad when the group was finally over.

At long last the surgery date came. Ironically, I worked a shift at the hospital, and the next day I was in the same hospital as a patient. The surgeon had not told me much about the surgery except that I would be sore for a few weeks, and would be off work in ultrasound for six weeks, and longer for x-ray due to the lifting requirements. When I awoke I noticed immediately that I could not move my arm. I felt like I was strapped in. A nurse told me my arm was in a sling with a part that went around my torso to keep my arm held against my body. I was surprised to hear it would be on for six weeks. The surgeon eventually came and explained he had found more damage than he anticipated. He explained the nature of the damage which had a name. It was called a SLAP lesion. Despite the grogginess from the anesthetic I was aware of the relief, the validation, and hope that came with this news. My pain, I believed was finally on its way out.

After six weeks the sling came off and I returned to physiotherapy. The physiotherapist, who had diagnosed my injury nine months prior, provided me with literature about the injury. The exercises were painful but over time the range of motion and strength improved. The pain lessened. I was still concerned my arm looked like it was still partially dislocated. At the three-month post-operative checkup, the surgeon said that at the time of the surgery he had hoped that that part of the injury wouldn't be a problem so he hadn't repaired it. I hoped so too. He said to stay off work for another month and continue with physiotherapy. As my luck would have it, the instability problem got worse and the pain returned. I was angry with the surgeon that he hadn't repaired both parts of the injury. To me, it was like putting air in a bike tire without fixing the leak in the tube.

Four months after surgery the surgeon decided the second part of the shoulder repair ought to be done, and my name was put back on the wait list. I could return to work part-time in ultrasound but I was not allowed to work in x-ray due to the demands of lifting patients and moving stretchers and machines. The ultrasound employer refused to give me part-time work and continued to refuse to permit me to use my healthy arm to do the ultrasounds. I went through another episode of feeling anger in many directions: anger at the driver who hit me; anger at my employer for being unreasonable; and anger at myself for not healing properly. My anger at the driver softened a bit when I met him at the Examination for Discovery,

the legal hearing held to establish the accident details. He was just a regular guy who had been talking on his cell phone. My anger returned when I saw his indifference to the damage he had caused. He had no idea what I had gone through in the past 21 months since his truck hit me, and didn't really seem interested in hearing about it. The driver was found to be at fault, and at long last the insurance company would provide me with advances from my insurance settlement. The final settlement would take another two and a half years to finalize.

At about the same time the hearing was held, I began working on a casual basis at a group home for senior citizens. My role was to prepare meals, tidy the home, and visit with the residents. Many of the residents suffered from long standing pain which evolved with age and medical conditions. Other residents had mental disorders, dementia, and addictions. Besides providing me with income, interacting with the residents developed my desire to help other people; an area I would eventually pursue. Between the advances from the insurance company and working, at long last I had money to pay the bills.

The second surgery was performed over two years following the accident. The surgeon repaired the instability problem using arthroscopy; a method used to speed up the recovery process because fewer muscles, ligaments, and nerves needed to be cut but required a small hole be made in the shoulder blade. I learned from reading and from the physiotherapist that this method, although less invasive, was also the least successful. I went ahead with this operation anyway. The surgeon re-repaired damage caused by the instability - damage he repaired the first time. This time he didn't predict when I would be able to return to work. The six weeks in the sling went by and when it was taken off I was happy to see that my arm was back in the shoulder socket where it belonged. Once again I began the painful process of physiotherapy. Six weeks without moving my arm left my shoulder and elbow stiff and weak. By now I was familiar with the exercises, and over time the strength and range of motion improved. The pain lessened while my arm had been in the sling and I was confident that the pain from rehab would pay off.

The day the physiotherapist noticed that my arm was again partially dislocated was very upsetting. A part of me had probably been expecting it since the technique used wasn't the most effective but it was extremely disappointing none the less. She noticed this positioning about six months after the surgery. Although the pain had persisted, I had thought that it was simply due to the healing and exercise. She advised that I immediately see the surgeon. The surgeon confirmed the repair had come undone. I found out the procedure had involved taking some of the tissue off the shoulder capsule and reattaching it tighter. To hold the arm in the socket until healing occurred dissolvable stitches had been attached which were then threaded through the shoulder blade. A knot was made on the skin surface of the shoulder blade to hold the stitches and my arm in place. Apparently the tissue hadn't healed adequately before the stitches had dissolved. And now that the stitches had dissolved there was nothing to hold my arm back in the socket. After seeing my arm, the surgeon told me there was nothing else he could do. I had anticipated that he would say he would repair the instability using the technique the research literature indicated was the most successful. When asked about it, he said "no". I was surprised and disappointed. I thought this technique would be an obvious treatment option but to him it wasn't. He advised me not to return to x-ray and ultrasound because these areas would be too hard on my shoulder. I had kind of expected this advice since I had already been thinking about finding a career in which I would not have to use my upper body.

The hopelessness and lack of control returned but not as strong as in the past. I didn't know what I was going to do next about further treatment, if anything. A part of me wanted to give up the struggle while another part of me wanted to pursue the option of the surgical technique that seemed to carry the hope of pain relief. With the encouragement of my physician, physiotherapist, and friends, I decided for the latter and with their help found two orthopedic surgeons who were known for their success in treating shoulder injuries. Although I decided to find a surgeon who would repair my shoulder using the technique the research and the physiotherapist thought had the best chance of success, I believed less that the pain would ever be resolved. I was however determined to get to where I wasn't afraid of my shoulder dislocating, and where I could resume some of my daily tasks and activities.

Referrals were made to the orthopedic surgeons. Both were out of the province since my home province did not have any other shoulder specialists. After three months I met with the first surgeon who agreed that another surgery was necessary, and that she would use the technique I had read about. I was put on a wait list. As it turned out, the provincial health plan would not cover the cost of the surgery because it was to be performed at a private hospital in a Canadian province. This news prompted me to

pursue the appointment with the second surgeon which took another four months. This appointment was held 38 months after the accident. The wait for this appointment wasn't as difficult as other waits had been because by this time I had enrolled in university and began the pursuit of becoming a counsellor. The pain continued to be intense but with medication and other aspects of my life more settle, it was more manageable.

During my appointment with the orthopedic surgeon a simple diagnostic test was performed which resulted in the pain disappearing, temporarily. This test involved injecting an anaesthetic directly into the shoulder joint. While my report of the absence of pain confirmed the shoulder problem for the surgeon, it was the first time in more than three years, albeit short term, that I did not have any shoulder pain. I could and did move it in all directions without pain. Interestingly, the diagnosis did not involve x-rays or an MRI, or any wait. I was surprised that this simple test could provide such relief and valuable diagnostic information. The surgeon described the problem and the surgical procedure he thought would be helpful. The procedure was the one the research indicated to be the most successful with a success rate of fifty percent. It was also more invasive and would require a long incision, and more time in a sling. These details didn't matter. Once again I felt hope that I had finally found the solution. The hope rose even though a few months earlier I seemed to have accepted that the pain was not to be ever resolved. My name was put on the waiting list which turned out to be short due to a cancellation, and less than two weeks after the initial appointment I had my final shoulder operation.

This surgery proved to be the most successful in reducing the pain and treating both the instability and structural damage to my shoulder. After about nine months of rehabilitation I was able to return to some of the activities I had enjoyed before the accident though in a reduced capacity. It was good enough. Both the insurance claim and the human rights complaint were eventually resolved and I continued with my goal of becoming a counselor and the newer goal of a psychologist. In the past few years the instability in my shoulder has returned causing my arm to move out of its position. This in turn has lead me to restrict how much I do and avoid some activities. I have learned massage therapy, physiotherapy, and yoga help in reducing the pain but these management strategies don't eliminate the pain completely. I continue to have shoulder pain on a daily basis, some days more tolerable than others. When the pain level is at a peak, I contemplate pursuing another surgical intervention I know is available. But when these difficult times pass and the pain subsides, the pain and its impact on my life are acceptable.

Upon reflection I realize I have, after a long and painful process, done what the first surgeon advised me to do; I have learned to live with my pain. I wonder if I have fully accepted it. I wonder what acceptance means. Is acceptance more like an endless journey of accepting moments rather than an experience with a start and end? The days when the pain is more intense, or when I feel sadness reflecting on my life before the accident and the lost dreams and goals; The days when I desire to have this retraining complete and my career solidified, and when finances are tight due to the retraining - these are the days when I doubt I have accepted anything. But when I feel confident about writing and my career progressing; When I see changes in my life that have occurred because of the accident and pain; When I feel like I have helped someone - at these times I think I have managed to overcome the accident, the pain, and the aftermath; That I have moved forward with my life, albeit in a modified direction, and the pain is acceptable. On these days, in these moments, 'Yes', I can say, 'I have accepted the pain'.

Looking back to the day I was told to 'learn to live with the pain and to accept it' I see that I was not ready or wanting to accept or learn to live with it. Maybe at the time part of me thought that acceptance and learning to live with the pain meant a life of uncertainty, a continuing inability to accomplish tasks and goals, and relentless intolerable pain. Maybe at that time I was so focused on finding a solution that 'learning to live with it' was unimaginable and impossible. The fear of the pain and all it meant at the time was very strong, so perhaps fear had a role in not accepting. Although going to physiotherapy, to the medical appointments, receiving injections, and having surgeries plus pursuing the complaint and the insurance claim required that I on some level acknowledge and accept the pain and its impact on my life, accepting and learning to live with the pain with the future in mind was different and more difficult. Perhaps if I had been offered guidance as to how I could learn to live with it, or how to accept it, at least contemplating acceptance and accepting may have been possible. By the time of the final surgery I had a sense the pain would never completely go away and the urgency of having a functional shoulder with less pain was less because I had made a decision to change careers. I wonder whether my

being an 'insurance case', and my insurance claim and human rights complaint influenced my learning to live with pain and on accepting it, and if so what role? I also wonder what the future holds in terms of living with the pain and my accepting it.

My personal experience with chronic pain, learning to live with it, and accepting it provide me with an insider's view of the acceptance of chronic pain. While my experience is likely to shape and guide this research endeavor, it would be impossible for it not to; I will use my experience with intention. I will embark on a personal reflective process which will include consultation, writing in a journal, and checking with the participants in order that the influence remains productive and does not overly sway the direction, content, or outcome of the research.

Background to Chronic Pain

Pain and illness are two of the most basic issues of human existence (Bellissimo & Tunks, 1984). The focus of this research is chronic pain rather than illness. The treatment of pain is a central task to the healing professions. When pain persists beyond the expected time frame, is more severe than anticipated, or persists despite usual interventions it poses great difficulty and problems for both the sufferer and the healer (Bellissimo & Tunks). A common prescription for pain that eludes treatment expected to provide relief or resolution, or which persists beyond the expected time, is 'learn to live with it' (Kotarba, 1983; McCracken, 1998). It is not known how many individuals with chronic pain are prescribed this directive, but Frank (1991) states that sooner or later the person with chronic pain will be presented with the idea of adaptation and asked to contemplate acceptance of life with pain. This is the prescription I received eleven months after my bicycle-motor vehicle accident. The prescription was given without guidance or advice as to how 'learning to live with, and learning to accept' the pain meant or how it was to be accomplished.

Pain is a universal and essential element in experiencing the world. As such, pain presents in a variety of ways such as hunger pangs, a sun burn, a broken leg, chest pressure, or an aching back. While typically unpleasant, pain is a critical factor in determining safety and danger during growth and development, as well as aging, and serves as a warning of injury and illness. Pain is also an expected sensation in response to physical exercise, including rehabilitation, which often emphasizes strength and range of motion. In these ways, pain is neither normal nor pathological, but rather an essential and desirable feature of life (Bellissimo & Tunks, 1984).

The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Bogduk, 1994, p2). This definition highlights that pain is unpleasant with both sensory and emotional components. The sensory component refers to the stimulation and activation by noxious stimuli of specialized receptors located in the nervous system. The activation of these receptors creates a nociceptive input which is then transformed into nerve signals. Neural pathways in the spinal cord transmit these signals to the brain where they are interpreted. Once this nociceptive input is received at the brain the interpretation is subject to emotional and psychological factors. The influence of these factors sets up a feedback loop whereby emotional and psychological responses are both the products of and influences

on the experience of pain (Eimer & Freeman, 1998). The IASP emphasizes pain is “always subjective. Each individual learns the application of the word through experience related to injury in early life” (Merskey & Bogduk, p. 2). Aronoff also notes the subjective nature of pain, defining it “operationally as a complex, personal, subjective unpleasant sensory and perceptual experience that may or may not be related in any way to an injury, illness or other bodily trauma” (Aronoff, 1985, p. 471). These definitions together with emotional and psychological influences highlight how pain is a unique and personal experience which cannot be fully shared by anyone else (Murray, 2000).

The complexity of chronic pain is further highlighted when we consider it in relation to acute pain. Acute and chronic pain are the two main subtypes of pain recognized by care providers and the public with a six-month temporal duration as the differentiating point (King, 2000). Murray (2000) differentiates between acute and chronic pain in terms of function; acute pain is protective while chronic pain is not. The protective reflex of a cut finger or interpretation of chest pain prompts a person to do something to protect self. In most instances of acute pain a threat is recognized which propels the person to take action. The interpretation of acute pain as threatening or damaging, influences the emotional and psychological responses (Murray) which then prompts action to be taken to prevent further harm. Therefore treatment for acute pain is often thought to be straightforward and effective.

Chronic pain cannot be understood by simply extrapolating from our understanding of acute pain. When pain becomes chronic it does not serve the same protective function as acute pain. The pain in chronic pain persists long after healing is expected and the threat is no longer present. Because response processes continue to be activated and the pain prompts us to take action it often becomes a central focus of a person’s existence (Bellissimo & Tunks, 1984) even though it is not serving a protective function. This circumstance obviously has a negative impact on quality of life (Eimer & Freeman, 1998). Grady and Severn (1997) describe chronic pain as an illness with its own symptoms, signs and complications in part because of its persistence and because it does not usually respond well to analgesics and narcotic medications, and many treatment approaches (Bass, Peveler, & House, 2001; Murray, 2000). The complications of chronic pain, according to Grady and Severn, are associated secondary changes with treatment focusing on treating the complications of the condition rather than the condition itself. The ethical obligation to manage pain and relieve suffering is at the core of the health professional’s commitment and a fundamental responsibility (Jansen, 2001; Rich, 2000). Chronic pain is therefore the most challenging and perplexing treatment, and unfortunately unsuccessful for practitioners and researchers (King, 2000) which may lead to the prescription advising sufferers to ‘learn to live with it’.

As if the complexity of chronic pain itself was not difficult enough, the term ‘chronic pain’ and criteria for its diagnosis vary widely but are critical given that a diagnosis is often the link to treatment. Chronic pain has a variety of definitions and criteria depending upon the context and setting in which it is being used, and who is using it. Pain which persists after healing is expected is subject to diagnoses such as chronic pain, persistent pain, and chronic pain syndrome. According to the American Psychiatric

Association, pain is specified as acute if the duration is less than six months and chronic if the duration of the pain is more than six months (APA, 2000; King, 1995; King, 2000; Sullivan, 2000). Statistics Canada (Millar, 1996) and several other studies (Moulin, Clark, Speechley, & Morley-Forster, 2002) use the six-month duration as the criteria for the diagnosis of chronic pain. Health and Welfare Canada considers pain that is of three months or more in duration and which persists beyond the normal time of healing, is associated with illness or is a symptom of a recurring condition, to be chronic pain (Opsina & Harstall, 2002). The IASP define chronic pain as pain which has persisted beyond normal healing time which is “usually taken to be 3 months” (Opsina & Harstall, p. 2). Opsina and Halstall acknowledge the lack of consensus regarding the definitions of chronic pain as well as the inconsistency of duration of the cut-off point to differentiate acute from chronic pain. Considering that patients may be required to wait weeks, months, or even years to see a specialist such as a neurologist or orthopedic surgeon, and then wait again for diagnostic testing such as the MRI, and then for treatment which might include surgery, the three or six month duration might be of little significance for the patient. The more important aspect of the diagnosis might be that it is made at all and thus allow the individual to receive treatment for ‘chronic pain’, as the anecdote suggests, rather than the duration criterion.

In recent years the term ‘chronic pain syndrome’ has evolved to describe individuals who “exhibit persistent pain, poor coping, self limitations in functional activities, significant life disruption, and dysfunctional pain behaviour” (Aronoff & Feldman, 2000, p. 158). A syndrome is a group of concurrent symptoms of a disease (Thompson, 1995). Chronic pain syndrome is not intended to be a diagnosis but rather a descriptive term used to understand, study and manage patients with long standing, unexplained pain (Aronoff & Feldman; Murray, 2000). However, the term is sometimes used imprecisely as a diagnosis despite the fact that the etiology of the syndrome is unknown. When appropriately used as a meaningful description of the secondary problems associated with chronic pain, Murphy (1994) proposes that a diagnosis of chronic pain syndrome may facilitate a multidisciplinary approach for the treatment of the physical, psychological, social, and vocational problems which sustain the syndrome.

As the numerous definitions and differing criteria suggest, chronic pain has attracted increasing attention in the past number of years. One of the reasons for this increase in attention is the number of people who are afflicted. The Canadian Pain Society released results of a survey revealing 33 percent of Canadians are living with moderate to severe pain on an ongoing basis with 16 percent living with constant pain (2007). A year prior the Canadian Pain Society (2006) estimated between 20 and 40 percent of Canadians were affected by chronic pain with prevalence increasing with age. These statistics are double what Statistics Canada reported a decade prior when Statistics Canada reported almost 3.9 million people, 17 percent of the Canadian population, 15 years and over, experience chronic pain or discomfort, according to the National Population Health Survey conducted by Statistics Canada (Millar, 1996). For the survey, respondents who affirmed having a chronic condition such as arthritis, diabetes, or migraine headache, for a

minimum of six months, were assessed for chronic pain. Chronic pain was assessed by asking respondents if they were usually free of pain or discomfort, the usual intensity of the pain, and how many activities this pain normally prevented. This figure was thought to be an under-representation because residents of institutions, many of whom experience chronic pain, were not included in the study. Fifteen percent of these individuals report severe pain while 55 percent describe their pain as moderate. Millar notes that back pain was the most common source of the pain (15%) followed by arthritis (13%). Aronoff and Feldman (2000) also found back pain to be the most common cause of disability in adults under the age of 45 years. Aronoff and Feldman also state that the number of people with disabling back problems increased by 168 percent while the population increased by 12.5 percent between 1971 and 1981. In a study for the Workers Compensation Board of Nova Scotia, Murray (2000) reports that chronic pain occurs in about 11 to 54 percent of the population in various forms. Breakdowns of this statistic or details about the nature of the chronic pain are not provided by Murray. These statistics point to an increase in chronic pain prevalence but they also suggest that a part of this change might be in part due to the definition of chronic pain and criteria utilized.

The challenge to separate true increase in prevalence from an increase due to criteria used continues with a study conducted to directly assess the prevalence, treatment, and impact of chronic pain in Canada. This study by Moulin, Clark, Speechley, and Morley-Forster (2002) found that 29 percent of adult Canadians report chronic noncancer pain. For the survey, chronic pain was defined as continuous or intermittent pain present for at least six months. The most common site of the pain was back (35%), followed by leg (21%), headache (15%), and neck (14%). A review of thirteen primary studies on chronic pain prevalence by Opsina and Harstall (2002) for the Alberta Heritage Foundation for Medical Research, found chronic pain prevalence to be 35.5 percent using the definition of the IASP. The range of prevalence of chronic pain across the studies was 10.5 percent to 55.2 percent. The evolution of our basic definition of chronic pain and the time frame for which the diagnosis is made may contribute to the variation of the prevalence of chronic pain (Opsina & Harstall). Opsina and Harstall also noted variability in the types of questions used by the studies to describe pain characteristics such as site of pain, quality, severity, its continuous or intermittent nature, and the level of associated disability. Information ascertained by these questions may also contribute to the variability of prevalence rates.

Statistics Canada (2003) revealed that one out of every ten Canadian adults had a repetitive strain injury. Repetitive strain injury is a condition which develops over time and which primarily involves the upper body. The condition may be serious enough to restrict normal activities. This type of chronic pain, similar to chronic back pain, has seen an increase in prevalence from 8 percent of adults in 1996/97 to 10 percent in 2003 (Statistics Canada, 2003). Regardless of the definition used or criteria applied the statistics clearly indicate that a significant number of people experience chronic pain. What is less clear is the rate of increase.

In addition to the sheer number of people experiencing chronic pain, chronic pain is a significant social and health problem for three main reasons. First, chronic pain is a condition that has huge financial costs. Second, as a life altering and persistent condition, chronic pain is distressing to patients, and finally, despite interventions and the money spent on diagnosis and treatment, chronic pain is difficult to manage and often persists (Murray, 2000).

The financial cost of chronic pain to society, businesses, organizations, as well as the person experiencing chronic pain is seen in lost work time, lowered productivity, sick days, compensation, legal costs, as well as medical expenses. The Canadian Pain Society (2006) estimated the cost of chronic pain to the Canadian economy to be \$6 billion annually with lost productivity and healthcare utilization the major expenditures. One third of individuals with moderate to severe pain in the survey by the Canadian Pain Society (2007) indicated they had lost their job and 50 percent stated they had seen a reduction in income, as a result of their pain. Personal expenses might include treatment not covered by insurance or medical plans, travel for treatment, child-care expenses, and costs associated with career loss or career change (Bland & Henning, 2002; Murray, 2000; Statistics Canada, 2003).

The cost to the health care system is one reason chronic pain has been researched extensively (Bland & Henning; McCracken & Turk, 2002; Millar, 1996) and a reason it is well documented in the psychiatry, medical, and psychology literature (Bass, Peveler, & House, 2001; King, 2000; Merskey & Bogduk, 1994; Sullivan, 2000). Although less than ten percent of all people with acute pain go on to develop chronic pain, patients with chronic pain account for three quarters of the overall costs of health care and compensation for pain, and are a group whose number is growing in terms of number of persons afflicted and the cost for treatment (Murray). Further, the costs of providing health care to patients with chronic pain conditions many of which rarely cause death might exceed the combined costs of treating patients with life-threatening conditions including AIDS, cancer, and heart disease (Millar, 1996; Turk, 2002b).

Despite the high costs associated with diagnosing and treating chronic pain, many of which have minimal impact on the suffering and quality of life for the person, health care costs comprise only a relatively small portion of the costs associated with chronic pain (Turk, 2002b). As the anecdote indicates, the financial costs associated with the motor vehicle accident insurance claim and the human rights complaint, including the legal expenses for each, were costs in addition to the medical expenses directly associated with the injury and the chronic pain. Turk (2002a) states that expenditures associated with providing health and medical care to patients with chronic pain comprise only a small proportion of the costs associated with chronic pain and that the "majority of the costs are associated with disability compensation, lost productivity, and lost tax revenue" (p. 357). Evidence clearly indicates that chronic pain is a condition which has a far reaching economic impact for the individual with the pain as well as for society.

The second reason that chronic pain is a significant health and social problem is the distress that it elicits for the individual with chronic pain, and for family and friends (Murray, 2000). This distress can arise in several ways and for many reasons. Chronic pain impacts not only physical health, causing fatigue and interfering with sleep, but also emotional, psychological, and social well-being (Bland & Henning, 2002; Millar, 1996). As the pain persists, the distress increases as environmental factors come to play a more significant role. The distress associated with chronic pain comes from the intrusion into many, if not all aspects of an individual's life including home, work, leisure, and relationships (McCracken & Turk, 2002; Millar). Chronic pain impacts unfavorably on the ability to concentrate, perform chores, exercise, socialize, and sleep (American Pain Society, 1999) which then leads to a disruption in relationships, emotional well-being, and self care (Millar). Pain interferes with the ability to go to work or school which then impacts the ability to earn a living resulting in further difficulties and distress. Over time many individuals come to experience emotional and psychological distress including anxiety and depression along with the chronic pain (McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999). Hardy (1997) asserts that chronic pain is characterized by the distress experienced by the individual rather than the pain itself. While the human costs of pain are not measurable like the economic costs, it is evident that they are large and that they create considerable distress for the individual.

Another source of distress relates to beliefs held about illness and injury (Bland & Henning, 2002; Morley, Davies, & Barton, 2003). Many people tend to hold to the traditional biomedical model of disease which suggests that if someone is ill or in pain, there must be an observable biological condition causing the disease or discomfort. A concurrent expectation is that once the particular condition has been diagnosed, treatment may be implemented, and that once the required time for healing has been allowed the symptoms will resolve. A straightforward cause and cure for the pain is assumed and expected (Bland & Henning). However, this path of treatment and recovery rarely occurs and many people continue to suffer from the pain and all of its secondary effects. In most cases, individuals with chronic pain engage in a vigorous quest for an explanation and cure for the pain. This quest is a key feature of the chronic pain experience (Fordyce, 1976; McCracken, 1998) and contributes to the distress associated with chronic pain.

The search for an answer and resolution to the pain, as well as the time expended in the pursuit contributes to the persistence of chronic pain for many individuals. The average duration of pain for individuals treated at pain programs is seven years (Turk, 2002a; 2002b; Turk & Okifuji, 2002). This persistence and difficulty in managing chronic pain despite money, time, and energy directed toward a diagnosis and successful intervention is the third reason chronic pain is a critical social and health problem (Murray, 2000). Given that freedom from pain is second only to living as long as possible (Fishbain, 2000) it is understandable that individuals with chronic pain would take action to achieve this important personal outcome. Holding the goal of complete pain relief leads many individuals with chronic pain to continually utilize health resources and to move from one health care provider after another searching for relief (American Pain Society, 1999; McCracken and Turk, 2002).

Despite the proliferation of our understanding of the anatomy, physiology, biochemistry, and psychology of pain which has led to more treatment options (Turk, 2002b; Turk & Okifuji, 2002) many individuals continue to suffer from chronic pain. Turk (2002a) notes that “none of the available treatments for chronic pain have been demonstrated to eliminate all pain for all patients” (p. 359). While many people with chronic pain continue to actively search within the health system for a resolution, a study conducted by the American Pain Society (1999) found that 39 percent of individuals with moderate to very severe pain were not currently going to a doctor to seek relief from their pain. Within this group 14 percent did not have adequate insurance or found the cost for treatment prohibitive, 15 percent found that treatment and medication were helpful, and 11 percent had learned to cope and live with the pain. No further information about coping and learning to live with the pain was provided and it is this latter group of individuals which is the focus of the present study. Specifically, this study will explore the experiences of individuals who have accepted their pain and who are living a meaningful life despite the disruptions the pain has created.

Need for the Study

This study is needed because chronic pain, as some people have realized, does not have to be an endless search for a cure or the end of a meaningful life. Many people are told they have to learn to live with their chronic pain, and some people manage to do just that through acceptance.

Chronic pain is a condition which affects many people, and which is associated with large financial costs and human distress. In the last number of years there has been a surge in the knowledge, understanding, and hence treatments available to assist individuals who suffer from chronic pain. These developments have greatly benefited many people with chronic pain. However, there are also many individuals who continue to experience chronic pain and the related distress. For many of these people, the search continues for an answer and a cure for their pain. Within the group of people who continue to experience pain even though they have undergone diagnosis and interventions, there are individuals who have learned to live with and accept their pain. Individuals who are more accepting of their pain report less depression, less pain-related anxiety and avoidance, less physical and psychosocial disability while reporting more uptime and better work status (McCracken, 1998). This initial research suggests that acceptance of pain is desired for the benefits achieved. Further study of acceptance as it relates to chronic pain will provide a deeper understanding of this positive outcome of pain and will hopefully provide hope in order to reduce the suffering for those whose pain is unmanageable with existing interventions.

Current understanding of acceptance of chronic pain may be influenced by the definition of acceptance applied, and the questionnaire/quantitative measure utilized. Research probing into the lived experience of the acceptance of chronic pain will contribute to the existing base of knowledge in this area by inquiring into the meaning of, and process of acceptance of chronic pain from the perspective of the participant. Results from this participant oriented research will capture the in-depth, dynamic experience of acceptance of chronic pain. The knowledge gained will complement existing knowledge related to the treatment of chronic pain.

Definition of Terms

In order to provide clarity for the reader, descriptive terms used in the study will convey the following meanings:

Chronic pain: Pain which has persisted for a minimum duration of six months (APA, 2000).

Naturalistic inquiry: The naturalistic researcher studies things in their natural setting and they attempt to make sense of a particular phenomenon from the participants' perspective (Creswell, 1998). It is defined at the level of the paradigm, not method (Lincoln & Guba, 1985).

CHAPTER TWO

REVIEW OF THE LITERATURE

For many people with chronic pain life is met with significant suffering and disruption of life. Often the search for pain reduction and cure does not yield the desired results, and the pursuit for a cure or relief persists only to lead to further suffering and frustration. The movement toward acceptance of pain is desired given that the intended results of pain management to date have proved unsatisfactory for those who continue to suffer with their pain. The acceptance of chronic pain is a relatively new, albeit counterintuitive, approach to chronic pain which may be more beneficial and satisfying than struggling and attempting to control the pain. This literature review will begin with an overview of the meaning of acceptance and the relationship to chronic pain. The focus is on chronic pain rather than chronic illness. An exploration of studies inquiring into acceptance and chronic pain, as well as the factors and components of acceptance of chronic pain will follow. Finally, acceptance based psychotherapeutic interventions are introduced.

Definition of Acceptance

While acceptance is a commonly used term it has numerous definitions and meanings. According to the Concise Oxford Dictionary, (Thompson, 1995) the word 'accept' is defined as 'consent to receive a thing offered'; to 'give an affirmable response', as in 'I accept the offer'; to 'receive an opinion or explanation as adequate, valid, or correct'; to 'regard favorably or receive as suitable.' To accept also means to tolerate or submit to, as in 'I accept the decision'. Acceptance is defined as a willingness to receive, a willingness to accept, or a willingness or ability to tolerate (Thompson). Etymologically, acceptance comes from the Latin root "*accipere*" which means to take or receive what is offered (Hayes, et al, 1999a; Hayes, Strosahl, & Wilson, 1999b). It is evident that acceptance has numerous meanings depending on the context, but that it generally involves a receiving or taking in, of a thought, feeling, or circumstance. Acceptance may also have personal significance and a particular meaning for each person who is faced with a circumstance which elicits or demands acceptance.

In addition to the multiple meanings, acceptance may be engaged in readily or resisted, and can evoke a plurality of emotions depending on the situation, circumstance, or event that is in need of being accepted. Eagerness and spontaneity may facilitate the acceptance of a gift, while acceptance of a cancer diagnosis or death is not so readily accepted. Similarly, joy or excitement may be generated when accepting a gift while sadness, anger, or fear are generated when struggling to accept the death of a loved one. There is no question that accepting positive circumstances is different from accepting the negative or undesired (Bland & Henning, 2002). The process of acceptance may also be a personal and individualized process with varying degrees of resistance or readiness as the experience unfolds.

Psychological acceptance has been defined as a willingness to remain in contact with thoughts and feelings without having to follow them or change them (Hayes, et al., 1999a). Hayes (1994) defines acceptance as “experiencing events fully and without defense, as they are and not as they say they are” (p. 30). Acceptance does not refer to toleration as a way to control or minimize a particular event, but rather acceptance indicates a willingness to remain in contact with and fully experience particular private experiences including thought, emotions, bodily sensations, and memories (Hayes, et al., 1999a). In this way acceptance involves abandoning avoidance and meeting events or situations fully while letting go of ineffective attempts to change (Hayes, Strosahl, & Wilson, 1999b).

As an active process, acceptance involves acknowledging feelings, thoughts, and memories without getting trapped in, or immobilized by negative interpretations or thoughts about the psychological events (Hayes, Strosahl, & Wilson, 1999b). “If one takes an acceptance approach, then the goals of treatment entail helping clients learn to take a different perspective on their thoughts and feelings, to give up the struggle against them, and to pursue those experiences and interactions that give richness and meaning to their lives (Dougher, 1994, p. 44). Further “by establishing a posture of psychological acceptance, events that formerly were taken to be inherently problematic, become instead opportunities for growth, interest, or understanding” (Hayes, 1994, p. 13).

The idea of acceptance is primary to and embedded into the helping professions including psychology and counselling. Acceptance that a problem exists at some level is implicit for seeking assistance for most problems or dilemmas including physical and psychological concerns. To receive treatment or help in the form of medical intervention or psychotherapy, both helper and the patient, and “the client and therapist must ‘take in’ the fact that there is even a problem to be worked on” (Hayes, Strosahl, & Wilson, 1999b, p. 77). Acceptance as a therapeutic concept has a history as a therapist quality as in unconditional positive regard and unconditional acceptance for the client as a person by the therapist (Rogers, 1942). Acceptance of self and others is a component of psychological well being (Dougher, 1994) and is a critical element of self-esteem and self-confidence.

Acceptance of chronic pain has been defined as living with pain without reaction, disapproval, or attempts to reduce or avoid it (McCracken, 1998; McCracken, 1999). Acceptance of chronic pain is more than a mental activity and is not simply a decision or belief (McCracken, 1998). McCracken et al. (1999) outline the thoughts, the psychosocial operations, and the actions of acceptance as “acknowledging that one has pain, giving up unproductive attempts to control pain, acting as if pain does not necessarily imply disability, and being able to commit one’s efforts toward living a satisfying life despite pain (p. 284). Action, according to Dougher (1994) is vital to the process of acceptance, because “acceptance is something one does” (p. 37). In this way, acceptance is an act or a behaviour. As behaviour, acceptance involves a disengagement from the struggle with pain, holding a realistic approach to pain, and an engagement in positive everyday life activities (McCracken & Eccleston, 2003). Acceptance then also entails a willingness to engage in positive everyday meaningful life activities regardless of the pain,

thoughts, and feelings the pain might evoke (McCracken & Eccleston). From the perspective of the person experiencing chronic pain acceptance then may have a personal definition and involve thoughts, beliefs, decisions, behaviour, and emotions.

Acceptance and Chronic Pain

The acceptance of chronic pain is a relatively new focus of study within the area of chronic pain. Many of the quantitative studies have been conducted by L. M. McCracken and C. Eccleston using the *Chronic Pain Acceptance Questionnaire* (CPAQ) which is a self-report measure. The CPAQ was originally based on a measure of acceptance and emotional avoidance called the Acceptance and Action Questionnaire (AAQ) developed and presented at a conference by Hayes, et al. (2004). The AAQ was subsequently modified by Geiser in 1992 for use as a measure of experiential avoidance in the area of chronic pain for a doctoral dissertation (Hayes, et al.). Although the results of the dissertation were never published by Geiser the results were used by McCracken for subsequent research (McCracken, 1998).

One of the first studies conducted on the acceptance of chronic pain showed that greater acceptance of pain was associated with more positive and productive adjustment to chronic pain. The study involved giving 160 patients seeking treatment at a pain management centre a number of self report measures including the CPAQ, the Beck Depression Inventory, the Pain Anxiety Symptoms Scale, and the Sickness Impact Profile. The CPAQ is a 34-item inventory designed to measure the acceptance of chronic pain. Results of the study suggested that a higher score on the CPAQ was associated with reports of lower pain intensity, less depression, less pain-related anxiety and avoidance, as well as less physical and psychosocial disability. More daily uptime and better work status were also found to be associated with higher scores on the CPAQ. The low correlation found between acceptance and intensity of pain suggests that acceptance of pain is not simply a function of having low levels of pain (McCracken, 1998). This early study drew out a preliminary relationship between acceptance and chronic pain adjustment. It would be interesting to discover how individuals who have accepted, or are accepting their pain, have done or are doing so.

Patient behaviour has come to be accepted as an important factor in the development and maintenance of chronic pain (Fordyce, 1976). Coping with pain has been a focus of research as one component of patient behaviour. The concept of coping holds an appeal by clinicians, and researchers, and has contributed to the development of treatments that produce benefits in the management of chronic pain (McCracken & Eccleston, 2003). A study by McCracken and Eccleston (2003) compared the 'acceptance of chronic pain' and 'coping with chronic pain on the 'adjustment to chronic pain'. Participants of the study were 230 patients with chronic pain seeking treatment from a pain management centre. The participants completed the CPAQ, the Coping Strategies Questionnaire, the Beck Depression Inventory, the Pain Anxiety Symptoms Scale (PASS), and the Sickness Impact Profile. The coping strategies of diverting attention, praying, and hoping were consistently associated with greater pain, disability, depression, and pain-related anxiety, less uptime, and worse work status. Only two coping strategies, self-statements and

ignoring pain, were found to have a possible positive influence on patient functioning. This influence was definitive. The coping strategy of self-statements or self-talk was found to be negatively correlated with depression while ignoring pain was found to be negatively correlated with pain-related anxiety. Results from regression analyses suggest that acceptance of chronic pain positively contributed to the adjustment measures which included level of pain, physical disability, psychosocial disability, uptime, work status, depression, and pain-related anxiety, independently of coping. Further, when the coping effects were removed, acceptance continued to independently predict adjustment outcomes. This finding suggests that coping and acceptance are not highly associated with each other. Interestingly, acceptance of pain was not related to the coping strategies of diverting attention or reinterpreting pain, only minimally related to the coping strategy of ignoring pain, and negatively related to the coping strategies of praying and hoping. These results suggest acceptance is not simply a distraction or reframing technique nor is it passively hoping for the situation to get better (McCracken & Eccleston, 2003). This study indicates that a greater acceptance of pain, as measured by the CPAQ, is related to positive adjustment of chronic pain. An in-depth exploration of the acceptance of chronic pain from a naturalistic and phenomenological inquiry perspective may yield information regarding the intricate relationship between acceptance of chronic pain, coping, and the adjustment to chronic pain.

The role of pain-related anxiety and acceptance of pain in differentiating subgroups of pain patients was the focus of a study by McCracken, Spertus, Janeck, Sinclair, and Wetzel (1999). Previous studies indicate that pain-related anxiety has an impact on the adjustment to chronic pain. Research has also found that patients with chronic pain are a heterogeneous group of people who may be characterized based on their coping behaviours into three different subgroups; dysfunctional, interpersonally distressed, and adaptive copers. The group labeled as dysfunctional report that their pain is significant and that it affects a broad range of functioning. A perception that significant others in their life are unsupportive characterizes the interpersonally distressed group, while the adaptive copers group is characterized by a denial of significant negative effects of pain. The dysfunctional group is also characterized by a demonstration of more pain behaviours, more affective distress, use of more pain medication, and increased rate of unemployment compared to the other groups. Higher scores on internal health locus of control is a characteristic of the adaptive copers group while increased marital distress is a characteristic of the interpersonally distressed group (Turk & Rudy, 1988).

For the study by McCracken, Spertus, Janeck, Sinclair, and Wetzel (1999) participants were 190 patients in a pain management centre. Participants completed self report measures including the CPAQ, the Beck Depression Inventory, and the Multidimensional Pain Inventory (MPI). The MPI measures key aspects of the chronic pain experience from a cognitive behavioural perspective and also classifies patients according to the three subgroups. Results of the study showed that patients classified as dysfunctional reported less acceptance of their pain and more pain-related anxiety in comparison to the other groups. The adaptive copers group reported more acceptance and less pain-related anxiety and depression than the

interpersonally distressed group. Overall, the best predictor of group membership was found to be acceptance of pain followed by pain-related anxiety and depression while pain intensity was found to be a weak predictor (McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999).

Research has been conducted which has explored the beliefs held by patients with chronic pain as well as the relationship between beliefs and chronic pain. Beliefs about the meaning of the symptoms and their impact on functioning, beliefs about the ability to control the pain and the impact the pain might have on the future are some of the beliefs found to play a role in chronic pain (Turk & Okifuji, 2002). Degood and Kernan (1996) found that the belief that pain was caused by others was significantly related to greater distress and behavioural disturbance for individuals with chronic pain. Using the methodology of concept mapping, the research by Knish and Calder (1999) revealed seven belief themes including denial/regret, self-defeating/passive, medications/pain focus, cautious realism, accepting limitations, adaptive coping, and responsibility for rehabilitation. Some of the statements generated relating to 'accepting limitations' are "I have to change my lifestyle to a degree to accommodate my limitations" (p. 170), "I have to accept that I need help to do some things" (p. 170), and "it is important to let people know where I am at and what my limitations are" (p. 170). As these participant generated belief statements might suggest, individuals with chronic pain may contemplate the possibility of 'accepting' as a management strategy for the chronic pain.

Rankin and Holttum (2003) studied the relationship between acceptance of chronic pain and beliefs related to the chronic pain. Participants, who were patients with chronic back pain attending a pain management program completed the Acceptance of Illness Scale and the Illness Perception Questionnaire. The Illness Perception Questionnaire measures five dimensions of illness beliefs: illness identity or symptom level, cause of illness, time-line or duration, perceived impact or consequences, and controllability or cure. Both of the self-report instruments were adapted for the study by replacing the word 'illness' with the word 'pain' for each item. Results of the study revealed a relationship between lower acceptance, greater pain identity, and more serious perceived consequences. However, the expected relationship that an increased level of acceptance would be associated with a longer projected time-line for the duration of the pain to continue, and beliefs about control over recovery was not found (Rankin & Holttum). Results of this study seem to be in line with other studies which have explored the role of cognition and beliefs in chronic pain. That is, there is evidence that cognitive representations, specifically beliefs, are related to functioning in chronic pain, but the specific relationship has not been determined. The inconclusive and unexpected findings by Rankin and Holttum might also have been influenced by the use of the self-report instruments designed for illness rather than chronic pain. Perhaps, the substitution of the word 'pain' for 'illness' is not able to capture the experience and beliefs about chronic pain as effectively as for 'illness'. The study does however show support for a relationship between beliefs about chronic pain and the acceptance of chronic pain. A qualitative inquiry into the acceptance of chronic pain is likely to yield information regarding the transitory quality of chronic pain beliefs.

A study by Viane et al. (2003) explored the influence of acceptance of chronic pain on mental and physical well-being. The Dutch version of the CPAQ was used to measure acceptance of pain, while physical and mental well-being were measured by MOS 36-Item Short Form Health Survey (MOS SF-36). This survey includes items which require the respondent to rate their health and the level of interference on their social activities by their physical health and emotional problems. As a generic measure of overall health, the survey also yields physical health and mental health components. Pain severity and pain catastrophizing were also measured. Results of the study found that greater acceptance of chronic pain, as indicated by higher scores on the CPAQ was related to better mental health, lower levels of pain severity and pain catastrophizing. Analysis of the data further revealed that acceptance of chronic pain was independent of pain catastrophizing which suggests that acceptance of pain is not simply the absence of pain catastrophizing (Viane et al., 2003). Personal communication with individuals who have accepted their pain as chronic is likely to provide insight into the role cognition has on acceptance of chronic pain, and how personal thoughts have changed, if at all through the process of acceptance.

Although a relatively recent area of inquiry, the acceptance of chronic pain appears to be a promising and hopeful direction within the area of chronic pain because of the positive outcomes that have been found to be related. Research indicates that a higher level of acceptance, as measured by the CPAQ is associated with better adjustment to the pain as indicated by more daily uptime and improved work status, less depression, pain-related anxiety, lower reports of pain intensity, as well as physical and psychosocial disability. Overall, higher scores of acceptance were associated with better mental and physical well-being, but a minimal relationship was found between acceptance of pain and coping strategies. There is also support for a relationship between acceptance of pain and beliefs about chronic pain. A naturalistic inquiry approach, based on phenomenology, will yield in-depth accounts of the experience of the acceptance of chronic pain. These accounts are likely to provide further insight into the meaning of acceptance, the thoughts, beliefs, emotions, and actions associated with acceptance, as well as the personal journey towards acceptance including roadblocks and facilitating elements.

Components/Factors of Acceptance of Chronic Pain

In addition to measuring acceptance of chronic pain, the *Chronic Pain Acceptance Questionnaire* (CPAQ) has also been utilized to determine key components or factors of acceptance (McCracken, 1999). Analysis on the 34 items which comprise the CPAQ revealed that four factors constitute acceptance of chronic pain. The first factor, Life Focus, relates to the engagement of normal life activities despite the presence of chronic pain. Cognitive control, the second factor, involves believing that controlling thoughts is helpful in controlling pain. The third factor, Acceptance of Chronicity, represents a recognition that the pain might not change. Avoid/control is the fourth factor. This final factor, the opposite of acceptance, relating to the need to avoid or control pain is reverse scored which indicates that a lower score on this factor contributes favorably to the total acceptance of pain score (McCracken, 1999; Viane et al., 2003). Following further factor and correlational analysis, McCracken proposes that engaging in normal life

activities despite the presence of chronic pain might represent the most essential component of acceptance of pain. In a study which sought to refine the CPAQ, only two factors, activity engagement (Life Focus), and pain willingness (Avoid/Control) were found to be related to functioning and distress (McCracken, Vowles, & Eccleston, 2004). Through the analysis the CPAQ was reduced to 20 items from the original 34 items (McCracken, et al.). McCracken and Vowles (2006) note that cognitive control and recognition of chronicity did not appear to be central factors in the quantitative analysis. The degree of presence of these factors was elicited through conversations held with individuals who accepted their pain as chronic.

A subsequent study investigating the item content and factor structure of the CPAQ was conducted by McCracken, Vowles, and Eccleston (2004). Similar to the study conducted by McCracken in 1999, analysis of the items revealed a four factor structure of the acceptance of chronic pain. The first factor, activity engagement, entails the pursuit of life activities despite the pain. Pain willingness, the second factor, relates to recognition that avoidance and control are often unworkable and unsatisfactory methods of adapting to chronic pain. The third factor, thought control, includes the conviction that pain can be controlled or changed by altering one's thoughts. And finally, the fourth factor, chronicity, involves a recognition that the pain may not change. From these four factors, McCracken, Vowles, and Eccleston conclude that acceptance of chronic pain can be considered as a behavioral domain with two components. The first component concerns the pursuit of life activities in a normal fashion despite the pain that is being experienced. Recognition by the patient with chronic pain that strategies which attempt to avoid or control pain are clearly ineffective, is the second component outlined by McCracken, Vowles, and Eccleston.

A study conducted by Risdon, Eccleston, Crombez, and McCracken (2003) derived eight factors or accounts of acceptance of chronic pain. The aim of the study was to generate an understanding of acceptance from the perspective of a culture rather than from the sole perspective of individuals who have a history of chronic pain. Utilizing the Q-methodology, a set of statements were derived about the idea of acceptance of pain from a number of different sources including pain clinicians, researchers, encyclopedias, historical texts, and papers relating to acceptance of chronic pain. The statements were then sorted by individuals recruited because they may have divergent understanding about the term 'acceptance'. There was no attempt to include or exclude participants based on a history of chronic pain. Analysis of the sorted statements produced eight accounts of chronic pain with each account representing a different version of how one may come to accept chronic pain.

The eight most dominant accounts of acceptance of chronic pain revealed are: taking control, living day to day, acknowledging limitations, empowerment, accepting loss of self, more to life than pain, do not fight battles that cannot be won, and spiritual strength. A summary of each account as outlined by Risdon et al (2003) is presented.

Account 1, taking control, suggests that pain and its negative affects are controllable. To accept chronic pain means to acknowledge that disability and hopelessness are not inevitable corollaries of pain. Acceptance means to control pain, not to surrender to it.

Account 2: Living day to day has similar features to account 1 of the need to control pain and its effects. However, here the control has a consequence of living in uncertainty, in the here and now, unable to plan and consider self in the future.

Account 3, acknowledging limitations, involves not the application of self-resources to overcome or control adversity, but the adaptation of social and personal goals to those more achievable in a life with pain.

Account 4, empowerment, foregrounds the importance of a resourceful self. Acceptance will mean that one has the personal strength to focus on what is pleasurable in life, not on aspects of life in which pain dominates.

Account 5, accepting loss of self, equates acceptance of chronic pain with the acceptance of a failure to live unchanged with pain and the loss of the former pain-free self. This account stresses the need to confront this change in self in order to then learn to live with pain.

Account 6, more to life than pain, strongly rejects any idea that self has changed and proposes that accepting pain means to control pain and to focus away from it, living in spite of it.

Account 7, do not fight battles that cannot be won, holds chronic pain as simply one aspect of life's unexpected quality. Acceptance here is achieved by holding a world-view that such events happen and that resistance is futile.

Account 8, spiritual strength, is similar to account 7 in its acceptance of everyday inequalities, and account 4 in the importance of being empowered, and account 1 in the need to control pain and its consequences. The source of the strength to accept pain is spiritual and it is this that makes this account separate from others. (Risdon et al, 2003, p. 383).

The eight accounts reflect intricate and separate ideas that reflect the diverse ways in which understanding of accepting chronic pain can be made. Further analysis of the eight accounts revealed three common features. The first common feature is the idea that a central task of acceptance of chronic pain is to focus on aspects of life other than pain. In the eight accounts, pain was positioned as only one part of a meaningful life, and to accept pain has, as a central component, the challenge of reducing the potential of chronic pain to overpower life at the expense of other day to day, meaningful life activities. Acknowledgment that a cure for the pain is very unlikely is the second common feature. Acceptance of pain involves acknowledging that the pain is likely to persist for the rest of one's life, and that changes will be required in order that adaptation will occur. Risdon et al. (2003) suggests that perhaps "a primary feature of acceptance of chronic pain is that *change* in life is required" (p. 383). The third common feature to the eight accounts is a resistance to the ideas that acceptance of chronic pain is a sign of inferiority, a sign of personal weakness, a failure in life, or the end of any meaningful life. Risdon et al. note that the common features of acceptance of chronic pain do not revolve around the experiential or sensory aspects of pain, but around its effects on social functioning, appraisal of self, and evaluation of social worth. Insight into the relevance and presence of these factors within the experience of the acceptance of chronic pain by individuals immersed in the experienced is likely to emerge from a naturalistic approach to exploring the phenomena.

Bland and Henning (2002) conceptualize acceptance as a complex multilayered phenomenon involving three components: control, emotional regulation, and cognitive behavioral structuring. People who live with chronic pain often experience an intense sense of lack of control which is heightened when the pain remains despite countless physician visits, surgical procedures, and other interventions. The inability to ameliorate or escape the symptoms is experienced as a lack of control which often leaves the person with a sense of hopelessness and helplessness. Since some pain is intractable, or less intractable to the level the patient may desire, and since the side effects of achieving complete absence of pain are unacceptable as in the use of specific types of medications or interventions, for some individuals, it appears acceptance is a reasonable approach. Acceptance as it relates to control then includes a definition of self and a worldview that incorporates new limitations on the ability to control self, including the pain itself and the reactions to the pain, and the environment (Bland & Henning, 2002).

The second component related to acceptance is emotional regulation (Bland & Henning, 2002). Emotional upheaval, in addition to the decreased sense of control, influences the world of the patient with chronic pain. Depression, anger, and anxiety, and their derivatives such as sadness, grief, fear, irritability and frustration, are the most significant emotions which accompany chronic pain. The range of emotions can be explained by looking not only at the symptom of pain, but at the level of disability and impairment, and the secondary losses including economic, social, work, leisure, and self-esteem. The difficulties associated with working within the medical system as well as insurance and compensation systems create additional stress and emotional upheaval for the person with chronic pain. Acceptance of chronic pain includes addressing negative emotional states which are often attached to definitions of self. Thoughts such as questioning personal value or worth, or beliefs that one is being punished because healing is not occurring, are laded with negative emotions. Acceptance of chronic pain is a process which entails acknowledgment of the feelings without allowing them to spiral downward with negative meanings or interpretations. Addressing the thoughts which accompany present life circumstances which help maintain the negative emotions is another component of acceptance (Bland & Henning).

The final component of acceptance, cognitive behavioral structuring, outlined by Bland and Henning (2002) focuses on the cognitive and the behavioural aspects of chronic pain. The cognitive aspects of chronic pain are based on the idea that sensory data, including pain, are mediated as it enters into consciousness (Fordyce, 1976). This processing of pain which leads to interpretations, beliefs, meanings, attitudes, and emotions is influenced by preexisting cognitive schema including current and past context, intensity and type of pain, prior experiences with pain, and learning (Eccleston & Crombez, 1999). The cognition accompanying the pain including the meaning and interpretations attributed, are inherently a personal and individual construction as evident by the unique stories and perceptions held by people with chronic pain (Bland & Henning, 2002).

The constructivist perspective of cognition relates both to the cognitive distortions accompanying chronic pain and the cognitive aspect of acceptance of chronic pain. Persistent pain, its related emotional

upheaval and the frequent real or perceived lack of control experienced, can and frequently does result in catastrophizing, over-generalization, learned helplessness, and other errors or distortions in thinking. The distortions are not limited to the present pain, but frequently spread to past and future events, and to self and others. Changing these patterns of thinking is believed to be a critical component of healthy functioning, and has therefore been the focus of the psychological treatment for individuals experiencing chronic pain. Acceptance of pain from the cognitive perspective involves moving away from negative thoughts and interpretations of self, others and the pain situation, toward perceptions that are more positive, or at least benign (Bland & Henning, 2002). The acceptance of chronic pain, according to Bland and Henning, involves interpreting the self in the pain situation and the pain itself in a more favorable and productive fashion.

The behavioural aspects of acceptance outline how a person changes their actions despite the sensory perception of pain. Pain behaviours are actions, including wincing, limping, grimacing, and decreased activity, that communicate discomfort and disability (Fordyce, 1976). Aronoff (1985) states a direct correlation between pain behaviours and extent of tissue damage, suffering, or resulting disability, does not exist. In chronic pain conditions, the function of these behaviours have been shown to negatively influence current level of functioning, exacerbate the pain (Fordyce, 1976), and increase the risk for future pain problems (Pruitt & Von Korff, 2002). Creating a new understanding of the pain is essential in order that the person with pain is to function as optimally as possible. Acceptance of pain includes behavioural modifications such as allowing more time to complete tasks, participating for shorter time periods, and including more frequent rest breaks. Modifications in behaviour, along with a tolerance for a certain degree of pain during activities fosters acceptance which then reduces the anxiety surrounding pain and increases functioning. In this way, acceptance of chronic pain, allows patients to find meaning and purpose in their actions as they move to focusing on what is possible rather than on limitations (Bland & Henning, 2002).

The range of concepts, features, and components relating to the acceptance of chronic pain illustrate the diverse qualities of acceptance of chronic pain. This diversity of components suggests that the perspective from which acceptance of chronic pain is viewed, whether from the perspective of the person with chronic pain, from the perspective of a person with understanding and interest in acceptance, or from a more conceptual perspective as Bland and Henning (2002) present, is influential, and contributes to the understanding of the acceptance of chronic pain. An insider perspective as acquired from the person immersed in the phenomena will provide a unique and important understanding of the acceptance of chronic pain.

Acceptance of Chronic Pain as Attitude, Cognition, Behaviour, and Process

Acceptance of chronic pain may be further understood through examining descriptive terms or qualities attributed including attitude, cognition, behaviour, process. McCracken (1999) refers to acceptance of pain as a “complex attitude (p. 93) while McCracken, Spertus, Janeck, Sinclair, and Wetzel (1999) described acceptance as an ‘attitudinal variable’. The term ‘attitude’ is defined as a way of thinking

(Thompson, 1995) and as an affective response to a topic (Tait, 1999). Attitudes have been linked to adjustment to pain as well as to responses to treatment and instruments which measure attitudes toward chronic pain have also been developed (Tait). Viane et al. (2003) state “an accepting attitude is captured by the first, third, and fourth components (p. 66) of the CPAQ.

Dougher (1994) acknowledges that acceptance has been referred to as a behaviour and as a cognition, but his position has been to understand acceptance in terms of its function and hence as an “act or a behaviour” (p. 37) and as “something someone does” (p. 37). Jacobson (1992) refers to acceptance as a “letting go of the struggle to change and in some cases even embracing those aspects . . . which have been traditionally been precipitants of conflict” (p. 497). In this way, Dougher observes, “acceptance is really doing nothing” (p. 38) but it is a behaviour nonetheless. On the other hand, McCracken and Turk (2002) have referred to acceptance of chronic pain as cognition. Specifically, McCracken and Turk suggest that psychological acceptance requires a “cognitive shift” (p. 2570) which promotes functioning despite the pain, and which is a “positive prognostic indicator of treatment outcome” (p. 2570). As a cognition, or encompassing multiple cognitions, acceptance of chronic pain fits into the cognitive-behavioural therapeutic approach. According to Viane et al. (2003), cognitive behavioural therapy commonly targets pain-related behaviours and thoughts and beliefs regarding the pain and the impact on life. Fostering the belief that a meaningful life is possible despite the presence of pain, and promoting a change in behaviour away from seeking a cure are both components of acceptance of chronic pain (McCracken, Vowles, and Eccleston, 2004) and of cognitive behavioural therapy (Viane et al.). The four factors of acceptance of chronic pain revealed by McCracken, Vowles, and Eccleston, activity engagement, pain willingness, thought control, and chronicity recognition, contain both behavioural and cognitive elements which suggests that acceptance of pain is not one or the other, but both.

Acceptance of chronic pain and acceptance of disability have also been referred to as processes (Bland & Henning, 2002; Li & Moore, 1998; McCracken, 1999; McCracken, Vowles, & Eccleston, 2004). The term ‘process’ is defined as a ‘course of action’; ‘a series of stages’; and ‘the course or progress of something’ (Thompson, 1995). McCracken, Vowles, and Eccleston state that “at its core acceptance is an active process” (p. 165). As a “dynamic process”, Bland and Henning (p.14) propose that “acceptance of chronic pain is not a passive nor a single event, but rather a complex, active endeavor” (p.14) involving emotions, cognition, and behaviour. McCracken, Carson, Eccleston, and Keefe (2004) stress the active and numerous events of the acceptance of chronic pain in describing acceptance as “not a one-time decision but a matter of moment-to-moment choices” (p. 6) which facilitates the adjustment to chronic pain.

Acceptance as a dynamic and active process is emphasized by Hayes (1994) in describing acceptance as a continuum. The initial steps along the continuum of acceptance, according to Hayes are resignation and toleration. Resignation and toleration are “heavily contaminated by a context of change and by the literal meaning afforded to the events” (p. 31). The deliberate abandonment of a change agenda in which the agenda has not worked is a higher level of acceptance. Emotional willingness, or an openness to

one's emotions, and deliteralization defined as "the defusion of the derived relations and functions of events from the direct functions of these events" (Hayes, p. 31) are higher levels along the continuum of acceptance. Further as one moves far enough along the process or continuum of acceptance "it is possible to begin to stay in the present and to do what works even with all of the psychological events that one has been previously struggling with and trying to change" (Hayes, p. 31). Paradoxically, according to Beisser (1970) "change occurs when one becomes what one is, not when one tries to become what one is not" (p. 77). According to Beisser, change is able to occur when an person takes the time and effort to be fully invested in the present situation. Conceptualizing acceptance as a process might also be captured in the multiple administration and scoring of the CPAQ where earlier in the process a lower score on the CPAQ might be received than later in the process.

Further, if acceptance of chronic pain holds qualities of "moment to moment choices" (McCracken, Carson, Eccleston, & Keefe, 2004, p. 6), it is possible that the score of the CPAQ may reflect this subtle dynamic quality. I wonder whether in conceptualizing 'acceptance' as a process, as in the active sense, perhaps use of the term 'accepting' might better reflect the dynamic and modifiable quality. The term 'acceptance' seems to hold a quality of completion, as in 'accepted', however, the term 'accepting' seems to reflect an ongoing nature. Zettle (1994) also queries the use of the term 'acceptance' versus 'accepting' particularly if acceptance is conceptualized as a behaviour. He observes that "it seems curious that "it" is talked about as a noun (acceptance) rather than as a verb (accepting)" (Zettle, 1994, p. 47). While the dilemma of the use of 'acceptance' versus 'accepting' exists, it may not be resolved until in-depth conversations with individuals with chronic pain and who are living a meaningful life with the pain are held.

Clearly, the acceptance of chronic pain may be understood in several ways. Regardless of which understanding of acceptance is used, whether as attitude, cognition, behaviour, or process, or a combination, the common feature seems to be an inherent malleable quality. This quality opens the door to exploring the process of acceptance including roadblocks as well as the facilitating qualities.

Acceptance Based Psychotherapeutic Interventions

Acceptance based interventions, or procedures based on similar principles have shown promise for the treatment of mental and physical health difficulties (McCracken & Eccleston, 2003) including major depression (Teasdale et al., 2000), psychotic symptoms (Bach & Hayes, 2002), and chronic pain (Kabat-Zinn, 1982). A few of the acceptance based approaches are Mindfulness-Based Cognitive Therapy (Teasdale, et al), Mindfulness Meditation (Kabat-Zinn, 1982; Kabat-Zinn, Lipworth, & Burney, 1985), and Acceptance and Commitment Therapy (Hayes, Strosahl, & Wilson, 1999b).

The focus of Mindfulness-Based Cognitive Therapy (MBCT) is to teach and assist individuals to increase awareness of their thoughts and feelings, and to develop a more detached relationship with them. By interpreting thoughts and feelings as "mental events" (Teasdale 2000, p. 616), the individual is able to achieve a more detached and less personal perspective rather than interpreting the thoughts and feelings as

accurate reflections of self or reality. The defining feature between MBCT and cognitive-behavioral therapy (CBT), according to Teasdale et al., is that with MBCT the focus is on accepting and reinterpreting thoughts and feelings, whereas CBT focuses on changing the content of the thoughts and altering related behaviours.

A study by Teasdale et al. (2000) found that Mindfulness-Based Cognitive Therapy (MBCT) significantly reduced the risk of relapse of major depression for individuals with three or more previous episodes of depression. Individuals with a history of at least two major depressive episodes in the previous five years, not presently receiving antidepressant medication and in remission from major depression comprised the participants for the study. Exclusionary criteria for participants included previous cognitive behavioral therapy, current psychotherapy more frequently than monthly, as well as current practice of yoga or meditation due to the overlap yoga and meditation have with MBCT. Results of the study found that following an eight week treatment period of MBCT and a 52 week follow-up phase, the rates of relapse and recurrence of depression for participants who received the MBCT were almost half the relapse rates for participants who had not received the treatment. This reduction in relapse rates was found only for individuals who had a history of three or more episodes of major depression with one episode to have occurred in the two years prior to the study (Teasdale et al.). The duration of the history of major depression and the success of the acceptance based treatment might have some relevance to individuals who suffer from chronic pain, particularly since the course of chronic pain may extend several years (Turk, 2002a; 2002b; Turk & Okifuji, 2002).

Mindfulness Meditation is a practice which strives to assume a posture of nonstriving and emptiness (Kabat-Zinn, 2002). In contrast to relaxation which has a goal in mind, mindfulness meditation is “about being with things as they are” (Kabat-Zinn, p. 35). Results from a study indicate that participants with chronic pain showed significant improvements in pain intensity, body image, activity, medication consumption, and mood following a 10 week program of mindfulness meditation (Kabat-Zinn, Lipworth, & Burney, 1984). Another study conducted by Kabat-Zinn, Lipworth, Sellers, Brew, and Burney (1984) found that the improvement in pain and psychological status were maintained in a four year follow-up of a training program by pain patients who received 8 weeks of intensive training in mindfulness meditation. The authors observe that mindfulness meditation is readily learned and applied by pain patients which facilitates compliance and enhances the positive outcomes.

Acceptance and commitment therapy (ACT) is a therapeutic approach that teaches individuals “to accept unavoidable private events; to identify and focus on actions directed toward valued goals; and to defuse from odd cognition, just noticing thoughts rather than treating them as either true or false” (Bach & Hayes, 2002, p. 1129). ACT also represents the acronym upon which the approach is based: The ‘A’ represents ‘Accept’, the ‘C’ represents ‘choose’, and the ‘T’ stands for ‘Take [Committed] Action’. Together ‘ACT’ interventions aim to “teach clients how to accept the things that cannot or need not change,

and how to change the things that can be changed . . . and provides guidance on how to know the difference” (Hayes, Strosahl, & Wilson, 1999b, p. 78).

A study utilizing ACT found the intervention to be beneficial for the participants who were inpatients of a state psychiatric hospital who were experiencing auditory hallucinations or delusions at the time of admission to hospital. The participants assigned to the treatment intervention received five sessions in the ACT approach including sessions with a focus on noticing thoughts and perceptions rather than believing and acting on them, accepting one’s symptoms even though the symptoms may not be liked, and accomplishing goals and how to develop more workable strategies for managing the hearing of voices. Participants who received the ACT intervention showed an increase in the frequency of reporting symptoms, lower distress from the symptoms, lower symptom believability, and demonstrated a 50 percent lower rehospitalization rate as compared to the participants who received treatment as usual over a four month follow-up period. The authors speculate that higher level of symptom reporting to be an indirect measure of acceptance. That is, participants who were more accepting of their symptoms are more likely to acknowledge them rather than deny them. Symptom believability and distress were both measured using a self-report rating scale. For the believability measure, participants were asked to rate their delusions and hallucinations such as “to what degree do you believe that X is true” (Bach & Hayes, 2002, p. 1132) with X being symptoms such as “gang members are stalking you” (p. 1132), or “the voices are telling you” (p. 1132). The result of lower symptom believability for the treatment group is thought to be related to the reduction in the distress created by the symptom resulting in lower re-hospitalization rates (Bach & Hayes).

Acceptance based psychotherapeutic approaches clearly hold promise in the treatment and management of a range of mental and physical health concerns including chronic pain. Insights into the acceptance of chronic pain from the perspective of the person with chronic pain will contribute to this body of knowledge.

Summary

In summary, the preceding literature review demonstrated that acceptance of chronic pain is associated with positive adjustment of chronic pain as well as positive pain related thoughts, beliefs, coping behaviours, and emotions. Upon examination of this review, the need for a deeper exploration of the acceptance of chronic pain from a participant perspective was apparent in order that a richer understanding of the experience and the process of acceptance and the impact acceptance has had for the individual may be realized. This study fulfilled this need as the remaining chapters, chapter four; results, and chapter five; discussion, will demonstrate.

CHAPTER THREE

METHODOLOGY

This study was conducted within a naturalistic paradigm of inquiry utilizing qualitative methodology. Naturalistic inquiry seeks to enter the world of the individual and to understand the phenomenon or experience from the person's frame of reference. The qualitative method of phenomenology provided the guidance for this study. Phenomenology strives to gain a deeper understanding of the meaning of lived experiences from the perspective of the person living the experience (Van Manen, 1997). As with naturalistic inquiry, the design of this study was allowed to "emerge, develop, unfold" (Lincoln & Guba, 1985, p. 225) because not all of the elements were able to be outlined beforehand.

Purpose of the Study

The purpose of this study was to explore, elucidate, and understand the experience of the acceptance of chronic pain. Using a naturalistic paradigm, based on phenomenological methodology, a description of themes and patterns was delineated to explicate the essence of the acceptance of chronic pain.

I hoped that this understanding of acceptance would a) provide insight into the experience of acceptance, b) allow for a deeper understanding of the meaning of acceptance of chronic pain c) be transferable into other areas in which acceptance may enhance life satisfaction and productivity, d) increase participants' understanding of their experience so that they are able to integrate and utilize this experience more fully and completely within their lives, and e) give voice to individuals who are living a meaningful life with chronic pain.

Research Questions

It was from my personal experience with chronic pain, interest, wonder, and desire to contribute to the understanding of acceptance that I put forth the following research questions:

What is the experience of acceptance of chronic pain?

What is the meaning of acceptance for the participant?

What has facilitated the process of acceptance?

What impact has acceptance of chronic pain had for the participant?

An Appropriate Paradigm

Naturalistic inquiry is used when researchers attempt to enter the conceptual worlds of individuals and understand the meanings individuals create around and of their experiences. This is done from what are called participant perspectives (Bogdan & Bilken, 1998). In other words, naturalistic inquiry seeks to understand the meaning of, and how participants both construct meaning and make sense of their lives from their own frame of reference.

The naturalistic paradigm is metaphorically similar to the human organism which makes it appropriate for the study of human experience:

A conscious being – say, a human being – is very complex and unpredictable. People behave one way now and a different way later. When they change, they often change suddenly. They are internally interconnected, consisting of many subsystems. They are externally interconnected with other people and the world around them. When people interact, they affect each other. Because of this complexity of interaction, people don't always see the same things; they have unique perspectives. In the same way, the emergent paradigm of the actual world is complex, holographic, heterarchical, indeterminate, mutually causal, morphogenetic, and perspectival (Schwartz & Ogilvy, 1979, p. 16).

This interconnectedness between the subsystems within a human being, and the external world, imparts the obvious, that is, experiences embrace the whole person and their surrounding world. Naturalistic inquiry receives and hears the whole person and all of their experience.

The naturalist paradigm is an axiomatic system which is characterized by a set of assumptions about the phenomena which it is designed to inquire (Lincoln & Guba, 1985). The axiomatic assumptions which underlie this naturalistic inquiry will be:

Axiom 1: The nature of reality:

Naturalistic researchers assume that there are multiple personal realities which can only be studied holistically. Each individual social reality is valuable resulting in multiple realities. Multiple realities will inevitably diverge so control and prediction are unlikely outcomes, although insight and understanding can be achieved. Participants were invited to present their reality through interviews which provided the framework for understanding their experience holistically.

Axiom 2: The relationship of knower to known:

The inquirer and the "object" of inquiry interact and influence one another - "they are inseparable" (Lincoln & Guba, 1985, p. 37). This reciprocal interaction is especially present when the object of inquiry is a human and another human is the data collection instrument.

Axiom 3: The possibility of generalization:

The aim of naturalistic inquiry is to "develop an ideographic body of knowledge in the form of 'working hypotheses' that describe the individual case" (Lincoln & Guba, 1985, p. 38). Generalizations across individuals, their experience and the phenomena itself may be impossible although transferability is possible (Bogdan & Biklen, 1998).

Axiom 4: The possibility of causal linkages:

An experience may be explained in terms of multiple and reciprocally interacting factors, events and preconditions, so establishing a complex cause/effect relationship is not possible. Naturalistic inquirers can at best establish plausible inferences about patterns and themes which are thought to provide the meaning of an experience. Participants in this study brought their own personalities, context, experiences, and interpretations forward, so the best I, (like other researchers), was able to do was to secure their rich descriptions and make plausible inferences into the meanings of their experiences.

Axiom 5: The role of values in inquiry:

Naturalistic inquiry is value-bound in four ways: inquiries are influenced by inquirer values; inquiry is influenced by the choice of research paradigm; inquiry is influenced by the theory (ies) chosen to guide the study; and, inquiry is influenced by the values embedded into the context. These values may add richness to the inquiry rather than be considered as factors needing to be removed or otherwise controlled. It was anticipated that the role and influence of values would surface in this study. When this occurred, the value(s) was brought forward and addressed through direct communication with participants, writing in my reflexive journal, and consulting with my supervisor, colleagues, and committee members in order that the influence was identified, and then minimized, or utilized with purpose and awareness.

Methodological Orientation

This study, while grounded in the naturalistic paradigm, was influenced by the principles of phenomenology, specifically hermeneutic, social, and reflective empirical phenomenology (Creswell, 1998; de Rivera, 1984; Van Manen, 1997). Hermeneutic phenomenology attempts to “construct a full interpretive description of some aspect of the lifeworld” (Van Manen, 1997, p. 18) which is impossible in practice, to achieve because “lived life is always more complex than any explication of meaning can reveal” (p.18). Further, the basic things about our world, our experiences, thoughts, and feelings are difficult to grasp let alone describe to another person. For these reasons hermeneutic phenomenology is a process and is never ending - we can only do the best we can in the moment. Social phenomenology is interested in how members of society make up the world of everyday life, especially how individuals consciously develop meaning out of social and interpersonal interactions. Psychological phenomenology expressed through empirical/transcendental phenomenology focuses on the meaning of individual experiences rather than group experiences (Creswell, 1998). Reflective empirical phenomenology is a method “which attempts to systematically arrive at a structural description of how persons live and participate in particular situations” (de Rivera, 1984, p. 682). Based on phenomenology, this study sought to describe the experience of the acceptance of chronic pain, while recognizing that this experience, however deeply personal and intimate, evolved from interpersonal interactions.

A difficulty with the phenomenological approach begins with the very issue which leads one to choose a research topic or question. That is, because research questions may “arise from a problem noted in the course of clinical practice, or from a significant experience that occurs in the course of everyday living” (Morse, 1998, p. 57). The problem “is not always that we know too little about the phenomenon we wish to investigate, but that we know too much” (Van Manen, 1997, p. 46). Specifically, because “the topics we study and write about are emotion laden, close to the people, and practical” (Creswell, 1998, p.19) our pre-understandings, biases, prejudices, and assumptions may direct the study and/or result in a premature interpretation of the phenomenon (Bogdan & Biklen, 1998; Van Manen).

The process of identifying one’s presuppositions about the nature of a phenomenon is termed reduction while the attempt to set them aside is known as bracketing (Creswell, 1998; Holstein & Gubrium,

1998; Osborne, 1994; Ray, 1994; Van Manen, 1990). In the pure form of phenomenology Husserl attempted to achieve presuppositionless knowing through reduction and bracketing in an attempt to see the phenomenon in its pure form (Osborne, 1994). On the other hand, Heidegger did not believe that presuppositionless knowing was possible and took the position “that presuppositions are not to be eliminated or suspended, but are what constitute the possibility of intelligibility or meaning” (Ray, p. 120).

Rather than simply ignore our biases, Van Manen (1990) suggests that researchers “try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character” (p. 47). Implicit in identifying biases is the “readiness and a willingness to grow as a person by constructively confronting and working through experiences” (Van Hesteren, 1986, p. 212), which may lead to an increased self-awareness and identification of assumptions. Biases, like values, were identified and reflected upon through consultation and writing in my reflexive journal in order to minimize and/or identify their impact.

Participant Selection

Participants were selected for this study using purposeful selection. Purposeful selection is used to select participants who are thought to have rich information with respect to the purpose of the study. “The purposeful selection of participants represents a key decision point in a qualitative study. Researchers designing qualitative studies need clear criteria in mind and need to provide rationales for their decisions” (Creswell, 1998, p. 118). Given the nature of the study, purposive sampling seems to be the most appropriate way to select the participants. Purposive sampling “increases the scope or range of data exposed . . . as well as the likelihood that the full array of multiple realities will be uncovered” (Lincoln & Guba, 1985, p. 40). Participants selected using purposive sampling are chosen “because they are believed to facilitate the expansion of the developing theory” (Bogdan & Biklen, 1998, p. 65).

Purposive sampling may be undertaken in a number of ways including criterion and maximum variation. Criterion sampling ensures that all participants meet predetermined criteria (Creswell, 1998). The criteria I used for this study were:

- 1) Individuals who were presently experiencing nonmalignant chronic pain.
- 2) Individuals who have had pain for a minimum of six months.
- 3) Individuals who experienced a disruption in their life as a part of the chronic pain experience.
- 4) Individuals who were living a meaningful life despite/with their chronic pain.
- 5) Individuals who indicated they have accepted their chronic pain.

The decision to use these criteria was made after reviewing the literature on chronic pain and acceptance. The rationale to include nonmalignant pain and to exclude malignant pain and pain associated with life threatening illness or conditions was implemented in order to focus on acceptance and living rather than existential concerns and end of life thinking which may arise with life threatening conditions. A

minimum six month duration was implemented in order to include individuals who would meet the chronic pain diagnostic time criteria. This time frame was also determined to be of sufficient duration to allow individuals time to receive the diagnosis, to experience a disruption in their life and time to have experienced acceptance. The life disruption criterion was determined to be important as it gave an indication of the pain intensity such that acknowledgment and adaptation of limitations were necessary and acceptance desirable. Acknowledging limitations and living a meaningful life were two factors of acceptance of chronic pain generated by clinicians, researchers, encyclopedias, historical texts, individuals with chronic pain, patient and career discussion groups, and other sources (Risdon, et al., 2003). Living a meaningful life with pain was used as a criterion because Risdon et al. revealed it to be an important outcome of acceptance and because Park (2003) found life meaning to be an important predictor of outcome for individuals with chronic pain. The final criterion was added a couple weeks after beginning data collection when it became apparent during an interview with a participant that she had not accepted her pain. This individual did not participate in the study.

A brief telephone interview was held with individuals who contacted the researcher expressing interest in participating in the study to ensure selection criteria were met. At this time demographic information including age, gender, type, and duration of pain was ascertained. A brief description regarding the disruption of life experienced, as well as how the individual perceived themselves to be living a meaningful life was acquired. In order to elicit the individual's perception of their meaningful life with chronic pain, inquiry was made into one or more life areas related to a meaningful life. These areas include relationships, work, learning, home and family, community service, leisure, and spiritual or religious worship (Colledge, 2002; Frankl, 1959; Zunker, 2002).

Twenty individuals contacted the researcher expressing interest in participating in the study within the first year of the study. Five individuals did not meet the selection criteria, two met the criteria but did not return phone messages to arrange an interview, and two individuals contacted me several months after data collection had been completed. A total of 11 participants were selected for the study and participated in the interviews with one participant subsequently withdrawing from the study. No demographic criteria were used to select the participants.

Site Selection

Participants were informed about this study through posters, advertisements, committee members, and word of mouth. Posters were placed at rehabilitation centres, chiropractor clinics, and massage therapy offices in at least two western Canadian cities. Posters had been distributed to committee members but it is unknown specifically where they were posted. An advertisement was placed on the Canadian Pain Association of Canada website. Participants were also informed via word of mouth by the researcher and committee members. Individuals expressing interest came from four Western and Central Canadian provinces and lived in six different communities.

Instrumentation

In this study the instrument of choice, as is the case with naturalistic inquiry, was the researcher. Humans are uniquely qualified as the instrument in naturalistic inquiry because of the characteristics they hold including responsiveness, adaptability, an ability to view phenomenon and context holistically, insightfulness, ability to process information, ability to generate and test hypotheses in the moment, as well as the ability to summarize data and provide immediate feedback to the participant for “clarification, correction, and amplification” (Lincoln & Guba, 1985, p. 194).

As a human instrument, I brought to the research process personal involvement, partiality, and empathy (Glesne & Peshkin, 1992, p.7). Because of this involvement I was required to be aware of my biases (Bogdan & Biklen, 1998; Creswell, 1994; Kvale, 1996; Lincoln & Guba, 1985; Rubin & Rubin, 1995; Van Manen, 1997), because “researchers’ biases, angers, fears, and enthusiasms influence their questioning style and how they interpret what they hear” (Rubin & Rubin, p. 18). My own experience with chronic pain informed this study and it may also have been a source of bias. In order to guard against my biases undesirably altering the research process and to mitigate, or at least identify their impact, I employed a number of strategies. I maintained a reflexive journal, wrote and reviewed notes pertaining to each interview, and participated in conversations with my supervisor, committee members, and colleagues. Further, I inquired of the participants about the process of the interviews, which allowed the participant opportunity and freedom to provide details, clarify, or move the interview in a different direction.

Data Collection

Data was gathered primarily through active/in-depth unstructured interviews (audio-taped) conducted by telephone and in-person. Some participants chose to provide responses to follow-up questions in writing rather than a telephone or face to face interview. This writing was delivered through (hard copy) regular mail and electronic mail.

Active/In-depth Interviews

Interviews are perhaps the most common method of collecting data in qualitative research (Osborne, 1994). In hermeneutic phenomenological research the interview is used to gather experiential narrative data that may serve as a base for developing a deeper and richer understanding of a human experience (Van Manen, 1997). The interview structure for this study was a combination of active interviewing and in-depth interviewing. The active interview is a conversation which is guided by the interviewer and the research agenda (Holstein & Gubrium, 1995). In-depth interviewing, also called unstructured or open-ended interviewing, is used to understand in detail the complex behaviour and lives of members of society (Bogdan & Biklen, 1998; Fontana & Frey, 1994). The process of in-depth phenomenological interviewing is divided into three sub-interviews, each with its own focus. Establishing the context of the experience was the focus of the first interview, while the details of the experience within this context were the focus of the second. The third interview focussed on the meaning the experience had for the participant (Seidman, 1998). Between two and three interviews were held with each participant.

The tenets of active interviewing guided the interviews while an interview guide (Appendix C) provided the direction. The interview guide was developed by consulting with my supervisor, committee members, professionals who work in the area of chronic pain, as well as individuals who have chronic pain. A pilot study was not deemed necessary.

A research interview, according to Kvale (1996), is a form of and is based upon the conversations of daily living. The life world interview seeks to “obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena” (Kvale, p. 6). Encouraging participants to describe their world and their experience in their own words and on their terms is more than an interview skill. It is also a component of qualitative interviewing philosophy and an approach to learning (Rubin & Rubin, 1995). Another component of the philosophy helps define what is ethical and what is interesting, and helps to set standards to assess the humanity of the interview relationship and the quality of the research. The final “component of this philosophy is that interviewing involves a relationship between the interviewer and interviewee that imposes obligation on both sides” (Rubin & Rubin, p. 2). Many feminist researchers suggest that this relationship would include aspects of collaboration and a sharing of the responsibility for determining the words and concepts in which lives and experiences could be described. From a feminist orientation, the interviewer would be open about themselves to their collaborators because it is both fair and practical. A feminist interviewer is not justified in asking another person to disclose what she/he is not willing to share. On a practical level “by examining your own feelings on the subject at hand you become more aware of what you are asking others to reveal” (Rubin & Rubin, p. 37). This approach also invites a greater spectrum of answers and provides an opportunity for greater insight (Fontana & Frey, 1994).

The interpersonal nature of interviews, specifically the interaction between myself and the participants undoubtedly impacted the interview process. In an effort to enhance the process and ultimately the outcome, I endeavoured to establish rapport and safety, to convey warmth and respect, and to listen actively in order to draw out meanings and follow the direction of the participant. Rapport was established and maintained by answering the participants’ questions, addressing their concerns including meeting in person prior to starting the interviews. My hope was that the participants would feel free to share their thoughts, ideas, and experiences, and express their feelings and beliefs. I believe this was achieved.

Research and therapeutic interviews.

Interviews are the predominant method used in qualitative research and counselling/psychotherapy (Hutchinson & Wilson, 1994). Although the goals of each are different, both types of interviews draw upon similar skills and elements which at times make it difficult to differentiate between the two. A more detailed look at the similarities and differences is warranted in an effort to streamline the research process and the role of the researcher.

In both research and therapy interviews the researcher/therapist and participant/client interact in a reciprocally influential manner. Establishing rapport and safety is essential in both contexts in order to provide a forum in which the participant or client feels the freedom to unveil feelings, beliefs, thoughts, and experiences. Within the bounds of safety and support, researchers and therapists ask questions and probe in an attempt to obtain clarity and depth of information.

Implicit to both researcher and therapist is a willingness for self-exploration and self-discovery. As Hutchinson and Wilson (1994) suggest, both “research and therapeutic interviews are reflexive in that they encourage self-exploration and attention to what the researcher/therapist is asking, feeling, and thinking” (p. 308). Thus, self-discovery and self-awareness are important elements in directing both the research process and the content presented. Self-awareness also plays a role in the ability of the researcher/therapist to remain as neutral and objective as possible. The ability to remain as neutral as possible will assist the researcher/therapist to receive, understand, and interpret the meaning of the stories and experiences of the participants and the clients.

In addition to these shared characteristics, other characteristics also differentiate between research and therapeutic interviews. One such characteristic is embedded in the theoretical underpinnings of each type of interview. Research interviews take root in the theories of symbolic interaction, ethnography, hermeneutics, and phenomenology, while therapeutic interviews are embedded in such theories as cognitive, behavioural, and family systems (Hutchinson & Wilson, 1994). Other differentiating characteristics include the aim of the interview and the agenda of the researcher/therapist. Put simply, research aims to acquire and develop knowledge, while therapeutic interviews aim to utilize knowledge to empower and facilitate change and growth in the client. The agenda of the researcher focuses on gathering information and the understanding of an experience or phenomena. While a researcher may provide emotional support or information, the “major role is that of scientist” (Hutchinson & Wilson, p. 305). In contrast, the therapist moves “beyond understanding and interpretation to intervention” (p. 306) in an attempt to elicit change, understanding, and an increased self-awareness in the client.

The reason for participating in the interview, (i.e., motivation) differs for the research participant and the client in therapy. Research participants are often recruited by a researcher, while for therapy it is the client who seeks therapy (Hutchinson & Wilson, 1994). Considering the differing motivation, it is feasible that both participant and client may undergo an increased awareness, insight, and understanding, even though this intent or goal is not present for the research participant.

My role as a researcher in this inquiry was outlined at the outset of the interviews with each participant. Although I utilized many of the same skills found in therapeutic interviews in order to provide the participant a safe and inviting environment, the goal of the interview was to gather information and acquire understanding of the process of the acceptance of chronic pain. As a by-product of participating in the study, some participants indicated they had experienced an increase in awareness, achieved insight, and widened their understanding about their experience even though this was not the intent.

Observation

Participant observation exists on a continuum from complete participant in which the researcher's role is hidden, to complete observer in which the researcher's role is limited to observing (Creswell, 1994). As indicated the introductory meetings and interviews were conducted either in person or by telephone. Financial assistance made it possible to meet with some of the participants who lived out of town/province. Meeting in person, and hence observing the participants, facilitated rapport but did not add to the data. Data came from the interviews.

Field Notes

Field notes are "the written account of what the researcher hears, see, experiences, and thinks in the course of collecting and reflecting on the data in a qualitative study" (Bogdan & Biklen, 1998, pp.107-108). I divided my field notes according to the division outlined by Bogdan and Biklen, into descriptive and reflective components. Descriptive field notes represent an attempt by the researcher to capture, in as much detail as possible, and as objectively as possible, the setting, people, objects, events, and conversations as they present themselves. My descriptive field notes assisted me in tracking the flow of the interviews and provided suggestions for follow-up questions. I kept separate descriptive field notes for each participant. Reflective field notes capture the researcher's personal account of the inquiry including feelings, ideas, concerns, and impressions. The purpose of this reflection was to improve the field notes which will hopefully create a better study.

Reflexive Journal

The reflexive journal is similar to a diary in which the researcher records information about self and method. The journal includes: (1) the daily schedule and logistics of the study; (2) a personal diary that provides the opportunity for catharsis, reflection, and insights; and (3) a methodological log in which methodological decisions and rationales are indicated (Lincoln & Guba, 1985).

Both field notes and the reflexive journal enabled me to identify my subjectivity, biases, and beliefs which may have influenced how this study unfolded. The act of writing helped me to slow the flow of my thoughts in order to identify biases and contemplate their impact. I reviewed these reflections and discussed them with my supervisor, committee members, and colleagues in order to minimize their impact.

Documents: Personal and Public

Personal documents are produced by individuals most often for personal reasons. This type of document includes journals, diaries, letters, and photo albums (Bodgan & Biklen, 1998). Personal documents may provide valuable information about lived experiences, particularly, the experience of the acceptance of chronic pain.

Public documents refer to documents produced by organizations for record keeping and for dissemination and distribution. Documents of this type include memos, newsletters, and files. Documents

produced for commercial purposes to inform, entertain, and persuade the public such as commercials, television programs, and news broadcast are designated popular culture documents (Bogdan & Biklen, 1998; Creswell, 1994).

I anticipated examining the personal documents of the participants. As appropriate, I invited participants to present and discuss personal drawings, documents, or writings from journals or diaries as they relate to their experience of chronic pain and acceptance. Participants willingly offered to show me photo albums, letters, video tapes, poetry, and books they had written which enhanced understanding and facilitated rapport. Examination of public documents was limited to a newspaper article shown to me by a participant.

Data Analysis

Data analysis is the process of arranging and reducing data in order to understand its meaning and present the findings to others (Bogdan & Biklen, 1998). The task of analyzing data requires “astute questioning, a relentless search for answers, active observation, and accurate recall” (Morse, 1994, p.25). It is a cyclical process of segmenting the data into meaningful units and piecing it back together in order to make the indiscernible obvious and connecting seemingly unrelated perspectives (Morse). Analysis is a creative process of organizing data (Morse), and involves being artful (Guba & Lincoln, 1994) and playful (Goetz & LeCompte, 1984).

Transformation is the term used by Wolcott (1994) to describe the variety of data analysis strategies which are the primary ingredients of qualitative research. Wolcott suggests that three types of transformation exist. The goal of the first type of transformation, description, is to tell the story of the data as descriptively as possible. Analysis, the second type, is the process by which the researcher expands and extends the data beyond a description. The emphasis during analysis is the search for themes and patterns. The third type of transformation, interpretation, entails the researcher offering an interpretation of what the data are saying. Description, analysis, and interpretation are not mutually exclusive nor will they all be necessarily part of one overall schema (Coffey & Atkinson, 1996).

The initial analysis of the data was conducted using the computer program ‘ATLAS.ti’. This program required the transcripts to be first saved into the program and assigned a primary document number. Transcripts were then reviewed for notable ideas and elements which were then highlighted and assigned a key word or phrase. Each quote was then assigned a quote number electronically which enables each phrase to be located readily within each document (transcript). The key words and phrases formed the basis of the themes and subthemes of the study. The analysis program provided a list of the codes along with the number of times it was assigned to a quote. Knowing this number facilitated identification of themes and subthemes. The program allowed all of the quotes for each code to be saved separately which facilitated writing.

After using ATLAS.ti for the initial coding and separation of the quotes the constant comparative method of data analysis was used. This method involves a cyclical process whereby the quotes identified were broken down further into separate segments in terms of their properties and elements. These segments were then compared to other segments seeking out repetitions and patterns further. The constant comparative method involved a process of moving back and forth between the data, checking and ensuring the emerging themes fit the data. Glaser and Strauss (1976) state that “by ‘fit’ we mean that the categories must be readily (not forcibly) applicable to and indicated by the data under study; by ‘work’ we mean that they must be meaningfully relevant to and be able to explain the behaviour under study” (p. 3). Clearly, data and themes are required to ‘fit’ and ‘work’.

Use of ATLAS.ti and the constant comparative method of data analyses allowed the patterns and themes which describe the experience of the acceptance of chronic pain, to emerge, develop, and unfold (Lincoln & Guba, 1985). Allowing and facilitating this process is not unlike how the design of a naturalistic inquiry comes about.

Trustworthiness

The trustworthiness of research refers to the perception that a particular inquiry is worth paying attention to, and worthy of respect and value. Trustworthiness incorporates four questions which Lincoln and Guba (1985) suggest need to be considered:

- (1) Truth Value: How can one establish confidence in the “truth” of the findings of a particular inquiry for the participants and the context in which the inquiry is carried out?
- (2) Applicability: How can one determine the extent to which the findings of a particular inquiry have applicability in other contexts or with other participants?
- (3) Consistency: How can one determine whether the findings of an inquiry would be repeated if the inquiry was replicated in a similar (or the same) context with similar (or the same) participants?
- (4) Neutrality: How can one establish the degree to which the findings of an inquiry are determined by the participants and the conditions of the inquiry and not by the inquirer’s (researcher’s) biases, motivations, interests, or perspectives?

Criteria which address these questions and the issue of trustworthiness are credibility, transferability, dependability, and confirmability. Lincoln and Guba (1985) suggest a variety of methods which address the trustworthiness criteria. The methods which applied to this study are presented.

Truth Value/Credibility

Truth value or credibility is concerned with the nature of reality. The naturalistic inquiry paradigm embraces a reality that consists of “a multiple set of mental constructions” (Lincoln & Guba, 1985, p. 295). Truth value is demonstrated when the naturalist represents “those multiple constructions adequately” (Lincoln & Guba, p. 296). Adequacy is achieved when the “reconstructions (for the findings and

interpretations are also constructed) . . . are credible to the constructors of the original multiple realities” (Lincoln & Guba, p. 296). The conventional or positivist paradigm embraces internal validity as the equivalent to credibility. Credibility may be established by using several methods including prolonged engagement, triangulation, peer debriefing, negative case analysis, referential adequacy, member checks, and ensuring the criteria of adequacy and appropriateness are met.

Prolonged engagement.

Prolonged engagement with the participants was attained through the interview process, which involved up to three interviews in addition to an introductory conversation and a follow-up exchange of information, by phone or in writing, with each participant. Interviews were between 60 and 90 minutes long. Completion of interviews and transcript review took a minimum of six weeks and as long as nine months with the majority of the participants’ process taking approximately four months.

Triangulation.

Triangulation is a process which involves checking and comparing information from multiple sources, methods, investigators, and theories. Triangulation ensures that multiple realities will be demonstrated adequately and which enhances the credibility of the inquiry. As there were ten participants, there were multiple sources for data collection on the phenomenon of the acceptance of chronic pain. The use of differing data collection modes is referred to as method triangulation by Lincoln and Guba (1985) and is helpful because “the imperfections of one are cancelled out by the strengths of another” (p. 306). In this study multiple data collection modes was achieved using multiple interviews. Thus the triangulation of methodologies was able to reinforce the trustworthiness of this study. Investigator triangulation was also used in this study to ensure that emerging themes were based in the data, and not unduly influenced by the researcher’s biases and subjectivity. My supervisor, committee members, and colleagues served as the external investigators in this study.

Peer debriefing.

Peer debriefing is a process of “exposing oneself to a disinterested peer . . . for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (Lincoln & Guba, 1985, p. 308). Peer debriefing served many purposes including assisting the inquirer to remain honest and self-aware to biases and position, testing tentative hypotheses which emerge, improve, and further develop the methodological design, and provide an opportunity for catharsis of emotions and thoughts. Peer debriefing occurred through meetings with my supervisor, committee members, and colleagues.

Member checking.

The process of member checking was undertaken, formally and informally, consistently throughout the data collection phase. Lincoln and Guba (1985) emphasize the importance of member checks as “the most crucial technique for establishing credibility” (p. 314). Formally, interview transcripts were offered to the participants to review their contributions for accuracy, clarity, and completeness.

Participants had the opportunity to edit their transcripts, deleting or adding comments, or offering clarification as desired prior to signing the data release form (Appendix D) giving me formal permission to use their transcript.

Participants were prepared to read the descriptive passages about themselves by being advised that the text was written verbatim and would contain the many pauses and ‘hmmms’ of ordinary conversation. Kvale (1996) emphasizes the importance of including these nuances of conversation because they yield important material for interpretation of psychological content and emotional tone. Preparing the participants for these nuances enabled them to focus their time and energy when reviewing the transcripts on ensuring the completeness of their experience rather than deleting what they perceived to be extraneous verbiage. A review of transcripts before and after participant review revealed the majority of edits simply clarified statements and did not alter the original meaning. Informal member checking occurred during the data collection stage whereby participants had opportunity to clarify or verify my interpretations during the interviews. The decision not to have participants review the analysis was made because it was the researcher who was familiar with all of the participants experiences as revealed through the interviews and transcripts, including the psychological content and emotional tone, whereas the participants would be familiar with only their own experience. Erlandson, Harris, Skipper, and Allen (1993) acknowledge the danger of member checks of the analysis by participants who do not support interpretations which point out perceived weakness or criticism or if they have the desire to mislead. Bradshaw (2001) notes the reality of research is often a “balancing act” (p. 208) which is guided by ethics that permit issues such as decisions as to the extent of member checking to be made with flexibility and sensitivity while being influenced by the researchers own experience and education which is often years in length.

Adequacy and appropriateness of data.

The criteria of adequacy and appropriateness of data are implemented in order to ensure rigor. Adequacy refers to the amount of data collected. Adequacy is realized when sufficient data have been collected so that saturation occurs and variation is accounted for and understood. Appropriateness refers to the selection of relevant information according to the theoretical needs of the study and the emerging themes. In qualitative research, the researcher collects data until repetition from multiple sources is obtained. This repetition “provides concurring and confirming data, and ensures saturation”(Morse, 1998, p. 76). The criteria of adequacy and appropriateness ensured that the results of the study are rich and the multiple realities of participants are represented. Participant selection was discontinued when it was determined that saturation had occurred.

Applicability/Transferability

Applicability is a criterion of external validity within the conventional paradigm and refers to the degree the findings of a given study apply to other contexts or studies. Naturalists assert “that at best only working hypotheses may be abstracted” (Lincoln & Guba, 1985, p. 297) and thus refer to the equivalent of external validity as transferability. Naturalists generally are not concerned with generalizability or

transferability because transferability “inferences cannot be made by an investigator who knows *only* the sending context” (Lincoln & Guba, 1985, p. 297). The responsibility of the original investigator is thus limited to “providing sufficient descriptive data to make such similarity judgments possible” (Lincoln & Guba, p. 298). Sufficiently “thick” descriptive data was created and is presented from the data collected from the ten participants through the interview process.

Consistency/Dependability

Consistency as a criterion of reliability within the conventional paradigm is referred to as dependability in the naturalistic paradigm. Reliability is typically demonstrated by replication which “in the traditional sense can be determined only within a framework –and that framework is itself a construction” (Lincoln & Guba, 1985, p. 299), and not an unchanging part of reality. However, the “naturalist sees reliability as part of a larger set of factors that are associated with observed change” (Lincoln & Guba, p. 299), and therefore “seeks means for taking into account both factors of instability and factors of phenomenal or design induced change” (p. 299). A research product may then be evaluated as dependable if the results could be replicated. Naturalists recognize the temporal nature of reality and recognize that while this temporality in itself cannot be replicated exactly, learning can still occur. Replication and hence, dependability may be established by providing an inquiry audit of the research process and ensuring triangulation. The audit trail implemented in this inquiry delineated the process of the inquiry as it unfolded. The audit trail includes a record of phone calls, email messages, and letters written. In addition, detailed notes of verbal meetings were kept, all written exchanges of communication filed, and personal notes developed.

Neutrality/Confirmability

Confirmability denotes a neutral stance within the naturalistic paradigm. Naturalistic inquirers acknowledge the interpersonal interaction between researcher and participant hence, pure objectivity is a myth. Rather, the naturalistic inquirer, through identification of potentially influential biases, takes the emphasis off the investigator and “places it where, as it seems to the naturalist, it ought more logically to be: on the data themselves” (Lincoln & Guba, 1985, p. 300). The criterion of confirmability was sought, as suggested by Lincoln and Guba, through the audit trail, triangulation, and the reflexive journal, which have previously been described. The main concern in assessing confirmability “will be to ascertain whether the findings are grounded in the data” (Lincoln & Guba, p. 323). The results chapter, chapter four will present these findings.

Ethical Considerations

The University of Alberta ethical guidelines for research with human subjects were followed. A formal application was made to the University Advisory Committee on Ethics for approval (Appendix E). Approval was received. Participants were informed of the purpose and anticipated benefits of the study, the extent and duration of their participation, and how the information provided will be utilized. Participants were informed that participation is voluntary and that they may withdraw from the study at any time. The

confidentiality and anonymity of participants is protected through use of a pseudonym of their choice, if desired. Signed informed consent was obtained from each participant. See Appendix B for a copy of the information and consent form. The audio tapes were transcribed by persons who were aware of the ethical requirements of the study and whom signed a confidentiality agreement form. Participants were offered the opportunity to review their transcripts to check for accuracy and omissions before signing the Data Release Form (Appendix D). In the event that participation in the study evoked an emotional response because of the nature of the subject matter, participants were informed that I would assist them in securing appropriate support including professional counselling services as necessary. Accessing this support was not necessary although additional time in an interview was provided.

CHAPTER FOUR

FINDINGS

The findings of this study evolved from interviews with participants who were currently experiencing nonmalignant chronic pain which had persisted for a minimum of six months. Participants had experienced a disruption in life because of their pain and were living meaningful lives with their pain. Most critical for this study, is that all of the participants had accepted their pain. Participants came from three Central and Western Canadian provinces and resided in six different communities.

This chapter begins with a profile of each participant. This is followed by an in-depth presentation of five themes emerging from interviews with the participants who shared their experiences on the acceptance of chronic pain.

Participant Profiles

The following profiles introduce the participants. Some chose to use a pseudonym indicated in their profile with quotations marks, to hide their identity, while others willingly used and even requested their real name be used saying “I have nothing to hide” and “I want people to know” about my experience. The researcher has made every effort to ensure anonymity where it has been requested. To facilitate readability without compromising anonymity, the profession of the participants who wish to remain anonymous and who are a health care professional will be referred to as ‘health care professional’. To further protect the participants’ identity all references to organizations will be described using a vague but descriptive label such as “auto insurance company” or “provincial disability plan”. References to other people, including family, friends, and professionals are presented as the participants originally presented them, except when the anonymity of the participant might be compromised. In these instances the person’s gender will be consistently referred to as “she”. The reader will become more familiar with the participants and their experiences as the themes are presented. See Appendix F for a character map of the participants for use as a guide while reading to keep track of the participant’s experience.

Bea

Bea was 65 years old at the time of the interviews. She retired a few years prior from her career as a cook. Bea had chronic pain from osteoarthritis and an elbow injury on her dominant hand, but it was the acceptance of the elbow pain that was the focus of the interviews. Bea’s elbow pain began with a fall a year and a half before the interviews. The pain persisted and the doctors and Bea realized three months after the fall that her elbow was dislocated. Despite two surgeries, Bea’s elbow remains dislocated. Currently she uses medication and receives physiotherapy to help manage the pain. Bea described the first months after her fall as a blur due to the intense pain. She was unable to take care of herself and because her family was not allowed to stay with her at the senior’s facility where she had been living, she moved into a house. This change in accommodation allowed Bea’s two adult children to live with her and provide assistance. Since her fall Bea has been unable to complete basic tasks such as dressing herself and she has had to learn to use

her non-dominant hand for tasks such as writing. Bea's faith, family, and grandchildren all have contributed to her living a meaningful life. Recently Bea has been able to resume playing bingo and cards, both of which provide enjoyment and contribute to her quality of life. Upon reflection, Bea thought that acceptance came when she found out her elbow would remain dislocated.

Elyse

"Elyse" came to Canada just over a year prior to the interviews for the adventure and experience of working as a health care professional and living in a foreign country. At the time she was in her early forties. Her chronic back pain began with a work injury a decade prior, however, she acknowledged that she experienced a couple of pain episodes as a child and then in her twenties. At the time of the injury and subsequent surgery and recovery, Elyse's ability to work, to participate in recreational activities, and maintain her home were all affected. Elyse knew from her employment as a health care professional that she would likely always have pain despite surgery. It was this knowledge, along with her attitude to live in the best way possible that facilitated her management and allowed her to continue and generally live a meaningful life. Her attitude defined acceptance for Elyse. She has learned what activities to avoid, at work and in her personal life, and which ones such as golf, that she can participate in without aggravating her pain. She has learned what to do when her pain becomes aggravated, which it does when she "is careless," as she puts it. In order to continue working, maintain a clean house, and participate in physical activities, Elyse maintains boundaries on which movements she does and which she avoids. Being honest about her capabilities to a Canadian employer lead to her dismissal from her hospital position a few days upon arrival in Canada. Elyse had accepted a position in Canada on a forensic unit believing that she would be able to handle the demands. However, when she arrived in Canada her employer informed her that she would be required to work on a geriatric unit which Elyse knew required lifting. She was terminated when she explained her limitations. Elyse accepted another position within days of her termination—a position that respected her boundaries and limitations and a position that contributed to leading a meaningful life with pain.

Elizabeth

Elizabeth was in her early fifties at the time of the interviews. She had knee pain for approximately five years and also fibromyalgia, which had gradually worsened over the past twenty years. During these years Elizabeth spent extensive time and energy searching for a cure. In the earlier stages of the fibromyalgia Elizabeth worked at three different businesses she owned in graphic design, catering, and gardening. She also raced cars and jumped show horses. She was also a single parent to her son. Elizabeth has been unable to work for the past five years due to her pain and relies on financial assistance provided by a provincial disability program. Elizabeth thought that the other participants in my study would also be on disability assistance and was surprised when I informed her that this was not the case. Accessing assistance has been difficult due to the time and effort required to prove she was incapable of working. In addition to not working, Elizabeth's income and financial situation are areas her life and that of her son, now in his twenties, have been affected. Elizabeth described the challenges of paying rent, buying food, and covering the costs of living on the assistance, which at times has been less than a \$1000 monthly. In addition to financial stressors, Elizabeth has at times had difficulty walking, and has experienced low mood, suicidal thoughts, and isolation. Elizabeth uses medication for symptom management and recently began eating a healthy diet and drinking water as part of her living a healthier lifestyle. Due to her financial stress Elizabeth worked hard to learn about and access financial assistance and resources. As a result of her search Elizabeth developed an interest in delivering information to agencies such as the food bank to assist others. She has gained meaning in life by providing information to individuals with disabilities and educating the public on fibromyalgia when able. These efforts along with attending to the welfare and happiness of her son and maintaining her home are ways Elizabeth has found life meaning. Acceptance began with a decision a few years ago, to be discussed later in this chapter, which she says led to acceptance of her pain and which has helped her to move forward with her life with pain.

Ginnie

“Ginnie” was in her mid forties at the time of the interviews. She had experienced pain in her feet for three years. The diagnosis that she eventually received was plantar fasciatus possibly caused by heel spurs. Ginnie described the pain as fairly debilitating to the extent that she takes several minutes to get out of bed and moving in the morning. The two main areas the pain has impacted are walking, a favorite activity, and teaching. Ginnie no longer walks. She instead swims and canoes. To date Ginnie has not allowed her pain to impact her work schedule or duties as a teacher; she continues to teach full time and carry out all of her duties including a full teaching load and directing the choir. However Ginnie has made modifications to how she delivers her instruction including sitting as she teaches or directs, and altering the speed at which she is able to complete tasks such as moving within the classroom. She also no longer goes to all of her students’ sports activities, which is one way she expresses her love of teaching and her students. Instead she is selective of the games and activities she attends, basing her decision on her energy and pain levels. Ginnie reluctantly takes two days off each month as instructed by her physician in order to rest and recover from the toll of the pain, which she describes as low grade depression. Ginnie had been taking a prescription medication that gave her great relief from her pain until it was pulled off the market due to concerns about side effects. Currently she takes an over-the-counter medication and has been receiving rolfing treatments, which she described as an alternative therapy. These two strategies enable her to get out of bed, to maintain fulfilling relationships with her husband and children, and to continue teaching. Teaching is a significant contributor to her meaningful life. Acceptance of her pain has been with Ginnie from the start of her pain experience as she does not think there is any other way to live. For Ginnie, acceptance is accompanied with hope for a future without pain.

Gordon

Gordon was 64 years old at the time of the interviews. He is a retired teacher but continues to work as a school bus driver. Gordon saw the notice for the study at his massage therapist’s office and recognizing he had accepted his pain, contacted me to participate. His motivation for participating in the study was to help others going through a similar experience. Gordon had been experiencing pain and numbness in his feet for about three years. Gordon’s symptoms have gradually worsened over the years but he believes massage therapy has helped slow the progression. After a few appointments with his physician and a neurologist Gordon was diagnosed with ‘idiopathic sensory predominant polyneuropathy’ which the physician described as an ‘old man’s disease’ in which there is a breakdown of the nerves that cannot be repaired. Receiving a diagnosis enabled Gordon to focus on what he could do to manage and live with the pain and numbness. Gordon’s approach to his condition is to ensure it does not interfere with his life while doing what he can to manage it. He has learned wearing heavy socks to bed is a simple yet effective strategy for reducing the irritation of the bed covers on his feet. Gordon also receives regular massage therapy which he credits for helping him to manage his pain. He rarely uses medication but knows it is available and effective if he chooses to take it. Gordon’s pain affects him the most during sleep. It is not just the pain that interferes with sleep as he was diagnosed with sleep apnea in 2001. He acknowledges a lifetime difficulty with sleep due to the apnea but his sleep has worsened with the pain. Using a C-pap machine along with wearing socks are the strategies Gordon uses to minimize this disruption. Gordon takes daytime naps to cope with sleepless nights. Gordon’s approach to his pain has enabled him to minimize its interference on his life and he is able to participate in all of the activities he wants including walking, dancing, working, and completing home projects. Despite his efforts Gordon acknowledges that he does not always enjoy himself as much as he did prior to his pain. Although Gordon has accepted his pain, he acknowledges his eyes are still open for anything that might help him manage or even cure it but, living life not finding a cure is his main focus.

Janice

“Janice” was in her mid thirties at the time of the interviews. Her chronic back pain began with a work injury as a health care professional when she was working in another country approximately 15 years ago. In addition to back pain, Janice had chronic leg pain originating approximately five years ago when she discovered a lump on her leg. Although the lump was removed, the bone did not heal, and she essentially had an unhealed fracture. In addition to searching for a cure for her pain, Janice’s pain journey included a lawsuit against her employers for loss of wages and pain. Janice felt the lawsuit was necessary because her employer was not required to carry insurance such as that provided by the Worker’s Compensation Board. Shortly after her injury, Janice returned to Canada so that she could access health care, which was not available to her in the country where she had moved because of her injury. Loss of livelihood, loss of her professional license, and inability to work for several years were some of the interruptions Janice experienced as a result of her pain. She noted her relationships with her family had been impacted. Acceptance was made possible when Janice’s lawsuit was resolved about eight years ago and she could focus on being more than her pain. Today, Janice continues to experience pain in her back and leg but is working at a desk job within the health care system. She also returned to school and recently completed a university degree. Family, faith, as well as career contribute to Janice’s meaningful life.

Lyn

Lyn was 74 years old at the time of the interviews. She was diagnosed with peripheral neuropathy in 1995. At that time her primary symptom was numbness in one foot. Her condition has progressed to where she now has numbness in both hands and both feet. The pain extends to her knees and necessitates wearing leg braces. Lyn first became aware of pain, another symptom of neuropathy in 2003. Today she finds it difficult to separate pain from the neuropathy. Lyn also has an autoimmune disease which requires daily Prednisone medication and monthly intravenous treatments administered at the hospital. Leg braces and a walker enable Lyn to be somewhat mobile, while physiotherapy and daily exercises help maintain strength. Daily medication and regular injections help Lyn manage her pain. Prior to her condition Lyn was active in sports, including skiing and golf, which she gave up in 1999. Lyn’s husband died in 2000 and she has lived on her own since. Lyn readily accepts help and identified home care as the factor that enabled her to live independently in her townhouse. Fortunately Lyn has the financial resources to pay for the services, equipment, and medication she requires. She attends a neuropathy support group where she has learned about neuropathy and socializes with others also afflicted with neuropathy. Lyn told of her 26-year career as a volunteer in guides and scouts. Today, she continues giving to her community through leading a writing group and performing in a kitchen band as part of a senior’s group. Lyn was passionate as she described her writing and believed writing novels, short stories, and poetry along with volunteering and maintaining close relationships with her four sons and their families contributed to her meaningful life. Lyn’s attitude, in the face of adversity and her life in general were strong features contributing to her ability to accept her pain. She stated a few times, “these are the cards you are dealt. You can either keep up or get depressed”. The following poems written by Lyn portray her experience and her attitude toward her situation.

Hands

hands feel
they perform intricate maneuvers
they embrace

I have felt the soft hair of my lover
the smooth skin of our baby
the gnarled hands of my parents

in hands of others
you can feel support

compassion
love

with peripheral neuropathy
my hands feel very little
mostly they feel funny

but that is OK
I now "feel" with my eyes

Lyn Thompson Copyright 2005

I Get Tired

Sometimes I get tired - of being a cripple.
I know that the word cripple is not politically correct.
Physically handicapped?
Do you think a change in words makes any difference to the one afflicted?

If I'm handicapped rather than crippled
does it help me to play an active game with my grandchildren
maintain proper dinner manners, or roll over in bed with ease?

I think not.

Then again, am I tired of having less quality in my life
or am I tired of being politically correct,
and having to explain to folks in what way
I am physically handicapped?
With slacks, my braces don't show and people don't notice my hands
Everyone understands cripple.

Either way, sometimes I get tired

Lyn Thompson Copyright

Sara

"Sara" was in her late twenties when she injured her foot while running. This injury occurred approximately two and a half years prior to the first interview. Initially her physician diagnosed her with tendonitis but over time she was diagnosed with osteoarthritis and reflexive sympathetic dystrophy (RSD). Sara's effort to receive a diagnosis and appropriate effective treatment for her pain was challenging, leading to frustration, and many tears. The pain Sara experienced has impacted her in many ways including her career as a teacher, her identity as a runner, her free and active lifestyle, as well as her mood. Sara was working part time and receiving part-time disability benefits at the time of the interviews. This income and that of her husband's, together with both of their employment benefits assisted her greatly in paying for medication, hiring help, buying convenience foods, and accessing traditional and alternative treatments. Sara recognized her life now is "different" from the life she had before her injury. She had come to realize different does not have to mean worse but simply not the same. Sara's acceptance of her pain came around the time of the first interview. She also knew that this acceptance had strengthened considerably in the six months interval between interviews. With acceptance Sara had found meaning in taking care of herself physically and spiritually - aspects of her life which were not as important before her injury as they had become with acceptance.

Tom

Tom was in his late thirties at the time of the interviews. Tom's pain originated from a motor vehicle accident approximately seven years prior. The accident which occurred at highway speed caused the death of three people, including a friend of Tom's, and the two people in the other vehicle. Another passenger, also a friend, did not sustain any injuries while Tom suffered a head injury, three fractured vertebrae, as well as injuries to his legs, knees, and ankles. Following the accident Tom went through intense rehabilitation for about a year. He went through a dark period of time during which he did not want to be around people, did not want to leave his apartment, and experienced depression. Along with recovering emotionally and physically from his accident, Tom has spent the last number of years dealing with the insurance company and the legal system. It is the insurmountable stress of these dealings that Tom finds most difficult and wants to be finished. Prior to the accident Tom drove a truck on the oil patches in Alberta. This employment was a major contributor to his meaningful life as evidenced in part by the meticulous photo albums he created and maintained documenting his career. Tom showed me these albums during the interviews. The important relationship with his son, who lived a few hours away, was altered following the accident because Tom could no longer afford to travel to see his son or to pay his son's expenses to come see him. After the accident Tom was unable to work for a few years. His re-entry into the workforce began with volunteering at the local hospital in a few departments including the reception desk. Despite persistent pain Tom gradually returned to paid employment as a maintenance worker earning only minimum wages. This decrease in income made paying the bills very difficult and traveling to see his son impossible. Upon reflection, Tom realized that he made a turning point toward acceptance when he made important life decisions such as leaving his apartment. He can see that acceptance is a long term process but looks forward to the day when his lawsuit is resolved. He anticipates that when this happens he will be able to move forward with his life.

Wilson

"Wilson" was in his mid fifties at the time of the interviews. Wilson's chronic pain originated with athletic injuries that occurred in his teens and twenties. This meant that he had been experiencing chronic pain for almost forty years. The major contributor to his pain was a fractured back resulting from a motor vehicle accident in his early twenties. As a result of these injuries, he was unable to consistently perform the physical tasks his job as a trades-person demanded. Wilson devoted many years to providing for his family so that they were able to have a very comfortable lifestyle that his income in the trades provided. However, as the years went by, Wilson's pain increased to the point where he decided to leave the trades for a job that was less demanding physically. This job is in health care and Wilson's position involves maintenance and assisting patients/clients. This change, which occurred about twenty years ago, was momentous and was the time when Wilson could see that he decided to accept his pain. The change in Wilson's career resulted in a lower income which decreased the family's standard of living. This ultimately led to the break up of his first marriage and the loss of his children who found the change unbearable. Despite these losses Wilson was committed to changing his lifestyle. Today, he is living a meaningful life with his second family, including another child, who are understanding of his physical limitations and the lower standard of living.

Guiding Themes

The following five main themes emerged from the participants' descriptions of their experience:

1) The Essence of Acceptance; 2) Interpersonal Interactions and Acceptance: Help or Hindrance; 3) The Journey of Acceptance; 4) Choices and Changes on the Journey; and 5) Where the Journey has Led . . . So Far.

The first theme, The Essence of Acceptance, offers an understanding of acceptance from the perspective of the participant. The participants shared what acceptance meant to them from personal

experience, while other qualities such as the language of acceptance, the ongoing nature, and the attitude of acceptance simply emerged from the interviews. Non-acceptance is a means to understanding acceptance. Beginning with the essence of acceptance provides a foundation from which to understand the remaining themes, and ultimately to understanding the experience of the acceptance of chronic pain.

Interpersonal Interactions and Acceptance: Help or Hindrance, the second theme, emerged as the participants described the many types of personal relationships and interactions that had impacted their acceptance. While many of the relationships with family, friends, faith, employment, and professionals were established prior to the onset of pain and others following, it was particular qualities, the experience and meaning of these qualities, and their influence on acceptance which held significance for participants in accepting chronic pain.

The third theme, The Journey of Acceptance, outlines qualities of the acceptance journey. The participants outlined the point when they began accepting their pain. They described the journey as a series of steps which only they could take as they moved toward acceptance. It was noted that it took time to accept and that the journey really never ends.

The fourth theme, Choices and Changes on the Journey, presents key choices made and important changes experienced by the participants during their journey of acceptance. The acquisition of knowledge from professional sources and from personal experiences were found to be important, as was assuming and relinquishing responsibility. Significant changes leading to acceptance included the recognition of available choices, changes in focus, and changes in the relationship with self, and perspective on control. Adapting to limitations and reevaluating values and priorities were other changes and choices participants made that facilitated their acceptance.

Where the Journey has Lead . . . So Far, the fifth theme, presents a picture of where the participants are currently in relation to acceptance. Participants described the stability of their acceptance and predicted how it might change if their pain intensity increased. They described the hope and the fear they felt when thinking about their future with pain as well as how they were living a meaningful life. Participants also identified unexpected outcomes of acceptance including increased self reliance and independence in their ability to manage the unknown and personal growth in the areas such as confidence and self-esteem. Participants also described a generally positive outcome to their difficult and challenging acceptance journey including living a meaningful life with their pain. The experience of talking about their acceptance experience and the impact this had is also presented.

In addition to the five guiding themes presented in this chapter, sub-themes are presented that draw on the participants' own words. These bring to life the essence of each theme and the experience each participant has encountered on their journey with accepting their chronic pain. Each of the themes presents shared experiences of the participants while sub-themes bring the theme to life while exploring individual differences. While each participants' experience is not shared in its' entirety, the five themes

presented portray the essence of the acceptance of chronic pain for these participants. To facilitate reading of the remaining chapters, 'acceptance of chronic pain' will be referred to as 'acceptance'.

Theme 1: The Essence of Acceptance

As the participants described their experience with acceptance, the essence of acceptance emerged as a central theme. Acceptance appears to be more readily described by what it means and what it is not, than by what it is. Along with the meaning acceptance held for the participants, an understanding of acceptance as an ongoing process emerged. The qualities of acceptance included acceptance language and attitude. The essence of acceptance provides a context from which to reflect on the remaining themes, and ultimately to understand the experience of the acceptance of chronic pain.

The Meaning of Acceptance

When asked, participants tended to describe what acceptance meant for them rather than give a precise definition. For Elizabeth, acceptance meant freedom. Elizabeth:

Freedom! The freedom to do whatever I really want to do. Not being under that rock of pain and doctors and narcotics . . . I guess be cool, ride the wave . . . I just ride with it. Go with the flow . . . and allowing things to happen. . . . I still take some pain medication, not regularly, when I need to. If I get a real bad flare-up, then I've got it here, but I kind of ride with it . . . I just let my body decide what I'm going to do.

To Wilson and Lyn acceptance meant an agreement. Lyn's agreement was with herself. She said acceptance means "agreeing with myself to live with it because that is the way it is. You know you play with the cards you are dealt and there's no benefit in saying 'why me?'" Wilson's agreement was with his body. Wilson:

The pain is there and the acceptance is that you have to agree with your body that it's going to be there but you can control it in the activities that you do. It's always there so you have to live with it . . . Try to live as happy as I can. I guess it would be that to just carry on. It's not going away. It hasn't gone away.

Acceptance for Gordon "meant a little bit of being at peace with myself". He described the relationship between acceptance and peace "in the sense that I have tried what I can and I have done what I can and although I'll probably keep on possibly looking for different remedies at the moment I am at peace with myself in terms of accepting what I am dealing with". Gordon acknowledged acceptance and peace do not always go together: "I guess once you have accepted something you wouldn't necessarily be at peace with yourself with it but for me that sort of has given me a little peace of mind". In a day to day practical sense peace and acceptance of pain for Gordon "means I don't worry about it, I don't fret over it. I just get on with my everyday activities and do what I want to do. That is what I view to being at peace with it".

Control was the word that defined acceptance for Elyse: "acceptance would be I don't let it control me". The way Elyse maintained control was to "lead the kind of life I want to lead. I'm able to work. I'm able to go out to socialize. I'm able to play sports. I just won't let it interfere".

Tom differentiated "between acceptance and being happy with it. Accepting it, I guess I can accept it but will I ever be happy with the situation, not ever". Tom noted how a person in accepting

“something as fact” could “set a road block for themselves”. Tom acknowledged he had other road blocks with respect to acceptance but he also believed acceptance did not stop him from working toward improvement. Acceptance for Tom meant “dealing with it, knowing that it’s there, knowing that it more than likely will not improve a whole lot more, but yet refusing to stop trying to be able to physically do more”. The willingness to continue to improve or search for remedies while at the same time accepting the present situation were important for Tom and Gordon as well as for Sara. In addition to accepting the present, acceptance for Sara meant letting go. Sara:

This is what I can do now. It’s not as much as I used to be able to do, but I can at least do this and maybe I will be able to do what I used to do. But I am going to be content with what I can do right now I think a lot of [acceptance] is letting go of the expectations that I can do nothing about, all those fixed plans and schedules I made myself which are too rigid and unreasonable when in fact the only thing that I can do is watch TV, that sort of thing. I’m trying to find some enjoyment in what I have right now.

Non-Acceptance

Non-acceptance or the time prior to acceptance is salient to understanding the experience of acceptance. Elizabeth described her life prior to acceptance as a time of searching for help

Elizabeth:

I went through the whole jumping through hoops trip. . . . rheumatologist, internal medicine, gastroenterologist, neurosurgeon, pain specialist. I was banging on doors. . . . One doctor says to go to this doctor . . . and that one says to go to that doctor, and you end up at the other doctor, where you were to begin with. . . . My [family] doctor . . . was sending me to the other doctors, and they are all saying there is nothing we can do, and . . . back to my doctor, saying . . . you’ve got to do something. And I didn’t accept it as my responsibility really. Well, I didn’t know really what is available. I was really lost and scared . . . It was up to the doctors. I couldn’t help myself, they had to help me. They had to give me more medication, or figure this out more . . . The pain sort of dictated what I was going to do rather than me. I didn’t think I was capable of doing it . . . I accepted it as life was over, and that was it. I’ve just struggled too hard for too long, and now I’ve got this, so it’s over. I just, that’s how I felt . . . I just figured that I’m just like scum in the bucket, and that’s that. And when [son] moves I get to [commit suicide] . . . I would have just laid down and cried and felt sorry for myself, probably, taken more pills.

Janice recognized her time of non-acceptance was characterized by searching for a miracle. In addition to the search she had confidence and placed trust in the health care system to deliver that miracle.

Janice:

When I hadn’t accepted my chronic pain . . . I had an expectation that this modern healthcare works and I think they should be able to make this better. The pain never went away. . . I was trying to find some way, some doctor to help me with the pain and trying to find some miracle pill to take, that would take away the pain and it was a very frustrating time because I thought there must be something out there that could help me . . . I was really, really angry because I thought somebody should be able to help me and get rid of the pain . . . And so it’s very difficult and I think it is because I am a [health care professional] . . . I guess I did have a lot of faith in the system that somebody would be able to help me. There must be something out there. And my family doctor said to me one time. He’s “so, have you found the magic drug yet that’s going to cure you?” He was very aware that’s what I was doing . . . I was still looking for my cure in a bottle . . . I was really sure there was something out there and I just hadn’t found it yet.

Feelings of anger and disappointment were paramount for Janice while she searched for her miracle. Janice:

I was still very, very angry. I felt very abandoned and that somebody should fix this, and I didn't take any ownership that it should be me (laugh) . . . I just felt like nobody cared, nobody wanted to do anything more for me and I was just put out with the garbage and that's what I felt like, that I just wasn't even useful anymore. And I was just so angry and I think at that point I was on a medication that was supposed to be helping, I can't even remember what it was. It was supposed to be helping with the pain but it made me so sleepy during the day that I didn't feel like I could really do anything . . . I just expected somebody else to fix the problem for me.

Janice also realized the impact the pain had on her identity and that it interfered with her ability to see a future for herself. Janice:

Before I had my injury and my pain I was a very goal-orientated person. Where you're always looking to the future and working toward that and then I lost that. And that changed who I was . . . because if you don't have something in mind where you're going to go and what you're going to do, then you're just drifting. . . . It's hard to look past [the pain] or get on top of it . . . It's hard to get around it. It seems to be blocking your vision into the future . . . You're just constantly focusing on the negative instead of looking at what you can do. And I was constantly thinking, well, I can't do this, and I can't do that . . . You're almost giving up and just totally giving in and feeling totally hopeless. . . Helplessness is a big part of it . . . And I guess up until that point, until 1996, I didn't think I had a choice. . . I don't think I would've seen any positive whatsoever if you would have talked to me when I was still so angry and hadn't accepted that this is my pain and this is my life. I would have not seen anything positive . . . You would have had a lot of angry responses And I've just come so far from where I was then.

Sara also spoke about her disappointment particularly related to healthcare because “every specialist appointment I have been to I have come home in tears because I'm just so discouraged about the lack of progress, and the lack of plan there is, and how this isn't going to fix everything, and that sort of thing”. Sara, like Janice, spoke about the change in her identity as a result of the pain, and the frustration she felt with her inability to do tasks. Sara:

I feel like I have lost my identity as an athlete for sure. I feel like I have lost control over what I can do and what I can't do. I can't just go for a run anymore. I can't just hop on my bike and go for a nice long ride and feel good. I used to get the whole runner's high. That whole endorphin high I don't get anymore. I've lost a lot of friends simply because I can't socialize in those circles any more . . . It's affected me on every level, physically, emotionally, my job, there is a bunch of girls my age that are my colleagues that I would love to be really good friends with and I am not because I can't keep up with them. . . I don't have that extra energy to go search them out and invite them for coffee.

Wilson and Gordon were succinct in describing their time of non-acceptance. For Wilson, non-acceptance was evident in his opinion of his medication use. Wilson:

I was ruining my health. You're taking pain killers like they were gum . . . I'd pop ten just to take the edge off, and that's all it does, it just takes the edge off. But you just continue, and you don't think straight, but you exist. And then at the end of the day you think you're doing a good thing.

Worry and concern about the unknown characterized Gordon's nonacceptance pain experience.

Gordon:

At first it was more of a worry and a concern because of the unknown . . . I wasn't angry about it or upset about it in anyway. I was more concerned that maybe my condition was something that would progressively or quickly get worse and worse and I wouldn't be able to do anything about it.

Non-acceptance for Ginnie was characterized by uncertainty and her need for help. She emphasized "probably six months to a year ago I was really feeling '*what* am I supposed to do?' I could have used some guidance. More than what I felt I was getting from my doctor anyway".

Reflecting on his time before acceptance, Tom recognized he had set up his "own road blocks along the way" which included "everything from at times just not wanting to move, stopping exercise rather than keeping doing, listening to 'I just don't want to leave my apartment for a week, two weeks'". The impact these roadblocks had was that Tom was "sitting at home feeling sorry for myself and thinking of other options [suicide] that I have disagreed with all of my life. . . My life needed to change before those [suicidal thoughts] were out of my head".

Anger, fear, uncertainty, reliance on an outside 'cure' and dependence on external factors to make change are qualities that characterize non-acceptance for the participants. These factors suggest nonacceptance is a more tangible concept but contributes to the understanding of acceptance. It is evident that this time was a low period for all participants, to the extent that some considered life not worth living.

Acceptance is Ongoing!

The participants' descriptions of acceptance clearly indicated that their acceptance experience is not complete. Rather, they described an experience that continues, is ongoing, and is very much dynamic.

Sara's experience exemplifies the idea that acceptance is ongoing. We completed the first interview at a time when she indicated that she had accepted her pain but while she was still going through extreme difficulties. Six months later we resumed the interviews with Sara continuing to acknowledge acceptance. At the start of the second interview Sara noted the changes in herself, her situation, and the passage of time. Sara:

When I got your message [inquiring about finishing the interviews] I started thinking about it. I'm like I don't even know if I'm the same person. I know I'm not at the same place I was six months ago but it really made me think about all the things that have happened and all the things that I've gone through since then. And a lot has happened. I still cry when I talk about it.

Tom verbalized his internal struggle with acceptance and change. Tom:

I wouldn't say no part of it I accept. I know I have my reality; my life is my reality. I don't like to think that I run around with rose-colored glasses on figuring that the world will change to my whim. I understand and accept that I was injured. I understand and accept that my life changed. Am I able to accept how much yet? Not really. That sounds a bit stupid to me because my life in my mind at least isn't done changing. I don't know what there is going to be but . . . I continue to change.

Gordon also thought his acceptance was not final. He said “I think it was a process over time that I gradually came to accept . . . It was more of a gradual process and I think that that process probably is ongoing. It’s not sort of a final thing”.

Seeing the advertisement recruiting participants for the study prompted Elizabeth to explore her acceptance experience. She noted “the dealings I’ve had with chronic pain, and how I know I’m getting above it now. And cooperating with it now, and when I saw your study [advertisement], I thought, that is kind of what I’m going through. Or I’ve been, not through it, because it keeps getting better”.

The Language of Acceptance

The language of acceptance—the words and the tone of the words used, independent of the content emerged as a powerful component of the participants’ experience of acceptance. The content will be explored in following sections but the focus of this section is on the language of acceptance.

The participants spoke about the ongoing presence of pain during acceptance. This was evident for Elizabeth who said, “I still have constant pain every minute of the day but I view it so differently, and I don’t rely on my doctor. I am not asking him for help or asking what am I going to do”. Elyse knew she did not focus on her pain even though she was aware of it. Elyse:

It’s there every day and for the most of the day every day. It’s certainly there when I get up in the morning. It takes me maybe about five or ten minutes to get the blood flowing and circulating to where it’s not in my consciousness, to where it’s dissipated to discomfort or whatever. And then I’m not aware of it . . . I’m not aware unless I’m thinking about it. Or of course if it is actually sorer than usual then it is in my awareness and that probably happens, depends what I’m doing, but maybe once or twice a week.

Lyn had been going through a low point with respect to her own condition and pain when her husband died. Lyn, like Elyse, was aware of her pain but chose not to focus on it even during this difficult time. Rather, “when my husband died I was just getting back some of my energy and I said to myself, ‘I have to have a way to get out of this house and be with people’” which she did. Similarly, at another time Lyn hosted guests even though she knew it would result in fatigue and discomfort but “it had to be done, and I had the discipline to do it. So I did. I kept saying, how come I am still going. I am feeling like the rabbit with the battery in it. I realize that . . . I had enough discipline to do it. Maybe that word discipline is important . . . I just amazed myself that I actually pulled it off. I pat myself on the back for that . . . I think I ‘m a bit stubborn with myself. I am not going to give in. And maybe that makes the pain hard to give in to”. Interestingly, Lyn was almost apologetic for participating in this study because she realizes that she manages so well by not focusing on her pain saying, “I am not your strongest case of pain, you know. I know that there has to be people with more pain than me”.

Tom, Sara, and Ginnie expressed uncertainty about the pain in their future. Tom said in a matter of fact way, I “know that there is going to be pain in my future. How well I will be able to deal with that pain, well nobody knows what’s in the future”. His tone expressed calmness even in the face of this uncertainty.

Sara also indicated uncertainty with her future with pain but spoke with determination. She said “if this is in fact chronic and it’s going to be here for more than just today, I have to accept it, there’s no way I can continue. I don’t want to be affected by depression and I want to make sure that I’m living and not just waiting for this to get better enough to return to life. So I desperately want to accept this completely and move on”.

Ginnie asserted acceptance was her only option: “Rationally, the pain is not going away. I’m still hoping it might, but it’s not currently being alleviated”. The only thing Ginnie thought she could do was “carry on because I can’t just stop. Like [stopping] is not a viable option. I can’t even begin to think how it could be different”.

Janice spoke about her pain after her court case was resolved. Janice:

After my court case settled . . . I finally just said ‘I’m not going to (pause) just lay down and give up’ . . . I made a decision that I was going to do whatever I could to get back to where I could be physically able to be able to even just work a little bit . . . I just had to figure out what I wanted. But I think I had to accept that first that it was okay to have pain and I could still be somebody with the pain, that the pain wasn’t everything that I was. . . . And then I had my [baby] and I decided that since I was able to do that I was able to do anything that I set my mind to. So when she was a year old I started to look at going back to school. I thought I could maybe teach [profession] or something, if I couldn’t physically [do the work] again. So I went through the [professional] refresher course . . . And part of it was I had to do a clinical. So I did the clinical . . . And I met just an extraordinary group of [professionals] and it was such a good experience for me and I found out that there was other [professionals] that were working and they had injuries and chronic pain, but they were able to still work and be productive, and that just showed me that I can do this. So I applied and . . . I started working part-time . . . and I was able to cope. So that was a really big thing for me. I was very proud of what I had achieved.

The language used by Bea, Elyse, and Ginnie as they described acceptance conveyed taking responsibility and control. Bea noted “it takes away most of the quality of life but you just learn to make the best of it in whatever way that you can”. Similarly, Elyse emphasized she maintains control by “lead[ing] the kind of life I want to lead’ which involved working “and I’m able to go out and socialize and that I’m able to play sports. I just won’t let it interfere with that”.

Wilson also spoke about doing the things that he wants to do and how he balances this doing with his pain because “you don’t want to stop life. That’s the big thing. But sometimes you have to slow it down in regards to what you can and can’t do. It’s like anything. You have goals, you want this, you want that, and if you’re going to hurt to do it, how bad do you really want to hurt? . . . Either you suck it up or it’s going to win and I guess when I accepted the situation it was me that needs to take control and not it and now I just live accordingly”. Ginnie’s response to a situation with a concerned family member was “she was a bit concerned about me and I said, “you don’t have to be, this is called management. This is what I do”.

And finally, confidence and the positive quality of the language was paramount for all participants. Ginnie recognized she is “kind of a ridiculously optimistic person in the first place, that’s a

part of my personality, so I am pretty sure that's another reason why I haven't given up". Like Ginnie, Bea also recognized that "I am a very optimistic person".

Elizabeth conveyed her confidence. Elizabeth:

They were challenges, and I knew we could get through them, and I could see how to get through all of them. It's definitely within the last six months. Once I started changing my appearance, and looking, and smelling, and feeling cleaner and better that's when I accepted. My thoughts and thinking completely changed or started to change. I started to see a little glimmer . . . and I started feeling better about myself.

Like Elizabeth, for Sara the months prior to the interviews had been a time of change and moving toward accepting. When Sara spoke about her experience with acceptance, her words indicated what had past as she used the word 'was'. Sara:

The learning curve is pretty steep but I know that that's the direction I need to be heading and I want to be heading in that direction, and it's going to take time but I've certainly got the resources in place to do that . . . When I think of a year ago, a year and a half ago, I was still very much in denial of how chronic this was. It was just something that I was going to get healed, and that would happen soon, and, and I was very much in denial of it being chronic. And now I recognize that this is my life. This is my daily schedule now and I have to respect that. I cannot ignore it and just try to continue to keep up on the hamster wheel that I was on before. I can definitely see the difference between where I was [year and a half ago] and where I am now.

The Attitude of Acceptance

The attitude of acceptance emerged in a similar fashion as the language of acceptance as participants described their experience. They verbalized the importance of attitude on acceptance. Each participant expressed thoughts and feelings related to acceptance, and hence the attitude of acceptance emerged.

Gordon's attitude was to "carry on, just fight through it . . . Don't let the pain be a negative influence on your life and what you do. Try to be more positive. Focus on the more positive things in your life and the negative things tend to become less and less". Carrying on despite the pain was evident for Janice as well when she talked about returning to school "because, you know what? I'm going to be alive for the next five years anyways, so why not go to school? Cause the pain's going to be there, whether I go to school or not. So I'm just going to do it the best I can with what I've got".

Ginnie noted "fatigue and mental state" obstructed her acceptance but a positive "mental attitude" facilitated acceptance. Ginnie's attitude of acceptance was also to "just get out and do something. Be useful. That's so important for managing pain or accepting pain. Don't stop, just quit and give up". Ginnie feared she might be forced to give up and "I think that would really be the beginning of the end. I know it would be for me". She also believed that "frame of mind is extremely important. Having some kind of feeling you've got control over what can happen".

A connection between control and attitude was also evident with Sara who told a story which had lead her to wonder about the importance of attitude. Sara:

There were two [students] when I was a teacher at [town] . . . one of them had a very serious type of cancer and one of them, not that any cancer is not serious but had a much less terminal form of cancer and the doctors were very surprised that the [student] with the serious cancer, she had such a positive attitude that she beat her cancer and the [student] with the lesser form of cancer they told her “oh you’ll make it. You’ll beat this, lots of people have” and she didn’t. So how much of it is attitude?”

Lyn’s accepting attitude manifested in the way she spoke about her pain, her limitations, and her life. Lyn:

Right now for some reason or another my left rotator cuff seems to be hurting. I think it is mind over matter . . . I figure the hurt will go away or it will stay and there is not much I can do about it so why add it to my worries. . . I just can’t allow negative thoughts make me worry. . . I think it’s in my nature to keep going . . . Even though things haven’t improved I still have the hope that I will finish my novel, find acceptance as a writer and enjoy many more years . . . with or without pain . . . I know what I have to do and that is accept what is happening. Accept what the doctor’s say and don’t try to second guess them. Accept the Gamunex i.v.i.g. because without it I will die from multiple infections. Accept any aspect of the condition including the pain. . . I only use two fingers, mostly my right index finger to push the keys. So I am slow but then what you’re dreaming up in your head isn’t all that fast either . . . I just feel very, very blessed that I have been so lucky . . . I mean it is not so bad that I can’t do what I want from my past way of life. You might say that I am getting nice assistance from all of the taxes I’ve paid over the years . . . The pain, could mean a ‘why me?’ attitude. I’ve never had that. I’ve always figured well, this is the end years of my life, everyone grows old and has their own unique way to grow old. I am just doing it my way. That’s always been my attitude.

Tom talked about the impact of his accident on his life. He described how his accepting attitude continued to evolve and the important role it has had for him in coping with the changes in his life, in accepting these changes, as well as accepting his ongoing pain. Tom:

I am a person. I am a whole person. My feelings are a part of that person and unfortunately the feelings I have over an incident in my life changed my whole life, my perspective on life. At the time I thought I had the world by the tail and could see nothing but a better life for myself in the future. Then to go from that happiness, that good feeling to literally, it may not have been the next second, but to me it was, from what I remember to waking up in the hospital, to me is a heartbeat. I remember nothing in between of the accident. And just to be happy, healthy, and strong to being someone that was hurt and pretty much an invalid in my eyes is a very difficult thing to go through. I know I’m not the first person to have this type of trauma to my life. Any kind of trauma affects people. We have to accept, I don’t know if it’s accept it but you’ve got to go with life because life doesn’t end just because a specific part of it ends. There are other options. There are other futures. You just have to be able to find them . . . Life goes on. If you allow yourself to go along with it, things are going to change. You need to stop and go with it . . . The way

I look at it is that if there isn’t the insurance company that’s being a major stressor in my life, there will be something else. Life is full of stress. It is just what a person is most focused on at the time.

Tom alluded to the idea that acceptance and an accepting attitude take effort. Lyn, Sara, and Gordon also spoke of the intention and effort it took to be positive and to maintain an accepting attitude. Lyn noted, “I suppose I have to remember to be positive . . . I just know that a negative attitude would kill me. I mean it would be no fun living with a negative attitude. And I like to be happy If I am to be happy I have to put up with it and work at being happy”. Sara disclosed a “tendency to stay with the

negative thoughts and allow that depression to build up". She acknowledged that she struggles to "stay positive and I am not nearly as positive as I want to be. There are people in my life that are so much more positive than I am and I have gained a lot of strength from them. I have learned from looking at how other people are dealing with their circumstances and what they're going through. My point here is that a positive attitude goes a long way and will help".

Gordon emphasized his effort in "trying to keep as positive as possible about things. I know that sometimes it's not easy but being negative about it and being down on it doesn't really help too much. In fact it doesn't help at all and sometimes it makes things worse so I think a positive attitude and focusing on positive things rather than negative things can be very helpful". His attitude extended to feeling "very thankful that this is all the problem I have as far as my feet are concerned. I mean I could be losing toes or I could be losing my foot of something like that which maybe would be far worse so my attitude is to be thankful for what you've got and don't focus on the negative part". He acknowledged. "I have to deal with it all of the time and I have accepted that and so . . . I don't get up in the morning thinking that things are going to be bad or anything negative about it. I just get up and, that's the way it is, so, just keep on going".

Summary

The essence of the acceptance emerged as a central theme and provides a context for understanding the remaining themes. Acceptance is an experience easier to describe than to define. The time before acceptance, nonacceptance is salient to understanding acceptance which was identified as an ongoing perhaps lifelong process. The language and attitude of acceptance contribute to the essence of acceptance.

Participants described acceptance as freedom and peace; freedom to do whatever was desired and peace knowing everything possible had been done to find a cure and manage the pain. Acceptance also meant acknowledging current limitations, while continuing to seek opportunities to improve their situation. Acceptance was described as an agreement with the self to live with chronic pain and the limitation in order to enjoy life as much as possible. Acceptance also meant not allowing the pain to take control. Finally, acceptance meant dealing with the pain, acknowledging its presence, and its likely persistence.

The non-acceptance period ranged from a few years to several decades and was characterized by anger, disappointment, uncertainty, and worry. Non-acceptance typically focused on finding a cure often resulting in lost hope when the cure did not happen. Lost hope lead to low self esteem and a sense life was over. Non-acceptance was often a time of looking outward to make change and for many participants a depressive time with feelings that life was not worth living.

As the participants spoke it became clear acceptance was ongoing. Acceptance continued to weave its way in their lives allowing them to continue growing, changing, and improving even though all accepted their pain and achieved acceptance. In this way acceptance is more accurately called 'accepting of chronic pain' and viewed as a life journey.

The language of acceptance was qualitatively different from the language of non-acceptance. Participant's word choice and tone conveyed confidence, independence, discipline, and determination. The language of acceptance claimed responsibility for the pain, actions and thoughts. Further, the overall tone communicated a positive perspective even though the challenge of the pain continued.

Attitude of acceptance emerged as participants described their acceptance experience. Components include an attitude of carrying on despite the pain combined with efforts to focus on being positive rather than allowing negative thoughts lead to worry. Participants recognized the nature of their attitude and the important role it had on their pain and lives. Attitudes of acceptance included being useful, that pain is a part of aging, that life is full of stressors including pain, and a focus on mind over matter. Participants acknowledged maintaining an acceptance attitude required effort and determination, and sustaining an accepting attitude is not easy. An attitude of acceptance contributed to living with the pain and to living happy, productive lives.

Theme 2: Interpersonal Interactions and Acceptance: Help or Hindrance

The participants described several types of personal relationships and interactions which impacted acceptance. Many of the relationships with family, friends, faith, co-workers, supervisors, employers, and professionals were established prior to the onset of pain and other relationships were established following onset. However, it was particular qualities, the experience and meaning of these qualities that held significance for them, and whether they hindered or helped acceptance. The qualities of these relationships and interactions which touched the participants' hearts and influenced acceptance related to support, communication, being believed, momentous interactions, others' response to chronicity, and shared experience.

Support as Strength and Comfort

The participants described the support they received from family, friends, their faith, workplace relationships, and professionals through ongoing relationships as well as specific interactions. They identified both the impact of the support they received with day-to-day tasks and their emotions as they coped with, and accepted their pain.

Bea acknowledged the help she received from family with daily tasks. Her "son and daughter . . . help me with meals, help me get dressed, help me undress . . . I have a lot of support and a lot of help and that really means a lot". A benefit of this help is Bea "didn't have to worry too much about things about being taken care of, that was a big relief off my mind".

Lyn also received support with everyday living tasks which facilitated managing and accepting her pain. In addition to the financial resources Lyn receives for her daily medical expenses there is a program in her city to assist with tasks such as cooking and cleaning. The program is set up such that a client's needs are evaluated and hours of assistance allocated. Based on Lyn's condition "they seem to feel that I need two hours, five times a week. That is what I am getting so I am not paying anything extra". The outcome of this support for Lyn is that she is able to manage her pain and her condition as best as she is

able without any financial restrictions or concerns which allow her to “maintain my independence and dignity and thankfully I have the financial resources to assist me with this”. Support for Lyn and Bea removed the burden of doing tasks essential to successfully living with and accepting pain.

The support and understanding offered by Ginnie’s family had an impact for her. Ginnie: The kids are great. They try all kinds of things, like they buy me stuff that they see on TV, like that magic bag . . . My family supporting whatever it is I have to do whether it is doing extra chores or [husband] reminding me to sit down. That’s been good. And having different expectations, like no I don’t have to go on that walk, because I can’t or no I’m not making supper tonight because my feet are sore . . . That family thing is huge.

Gordon believed “it’s very important that you have people around you: family members, your medical team, friends that support you in what you are going through”. He had a hard time imagining “what it would be like to go through this on your own without that kind of support” because that is not his reality. He thought “it would be very difficult to deal with. It would maybe take you longer to come to the point of acceptance”.

Wilson recognized “it’s not you that’s in this soup by yourself. It’s your circle of friends, your extended family. Everybody has to understand that this is the way it is . . . because if you don’t have the support of your immediate family and the people around you, you’re in trouble”. Wilson realized “if they’re not willing to accept the situation with you, good luck . . . You have to have a family that’s on your side”. This insight came to Wilson after he went through a difficult time with his pain which was compounded with his desire to provide for his family and their desire to have him provide. With his first family Wilson not only “needed to make a living” but he also strived to “to be like the Joneses”. His wanting to keep up with the Joneses was also perpetuated by his first family “always wanting. They needed this, they needed that. They wanted this. They wanted that”. The result for Wilson was an increase in pain and feeling “very irritable” which lead him to “distance yourself because it just gets so aggravating”. At the time Wilson felt like “just a wallet”. Upon reflection Wilson felt he was sacrificing “my life and my body to keep them happy, and then as soon as I started slowing down then there was resentment”. Wilson “did not want to stop providing in this way but he did” eventually. This lack of support increased Wilson’s burden and increased the difficulty in managing his pain.

Later in his pain experience and with acceptance Wilson’s relationships changed. He “lost one family, all my assets, and everything else because I walked away from it”. Over time he established a second family who understand, support, and say to him ““don’t do that. If you need to get it done you let us know. We’ll help’ . . . So it’s reversed itself”. He explained to his child, from his second family, “what I’m able to do, and why, and she sort of understands. She’s only [a child], and she sort of understands what I have to do, but she still wants, she still has that child need so I try”. After a long time Wilson has realized the importance of having people on his side. He is now able to see that “positive situations around you always work but when you’re fighting people around you for just existence, it’s a losing battle, and everybody loses”. In contrast to the unrelenting weight of his burdens experienced with his first family,

through his current support Wilson's load had been made lighter and his burden lessened which facilitated his acceptance.

Janice spoke about the support she received from her husband in handling the emotions that accompanied her pain. Janice:

There's a certain amount of depression that hits you with chronic pain and if you don't have anybody to help you get through that and to go through those emotions. Which comes first, the pain or the depression? And does the depression cause the pain to be worse? . . . I know I couldn't have made it through that if I didn't have somebody that I could talk to and have that sounding board there and somebody that was willing to take me no matter what was going on with me. I have a supportive family in my parents and my siblings, but I think it's important to have a relationship that somebody's there to listen to you and to challenge you.

The participants also spoke about the support of friends. For Ginnie, this friend was also her "next door neighbor . . . We had a conversation about how my ridiculously expensive shoes were starting to wear out and that I wasn't able to really even consider buying anymore because they're \$400 shoes and I'm sorry I can't buy \$400 shoes. That's the reality. I have bought one pair and they're starting to wear out. So stupidly I mentioned this to [neighbor] about a month before my birthday, I don't know what I was thinking . . . I should have never said it, because [neighbor] is the most generous person in the universe. Anyway, guess what I got for my birthday? Ridiculously expensive shoes! They're exactly the shoes that I need for my feet . . . Just knowing that she would even consider doing that is really helpful, really supportive". The nature of this gesture of giving was particularly meaningful because it was unexpected.

Not all of the participants had a network of family and friends to offer support and understanding. While Lyn had a supportive family, not all members of her family lived nearby, and those that did were living their own lives and so they simply did not have much time available. Lyn wistfully stated, "I wish I had more close friends" even "a couple more close friends with whom I can ask for favours" and who would be supportive. While having a number of family and friends was helpful for the participants for the support they gave, Elizabeth believed in the importance of having "at least one person that you can lean on or get hugs or that believes you - at least one person. The only person that I had was my son" who offered Elizabeth the support she needed and this facilitated Elizabeth's acceptance. Having just one person helped manage the load of pain.

Janice, Bea, and Sara spoke about the strength and comfort their faith offered in their lives generally, and specifically with pain and acceptance. Bea described her relationship with the Lord. Bea:

I've been a born again Christian for over well over 25 years now . . . Love the Lord with all my heart . . . The Lord has helped me a great deal with this pain, I tell you, right now. Lots of times it's just been a miracle and I haven't been able to sleep or anything and just been up for days, with no sleep but he would just help me and I would go to sleep for a while . . . I know I never could have got through it without God's help, I know I couldn't have. Because there was times a person just thinks about ending it all because you just hurt so much. But it never entered my mind to do anything like that because I knew that God was in control and he would work things out somehow which he did.

Sara acknowledged “I’m pretty much incapable of dealing with this on my own and if it wasn’t for the strength that God gives me every day and has promised to always take care of me that I wouldn’t have the positive attitude, I wouldn’t be able to get out of bed in the morning”. The support Sara received from her faith lead her to “let go a lot of my . . . beliefs, the way I used to live was all about me . . . Whereas I’m relying a lot more on just the grace of God to get me through the day”. The specific support Sara noted was God is “the only thing I know for sure will be there today. I don’t know if I’ll have the energy and I don’t know if I’ll have the strength and I don’t know what my pain level is going to be but I know that no matter what it is I’ll be able to get through the day if I rely on God . . . I am just so thankful that I have my faith cause I don’t know how I’d make it through this without it. I really don’t”.

Janice’s relationship with God began when she was a child. She “was brought up in a very strong Christian home and I remain a very strong Christian now, and I think that had a big impact on me being able to survive [pain] as well”. Janice recognized the permanency of her faith saying, “I always had my faith, even when I was so angry and really down, I still had my faith, and I was a very strong believer in when one door gets closed, God opens a window. And that’s always been a very strong influence in my life”. Janice philosophically spoke about her life, which now includes her pain and acceptance experiences, and how both she and her faith have been changed. Janice:

I think life just changes how you think about things and how you approach things. It’s really hard to say how much pain has changed that because pain has made me who I am and without the chronic pain experience I’ve had I wouldn’t be the same person. I can’t really say if it would’ve changed my faith. I didn’t lose faith when I didn’t get better.

In contrast to Janice, Sara was clear the strength of her relationship with God and that her faith had increased through her pain and acceptance experiences. Sara:

My sense of faith has increased since [my injury]. I am much more spiritual now than I was before I injured myself . . . It’s a lot more real now but at the same time, I’m very angry and my anger is something I’m having to deal with. I used to just believe and now I’m questioning things a lot more and I’m not just taking everything at its word. I think that makes the conclusions that I’m coming to more solid and I think it makes my faith more real because it’s based on my own life experiences and what I’ve observed instead of some theory that I read about ‘sounds good so this is what I believe.’ It’s a lot stronger. It’s so much a part of my daily life . . . My relationship with God is much stronger than it was before.

Faith clearly assisted Bea, Sara, and Janice with their pain by providing support and strength. The support God provided was a sense of security and comfort. And it was within this relationship the participants were able to express anger, live with their seemingly unbearable pain, and to accept it.

Participants who were employed spoke about the support offered by people in the workplace. The support influenced their ability to return to and continue in the workforce, and to better accept their pain. Tom’s return to the workforce after his accident in 1998 began with volunteering at a hospital and then at the Y.M.C.A. The volunteer position at the Y.M.C.A. lead to paid employment. Initially Tom’s role “was [to] just walk around and hear that this machine isn’t working or need heat in this room or cold in that room or whatever. And I would walk to whoever could deal with it . . . they got the information, it was dealt

with and I started a line of communication” because “just walking up those stairs once was enough for one set of exercise, or one repetition when I first came here”. Tom progressed “from being able to just stand around and more or less talk to somebody, to folding towels, to little chores here or there. Going up to daycare floor and seeing those little rug-rats tugged my heartstrings and if they needed something well I made an extra trip up and down those stairs”.

The understanding and patience of the Y.M.C.A. staff, particularly the Chief Executive Officer gave Tom the opportunity to heal emotionally and physically, and to learn and grow. Tom explained “if something hit a chord that I was very very angry, took something very personal, yes I went for a walk”. This Y.M.C.A. work environment was a new experience for Tom and presented a challenge because “I used to be a trucker. I never dealt with men in the nude [in the locker room at the Y.M.C.A.]. I never dealt with people looking at me as if I am a peon because of the job that I do now. It’s just something that I have had to . . . over come”. Tom wasn’t sure if he “would have the same understanding” with other employers because “most of the time I can do my job, I can do it well” but “if I am sidetracked they have given me lots of leeway”. The patience and support from Tom’s supervisor “allowed me to work through my frustrations, see that not everybody was against me. Not all life was against me”. After four years Tom went on to other employment. He appreciated when his supervisors “gave me, I couldn’t ask for better references and being that it was given by people that wouldn’t lie for me”. The support of the staff and patrons at the Y.M.C.A. enabled Tom to continue healing while developing skills, increasing his confidence, and providing him with a sense of purpose all of which contributed to his acceptance of his pain.

Janice described her current boss as a “very supportive boss who’s very aware of my needs. My office is down in the basement but there’s an elevator and she was willing to move my office . . . And when I’m having . . . probably once every six months my back still does go out completely, where I’m flat on my back for three days. So when that happens she’s very supportive”. Because of this understanding and willingness to adapt to Janice’s needs, Janice does not “really have to worry that my job’s in jeopardy”.

Although Janice’s current boss was supportive, previous employment situations had not offered this support, initially. Prior to the lump in her leg, Janice worked in her occupation and was able to work with her chronic back pain. However, securing this position was difficult because she “didn’t think that anybody would even hire me once they knew that probably at least once a month I would be flat on my back for three days. Nobody really wants to hire you . . . so I had to get the union representative to help me get hired in the first place”. Having someone “go to bat” for Janice made a difference in her return to work. And now, after all Janice has gone through and worked toward she is in a position she is able to manage and has “a very good boss”.

Like Janice, Elyse experienced both support and its’ absence in the workplace. Her employer in her home country was “really supportive. They were taking me on even though I sort of needed recovery in

this injury”. However, an employer was not understanding and not at all accommodating when Elyse came to Canada to work as a health care professional. Elyse:

I was told before I came over here that I'd be working in the forensic unit, which is fine because I've worked in lots of forensic units . . . So I get over here and strangely things in Canada things don't work the same as they do in [home country], like if you're employed to work in a forensic unit despite the fact that it is part of a large hospital, that's where you're working. Over here it's a lot different because in this hospital they have a geriatric unit, a brain injury unit, rehabilitation units, admission unit and a forensic unit. And on day three of my orientation they informed me I would be working on the geriatric unit. Well I nearly had a fit. . . . I had a meeting with the director . . . and I said, 'look, it was my understanding that I was contracted to work in the forensic unit and I will . . . but honestly it would not be a clever thing to be putting me into . . . the geriatric unit. . . . That's adding to my level of risk and I don't really think that's an intelligent way for me to work'. So . . . they actually fired me after day four . . . 'We're not going to employ you in any capacity much less like the forensic unit' . . . Here I was being up front and honest and they actually thanked me for being honest but then they sacked me . . . I thought that was strange because I do not see myself as having a disability. I just see me as having certain limitations to what I can do. And I'm pretty good at knowing what they are.

Although Elyse's former employer was not flexible with respect to her limitations, she did not let this situation bring her down. She immediately was hired by another organization and ultimately “landed on my feet very well . . . This [current] job is actually much better than what I would have been working [at the hospital]. It's actually suited me much better and it utilizes my skills a lot better than it would have over there, so they actually did me a favour”.

Ginnie and Sara also spoke about their respective work environments which they described as supportive. Sara was assigned a classroom close to the staff and administrative rooms which reduce the amount of walking required. Ginnie was encouraged to take sick days regularly and both had the option of taking longer periods of time off work. They appreciated the accommodations and the encouragement to practice self care.

Wilson's current employment situation was such that he does not “have a supervisor or boss kicking down my throat ‘get your butt together’” because in Wilson's his job he has the “ability to say ‘no I am not going to do that all today’”. Wilson knows his boss has given him the responsibility of his job but “there's not that many jobs out there that allow you to do that. The majority of people are usually under the knife by a foreman, a supervisor or boss of some sort cracking the whip and it makes it hard because the foreman don't give a damn. They just want productivity and you're a commodity”. Wilson believed that had “the do all of want all jobs because I can control it as much as I need to” and he valued having “a boss that's on your side”.

Generally the participants' current work environments offered flexibility, understanding, and accommodation to their needs. In contrast to the lack of understanding and lack of support many had experienced at work in the past, this type of support clearly facilitated their continuing with or returning to work while continuing healing, and gaining self confidence all of which influenced acceptance.

Some of the participants spoke about the support received from professionals. The support that Janice received from her present physician was encouragement and understanding. She went “to her and said ‘You know what? I want to try downhill skiing again.’ I asked her what she thought . . . She’s like ‘you need to try and do whatever you think you can do and see how it goes’, and she’s been very supportive of me trying new things, so that helps”.

Ginnie acknowledged her physicians’ support, but she also hinted that something was missing in her care and support from him. Ginnie:

Doctors are very busy people. My family doctor’s been very supportive in general but he (pause), I don’t know, I am going to go back and see him again this week. Just tell him about the Rolfing, what I’m doing, and see if he has any other bright ideas. He’s supportive. He’s just busy. I can’t blame him. I know they’re busy these days . . . I guess his sensitivity to pain is nice.

I sensed that whatever was missing related to the physician being busy and interfered with Ginnie’s confidence in him and believing that all avenues of diagnosis and treatment had been pursued. Regardless of the specific circumstances, something about Ginnie’s physician’s being busy seemed to interfere with her acceptance.

Only a few of the participants had received counselling or psychological services during their pain and acceptance experiences. Sara thought this support was helpful while the other did not. Following his motor vehicle accident Tom “had about 80 appointments with . . . a psychologist, psychiatrist, something like that. Anyway it’s been a while since I’ve seen him. I really don’t know what the psychology profession can do for me . . . I never used to be the type of person that sat around going “waaa, poor me” Going to somebody and sniffing does not turn my crank. I don’t need anybody to whine to. I need to get on with my life”. Tom did not discuss details about the sessions nor his relationship with the professional but it was clear that he did not see any benefit from the sessions. Interestingly, Tom did not comment on the relationship with the professional that would have formed, at some level, after having numerous sessions.

Sara on the other hand had been seeing a counsellor prior to her injury. After her injury the focus of the sessions changed to her pain. Sara found the sessions to be helpful, albeit difficult saying it “brings it all up to the surface and then I am actually dealing with it. Like I didn’t realize how significant it was, how big of a deal this injury was, how much it was affecting my life until she pointed it out . . . Today for the first time I realized that this is actually a trauma. I have never thought of my injury as a trauma before. So it is very good. But it’s painful. (Pause) But it’s totally necessary”. Despite the emotional pain counselling evoked, Sara trusted the process and benefited from the sessions and the support of her counsellor.

Communicating to Connecting

Communication was identified by the participants as an important quality of relationships during acceptance. Communication involved what the participants said and also what they received in the interaction. Lyn and Gordon alluded to striving for a balance between requesting and receiving support from family and friends, and not talking about their pain as a way of sustaining the relationships. Gordon recognized the importance of telling others about his situation but “you don’t want to overburden them with

the fact that you've got a problem but at least if they understand then they can either make suggestions or just understand what you are going through. That's very supportive. That's very positive for a person". Sharing life circumstances with others serves to link lives and helps makes the unbearable bearable.

Communicating with her family about her pain without complaining was the balance that Lyn also worked at maintaining. Lyn:

They recognize my condition as it changes because I tell them of the various doctors reports. My family and I don't speak of the problems much. They just accept me as being able to do all of the things that I can do . . . I'm living a meaningful life because whatever I am doing, without complaining about pain, allows my sons and their families to enjoy my company. That is, I am not a pain in their neck. I may be a pain to myself but to me not complaining is trying to do something meaningful. Or call it respect for my kids to not put my problems on them. . . . I don't mention my pain to them very often at all.

Sara found it easier to communicate with friends rather than family about her pain. She found "it difficult to talk to some people in my family as candidly as I can my friends simply because they just don't have that frame of reference, and . . . it's like two different worlds, and I just don't know how to bring the understanding from one [world] to people in the other". The benefit of communicating with her "[husband], and other family members, and friends who . . . haven't gone through anything like this personally" for Sara was "they're still able to support, but it's not in any way a validation. They see what I'm going through, and they recognize my efforts, and show me they accept me, and they love me the way I am". For Sara, the connection of family was such that communicating about her pain seemed related to feelings of vulnerability not experienced with friends.

For Sara, like Lyn and Gordon, talking or not talking, with family and friends about her pain was a conscious decision. Sara "still very much, I have to consciously make a decision to talk about it. When I'm on the phone with them it's still very easy to just say 'how are you?' 'I'm fine.' But that's so not the case. I'm so far from fine but I'm not doing anyone any favours by shielding myself from that and they'll never understand if I don't share". Talking, or not talking, about pain and acceptance with family and friends was a choice that had benefits and challenges resulting in feelings of connection that varied as a result.

Sara described the strain chronic pain placed on her marriage and how communication, or the lack there of, impacted the pain but also acceptance. Sara:

Our relationship has changed almost as much as it possibly could. . . . Two years ago we separated for six months, and at the time we didn't acknowledge the injury, and all the stresses that it had caused . . . was part of the reason why we were having so many problems, but we recognize now that it was a huge contributor to the problems that we were having . . . We're definitely not the same people we were prior to all this happening. Even in the past year . . . we've both changed dramatically I don't even think we'd recognize ourselves. And our marriage is much better now. It's much stronger.

Sara reflected on how the change in communication influenced her marriage and acceptance. She notes "we communicate a lot more about how we're feeling, and I think it's important that we be able to even say things like 'this is really frustrating me' and 'I just want to leave right now.'" Previously this had

built up becoming “bitter resentment” which “ends up poisoning things”. This change in communication evolved as Sara and her husband felt “secure enough in the relationship that we’re able to share those sorts of fears and frustrations” but this security evolved because Sara is “not worried that he’s going to leave. I just know he’s so frustrated he wants to leave”. Out of this communication came a sense that Sara and her husband are “much more of a team now trying to work through things together, whereas before we were both kicking and fighting trying to stay on top of all of the issues separately”. Communicating fears and frustrations facilitated Sara’s connection to her husband and over time strengthened their relationship and assisted in acceptance.

Also of value to acceptance was what the professionals told the participants, and how this was communicated. Lyn found value in her family physician “taking time to explain things in a layman’s way and he knows that sometimes I will come just for questions but I always type it out so he can go down the list until he answers each one”. Not all of Lyn’s physicians communicated in this way and Lyn thought maybe the hematologist “thought I was too dumb to understand if he tried to give me an explanation or he just didn’t want to take the time for a long talk, he had other people to see . . . And I suppose he figures his report goes to a doctor, and it’s up to the GP or someone like that to explain”.

Lyn recognized the style of her physician’s communication was that he “works very hard at accentuating the positive and not the negative”. She thinks his positive outlook for her was his way of telling her what she needed to know in the moment. She thought “perhaps he knew what was ahead for me but as I didn’t need to know ahead of time and worry myself over it, he didn’t mention the future”. Lyn wrote him a poem expressing the importance of their relationship and the significance of his approach in her life. This poem was written about two years prior to the interviews. **Note Lyn wrote about ‘accept’**. She gave permission to use it in this dissertation.

Peripheral Neuropathy

*As my mittens and knee socks tighten
I bring you my fears and pain
You tread softly but with agility
Ever gentle in touch and voice
Telling me of reality with sugar-coated words*

*Secure, I leave, clad in hope
Ready to weather the future
Of which I know nothing
Protected by you and your knowledge
Willing to accept what will be*

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The ability and willingness of Lyn’s physician to maximize the positive and minimize the negative enabled her to leave the visit and “go home thinking that there is going to be some progress even if it never comes”. The outcome for Lyn was hope - hope to “look forward to things changing just because I really didn’t know it was going to be chronic”. Hope that her condition would change was also experienced by

Ginnie. Ginnie's hope was facilitated by her Rolfing therapist who said, "it will [get better]," and I believe her. And maybe two years from now, she said, ten sessions should do it. That's about two years from now. Maybe it will be over. And that helps me accept". Communication for Lyn and Ginnie allowed hope and acceptance.

This is Significant: Momentous Interactions

Participants told of particular situations and interactions which stood out and were meaningful to them. Some of these interactions had a positive influence toward acceptance, while others were not so positive but all were momentous – and meaningful. Tom described an interaction he had during his rehabilitation. Tom:

When you see that someone is actually working and making an attempt there is some things that shouldn't be said to them, i.e. 'not working hard enough'. So at 3.8 km per hour when I heard, more or less that I wasn't working hard enough I hit the stop button and checked that attitude in a very quick hurry, trucker style. She was young. She was just starting out, and not only the working fast enough but totally the wrong words but words she used . . . told me that I was a thief by expecting my insurance company to pay me a wage until . . . I can return back to my employment, which will never happen.

To Tom this incident was an example of "the medical attitude" he "had a problem with". He "needed people to deal with me on a human to human basis rather than the sterile, disinfected attitude you get from most medical staff". In addition to being supervised by a professional Tom felt was "unfeeling and uncaring", Tom felt accused of stealing from the insurance company. This incident threatened Tom's sense of self and did not facilitate healing nor acceptance.

Gordon described his first appointment with his massage therapist as memorable. But more than memorable it was critical to how he viewed his progress, or lack there of, and how he viewed this professional. After Gordon "spent some time explaining to [massage therapist] what my problem was and wondered if he would be able to help. And [massage therapist's] response was "I don't know." He said "we will do the best we can. We will work on different things and try different things and we'll see if I am able to help you or not." Gordon appreciated the honesty and the therapist's calm and gentle self recognition of limitations and abilities. It was this honesty and security that enabled Gordon to approach massage with cautious hope and realistic expectations and facilitated acceptance. The therapist's honesty allowed Gordon to be with his pain rather than on claims of success that other professionals might present.

Janice and Tom described how their families treated them and responded to their pain and their attitude toward their pain. Tom's family "refused to leave me alone. Days that I wanted no part of anyone around me my brother-in-law would come and grab me and 'you're coming over to my place even if we're just sitting in the back yard doing nothing all day'. They'd give me space but they'd also force me into their space. I needed that". When Tom was feeling "sorry for myself over what I had lost, my friend, to the changes I was going through" and "needed an attitude adjustment" or "if Tom was feeling sorry for himself and whining about my life and everything was going so wrong" it was his family that challenged him. As Tom put it, "I have got a mother with a big stick and I have got a sister-in-law that's a psych nurse and a

sister that has quite the attitude as well about someone feeling sorry for themselves. They got my attitude and mind in gear". Tom "knew from first hand personal experience she did not go to nursing school to tell somebody what they wanted to hear. When she had something to say to me I knew it was fact" and "she made me see that if I'd only take a look, there are some good points". As a result of his family's refusing to give up on him, over time Tom did see some good points to his pain situation and to his life which evolved into acceptance.

Tom knew his willingness to be challenged and hear hard facts from family than from professionals was due to "a trust I didn't have to build. It was already there". He "was more willing to listen to someone I knew, loved, and trusted rather than some cold unfeeling [professional] that at some place and time I just did not like because of my situation". And because of this trust and love for and from family Tom "was less likely to lash out at them and more likely to listen". One outcome of these interactions with family was Tom's willingness to ask himself tough questions about whether he wanted to continue with his current difficulties or "did I want to put a stop to them?" Tom recognized he "didn't like the road I saw ahead of me once I heard someone else's perspective or view of my situation" from someone "I cared about". Over time Tom realized "life wasn't over. If I wanted to see any kind of improvement or any kind of a future, I was going to have to get off my ass and do something about it". Knowing the challenge was coming from on love was significant and helped Tom make changes to his life.

Janice described two significant conversations with her husband. The first conversation occurred when her "court case was over and I started focusing on 'I need to be more than pain. Life has to be more than pain'". Janice's husband was "a very good sounding board and when I come and I talk to him, sometimes he's just quiet and he lets me answer, and sometimes he just says things back to me I've said before" and when she came to him after her court case settled "I think he really challenged me 'Well, if you don't like the way your life is now, what are you going to do about it?'" Janice recognized the timing of his challenge was significant "because I think before that I don't don't think I saw it that way. And if he would have said that to me earlier on I probably wouldn't have responded". This conversation lead Janice to make significant changes to her life.

The other conversation Janice described began with her husband listening "to what I have to say . . . and when we were trying to decide if I should have another child . . . he just said, 'well, you know, physically you can't have another child if you're on a bunch of medication for pain'. And that challenged me" to stop the medication and have another child. The marital relationship was strong enough for Janice to receive the challenges from her husband, and to do something different, which contributed to the acceptance. For both Tom and Janice it was the love and trust of familial relationships which enabled each to see beyond the challenge of their beliefs and actions to what the challenge meant to their life. And it was the safety of the relationship that supported each to tolerate difficult feelings that arose from the challenges.

Believe it or not!

The most frequent professional relationship described by the participants was the relationship with their physician. It was within this relationship the participants felt their pain was believed or discounted most often. And, it was within this relationship being believed, validated, or discounted had the greatest impact. Ginnie's family physician "just listens to me. He lets me tell him what is good and what isn't good. He believes it and he writes it down". She predicted if her physician doubted or belittled her pain it would be "a downward spiral especially if you don't have the greatest sort of ego in the first place. I would be folding up". Ginnie thought if a physician doubted a person's pain that person would "guess there is something wrong with me, or I am losing my mind because this professional says so. Well, no, that professional is an idiot, go find a good one". Ginnie evidently would not put up with her physician doubting her pain.

Elizabeth and Janice described distressing interactions with physicians relating to being believed. Elizabeth described a time when she was in pain and "went to the hospital one night and the doctor came in and told me the hospital was for sick people, and to get out . . . None of them would believe me". Janice had a "bad experience with [a doctor] where she was just very negative and you just have to get off your butt and you can't just lay in bed, that type of approach. That tough guy approach really didn't work for me because I felt like she was totally not validating my pain . . . I didn't need that". Janice thought "looking back I think I needed somebody to sit down and talk with me and say 'Yes, your pain is real, and let's talk about what we can do to help you learn to accept to live with your pain'". Not being believed and validated touched Elizabeth's and Janice's inner core similar to Tom's experience of being accused of misusing the insurance system.

Bea experienced physicians who believed her pain and one who discounted it. Her dislocated elbow went undiagnosed for three months following her fall and "every time I would go there [the physician] would grab my arm and jerk it up and down saying 'you have to move your arm' . . . I never felt anything so horrible in all my life . . . After he saw the x-rays and that my elbow had been dislocated he couldn't get over herself enough to apologize". Being believed enabled each participant, and, by extension allows each of us to settle into a situation in a way that allows forward movement, healing, and acceptance.

Abandonment or Support: Physicians Response to the Uncertainty

As with being believed, participants described how professionals, again most frequently physicians; the professional who is the 'gatekeeper' to referrals for specialists, to the important diagnostics tests, and to treatment, responded to the chronicity and the uncertainty of their pain. Bea was referred to a physician trained in pain management. Bea's family doctor "doesn't specialize in pain medication but he referred me over there because he knew I needed special help". She described this pain doctor as "wonderful" because "he knows the pain I've been under and he helps me with the medication that I need". This physician is "strictly for pain management. That's what he specializes in". From Bea's experience it is

evident that knowledge, understanding, and recognition of limitations are important qualities of a professional in helping participants manage and accept their pain.

Recognition of limits are not enough to facilitate healing and acceptance as Janice's experience illustrates. Janice felt her "orthopaedic surgeon doesn't doesn't want to talk to me anymore. She's like 'I've done everything I can. Goodbye.'" Janice stated when she and other professionals responded in this way she felt "abandoned . . . by doctors a lot of times, because you go and you talk to them and you think that maybe they'll help you, and all they say is 'Well, I don't know what's wrong . . . it must be something psychological then'. And I'm going, 'well, bone not filling in has absolutely nothing to do with psychological.' And so it's very difficult". Feelings of abandonment lead to lost hope, increased uncertainty, and despair for Janice, all of which were not productive.

Sara realized with chronic pain "the doctors are frustrated, too, but I think if the doctors acknowledged their frustration to me I wouldn't have felt like I wasn't a member of a team". The significance of working as a team with her physician and other healthcare providers resulted in Sara thinking that "[pain] was something we were trying to solve together . . . so you don't feel so hopeless, and you don't feel so frustrated, and you don't feel so alone going through it". A sense her physician was just one member of her team reduced the power and responsibility given to this professional. And, feeling like she was a part of the solution rather than solely relying on a physician, who doesn't always have all the answers anyway, was important to Sara's acceptance. Further, having a professional who acknowledges limitations, as Bea's physician and Gordon's massage therapist both did, is a factor in feeling believed and validated and allows each person to settle into their pain experience and ultimately facilitates acceptance.

We're Not So Different After All: Shared Experiences

The sharing of experiences between the participants and professionals, coworkers, and group members was identified as influencing acceptance. Janice described one of her physicians as "really good... . . . because she had chronic back pain. As my doctor, she told me he had back pain and she was sharing with me some other things that she had done and I found that very comforting to know that she knew". For Janice the self disclosure by her physician led to a more personal relationship which Janice found soothing and informative.

Ginnie's supervisor of seven years "had the hugest influence on me . . . She could see I was doing way too much for too many people and not taking care of myself and she . . . just made it her own little personal job to make sure that I figured out I was not going to be able to do this forever". Ginnie knew her supervisor "also had chronic back pain so she knew a lot about it. She knew I was becoming debilitated emotionally and she was on a little crusade and she had a huge influence". This supervisor "made sure I was taking two days . . . If I'd only taken one day and it was the last week in the month she would basically force me to take one of the last days of the month and she wouldn't take no for an answer". This experiential knowing of chronic pain by Ginnie's supervisor helped Ginnie acknowledge her limitations and to take care of herself.

Tom's event involving shared experience came during rehabilitation while he volunteered at a hospital. This volunteer experience involved "a bunch of 60, 70 year old ladies, 80 year old ladies, and Tom". Significant to Tom was not the volunteer tasks but "talking to my elders always did something for me inside. Being around them for two, three, four hours a day, hearing their stories, what they have gone through. I am not the first one that's had a terrible experience in his life. Hearing some of their experiences as well and they lived. And they seemed like very well adjusted people". Seeing how others came through difficulties encouraged Tom and gave him hope to go on with his own recovery.

Sharing of experiences through psychoeducational and support groups were described by the participants as both positive and negative. Lyn began attending a group about five years after the onset of her neuropathy. Prior to attending the neuropathy support group Lyn did not have pain. At the meeting "everyone was talking about pain and I was saying 'my aren't I lucky I don't have any. It's just numb'". She "had numbness and tightness and certainly it was always with me but I didn't really have burning and pain until the month after the people were discussing it at the group". The benefit, Lyn noted from attending the group and hearing what others were going through was "I can be happy that I don't have as many problems that some of the people at the neuropathy group have". Lyn's perspective about her pain situation and that of other people her age is that "mine is just a different kind of pain but I am sure all of the other seniors have their problems too. So I don't see that I am any different".

Over the course of her pain journey, Janice attended two support groups. The first one was for fibromyalgia. Janice:

I went to a group for fibromyalgia . . . I went to the first meeting, and I remember everybody was telling their story and how they were diagnosed and it was spiraling downwards really fast. Everybody was blaming the doctors and blaming everybody. I remember feeling really horrible after that meeting and not wanting to go back because in my mind . . . if you're going to have a group where people have gone through something the same as you, you want to have people at different levels. So people that have already accepted all the things can be paired up with people that haven't accepted it yet so that they can see that there's light at the end of the tunnel and there was none of that . . . There was no light and that's not good for anybody and I knew it needed to be different.

The second group Janice attended was for chronic pain and was offered by the health region. She attended this group about a year after the first group. She remembers "being at not a very good place as far as accepting my chronic pain". Looking back Janice recognized "I totally wasn't ready to be there" because "I was still very, very angry. I still felt very abandoned and somebody should fix this". Janice remembers "a lot of people were at the same point and so there was a whole lot of anger in the room". Even though Janice's readiness didn't match the goals of the group, she felt connection to another member who had "a back injury as well, and she would just push herself until she physically collapsed a couple of times. And she totally wasn't even accepting the fact she should slow down or do anything. And she was just so angry because she'd had surgery . . . and I remember feeling a little bit of solidarity with her because I could

totally identify with her anger". The solidarity felt between Janice and this fellow group member around anger enabled Janice to realize she wasn't alone with her feelings.

Despite not feeling ready to be at the group Janice heard what other members were going through and realized "many people were going through divorces because their spouses couldn't handle the fact they had chronic pain or didn't believe them . . . I don't think I could have dealt with anything if I didn't have a husband who was behind me and who . . . tried to understand and was willing to help me go through what I needed to go through. And just to look at some of the other people who were in the group and they were going through divorces. I'm incredibly lucky". The benefit of sharing experiences with other people for Janice was "when you're feeling really, really sorry for yourself and then you meet somebody who is either the same or worse off than you, I think it helps. I'm not sure why". Janice realized "I've just come so far from where I was then" [attending the group].

At the time of the interviews Sara was attending three groups. The first, Sara described as a class that focused on living with a chronic condition offered by the health region. The content of the course was "not rocket science. It's all very basic stuff" presented in a way that enabled her to acknowledge "you've got a chronic condition. You have to manage it. You are the person who lives in your body so you are the expert and you really need to take responsibility for your body and for your mind and take care of yourself". She rated the group as "very good" and "very useful". Sara benefited from the group "partially because it's given me a chance to see how other people have dealt with [their condition] and out of all of the other participants I'd say I'm the least disabled by my condition". The sharing of experiences allowed Sara to "see people at different stages of their acceptance and at different stages of their lives, plus where they are dealing with their disability and their chronic illness, see how they're coping. It's been very interesting that there are so many things that are exactly the same whether you're talking about Parkinson's or MS or COPD, the anger and the frustration and those sorts of things, we all have in common". Sara realized she wasn't so different. This realization was helpful.

The second group, Sara attended was a grief support group offered by her church. Members were "grieving some sort of a loss in their life" including death, divorce, loss of a lifestyle resulting from chronic pain or chronic illness and "different losses they've had in their life". The benefit of this group was that Sara and the other members were "working through the pain" which gave them "new perspective, new optimism, and then new hope. There are blessings and your life has become better because of what you've experienced. You'll never get there if you don't deal with it. That was a very scary step to acknowledge I actually was feeling loss".

A church-based chronic pain and depression support group, was the third group Sara was attending. The group met on a weekday morning twice a month. Sara went "before I head into work . . . I really enjoy visiting with them". The benefits Sara reaped included "companionship. I feel encouraged by them. We pray together and we share . . . how they have been dealing with their own illnesses and their own depression. And they're very loving, very caring people". Feeling "supported by other people" and

feeling like the group is “where I belong and where the other people truly understand what it is that I’m going through. It doesn’t matter how I’m feeling or where I’m at, that’s an okay place to be”. Seeing how other members manage their condition encouraged Sara. She was “amazed by the things that they’re able to do and how positive they’re able to stay despite all the discouragement and all the obstacles they have in their own lives”. The facilitators were another source of inspiration. Sara saw how they “have taken their pain and their suffering and instead of concentrating on themselves and feeling sorry for themselves, they’ve found a way to give to others These people have such incredible relationships with God and so much faith that’s just rock solid, and . . . for most of them that’s pretty much the only thing that’s got them through”. Witnessing the strength of faith in others was “encouraging cause that’s really important to me and that’s where I want to be, so the more I am around people like them the more encouraged I feel”. Sara summarized her group based support. Sara:

The support I get from others that is the most meaningful is the support I get from people who are going through something similar because I know their support is based on their own life experience, and just knowing that . . . means I can validate my own [situation] myself through my own experiences and I don’t need other people’s validations.

The significance of sharing experiences whether chronic pain or any other human experience is that it creates connection to others which gives hope and offers support. And as Sara indicated, sharing experiences enables us to validate and believe in our own experience to a greater depth than is possible than believing we are the only one. With this validation comes responsibility and desire to move forward toward acceptance.

Summary

Participants passionately described significant relationships and interactions influencing their chronic pain and acceptance experiences, and touching the very core of their being. It was the specific qualities of these relationships and interactions that had an important impact on participants. These qualities included: support from others; open and honest communication; meaningful and memorable interactions; validation by others; physician’s response; and sharing the pain experience with others. Most crucial in these relationships and interactions for acceptance was participants’ being believed, knowing someone cared and communicating this care.

Participants experienced support from at least one other person as soothing which reduced life’s burden and pain. In contrast, lack of support more likely lead to depression. Depression then interfered with pain management.

Clear, open, honest communication about thoughts and feelings facilitated participants’ acceptance. It allowed them connection with significant others, accepting support and suggestions, which in turn made life bearable. In contrast, unclear communication left them feeling empty, vulnerable and alone, and interfered with life with chronic pain.

Depending upon the nature of the interactions, they could be meaningful and memorable and have both positive and negative effects. Interactions, even challenges, delivered with gentleness, love, commitment and honesty lead participants to feel secure and hopeful, often allowing them to try something new. However, participants felt that cold and uncaring messages and accusations were both memorable and destructive. Similarly, being believed and validated carried relief and facilitated acceptance while being doubted generated despair, self doubt, anger and mistrust of the other.

As gatekeeper to treatment, insurance benefits and hope, physicians' responses to the uncertainty and unpredictability of chronic pain was particularly important. Participants felt supported and hopeful when a physician acknowledged their own limitations and uncertainty as doctors while validating the pain. However, participants felt abandoned and hopeless when physicians said there was nothing more they could do as a doctor to alleviate the pain.

Finally, participants' acceptance of chronic pain was facilitated by sharing with others. Hearing others' expression of raw emotion resulted in feelings of solidarity and support. The sharing provided validation of personal experience and acknowledgement of one's limits and abilities.

Theme 3: The Journey of Acceptance

Participants described acceptance as an ongoing experience with qualities of a journey. Every journey has features that make it unique and the journey toward acceptance is no exception. Qualities of the acceptance journey emerged as the participants spoke about their lives, including their pain, up to the time of the interviews. The participants described when and how their pain journey evolved into an acceptance journey. They also spoke about what was and continues to be involved in acceptance. Specifically, they described the journey as a series of steps and as a personal solitary quest. Finally, participants recognized it took time to get to where they were in acceptance and that it was a long-term, perhaps life long, journey.

The Start of the Journey: The Decision

As with other journeys, the acceptance journey had a starting point. Gordon describes his turning point toward acceptance as: "After having checked out a number of sources as far as what my condition was and how serious it was, I came to the belief that my feet would probably always give me trouble . . . Because of the condition I just decided to accept the fact that that's the way its going to be and there wasn't a great deal I could do about in terms of turning it around and reversing it". The turning point was "a decision" Gordon made when he "decided that . . . if somebody can't help me in what I have, can't make things better, then I'll just live with it and do the best I can. So it was a thought, a process I think that I went through and came to a decision, get on with things and forget about worrying about it too much". With the decision to accept Gordon was doing his best to manage his condition by his willingness "to work at it through massage and whatever other means I can think of that might be of help". These other strategies included wearing socks, exercising, and keeping busy.

Elyse also began her acceptance journey with a decision, stating "[I] obviously made a decision to push through this so I could get my life back". She made the decision when she had back surgery, which

she believed would result in constant pain. She recognized “at some point you must decide ‘well I’m going to have this for a very long time, how do you want to deal with this?’” She dealt with her pain by accepting it as well as the limitations that accompanied it.

The journey toward acceptance for Wilson also began with a decision which was precipitated by a talk he had with himself. Wilson:

That decision was really hard. . . . It got to the point where I had to talk to myself in the mirror. The hardest talk I ever had in my whole life was looking at that guy in the mirror and calling him stupid, and accepting it . . . There were only two people in the room, me and him. It was a hard decision to change, to physically change the way you always done things for 40 some years . . . But I think in the first 2 or 3 years of making that decision the physical change in myself became so much better because I didn’t wake up and have that aggravating sharp pain all the time.

As with Gordon, Elyse, and Wilson, Elizabeth’s journey toward acceptance had its start with a decision. And, like Wilson, it took time for her to see observable change as a result.

Elizabeth:

I think making the decision to, I used to wear a transdermal patch, a narcotic, for pain, and I was on a very high dose. I decided to see how I would do to slowly go off of it. I don’t know why, I just thought, ‘I wonder if I have to keep taking this. I’m going to see’. And that’s probably when this whole positive thing took root. I did this with my doctor, and took months, and months to slowly condition my system to less and less amounts. And I was half the amount and in a couple of months I’m thinking, I’m fine still, I’ll just keep taking this off . . . I was feeling more positive. I started showing interest in stuff. And then I went off it, and I think, that’s great . . . I kept going from there . . . and then I started taking charge of it.

The turning point for both Tom and Janice began with a desire to live a life that was more than pain. For Janice this turning point came after her court case settled. She “started focusing on ‘I need to be more than pain. Life has to be more than pain.’” She made “decisions about what I was going to do with the pain” including “I was going to do whatever I could to get back to where I could be physically able to be able to even just work a little bit”. She also “decided to have another child. And I was able to physically have a child, even though I did spend a lot of the pregnancy on my back with complications due to the pregnancy, which complicated my back pain. I was on absolutely no medication for that time, up to the pregnancy to show myself that I didn’t need to be on any medication, I could manage my pain”. As a result of these decisions and accepting her pain Janice realized she can and does live a life that is more than pain.

Tom’s journey toward acceptance also began with decisions: “One day I decided I didn’t want to be inside so I went outside”. This led to “deciding I’ll go for a walk down by the river bank”. At some point early in acceptance Tom came to the point where he refused “to sit in my apartment and feel sorry for myself. There has to be something better than what I had when I woke up” in the hospital after his accident.

In making his decision to change, which gradually led to acceptance, Wilson realized “I tried to change and I tried to change them, and you don’t just change people because you need them to change. They only change if they want to change”. The acceptance decision Wilson and the other participants made led to other changes which will be highlighted in theme four.

The Journey as a Process; A Series of Steps

The participants described the acceptance journey as a process rather than a single event. For Bea the process of acceptance was about learning and receiving help. Bea:

You have pain and you have to learn to live with it. You have to learn what helps and what doesn't help and if something makes you feel worse, you're definitely not going to do that again. But it's a process, a learning process. . . You do things that normally you wouldn't do. You wouldn't [normally] have somebody come and help you to bathe or somebody to come and help you dress and put your bra on you and things like that but you have to get over it. It was hard at first. Even though they are my daughter and son I still had a problem with that . . . So you have to accept what comes and learn to live with it in the best way you can. Learn to do what you can and what you can't. You've got to have someone to help you.

For Elizabeth the process of acceptance unfolded "little bits by bits, every day. It wasn't just an awakening. Just little bits". And like Bea, Elizabeth's acceptance is "it's getting better, well I keep getting better. I don't think it ever stops. It depends on how much passion I guess you have and I've got a lot of passion. A year ago I didn't have any. None". She acknowledged the acceptance process is something "I've been, not through it, because it keeps getting better".

While Bea and Elizabeth indicated journey with acceptance moved in a forward direction, Gordon thought his journey had a back and forth quality. For Gordon acceptance was going "through a process in your mind, in your body, over time. And you gradually put things together, the information you have about your condition and you deal with the unpleasantness of the pain and over a period of time you would decide this is the way that its going to be". Gordon thought "there are times when you feel one way and then as your condition changes you will feel quite the opposite and it goes back and forth until you arrive at a point where you feel this is where its going to be". In order to arrive at the middle point between going back and forth, Gordon recognized "it wasn't a sudden kind of thing that one morning I work up and said 'well I accept this' and that's that. It sort of gradually came about. I don't think it was a sudden feeling or an understanding. It was more of a gradual process and I think that that process probably is ongoing. It's not sort of a final thing".

The participants recognized the process involved a series of steps with future progress dependant upon taking the previous steps. For Wilson the journey was "a long, long life process" taken "one day at a time, and you just can't skip the first 15 steps, you got to take them all whether you like them or not. And a lot of times you don't. You don't like the steps but you try to push through it harder, and sometimes that's worse . . . and I'm hoping that . . . I'm able to be better for it". Elizabeth also recognized the value of the previous steps because "I couldn't arrive at where I am at right now, if I didn't go through what I went through". She described her process as "I guess a reasonable analogy would be that there is no set time for how people can get over a death of a loved one or a spouse, everybody has different times. There is no set rule, and it's just, I guess what you have to go through, it's your own timing in order to accept it".

Janice recognized her journey involved steps, stating "acceptance of pain is a process. You have to go through it step-by-step and I don't think there's any fast track to the end. I think you have to go through.

You can't just skip through to the end. Even if somebody's there to tell you this is what you need to do, you still have to go through the steps yourself". Like Elizabeth, Janice thought acceptance had similar qualities to grief, although Janice identified the anger stage in her acceptance journey. She sees "anger as being, I don't want to sound like Kubler-Ross, anger, denial, and all that. It's pretty close to that but anger seems to be all the way through up to the end".

Sara also believed her acceptance was a process that involved learning. Sara's "learning curve is pretty steep but I know that that's the direction I need to be heading and I want to be heading in that direction, and it's going to take time but I've certainly got the resources in place". Through counselling and attending groups Sara recognized "a huge part of acceptance for me was allowing myself to grieve . . . [I] didn't realize this was a grieving process I needed to go through. I didn't realize that at all. I never thought of it as a loss that needed to be recognized or experienced as a loss . . . It's a life long change". Sara described the grieving process for herself as "some weeks some things clicks and you get something out of the group and some weeks you feel like you're back at square one, but it's all cyclical. I'm starting to recognize that. That everything's cyclical like even the grieving process. You go through it. You just don't go through it once. You go through it over and over and over again. If I don't catch something this time around I'll catch it the next time". Sara also realized the cyclical pattern in other areas of her life and really "any situation I have to go through the whole process again".

Finally, Sara realized her journey is in progress as she described a group member whom she feels is further along the acceptance path. When Sara thinks about where this group member is "I think partially it's just because she's been dealing with things for a lot longer, so I see her maybe seven or ten years further down the path than I am, so she's just got that many years of wisdom and experience to help her". As hard as attending the group was, Sara believed she would "miss out on all that these people have to teach me, and all they offer of themselves. There are still a lot of things I haven't accepted, but I know it's a process, and I'll get there".

Acceptance as a Personal Journey

The journey toward acceptance was identified as a personal journey. Bea acknowledged the pain "is just something you have to live with". She also recognized the pain is something she "can't change it so you have to survive in the best way that you can and whatever is going to give you some relief". Similarly, Sara had "some personal decisions that I'm still struggling to accept but I'm working on it". Both Bea and Sara believed the acceptance journey was a journey that only they could travel. This was something Wilson also recognized. He described a conversation he had with a psychologist who said "'Wilson, you're going to have to change your ways.' 'No way.' Nobody wants to accept that kind of situation. Nobody!" Over time Wilson recognized "the sooner you accept it the happier you're going to be. And that's just experience. But people have to, unfortunately they have to go through it . . . You can't buy that knowledge".

Elizabeth and Janice experienced the difficulty of hearing advice given by well intentioned others. Janice acknowledged her stubbornness saying “I think that stubbornness doesn't go away with chronic pain. You're still going to be stubborn about everything and that's why I don't think anybody coming to me earlier on, no matter how they would've approached it, I don't think it would have made a difference”. But it was more than simply being stubborn for Janice. She recognized “I still would have had to go through making those decisions and trying to problem solve for myself and no amount of anybody else telling me that you shouldn't do that is going to make a difference”. Janice reflected on advice given to her about stopping her litigation in order to help her pain because “they had heard people that were in the middle of litigation generally had worse symptoms . . . I didn't listen to them. Because I didn't see that it was until after I had settled”. Janice also believed there was really nothing that could have been done to assist her with her journey because “I don't know if I would've listened to anybody. . . I can't really say if it would have been different if somebody would've said to me ‘You know what? You need to make decisions yourself and you need to decide what you're going to do about this instead of just waiting around’ ”.

Elizabeth also had well-intentioned people trying to help her. But “I knew all the things I had to do. And I was sick of people telling me. I know what I have to do. Shut up. I don't feel like doing it. And you know, leave me alone”. Participants acknowledged that ultimately the decision to accept came from within themselves. With Wilson's recognition that acceptance was a personal journey and the difficulty in listening to and following the advice of others, he wondered how this study would be of help to people like him with chronic pain. Wilson:

I understand this is a good thing you're doing, to get that understanding. But the end result is to find the bottom rung on the ladder before you hit the ground. What would you do to physically change your life to do whatever you needed to do for yourself without other people involved? It's hard. That was a very hard situation. And I don't think anybody can answer the questions . . . They could give you the three or five-cents worth of information, but you still have to make the decision.

The Journey Takes Time: Time for Acceptance

The participants have indicated the journey of acceptance takes time. Lyn's experience with pain taught her “the longer you have the condition the more you accept the problems you have, then when new ones come along, bit by bit and it all gets accepted”. Gordon also recognized that he “had [the pain] long enough now that I have learned to live with it and I have sort of accepted that that's the way things are”. Wilson and Janice concurred with Lyn and Gordon. Janice described her process recognizing what she was able to do so her pain would not “be so bad that I'm never going to sleep tonight. And that's just something I had to learn a little bit at a time”. Janice was also “a firm believer in you can't hurry anybody along to accepting chronic pain. You have to let them go at their own pace. I honestly don't think there's anything you can do to speed up the process”. Wilson spoke about what he went through in learning what he could do while keeping his pain intensity manageable. He said you “still want to enjoy life but you're going to pay for it. So you got to know how much you're going to allow yourself to hurt because you know you're

going to hurt . . . You learn that in time". Wilson also learned the journey was "long term. It's not a one, two-year fix. It's a long long haul". Bea also recognized the time element and the learning. She knows that doing specific movements will "cause me more pain. So you learn and it's taken a year and a half".

Tom described his experience as he got stronger. He realized "the more I walked the stronger I got and all of a sudden I could do a little bit more. And when I sat back after a few months and looked at what I was doing physically as well as how I was thinking when I first came here, I felt after four, five, six months sitting back and looking I saw an improvement". Tom didn't "know if anybody could have helped me. I needed time to get myself to a place where I felt safe to be around others, to start getting over my injuries". Evidently time and all he did helped Tom feel stronger both physically and psychologically.

Similar to the other participants Sara acknowledged "time, for sure, has helped me". She also realized "the more time I spend with this the more everything I practice will be easier to do". She thinks "with time I will be even more accepting and gentler with myself in all ways. Plus, I think with time you've practiced those routines and you've had more chances to work out schedules, and find the activities you can still do and do well". Her hope that time would help her continue improving came in part from interacting with another group member who "has Parkinson's disease, and I know she's had it for 16 years, and she's very much at peace with her disease, and I think that it's just because she's been dealing with it for so long that she's so much more accepting of where she's at and what she can and cannot do". Sara knows "I've only been dealing with [pain] for three [years], and really thinking of it as a chronic condition . . . for one. That just with time" it will improve.

The participants spoke about the longevity of their pain and acceptance experiences. Bea knows that since her bones have healed her "elbow will always be dislocated so no matter what" and she will likely always have pain. The long term nature of Wilson's pain meant that his acceptance journey included "accepting the fact that it's always there, this is forever". Similarly Lyn "think[s] part of acceptance is knowing that it will never go away so why fight it". Sara, on the other hand, was not so sure her pain would last forever and "it's not the way I would like things to continue forever, but for right now its fine, and if right now turns into forever, well, that'll be fine, too. But really, its okay today, and that's all that matters".

Summary

Participants described acceptance as an experience that was not finite and which continued to influence, change, and weave through their lives. In this way, acceptance was viewed as a life long journey. The journey often began with a decision and involved a series of unavoidable steps which took time to take and which only the participant could take.

The decisions which signaled the start of the journey included the decision to move on with their life that now included long-lasting pain, to live with the pain, and a willingness to do things differently in order to live a meaningful life. The decision to reduce medication as a step toward having a life more than pain was made by other participants. These decisions were momentous thoughts, often taking a period of time to observe change, but the significance was in the decision itself.

For some participants progress toward acceptance generally moved in a forward direction while for others it held a back and forth quality. For one it held a circular quality whereby parts of the journey were revisited repeatedly, but from a changed perspective each time. Regardless of the directive nature, the participants described acceptance as a series of steps, noting that no step could be missed, avoided, or fast tracked. Rather, participants needed to take each step in order to move toward acceptance. Acceptance was seen as similar to the grieving process in that both involved a series of steps or stages.

Participants identified acceptance as a personal experience. They acknowledged the difficulty in heeding the advice of others because the learning had to come from personal experience. And, as a personal experience learning and growth could not be purchased. Ultimately, participants realized they had to go through the challenges and the difficulties they did in order to accept.

Participants realized with experience that time was required to learn all they had learned, required to go through all the steps they did, and to notice any change. Given their pain was likely to persist they also realized pain and the acceptance of it were now a part of life.

Theme 4: Choices and Changes on the Journey

As the participants spoke about acceptance, it became obvious the journey was an eventful and complex one. As they spoke it became clear each had been presented with choices to make as well as numerous opportunities for change and growth. The choices and changes the participants described included acquiring knowledge, taking responsibility, and recognition of choices. They also described change in focus, in their self relationship, and with control. The specific ways and approaches in adapting to pain were also identified. Finally, they spoke about reexamination of personal values and priorities. It will become noticeable that specific changes and choices for individual participants predated, and thus lead to other choices and changes, but otherwise these events did not occur in the same sequence for all. It will become evident these choices and changes are not exclusive to one other and that they overlap.

Knowledge and Learning

During the journey participants acquired knowledge and learned about their condition from a medical perspective, as well as through their own pain and acceptance experiences. Both sources of knowledge influenced the journey toward acceptance. Sometimes the influence on acceptance was indirect as for Lyn who said she “can reduce the severity of some of the problems because I understand my medical condition” but “I would worry about the pain I didn’t know about”. This worry was reduced because Lyn’s general practitioner “knows that I want to understand and he quite often tells me in laymen’s language what the specialist tried to say”. Reduced worry enabled Lyn to focus on other aspects of her life such as her writing. Knowledge about his condition also reduced the worry for Gordon and enabled him to carry on.
Gordon:

Going to the doctors and specialists and finding out more or less what my condition is. I’m still not sure they have diagnosed it properly but it gives me a better understanding I think of what is happening to my body as far as my feet are concerned, and that was somewhat of a help because I guess it relieved my mind as to more serious things it might have been . . . that I wasn’t aware of .

. . . Once I found out from the neurologist that it was a condition where the nerves probably wouldn't get any better and maybe even get worse I just accepted that as a fact. It may not be true. I don't know. I am just taking his word from his experience about it.

Another benefit of knowledge described by the participants was the influence on the amount and type of activity they could do and how much pain to expect following. Tom was able to "take that knowledge and information and relate it to my pain. Make myself do what the medical people told me to do. And hopefully in the future with what they said I would get better mobility, I would reduce my pain". Tom took the information and "put it in my head the way to help me understand what I was feeling . . . I'm not saying it made me any less afraid, but it made me push ahead". Similarly, Elyse used the "knowledge and education about what you've got and what your limitations may be". The information told her "what's good to do even though there might be some pain or discomfort involved . . . It's like there's an element of, what's that saying? No pain no gain".

Gordon indicated he sometimes questioned his diagnosis and hence the opinion of his physician. Elizabeth notes she also questioned the opinions of those who helped her while continuing to learn and "educate myself about what are the best things for me . . . and to research and to find out for yourself, and to not take an opinion as the final word, that it's okay to find other answers. There isn't any just one way anymore for me. There are so many options". To Elizabeth "knowledge is good" because "it's giving me back my power".

Although the participants thought the knowledge they gained about their condition was helpful and that it typically assisted them toward acceptance, the information presented sometimes had the opposite effect. This was the result for Janice when she was given information about chronic pain. Janice:

I think because I was a [health care professional], and they start talking about 'Well, you know, it's chronic pain now' and they talk about the gateway theory and all that stuff about the signals are just being sent. . . that it's just your nerves playing tricks on you, the pain's not real anymore, it's just this physiological thing that's happening. But it's still real pain. You still feel it every day . . . It doesn't matter whether the message is true or not, it's still a message being sent up nerves, it's still saying the same thing: 'I hurt.' And somebody telling you that it's not supposed to be doing that, really has no effect on the fact that you have pain . . . It kind of pisses you off because you're going, it still hurts. . . It doesn't help. It's the same as when people say 'Oh, you're a hypochondriac; it's all in your head'.

While this particular instance of receiving information was not helpful for Janice, she did find her own personal experience helpful in learning to manage as well as accept. She compared learning about her pain to how children learn noting you need to "try. And it's the same thing when you have kids. You can tell them not to do something but chances are they're going to have to experience it themselves because they're not going to believe". Specifically, Janice learned from personal experience that "if I stay in bed all day my back does not like that. It seizes right up and I can barely walk. I have to keep physically active but you have to balance that with resting because it has to recover". She learned from the "whole trial and error of what can I do and still be productive. And that's a really hard balance. And the only way you can learn that is by doing and learning from what you've done".

Part of the trial and error for Janice was making “decisions. Is it worth it? Is it worth it to go out and do a round of golf and enjoy it and know the next day I'm not going to be moving around very much because I'm going to be in a lot more pain? And sometimes it definitely is because it makes you feel like you are out there and you are living, instead of just sitting at home”. Learning “what to do and what not to do” is also what Wilson learned about how he responded to activity and work. He learned “how to accept what your body's been telling you. You want to tell it to go to hell sometimes but you have to learn to accept different ways. You have to come up with strategies so that you can continue”. Bea also “tried different things and I know it just didn't work and there were some things that did work so you just experiment a little bit and you know how far you can go”.

Through trial and error and experimenting with strategies participants learned about themselves. Lyn learned “the more an area in pain gets tired in a day, the more it hurts” while Tom found out “the stronger I get . . . the less pain I have in my legs or the less stress I feel in my leg area”. Elyse realized “it will be alright. It always is. It always gets better. It always recovers . . . I'm not going to die. There may be a couple of days where I'm a little uncomfortable . . . but I'm going to be sort of happy that I gave it a go”. Similarly, over time Wilson realized sometimes “it's excruciating . . . but it's not going to kill you and that's learning. That's something learned”. Ginnie summarized her learning as “knowing from experience I am quite capable of doing it and it will hurt but I can still accept my pain. It can't stop me from doing it”.

Sara indicated her learning came from practice and “the more time I spend with this the more everything I practice will be easier to do because I know recognizing my limits and trying to plan ahead to take care of myself, and then knowing that I'll need recovery time afterwards”. Sara found that with her “condition the symptoms were changing and the course of action to deal with the symptoms was different, and it's just been in the last six months, ten months that it's become stable . . . and the course of action to deal with it isn't changing, so now . . . finally now I can get more familiar with just this one way things are having to be dealt with, and now finding something that works in this stage”. The benefit of the stability was that “there's a lot more predictability now”. This allowed her to practice a single routine and plan appropriately.

Elizabeth spoke about what she has learned about herself and the impact this learning has had on her outlook toward her pain and her life. Elizabeth:

Was it Shakespeare that said, ‘to thine own self be true’? . . . I believe that holds an awful lot of meaning in being completely honest with yourself, and true to yourself, and thus knowing yourself, and wanting to know yourself and your limitations. . . It's an inner thing and it affects everything outer. Have you heard that one saying about ‘physician heal thyself’? I understand where I can apply it to myself as I am my own physician and you have a lot of the power to heal thyself. Look after yourself. Don't just look after your car and put oil and gas, and stuff in it. Look after your body. Look after yourself. It's a machine too and if that's the only way you can look at it then do it. At least look after it.

As the participants indicated, information from both professionals and self learning were important in acceptance. And while both sources of knowledge had an impact on their pain and acceptance, it is evident that the self learning could only come from personal experience.

Taking and Giving of Responsibility

Taking responsibility was one of the choices many participants made at some point during their journey. For each, the choice to take responsibility for their pain situation was made for personal reasons and the implementation and outcome were equally personal. Janice realized “somebody else wasn’t going to make this better and it was the realization that if I wanted to do something then it was up to me”. Janice understood “it really was up to me. It wasn’t somebody else’s problem, it was mine. I had to take ownership”. Likewise, Elyse recognized “I’m going to have this for a very long time, how do you want to deal with this?” For Gordon taking ownership meant he “just tried to deal with it on my own by going to [massage therapist] and having him do massage”. For Elizabeth taking responsibility entailed recognizing “things I can control right now” and deciding “I’ve got to start taking control of things going on” because she also realized “it wouldn’t matter if I had a million counsellors, or the best guru, or the best psychiatrist in the world, it had to be something from me”.

On the other hand Sara found it was the giving away of responsibility, not the taking of it, that facilitated her acceptance. Sara:

A lot of days I’ll do nothing that should cause my pain to increase. It’ll be a restful day. It will be an easy day as far as physically what I’m doing and yet my pain will be really high. And I question what I’ve done wrong to cause that . . . What have I done wrong? Why me? How am I responsible for this situation? And somebody [in the group] used this analogy . . . when you have a chronic condition you’re just walking down a path. Some days it’s downhill and its easy going, and some days it’s up hill and it’s really hard. And it’s not your fault. You’ve done nothing different. That’s just the way the path goes. Sometimes there are obstacles and sometimes there are ruts. And sometimes it’s bumpy and rocky and sometimes it’s flat, smooth, and easy. And it’s not because of what you’ve done, it’s just the way the chronic illness works. And I love that analogy. I love the idea of it not being dependent on me.

The participants implemented responsibility in ways that helped them manage pain and live their lives. Tom accepted responsibility for getting himself moving by knowing “the more I’ve got myself moving the more improvement I see. . . . I see improvements which tell me to keep on doing what I’m doing. It might not be an exercise program set up by an exercise therapist or physician but it is still work. It’s kept me moving. It’s obviously improved my physical abilities”. Lyn took responsibility for doing her exercises and knew if she “didn’t do my hand exercises and things they wouldn’t be as supple as they are. They would be worse”. Lyn also realized the importance of doing other things she “want or needs to do. I will bull ahead because if I didn’t I would have a poorer quality of life - no fun, no time with my family and friends, nothing to keep me in a happy state of mind”. Elizabeth referred to taking responsibility as taking charge. She “started to take charge of my health. Rather than taking health pills take a gunky glass of water once a day”. But she knows no one could make the decisions, take the responsibility, and “no one could have got me to where I am today except myself”.

Lyn offered her philosophy on how responsibility and acceptance fit into her life and possibly the lives of others. Lyn:

I think it's because they don't want to give into the fact that the doctor says they've got a problem and so they deny it. It's as if another little piece of their life has been lopped off by recognizing they have a problem. Another reason for accepting pain which might escape some people is 'I accept it is my problem my body has foisted on me.' Some people don't think of this. They think to themselves, 'I seem to have a problem and it is up to the doctor to fix it and he is failing so it is all his fault.' They like to shift the blame away from themselves when maybe it is the way they lived their lives that caused the problem, like smokers who won't admit smoking has damaged them, or farmers who, because of their work, have lifted too many things in their lives. And now getting into my homespun philosophy, in our population there are those who take on life and try to improve their lot and those who sit back and think most things are someone else's fault. They expect the government to cure the problem, their union to make a good deal, their boss to quit harping at them. This latter group may be the one's who can't accept their pain, because they have never accepted much in their lives as being of their own first choices. They have grown up in families that taught shifting blame and now they want someone else to cure the pain, when there is no medical way to do so.

Lyn's philosophy suggests acceptance and taking responsibility in general maybe long-standing challenges for some people. Janice described more specifically why taking responsibility and acceptance is difficult for her and perhaps for others. Janice:

The pain is stopping you from doing stuff . . . It's almost like a relief because . . . it's this built in excuse to get out of everything and when you start accepting your pain you have to give that up, and that probably is very difficult for a lot of people, because it's a really good excuse to get out of stuff. And so you lose that when you accept, because you don't have that pat excuse of 'I can't do anything'.

For Janice "you have to take responsibility for what you're doing" and this involves at its core "taking back the first person in your life". This "taking back" was noted by the use of "I" language, also known as first person singular, the participants used when they described their taking of responsibility.

Recognition of Choices

The conversations with the participants revealed an array of thoughts and beliefs about choices. Some believed they had choices related to their pain, their acceptance of the pain, and how they managed it, while others believed that they had no choice. Still, others held both views believing they had choice in some areas but not others. Elyse was clear of the role of choice in her own life. Elyse believed "you are in control of whether you do [accept] or not, it's a choice you make. And it is control. You do have control over everything you do. You can choose to do it or you can choose not to do it. But to take that away and say I don't have any control over this at all . . . that's what I could say if I wanted". She acknowledged that acceptance takes effort and "it is in my every waking moment but I've got to remind [myself], it's like I'm overriding [not accepting]". She knew she could "sit here and winge about it and drug myself silly so I'm not in pain, but geez that's not a life I want to live". Similarly, Gordon stated "I don't let [pain] stop me" . . . I just haven't really let it affect me too much in any negative way" indicating he believed he could let the pain affect him if he chose to.

Janice was equally clear that she had choice, now, although “up until [ending of the court case], until 1996, I didn't think I had a choice. I just thought ‘This is it. This is my life’”. However, after her court case ended she was able to recognize she did have options and over time she came to accept. On the other hand Bea believed she did not have a choice. Bea:

You don't want to accept it but you have no choice. What choice do you have? You have pain and you have to learn to live with it. You just have to do it. You haven't got a choice. You have to accept what comes and learn to live with it in the best way you can . . . You can't change it so you have to survive in the best way that you can . . . What else can you do?

Wilson also believed “you have no choice. It's there. It's not going to go away and you have to carry on”. When it came time to dealing with the pain Wilson believed, “it is still choices. You have to create your own non-pain day somehow”. He talked about choosing to staying alive, saying when he “hit bottom it's make a decision and like I told [psychologist] one time, I said, ‘its easier to stand in front of a bus at 60 miles an hour.’ That was an easier decision than the one I did . . . ‘cause it would have been so easy just to step off a curb, but it's a big mess for everybody else, and you took the easy way out”.

Like Bea and Wilson, Ginnie also believed the only choice she had was to accept. Ginnie:

I have proven to myself over the last two years that I can continue to teach and pay bills and be in a profession I love to be in and deal with the pain, just because I've managed to do it. But I can't see dealing with this for the rest of my life. That, I have a hard time accepting; I mean I've accepted it for now, temporarily. I am just assuming that one day I will figure out a way I won't have to accept it but for now I have to. I don't see what my choice is. I don't think I have any choice but to accept it and not to give up hope. Is that contradictory? I'm not sure. . . . I have to cause I don't have any choice . . . I don't feel like I have an option. I feel like I have to accept it and that makes it a little easier to deal with. . . It's like I don't have a choice, it's not like I'm consciously accepting it or not accepting it. I don't know what not accepting it means. I don't understand what that means. Like suicide, I guess. Like what else would be non-acceptance of chronic pain?

Ginnie initially held the view there weren't options available with other aspects related to her pain. Regarding what choices she had around taking time off work and receiving benefits, Ginnie had “looked into that because I was thinking of taking six months off work for surgery and to recuperate . . . That would be hard I don't think I could do it at all . . . There's no way . . . So that's just not an option”. She acknowledged, “it just comes back down to that ridiculous work ethic and the connection I feel with my [students], I guess. And the bottom line issues like we'd have to sell the house and do all kinds of ridiculous things that I can't even begin to think about if I didn't have a pay cheque. . . . There is no other option”.

Ginnie came to realize “there is no alternative in my own mind. My little brain cannot imagine any alternatives I could live with. I think it has to do with being needed. It has a lot to do with being needed. It's a mothering thing too”. Ginnie saw that it “seems like I don't have a choice or at least I have convinced myself I don't have a choice. Because I just don't, for myself personally and for myself financially, I don't have a choice”. However, I knew she had benefits from her employment as a teacher so I was not buying

her rationale about the finances and continued pressing her for clarification. Through our conversations Ginnie arrived at a new level of insight with her perspective of choice. Ginnie:

I would like to be in control of my own destiny, if I feel I need to [take time off work], I will but don't you tell me what to do. The control over what happens is really important to me. That would be horrible if I felt like I couldn't choose between working and not working, if I had to work or if I had to quit. I am in a very cushy position where I can go either way. It's entirely up to me and I know it and that helps me deal with it. If it gets really bad I'll take two months off. I keep telling myself I will. . . I hope the health care providers out there are hearing, or the health insurance people or the workers comp. Choice is very important. . . As long as there is a choice. There is self-imposed lack of choice too, like when the kids were little, I used to think, I have to get up and do that chore because if I don't something terrible will happen to my children, and so it was a maternal instinct self-imposed lack of choice. But even then I knew intellectually that all I really had to do was ask my husband to do it, or ask my neighbor to do it. But sometimes I feel like I'm the only person that can do it properly, therefore I must do it.

Ginnie came to recognize she did have choice regarding work. And once she was able to acknowledge her self-imposed lack of choice and that she did in fact have choice, we were able to explore her deeper reasons for her not wanting to take time off work. At this point the importance of control as it related to choice became evident.

Ginnie was not the only participant who had difficulty recognizing choices were available and that their decisions did involve choice. This was apparent with Sara, also a teacher. At the time of the interviews Sara was working part-time and receiving long term disability benefits part-time, which meant "financially I'm still making the same amount of money I was making when I was full time even though I'm only working half time now. So I'm very fortunate I have that". Sara's and her husband's income combined along with each of their employment benefit packages provided Sara with financial resources and availability to treatment and a standard of living not available to someone like Elizabeth who relies on government assistance. Sara realized "there is no way I could leave this job just because of the benefits. So it kind of scares me too because all of the coverage, where on earth would I go?" But, "I like the fact I have a well-paying, full time job and I'm on disability so I'm making just as much as I was before". With the financial resources she has Sara would obviously have choices available that others like Elizabeth did not. But Sara's language suggests she did not recognize she had choices available or that she really was making choices. Sara:

We figured out in the first two months of my injury we had spent over \$2000 just on physio and medications and specialists. That's ridiculous. And when I add my loss of income I cannot believe how much this really has cost me. It's just insane. And we had to change our finances in the house as well 'cause a huge amount of my income now goes towards all the treatments that aren't covered under the health plan, my acupuncture, and once I hit my physio limit, which I hit in January of every calendar year, after that it comes out of my pocket, and right now I'm trying some herbal medications and I take lots of vitamin supplements. . . . We recognize we're going to have to spend a lot more money on those sorts of things, and then we decided to hire a cleaning lady because I can't do the cleaning here in the house, and so more money is being put aside for that. And then our grocery budget, because we just need to eat simpler meals, we buy a lot more frozen meals, ready go to packaged stuff, which is more expensive, and we eat out an awful lot,

and so we just know that that's where our money's going, and that's okay 'cause it makes our life easier, and that's what it's all about.

As Sara described her expenses she used the words 'had to,' 'have to,' 'can't,' which imply an external source of control and lack of choice. In contrast Sara's description of her summer outlines the moment-to-moment choices she made. For instance she "was able to take a full day, like I would go golfing one day and then the next day I wouldn't get out of bed maybe not even in the morning. . . . So I really let myself rest because I had that freedom and that was fine". She recognized "I'm back in the real world (laugh) where I'm working and working is not the same as golfing, it's stressful and it's not nearly as enjoyable on a regular basis and it's very scheduled so I don't have the flexibility I had before and . . . I'm now having to figure out how I'm going to cope and try to do the day to day things". So, even though Sara did not use the word choice or options, the words 'try,' 'freedom,' 'wouldn't' and 'would' all hold a quality that indicate she made choices even if she did not know she was making them.

The role of choice and availability of options, and also a lack of awareness with respect to money and finances continued to surface as emotionally powerful areas. One of the roles of money is to pay for both essential living expenses as well as the extras. Wilson eventually chose to leave a physically demanding job because of the resulting pain. However, this was "a big sacrifice in pay because you go from mid \$70, \$80,000 to \$45, \$50,000 that's a big sacrifice". As Wilson noted, it wasn't so much the decrease in income, although that was difficult enough, the difficulty was also that the wants and desires the higher previous income provided were still present. Wilson observed "there's no planning involved, and then to have a total life change due to an accident . . . If you don't have, the wants aren't there as easy. It's when you had, and you don't have the ability to do it again, that's wicked". For Wilson, the financial challenges and stressors focused on providing extras he and his family had grown used to, rather than providing basic needs of shelter and food.

Maintaining a way of life and the role of money, choice, and pain also arose in interviews with Janice and Tom. For Janice, part of the motivation for proceeding with her court case was to "get enough to help somewhat with the finances" because her husband worked "usually two or three jobs" to pay for the living expenses and the expenses related to her rehabilitation such as "physiotherapy". And like Wilson, part of the financial challenge of chronic pain for Janice was that "we were used to having two incomes and it was a huge blow to our way of life". A notable moment which prompted Janice to settle her court case occurred when her husband "was working a full-time job during the day, and . . . [dealt] cards at a casino in the evenings and weekends. And I remember [daughter], she was about three, asking when dad was going to stay overnight again. Because he was gone when she woke up in the morning and he wasn't home to tuck her in at night. So the only time she would see him was sometimes at lunchtime. I would take her down [to his workplace] and we'd have lunch together. So it just wasn't working". This moment contributed to Janice's decision to choose to settle her case out of court.

Staying afloat financially and emotionally as a court case works its way through the legal system is difficult, as Janice and Tom described. Prior to his accident Tom had been earning a good living working on the oil rigs but at the time of the interviews he was earning minimum wage. As a result, the “last two [years] have been more than a little difficult because [insurance company] has financially cut me right off and it’s been just about three years since they cut my wage back”. Living on minimum wage impacted Tom because “if you cannot afford to keep a roof over your head how can you afford . . . to take time off work to go and see [my son]. It is a very difficult thing to do”. Tom’s son lived in another town and traveling to see him was prohibitive due to the cost and because Tom was unable to drive due to his head injury. This situation caused Tom a lot of distress and he did not see any options for himself. In addition to the financial stress as a result of his accident, Tom was also dealing with the “the stress I am under due to the insurance company and their actions are part of my pain. The stress I am under increases the physical pain I feel, if that makes sense?” Tom desperately wants the litigation to be over and has “been very vocal to my lawyers as well as theirs, get off your ass and do something, end this, quit bringing me back to this incident in my life. Let me get on with my life whatever it’s going to be”.

Initiating litigation is often done to receive compensation for lost wages, pain and suffering, and to receive assistance to pay for rehabilitation and other expenses. Many people see litigation as the only way to receive the compensation and financial assistance and do not see it as the choice it is. Tom and I did not talk about how his court case started but I sense that he initiated legal action to help pay for his medical expenses and to cover lost wages. When asked about ending the court case prematurely due to the stress, Tom stated that he did not have a choice but to continue because he was too far into the case financially to back out without receiving a settlement. Given the pressure of the legal bills Tom did not see his choices so he felt trapped to continue on even though the stress was so great he had contemplated suicide.

In some situations participants recognized available choices, while in others they did not recognize choice even though they had made a choice as in the phrase “no choice but to accept” many used. Yet for some this phrase became a clue that a choice was available even though the participant may not have identified it as such. Words such as ‘prefer,’ ‘could,’ ‘would,’ ‘don’t see,’ ‘want,’ ‘freedom,’ ‘try,’ and ‘don’t let it’ when spoken and heard in context suggested choices were available. A sense of freedom was an emotional outcome for participants such as Elyse who believed in and recognized her choices, while a feeling of entrapment was central for participants such as Tom and Sara who were unable to recognize they had choice.

Change of Focus

Participants talked about their focus and attention during their pain experience and how this focus changed when they began movement toward acceptance. They also described the direction their focus changed, if it did in fact change and how it impacted acceptance. As I spoke to Lyn about her pain and her acceptance, she realized the impact of changing her focus to her pain during the interviews. Lyn:

This sounds odd, I've always done my best to ignore any pain, but I feel that because I have been analyzing myself for pain to answer your questions and that I have paid more attention to when my pain happens and what it's like, I feel that I have experienced more pain. Maybe I have put a chink in my armour against pain by making myself think about it, or maybe I truly have more pain . . . I'm not saying this to make you feel that somehow you have contributed to my pain. I merely am bringing forth the point that maybe mind over matter can be a very strong cultivated force.

Lyn's focus does not remain on her pain. Rather, she knows it is there and what she needs to do to manage it so that she can focus on "doing something meaningful because I run a writing group that helps these writers and I am in the choir and kitchen band and this outreach program that helps other people. And I think it's meaningful that I have . . . one book published . . . a book on hypothermia". The value of "my writing helps me to feel I am doing something useful. Part of it is being useful to others, if they read it and get some good out of it or enjoy a poem because I've tried to give them a little solace when their husband died with a particular poem I've got". With this ability to focus on writing Lyn says, "I think I am doing something useful for myself by getting published. I have a feeling I've done something". It was these successes that assisted Lyn in keeping her focus off her pain.

Gordon described how he had not "given up looking for relief or solutions to the problem. I am still open to try various things if I think that it might be helpful". His eventual focus was such that he was "not sort of constantly thinking about how I could do things differently or what I might be able to get for relief or that sort of thing, that's not foremost on my mind anymore" but at one time it was more on his mind.

Janice spoke about how her focus changed and the connection this change had with acceptance of her pain. Janice:

When you're in pain it's hard to look past it or get on top of it . . . It seems to be blocking your vision into the future. . . . because you were constantly [asking yourself], how is this going to affect you? You're thinking 'I'm not going to be able to work. I can't even vacuum or things like that'. You're just constantly focusing on the negative instead of looking at what you can do. And I was constantly thinking, I can't do this, and I can't do that, instead of, I'm going to try and do this and see how it goes . . . And then I started making goals. And so now I have really clear and big goals.

Janice also talked about the relationship between acceptance and goals. Janice:

It's hard to say which one came first the acceptance or the goals. I think it was acceptance first and then I really just had to figure out what I wanted. I think I had to accept first that it was okay to have pain. . and it was okay to be somebody that has pain and could still go on and do something instead of just wallowing in the (laughter) poor me which is really easy to do . . . If you're not accepting the pain and you're spending all the energy fighting it you don't have any energy left to do anything else. You've got to have goals and plans . . . I've learned that if you use up all your energy fighting against it instead of accepting it, you're just going to be really sick and tired. I've just been so much more productive when I focus energy on accepting and moving forward instead of fighting the pain . . . I think the biggest thing is just to know you have to keep going forward cause if you're wasting all your time being angry and not accepting then you can't go forward.

Janice recognized having goals helped her to get unstuck from the past because “you're stuck in the past if you're not accepting your pain, and you're doing the what coulda been and what shoulda been and what would happen if? And the what ifs? Instead of this is what I'm going to do. This is what I can do. You're focused on the pain and the anger. You're focused on I can't do this, and I can't do that. And you're stuck in the negative”. Setting goals “helped me to look into the future and say ‘Okay, what do I want to do? And how can I go about doing it?’ Cause I think before that I never looked into the future. I was too much caught up in the pain. So once you accept where you're at with the pain, then you can go ‘Okay. What do I want to do?’ And I realized that I didn't want to just do nothing. I wanted to work and be contributing to society”. Having goals and accepting her pain enabled Janice to get “unstuck from the mire of the pain and the anger and looking to the future of what am I going to do? What am I going to do about it? How can I change what's happening right now? And with that you have to accept it and figure out how you can live with it instead of fighting against it”.

Resolution of Janice’s court case was a significant step. This enabled her to look forward and “then I could really start to accept what my life was and what I was going to do about it, what I could make out of myself, instead of just sitting there and being a victim . . . Because before that I couldn't really think ahead” or see the difficulty the case was creating because “when you're in it, at the time, you don't know what it's doing to you”.

Janice can now see the litigation process “didn't help [me] as far as accepting [my] chronic pain, because [I was] so focused, doing daily dairies of how bad the pain is and how it's interrupting your life and it's constantly in your face and so I ended up just settling, because I just couldn't handle it anymore”. Janice doesn't know if she would have listened to the advice of anybody or done anything different. She recalls someone telling her “people in the middle of litigation generally had worse symptoms and I remember them telling me I should try and get out of the court case so I would feel better. And I don't think that did anything. I didn't listen to them because I didn't see that it was [different] until after I had settled and then I wasn't focusing on it all the time and that made a big difference”. This difference was something Janice could not have known until her case settled.

The difficulty Tom was having moving forward with his life while in the midst of litigation was similar to Janice. The influence his court case was having on his ability to see his future was evident. When asked about a future he responded, “Have I decided on a life goal or life occupation or do I know where I am going in my life? Nope. . . . The only goal I have is to get out of under [insurance company] . . . You cannot plan, you cannot even think about having a future when you are going through what I am”. At the time of the interviews Tom was unable to contemplate any plans beyond the short term because “one thing this taught me is best laid plans can be changed quickly . . . So long term goals, no not at the moment. It's just survival”. Nevertheless, after talking awhile Tom hinted at a goal he had “before I got hurt, I wanted to be somebody I respected. It took me a long time to figure out who that person was. I'm hoping that it doesn't take me as long the second time around”.

Wilson also recognized the importance of having goals and a focus other than pain. He had heard people say “find a goal, strive for it, and succeeding in life is that goal.” But he also recognized his pain fits into his goal setting. He knows having a goal is positive “but have chronic pain to go with it and that goal is not achievable because your expectation is way too high. But if you bring the goal right down to almost being able to touch it and just keep that goal that high, and just keep making new ones at that level all the time, you don’t get ahead that far but you still exist and you have achieved slowly”. Wilson’s rationale for this type of goal setting was because he had “learned that no matter what you’re going to do, tomorrow is another day and in order to get to tomorrow, today’s goals need to be realistic”.

As Elizabeth came to accept her pain her focus changed to “finding out everything I can available for my son and I through government and agencies . . . to help us financially . . . There are things that are solely available for people with disabilities or people on low incomes that the government never tells you about . . . And I am finding out stuff that are really going to help me and [son], plus they are really going to help other people”. As her own situation improved, Elizabeth’s focus shifted to helping others. A project “I’ve got on the back burner is I’m going to compile all this information, phone numbers and addresses and web sites, and make copies of it, and deliver it to the food bank, shelters, children services, and all of these different places so when people are there, they can find this information”. This was an important and meaningful endeavor for Elizabeth because it was not available for her and her son when they needed it.

Adaptation to Limitations

Part of acceptance was recognition of and adapting to limitations. Participants described how they had adapted to their pain in order to continue living meaningful lives. Ginnie spoke about “changing my lifestyle. I started to do less walking, less standing”. She also wore “different shoes. There’s a change. I used to wear high heels all of the time and I used to go bare feet”. For Lyn adapting included typing using “two fingers, mostly my right index finger to push the keys. I am slow but then what you’re dreaming up in your head isn’t all that fast either”. She also doesn’t “entertain anymore unless I buy the meal”. Lyn also adapted by hiring help so she can continue to live independently. Sara and her husband discovered “new things to do together” because “the activities where we really enjoyed each other’s company, a lot of them we couldn’t do anymore”. This involved letting “go of a lot of judgment about what sort of things I consider to be quality time”. Allowing herself to sleep is one of the ways Elizabeth adapted. She learned “with the pain, if I have to sleep for two days, then I will and that means I don’t touch a computer, or I only answer the phone if I have to . . . If I have to do that, that’s what I do. I am not going to fight it. And it seems to be working”.

Adequate financial resources facilitated adaptation for Lyn, Sara, and Elyse by allowing them to pay someone for services such as house cleaning. Elyse’s attitude, more than her ability to pay, stood out as she described her adaptation to her pain. Elyse’s situation was such that compared to the other participants who had up to two incomes and two sets of benefits in their households, Elyse relied on only her income and workplace benefits. To manage her pain Elyse made adaptations such as hiring a cleaning person,

flying business class enabling her to lie down, and purchasing a vehicle with a suspension seat. Her attitude toward the expense of these adaptations, particularly the house keeping was that "I'd rather fork out 40 bucks and be able to go work tomorrow than do it myself and not be able to go to work. And then there's the pain and discomfort of knowing you've got to lie around for the next two days. That's not worth it". The pain resulting from doing tasks Elyse knows aggravates her pain "would annoy me more than having to pay someone to come in". Part of acceptance for Elyse was related to her acceptance of what she is able to do physically without causing her body to be in pain and the choices she makes in order to avoid doing specific tasks

The participants also spoke about adapting in general terms. Lyn described this as "you have to be willing to change your life and work at new pastimes so you aren't bored with life and possible living a solitary existence," while Wilson described his adaptation as learning "new ways of doing the same thing". One of the ways he changed was "I'm starting to think smarter instead of doing things differently and just controlling what I do is a big thing. But before I would push myself to do what I wanted to do instead of what I needed to do". These changes occurred "over the course of . . . the last ten years".

Another way participants adapted to their pain was restricting what they did for others. Janice "had to learn to say no to people and that's not easy". Wilson also learned to say no which gave him "some type of control of the event . . . and that's the hardest part in anybody's life" but it also enabled him to set limits with others. This is also Ginnie's approach. Ginnie:

Put myself first if necessary. And I never could have done that until last year. For me, limit what you do for other people. That's important. I used to do way too much for other people, and now I limit it. If somebody is coming over for supper, I don't have to cook supper. [Husband] can make supper. Or somebody can bring a potluck thing. We'll all pitch in. It's not like I have to be Martha Stewart just because people are coming for supper. That would make a big difference in how I feel the next day.

Ginnie and Sara, both teachers, described the ways they adapted to the demands of their profession. For Ginnie "the hard part, if I say I am giving them back tomorrow, I will just about kill myself to make that deadline so I try to say 'I'll try to hand them back tomorrow, we'll see how it goes.'" So I've changed the way I talk about what I will do for them". She also says, "I will try to come to your soccer game. I'm not sure if I'll make it' instead of 'yeah I'll be there.'" Sara came to "recognize that most days I can't offer them time after class to work on more things 'cause I'm just physically too tired, yet it's very easy for me to say, 'oh, sure, I'll just, just come and meet with me after school and I'll work with you.' . . . I have to respect those limits".

In addition to the adaptations made, participants described how they responded when they realized their need to adapt. Elyse realized "there are things I know I cannot do. As frustrating as it is, I know I can't do them so I just have to get a grip on that". Lyn realized that along with being "motivated" to host parties she "was delighted to have people here even if I did likely bite off more than I could chew. At least I had the sense to hire a lady to help me". Ginnie became aware she "had to change the way I looked at [the

adaptation]. I had to learn that just because I am not standing there waving my arms around [demonstrating while teaching] it doesn't mean the world will stop turning". And importantly, Ginnie realized "what I tell myself I need to do has changed". Elizabeth also spoke about changing her perspective on her adaptations. She sees "time completely different now. It doesn't matter what time it is. It's my body decides when it's going to sleep, and when it's going to be up". Ginnie also gave her impression of acceptance and adapting. Ginnie:

Adapting adaptation. I feel like everything I've done that has lead to my being able to accept the situation I'm in has to do with adapting my behaviour and other's. Adapting to other people and having other people adapt to me, adapting my own behaviour . . . I don't think a person would adapt if he or she didn't accept. You know what I mean? If you're not going to accept something then why would you adapt to it?

Relationship with Self

Along with the many other changes participants initiated and experienced through their journey, they also reflected on the changes they had noticed about themselves and changes in their relationship with the person most impacted by the pain and their acceptance of it — the self. Participants recognized they had been more demanding on themselves than others had been on them. Sara acknowledged "I know I am my own worst enemy and I'm much harder on myself than anyone else is". This is similar to Ginnie's who said "I have a tendency to think that nobody can quite do as good a job as I can. I know that is terrible to say but I do have a tendency to think that. I've been my own worst enemy in terms of taking sick leave". Wilson held a similar view about himself earlier in his journey but he no longer held this view. He recognized "I was my worst enemy in regards to just killing myself. And I was ruining my health". A contributing factor to this according to Wilson is "probably the biggest person that's in the way is yourself, 'cause you never, I don't think anyways, I don't think people intentionally want to do less. You always try to do more and I think you're the biggest stumbling block, the person themselves".

Ginnie described the changes she noticed in her own response in two particular situations from the time even before her pain started to today. Ginnie:

I am much kinder to myself [now]. I used to be so hard on myself. If I was sitting on my butt doing nothing there would be a little voice in the back of my head about all the things I should be doing. That piano bench is dusty. And now I can look at the dust and I really couldn't care less. Five years ago I would be up and over there and it wouldn't be dusty anymore. . . But look at me, I can see the dust and I am not anything about it. I can look at it. . . I berated myself to no end. I was really hard on myself. . . I can forgive myself. . . One of the biggest expectations I had the hardest time with for a long time, my husband is an [entertainer] . . . and for the first 25 years of our relationship I went to every single [performance]. That is an unbelievable accomplishment on my part . . . this coincided with the developing pain where the idea of getting off the couch and down to the [performance] . . . was just very close to impossible. . . That was probably the hardest thing I ever had to say, 'well no, I'm not coming to your [performance] tonight'. . . For a long time he was hurt and thought I didn't love him anymore because I didn't come . . . but 'no [husband] it's because my feet hurt'. . . Finally he got to the point where he doesn't bug me about it and doesn't necessarily expect it. He is pleasantly surprised if I come and if I don't come it's nothing for him to get upset about. That was one of the hardest ways for me to say no . . . and then to be able to live with myself.

Like Ginnie, Sara observed changes in herself. Initially, “my problem was I was judging myself with unrealistic criteria, and that was not helpful. . . . Nobody else is telling me that what I’m doing isn’t good enough, it’s my own personal belief I had”. Over time Sara started “being easier on myself and not judging myself so harshly . . . It’s the pressure I was putting on myself . . . so it’s been getting rid of that pressure, acknowledging it doesn’t need to be there, and it’s not helpful”. Sara speculated “had I continued I would have become very depressed, and lost all optimism for getting better and felt like I wasn’t good enough. I can see that happening”.

Sara also spoke about how she thought her identity had changed. Sara:

My identity was very much wrapped up in what I can accomplish, what I can be counted on for, and that’s something that’s I’m still learning to let go of. I still have a long ways to go but I’ve come a long ways. I’m a woman. Some words I would use are I am loving. I am caring. I am a sister. I am a daughter. I’m a wife. Ones that aren’t so dependent on what you do, just who you are They are not likely to change. I am a child of God. I am a Christian. I am a loving person and creative. I’m still that same person but my value isn’t because of the things that I can accomplish. It’s who I am . . . I’m Sara.

Sara went on to talk about the connection between denial, acceptance, and her relationship with herself. Sara:

Mostly [acceptance] means not being so hard on myself. Not judging myself because I’m not able to live the life that I used to live. And being okay with how I am right now. Okay in my own skin . . . I think my optimism is now I’m going to be able to handle whatever it is that comes my way, and that my life will be very different, but it will be as good, if not better. . . I’m still pretty unhappy with the limitations I have, and I don’t walk around with a smile on face all the time, and I’m not thankful for every day that I’ve got, but I’m much more thankful than I was. I had to go through a very dark spell in between the denial and the acceptance. . . I still deal with that, possibly daily where I’ll have my low moment and, (sigh) go through all the grieving, especially with some of those issues that are more difficult to accept . . . And the denial allowed me to keep judging myself so harshly, and, and the acceptance means that I’m not judging myself anymore.

Control: Some Giving and Some Taking

As the participants described acceptance it became evident the concept of control was important to them and for acceptance. For some participants it was giving away of control that was important, while for others it was taking of control that was important. Elizabeth described her locus of control before she embarked on the acceptance journey as “the pain sort of dictated what I was going to do rather than me”. But when she began to accept, the locus changed to “I’ve got to start taking control of things,” which she did. One of the ways she took control was by writing a letter to a woman’s shelter when she was in dire straits. “This was the type of letter, Audrey, that is so personal, and when you tell people your circumstances and they’re really not good . . . you expose yourself completely. . . . You feel like a loser because you’re telling these people how desperate you are”. Elizabeth received a phone call from the shelter “the next day and . . . it was a godsend . . . They just believed me and accepted me and said, ‘what can we do to help?’ . . . It just helped me get back on my feet right there to have someone believe in me”.

Elizabeth was grateful despite “the shame you feel because you’re not being a provider anymore”. Writing a letter was a step toward control for Elizabeth.

Gordon and Elyse, like Elizabeth, acknowledged that while their condition was out of their control how they responded to the pain and the intensity of pain was in their control. As Gordon indicated, “I just don’t let it bother me too much” and “I don’t let it stop me”. Similarly, Elyse said “I think it’s got to be something to do with the way you let [the pain] impact, whether you allow it to control you rather than you control it . . . It’s some sort of mind set where you just think ‘okay this is going to be around for a very long time, what do I want to do about it?’ Or how do I get control over it rather than it over me”? She extended this control to working and remaining active, saying, “you are in control of whether you [contribute and keep going] or not, it’s a choice you make. And it is control. You do have control over everything you do. You can choose to do it or you can choose not to do it”. The connection between acceptance and control for Elyse was “acceptance would be I don’t let it control me”.

Similarly, Wilson believed he could control his pain through his choices. Wilson:

You bet I can [control the amount of pain]. It’s just like anything else, you push yourself to the limit, and you know you’re going to hurt, so you stay away from the end of the limit and just get into it a little bit. You don’t want to stop life . . . but sometimes you have to slow it down in regards to what you can and can’t do . . . It’s no fun. I’d rather be just like every other dad, just do what you want to do, and how you want to do it, but I can’t. I’ve got to limit what I’m able to do . . . And you at least become somewhat in control of your life instead of the pain. Cause it’s not going away so you’ve got to learn what to do and how to do it.

Taking control was evident for Janice in the choices she made to move forward in her career and life. After her court case ended, Janice felt able to move ahead in several ways including earning her professional registration back, returning to employment, and having another baby. Janice and her family’s financial situation settled as far as her back pain was considered until she discovered the lump in her leg. Due to the treatment for her leg Janice was off work and on “long term disability from my job in [city] and it had been two years and they were about to cut me off . . . They said I should be able to get a job. They agreed I probably wouldn’t be able to get a job in [profession] with [out a degree] and I would just have to get a job doing something else”. Janice suggested the disability plan pay for her to return to school to complete a degree, which would enable her to get a desk job within her profession. The response was “no. They wouldn’t do that”. Janice decided to return to school at her own expense. At the time of the interviews Janice was completing the final course for her degree.

Gordon, Lyn, and Bea were all retired and each was receiving a pension. And although each had expenses related to their condition, they spoke about their chronic pain and related circumstances including their financial situation with a confidence, perhaps a sense of control not observed in the participants of working age, particularly, participants whose income was on shaky ground due to the pain. For instance, although he was finding paying for the additional expenses associated with his condition a challenge, Gordon was able to pay for these and his day to day expenses out of his pension. Gordon had medical coverage through a group medical plan “but they only cover \$250 a year for massage and so the rest of it is

coming out of my pocket". His perspective on paying for these treatments was it was "a bit of a concern because it is expensive and I don't have very much coverage . . . But I look at it this way if I find something that will give me some relief and improve the quality of my life then I am willing to spend money to do that because we quite often spend money on other foolish things".

Bea's calm and confidence despite her pain might have been in part because she was in the final stages of her litigation due to her fall on an ice covered sidewalk. She "talked to my lawyer just last week and he said . . . nothing is left now that has to be done . . . So it's just up to them now to cut the cheque. . . . They know they have to pay. They know it was negligence on their part". She "sued because . . . the caretaker was negligent" for not maintaining the building which lead to her slip. As a result of her fall and resulting pain Bea's "medication bills had been around anywhere from \$150 to \$200 a month. And I only get a widows pension so it has been very, very difficult to make ends meet". Bea received her cheque a few days after the final interview. She planned to use some of the money to pay the bills she had been struggling to pay and to renovate the home she now lived in with her children. She was also contemplating travel. Despite the expenses related to their pain, neither Bea's, Gordon's, or Lyn's income was at risk and in this sense each were able to live with a sense of security and control of their lives.

A sense of lack of control was paramount for Tom who felt that due to his ongoing court case he had "no control over my life; it is being controlled for me and it's not a position that I appreciate being in". Part of this control as Tom experienced it was attending numerous hearings over several years for reasons he did not understand and "you don't know when they are going to drag you back in. You don't know what they are going to say to you. All you know is that you've got to through it again and again and again and again and there seems like there is no end". Further, Tom did not believe he had any control regarding when his case would end. But when talking about his pain and his ability to manage it he acknowledged that he has some control over the intensity by doing "everything from sleeping as much as possible whenever possible to not doing anything, popping the few pain killers that I am allowed, or will allow myself".

In contrast to Tom who was upset with his inability to control his life and situation, Sara's and Bea's acknowledgement of their lack of control and their willingness to give it to God was helpful. Bea's situation was such that "I know I never could've got through it without God's help. I know I couldn't have cause there was times a person just thinks about ending it all . . . But it never entered my mind to do anything because I knew that God was in control and he would work things out somehow which he did". Similarly, Sara recognized "this isn't anything I can control, this is beyond my control. I can't change the outcome so I have to let go of that . . . Just giving that to my higher power and letting go of it, giving it to God and just trusting that whatever happens will be for the best". The giving up of control was accompanied by uncertainty for Sara. She doesn't "know where it is going to go yet" but "I don't have to have the answers right now. I don't need to know how it's all going to turn out. I just need to worry about

today. That's a big part of acceptance is trying to not control the future, acknowledging that it's just not in my control. That whatever happens we will deal with".

As Sara indicated, acceptance entailed trying not to control her future which Gordon and Elyse also talked about. For Gordon "acceptance for me I think is that fact that I can't really change too much of the way that things are. So I have to accept it. I have to move on". And for Elyse "acceptance would be I don't let it control me".

Finally, in speaking about the connection between control and acceptance Ginnie thought "frame of mind is extremely important [to acceptance]. Having some kind of feeling like you've got control over what can happen". In her pain and work situations she stated, "I would like to be in control of my own destiny. If I feel I need to [take time off] I will but don't you tell me what to do". Having "control over what happens is really important to me. That would be horrible if I felt like I couldn't choose between working and not working . . . I am in a very cushy position where I can go either way. It's entirely up to me . . . and that helps me deal with it".

Values and Priorities Re-examined

The participants' descriptions of acceptance included evaluation of, and sometimes changing of long held beliefs, values, and priorities. Wilson talked about his desire to provide for his family, the difficulty in keeping up with the Joneses, and ultimately his decision to live a meaningful life with pain.

Wilson:

A root of the problem had nothing to do with the [pain] . . . It was the family wanting and there was me wanting to give, and sacrificing, and then in the end I still had to sacrifice everything. . . . You want to be like the Joneses . . . You make do with what you have and what you need is nothing. Material things are very low because I had them all. I had the fast boats, the snowmobiles. I had the cars. I had everything but it sure didn't make my life happy. But it made me work my ass off to get it. But you give it up for a meaningful life. I think, anyways. That was my decision. I had to do it for me. I still wish I had all those toys. See I don't keep up with the Joneses anymore. . . I wish them luck. Their \$400,000 house, their brand new cars, and the payments coming out, and they don't have anything after the fact. . . But it's a choosing. You have to be able to want to do that and give up a lot of personal stuff. . . Everybody wants to make a good living, and have all the toys, and give to their family . . . You don't want them to have what you had which was less. You always want them to have more . . . I've accepted the fact that I don't need that brand new car. I want it, but I've accepted the fact that I don't need it. So there's a big difference. . . . Keeping up with the Joneses I think is the hardest thing in life.

Ginnie and Sara talked about how values and ways of being from their family of origin influenced their pain. They discussed what they did to change these influences while on the acceptance journey.

Ginnie realized "my mother would say 'if you can't say something nice don't say anything at all,' so I just don't and then they're surprised that my feet hurt . . . It's one of the toughest things . . . It sounds really silly but it is hard". This difficulty extended to making medical appointments. Ginnie said "I really have to work hard on that. It is *okay* to . . . go see my doctor if they're not getting better. I have to *really* work hard on that. It does not come naturally at all because I was not brought up that way". The desire to keep her pain to herself affected Ginnie's relationship with her husband before acceptance. Before acceptance "I

would have said there was no problem, I wouldn't complain and I wouldn't have even told [husband] that I was in pain. I would have just kept it to myself, because you know, that's part of my upbringing, keep a stiff upper lip, don't complain. . . . Everybody's got problems and we don't need to hear about yours (Laugh) . . . That's just what I grew up with".

The influence of family values also impacted Ginnie's decision to continue working through her pain rather than take time off from work. For Ginnie, taking time off went "against my nature . . . That would be the toughest thing for me, way harder than to accept my pain, accepting that this is what I have to do for the next six months . . . The work ethic . . . Cause you know I grew up in a very diligent family. You know work, work, work, and always do your best and there is never any excuse for not trying. All that stuff". However, as Ginnie mentioned previously, in addition to adhering to family values, her choice to take time off work or not, was a decision that was in her control.

Sara also recognized the influence of family of origin values on her pain and acceptance. Like Ginnie, communicating pain for Sara was difficult "especially with my immediate family with my father and my step-mother who are huge runners." The difficulty was also because "so much of their lives is dependant on what you're physically capable of achieving" so talking "was really hard and I had always left my pain out of our conversations because I was brought up not to complain so I wasn't going to talk to them about all the stuff I couldn't do".

Sara's challenge with acceptance was also influenced by her "family background . . . The communication in my family was never good enough that I was able to talk to them about how frustrated I was with my injury . . . And they weren't able to guide me in any direction that would have helped either. If anything the high family values are what kept me in denial because everyone in my family, we all have the same high work ethic, and, and put our value into what we accomplish as opposed to who we are". As Sara's journey toward acceptance unfolded she made changes in family patterns. She recognized "it has been a big change, and I still find it difficult to talk to some people in my family as candidly as I can my friends". Over time Sara made gains and was now able to talk to her family. With communication Sara realized "being more honest with them helped".

Similar to Wilson, Ginnie, and Sara, Janice also had a strong work ethic and desire to provide for her family. This often lead to increased pain as she strived to do all she believed was expected of her and what she expected of herself. Janice talked about what helped her in re-evaluating her priorities. Janice:

I have a [relative] who was diagnosed with MS and she helped me a lot in learning that sometimes you just have to make lists and you have to just do the top three. And make sure the top one is to be nice to your family. She taught me a lot about that and to say it's okay that you don't have to be that supermom; you don't have to get everything done all at once, because then you're no good to anybody afterwards. Cause . . . sure you push yourself and you do everything that you wanted to do in the day, but then the evenings you can't even lift your hands to wave at your family then what good is that? And she really taught me that . . . And I think that's a really hard thing for a woman to do 'cause you have so much coming at you. You need to do these things for your children, for work, for your husband, and . . . you feel that you're pulled in so many different directions. But if you don't take time for you then you're not good to anybody 'cause then I'm stuck

flat out not being able to do anything because of the pain and that doesn't help anybody. But we run on guilt, as women . . . You have to keep the priorities straight.

Elizabeth also re-evaluated her priorities during acceptance. Today "I'm still boiling water in a pot [not a kettle], and I don't care" which indicates what is important in Elizabeth's life. And, as an outcome of acceptance Elizabeth stated "accepting the pain has helped me to accept so many other things and make me realize the smaller things are so small".

Summary

The journey toward acceptance was an eventful time for the participants who were presented with numerous choices and opportunities for change. Choices and changes identified as important to acceptance were learning from professional sources and personal experiences, change of focus, adaptation to limitations, relationship with the self, and reevaluations of priorities, values and beliefs. Participants identified availability of choice as critical. The role of personal responsibility and control were revealed as important.

Acquiring knowledge and learning from a medical perspective as well as from personal experiences was important. Learning from a medical perspective provided information about the condition including a diagnosis, which activities to do and which ones to avoid, the intensity of pain to anticipate, and how long the pain might last. The information ruled out more serious conditions which reduced worry. Most information was helpful however an explanation about the physiology of chronic pain was received by one participant as dismissive. Becoming familiar with the pain over time and from trial and error was beneficial. Participants learned their pain was not life threatening, although it might feel that way.

Choices made included taking responsibility. This meant owning the pain and taking action to deal with it rather than waiting for a cure or relying on others. Some participants believed giving responsibility facilitated acceptance. Regardless of taking or giving, action involved doing prescribed exercises and other physical activity, and taking charge of one's health. One participant's philosophy on the difficulty of taking responsibility entailed a person shifting responsibility of a problem to someone else to solve. Another wondered if avoiding responsibility had more to do with sustaining an excuse for not completing tasks.

Participants held a range of thoughts and beliefs about choice. Some thought they had choice, some thought they didn't, and still others held both views. Some talked about available choices including choosing to accept while others were adamant they had no choice but to accept. Others believed they did not have choice about having pain but they had choice in how to manage it. Some recognized that in the past they weren't always aware of choice but with acceptance the choices available become evident. Other participants did not recognize their choices particularly in areas related to accessing treatment and finances. Those who believed choice was unavailable or who did not recognize available choices felt trapped and powerless. Use of 'have to' and 'can't' suggest this lack of awareness of choice. Multiple perspectives about the awareness of and making choices contributed to acceptance.

As they came to accept participants found it possible to change their focus and to adapt to it. With acceptance participants changed their focus away from the pain and its effects to a focus on the future, including having goals and dreams, setting goals, and helping family and others. They also recognized and adapted to limitations. Participants described specific changes they had made to adapt including changing lifestyle, participating in different activities, buying meals, limiting amount done for others, and increasing rest. They also described the importance of a willingness to adapt in order to make these changes. Financial resources and limitations influenced the ways a participant could adapt. With acceptance came an increased awareness of their response to and thoughts toward the need for adaptations enabling each to take action toward adaptation. Finally, one participant thought adaptation and acceptance went together as adaptation evolved from acceptance.

Participants described changes in how they viewed and related to themselves internally. Many acknowledged they had been harder on themselves than others had been. Through acceptance they became more accepting of themselves including being kinder and less judgmental about their limitations and preferences.

The concept of control emerged as important. For some, it involved taking control of how they responded to pain. This included being physically active and selecting appropriate activities to control pain intensity. Others relinquished control to God or a higher power. Participants who were retired alluded to an aspect of control not seen in the working age participants and whose career and income were vulnerable due to pain. Having control over particular aspects of pain management such as the choice to take time off work or selecting treatments emerged as an important aspect of acceptance.

Finally, change relating to values, beliefs, and priorities was identified. Acceptance and a reevaluation of the importance of material possessions were integrally related for some participants resulting in the decision to sustain and nurture relationships rather than pursue possessions. Family of origin beliefs about communication and work ethic were ultimately challenged and changed enabling participants to speak openly about their pain and to make important decisions about continuing to work. Overall, the choice to make changes in values assisted the participants in living meaningfully with pain.

Theme 5: Where the Journey has Lead . . . So Far

The theme, Where the Journey has Lead . . . So Far, naturally evolved through participants' descriptions of their lives with pain and their current experience with acceptance. They commented on the stability of acceptance given their current pain and acceptance. They also offered a prediction on their level of acceptance if their pain intensity were to increase. Hope and fear felt for the future were discussed. And while the challenges of having pain continued in varying degrees, many unexpected outcomes of acceptance were noted. Some outcomes were beneficial yet unintended, such as managing the unknown and personal growth. Other outcomes described were living a meaningful life, living with chronic pain, and a generally positive outcome to their difficult journey, which now included participation in this study.

Stability of Acceptance

Participants commented on the stability of acceptance. Janice thought her acceptance was stable even in times when her pain increases when “it increases my frustration, but it doesn't change the acceptance”. This was similar to Lyn, although Lyn noted that as her condition changed “the type and severity of pains change around and get accepted”. For Lyn, having a specific pain long enough allows it to “become old hat. [Different pains] are just accepted”.

Elizabeth on the other hand said “the intensity of the pain does make a difference on how much I can accept”. For Elizabeth this means she “can tolerate the pain quite well but then I have to tone down everything else, and it comes to a point where I've got to dim the lights and be quiet”. She gets “ultra sensitive to everything. I can still cope though, and I can still be pleasant, but I'm not very approachable, and I really don't feel like being too social or anything like that”.

At the time of the interview's Gordon's pain was stable and well managed which enabled him to accept it. Gordon thought, “it may not be that way if the pain got to the point where I wasn't able to live with that level of pain then my acceptance might be a little bit down”. Further “I think if the pain were to change, to be more severe, then I probably wouldn't be so accepting of it. I would be probably working harder to try to find ways in which I could lessen the pain”.

Ginnie held a similar view about her present pain level, her ability to manage it, and her acceptance. Like Gordon, she was concerned that her pain intensity might increase and how her acceptance might change if this happened. Ginnie:

This is a very scary thought, what if it actually gets worse? So far with the treatments I've tried it sort of stayed about the same. But if I don't continue trying to do things . . . will it get worse? And that's a horrible thing to think of. I'm not sure if I could deal with that. I mean if I couldn't stand up without crying what's the point of that. I can't imagine that. So sometimes I think I'm just wimpy. (Sigh) Maybe it's just not painful enough. Like if it was more painful I'd have more trouble accepting it. So maybe it's the degree of pain.

Looking to the Future: The Hope and the Fear

Along with acceptance of the present with pain, participants looked to their futures with hope and sometimes fear. Bea was “hoping that as time goes on it will keep getting better because I sure don't want to live on pain medication for the rest of my life”. And given the difficulty of the past few years, Bea also “[hoped] I can have some good times and not be feeling too much pain, so that's something I am going to venture out and try to do”. While Bea's hope was for improvement, Gordon “just assumed it is not going to get better but I will have to just try to hopefully keep it from getting worse and that is why massage seems to be the one”.

Like Bea, Lyn expressed hope her situation would “get better”. Lyn described the direction of her hope. Lyn:

I believe part of the reason I accepted the illness in the beginning was because it was rare and no one knew if it could be cured . . . I always had hope. Even though things haven't improved, I still have the hope that I will finish my novel, find acceptance as a writer and enjoy many more years

because what the doctors have achieved is buying me time to have more future with or without pain. The pain doesn't figure in the equation of hope.

And like Lyn, Tom held hope for areas of his life other than his pain. He said "will the problems that I personally have in my life change once I am done with the legal system? I don't know. Do I hope so? Yes".

Ginnie's "hope for the future" was sustained because of her belief "there is always possibilities. I keep telling myself that". Ginnie held hope her Roling treatments would succeed because the therapist "said it will, and I believe her. And then maybe . . . it will be over. And that helps me accept it". Hope "that at some point in my life this might not be an issue anymore helps me accept that it's an issue right now".

Ginnie went on to explain the importance of hope in relation to acceptance. She had "proven to myself . . . that I can continue to teach and pay bills and be in a profession that I love to be in and deal with the pain". However, when she looked to the future Ginnie "can't see dealing with this for the rest of my life. That, I have a hard time accepting. I mean I've accepted it for now, temporarily. I am just assuming that one day I will figure out a way I won't have to accept it but for now I have to". Ginnie doesn't think she has a "choice but to accept it and not to give up hope". For Ginnie, acceptance and hope are inseparable.

Sara also spoke about acceptance of her present pain while maintaining hope healing will happen in the future. She acknowledged, "I'm trying really hard to stay hopeful about the fact that I am going to be healed". But "it's such a fine line between when is being hopeful and you're waiting to be healed so you can get your life back. And at what point is it giving up when you accept it? I'm trying to stay hopeful while I'm trying to accept that this is where I'm at". The role of hope to Sara is "if you don't have hope I don't know how you'd make it through any of this". Sara recognized the importance of feeling "optimistic and hopeful about the future but even if the situation doesn't change I need to be okay with myself the way I am". She predicted that "what will happen is that I will become better at managing it and better at being content with what I can do, and so in that way my life will improve but it won't be because I am doing more. It will be because I am happier with what I am able to do".

Along with looking to the future with hope and optimism, participants expressed fear. Lyn's fear was "that there is no backup treatment. I have come to the end of the road with treatments". Sara's fear was for her future. She was "really worried about [the future]...and I'm so young, it doesn't make sense that I would be this disabled at such an early age. And if I'm like this at [20's] what am I going to be like when I am 59 or 89? Am I going to have any quality of life then or am I going to be so sick and miserable that I can't do anything? I sure hope that's not the case So I find that pretty scary".

Ginnie's fear was "what if it actually gets worse. I mean so far with the treatments that I've tried it sort of stayed about the same. But if I don't continue trying to do things for my pain will it get worse? And that's a horrible thing to think of". Ginnie also worried about her mental health if she took time off work which lead her to decide she was "definitely not going to take time off work because (pause) I value my

work too much and I'm kind of scared of what that would do to me mentally. I wouldn't know what to do with myself". At the time of the interviews Ginnie was working full time and had no plan to be off work.

Managing the Unknown

The journey of pain and acceptance seemed to be also a journey with the unknown and uncertainty. This was a journey the participants hadn't anticipated but rather lived day to day. Many described the disappointment, despair, and anger they felt when they realized the medical treatment they had received was not as effective or as certain as they had believed it would be. But, as they came to accept their pain, unexpected outcomes were the ability to, and a sense of calm in managing the unknown aspect of their pain and the uncertainty of the future. Tom voiced a calm confidence while describing the uncertainty of his future with pain. Tom acknowledged "I don't know if I really understand acceptance yet. Have I accepted that I am going to have pain? Yes. Have I accepted that I will no longer get any better? No". However, he also knew "that there is going to be pain in my future. How well I will be able to deal with that pain? Well nobody knows what's in the future".

Gordon has also come to accept "the fact that I am going to have to probably deal with it from day to day, night to night" but does not know this for certain. He "realized that it can happen to anyone. It's not something that you necessarily would have any control over".

Sara spoke about the uncertainty in her life and the role of acceptance and faith. Sara:

There's a lot more things in life I'm less certain about now. Cause before . . . everything seemed to be very certain and there was a definite answer about everything. I'm recognizing that as far as science goes we know a little bit but we don't know it all . . . I think that's where my faith has helped me because as long as I have my faith I can deal with the uncertainty and always hope. If I didn't have my faith that uncertainty would just seem like a (pause) prison sentence . . . It's not the way I would like things to continue forever but for right now its fine, and if right now turns into forever, well, that will be fine too.

Personal Growth

Another unexpended outcome of acceptance participants described related to their personal growth particularly self esteem and self confidence. Elizabeth acknowledged acceptance was "just the biggest boost for my self esteem, Audrey. And it was really, really low". Elizabeth able learned about herself and her value. Elizabeth:

I feel . . . everything we feel about ourselves is from within. To strengthen and to know yourself and realize your potential. There's pretty well nothing you can't achieve and I guess nurturing that little person inside, or whatever it is, that keeps us motivated, and passionate, and loving, and all those things and realizing that it's there, that it's not in the hands of anyone else. It's mine and it's my choosing. And that's great! I like to be able to choose . . . I kind of figured back then that what's happening with me now, if that's all that I've got, that's all that I deserve, if in fact I don't deserve anything because I should be working. And now I don't feel that way. I contribute as much as I can. I don't feel guilty anymore . . . I've realized my value again, more than I ever have . . . I'm realizing how valuable a life is, and my life . . . recognizing a lot of the good things that I've done in my life, and that I'm going to continue to do, and just be happy.

Like Elizabeth, Janice experienced an increase in her self esteem. One way she knows is “because I can talk about the pain and where I was before. And that makes me feel good to know that I’ve gone past that point. I’m a different person than I was then because I didn’t like myself very much then, when I was so angry”. Another part of Janice’s self esteem and confidence came with achieving her goals even though “at first I just told people ‘I’m going back to get my degree’ . . . I had a lot of people being very negative . . . but I did it. So I think every time I do something it’s a little personal victory for me and it just feeds into my self esteem and helps me say ‘Okay! I’m ready for the next challenge, let’s go’ ”. Janice sees “a big part of my self-esteem was gone, and I was able to get that back. And it didn’t matter whether I had chronic pain”.

Tom spoke about the changes in how he perceived himself and others particularly in the year prior to the interviews. He spoke about the “people I’ve met in the last year or so. Allowing myself to see that there are good people out there you’ve just got to find them and that I might be one of them”. And even though he continues to experience the difficulties of the court case and people telling him “that I am a low life, a liar or whatever they want. I know better. I came here [to this research interview]. I’m slowly becoming the person that I was before I got hurt”.

Sara was also able to look inside for value. She identified “my value isn’t wrapped up in what I accomplish anymore. Thank goodness! (Laugh) I would be very miserable if I was still holding onto that”. Sara also developed a trust in herself regarding her pain experience. In the past “I certainly doubted [the pain] a lot more. I would second guess it, and I was always looking outside of me to other people to validate and to tell me that what I was feeling was okay, and my experience was correct . . . I still need that to a certain point . . . but I’m not nearly as dependent on it now . . . whereas before I didn’t feel like I could feel good about where I was at unless I had that validation coming from an outside source”. Trust in herself came from “knowing that I know the truth about [the pain] and I’m the one that’s living it, so I know what it is that I feel and what I need, and to not be so concerned about others”.

Sara also developed confidence, which evolved out of her optimism. Sara acknowledged, “I’m going to be able to handle whatever it is that comes my way, and my life will be as good as it was if not better”. This doesn’t mean that everything was all rosy for Sara who was “still pretty unhappy with the limitations I have, and I don’t walk around with a smile on face all the time, and I’m not thankful for every day that I’ve got, but I’m much more thankful than I was”. She realized “I had to go through a very dark spell in between denial and acceptance . . . The denial allowed me to keep judging myself harshly and the acceptance means I’m not judging myself anymore”. Sara can see “I’m more resilient than I thought I was to make it through all this”.

Elizabeth developed self confidence in her personal life as well as her ability to manage her pain. She spoke about a “doozie of a migraine a few days ago, just a killer but I know it’s going to be over eventually . . . I can ride through it and be okay”. She developed confidence to handle “challenges, and I know we could get through them, and I could see how to get through all of them”. With acceptance

Elizabeth “got my confidence back . . . I have a whole different outlook now. It’s like what have you got to lose. I don’t have those fears or worries or anything like that anymore. I’m not afraid to speak up. With diplomacy and respect I’m not afraid to say, ‘hey this isn’t right and it’s got to be fixed’ ”. [Acceptance] has just done so much for me”.

Ginnie and Tom expressed confidence when they talked about their pain. Ginnie is “quite sure it’s manageable”. And the evidence she has to support that is she has “proven to myself . . . because I’ve managed to do it”. Tom also spoke about changes in his confidence. His “confidence in myself and my abilities, my ability to just drag myself out of bed and out of my apartment has changed and improved”.

The beginning of Janice’s increasing confidence and her ability to manage pain began when “I decided to have another child . . . I was on absolutely no medication for that time, up to the pregnancy to show myself I didn’t need to be on any medication, I could manage my pain”. Her confidence continued to get “stronger [by] making my goals and . . . I know I’ve survived things and I know I can handle it”. Janice’s confidence continued to blossom and “it was probably about two years ago I finally said ‘I want to go to medical school’ and then I looked into what I needed to do to do that”. This is the goal Janice is pursuing.

Living a Meaningful Life

Living a meaningful life was another outcome of acceptance participants described. Participants, like Bea, were able to resume activities that contributed to their meaningful life prior to chronic pain. For others, living a meaningful life with pain necessitated changing pursuits. Bea recognized “you have to go on living. There [are] things I like to do. I like to play cards. I like to play bingo. I like to do things with the church”. And over time she started “getting out more. Now I can take in a bingo once in awhile, dab with my left hand (laughs) at least it’s some place to go other than church”. Bea recognized the efforts she made in order to return to previously enjoyed activities in “now I can play cards. . . . For the whole year I couldn’t go to the crib tournaments because I couldn’t deal the cards but now with just with my thumb and one finger . . . I’ve learnt to deal the cards. . . I can’t hold them in my right hand. I have to use my left but at least I can play cards again”.

To Elyse living a meaningful life included being “willing to get out there and give it a go and at the end of the day go, ‘oh geez I had such fun but my back’s killing me now’ . . . And now let’s take care of it. Let’s give it a rest. It’s having its moment now but it was worth it”. This approach enabled her to participate in activities she had enjoyed prior to her back injury as well as new activities. Elizabeth recognized the difference between the present and when she was sick. Presently “I feel useful, too, and that’s important. I wasn’t useful before when I was really sick”. Previously Elizabeth described finding resources for individuals with disabilities contributed to her living a meaningful life.

Living a meaningful life for Janice involved functioning in and contributing to society.

Janice:

I think the big thing to know . . . I'm still functioning in society. I'm still helping. I'm still making a difference even though I have the pain. I think the biggest part of what I missed when I wasn't a [health care professional], even though I was a mom, and I was taking care of my [baby], it wasn't the same. It was really hard when I lost my [professional] registration because . . . you meet somebody and they say 'Oh, and what do you do?' And I had a really hard time being a stay at home mom. And I just think it was a big part of my self esteem when I lost my registration . . . and I was able to get that back. And it didn't matter whether I had chronic pain. I could still do my job . . . When I wasn't accepting my pain I don't think I was a very good person to be around . . . I am happier now than I was then. Because I am feeling like I am contributing to the world instead of just being a burden to everybody around me.

Lyn participated in many activities that contributed to her meaningful life. Lyn is "doing something meaningful because I run a writing group that helps these writers and I am in the choir and kitchen band and this outreach program that helps other people . . . I always said I would be happy if I got one book published, well I did—a book on hypothermia". And like Elizabeth, for Lyn feeling useful also contributed to a meaningful life. Lyn thought "my writing helps me to feel I am doing something useful. You know part of it is being useful to others, if they read it and get some good out of it or enjoy a poem. . . I think I am doing something useful for myself by getting published. I have a feeling that I've done something". In addition to her writing Lyn's life was made meaningful by "doing something for the residents of the lodges and nursing homes when we go out to perform". All of this in addition to Lyn's other activities and important relationships "helps my life feel meaningful".

Despite the burden of his ongoing litigation, at the time of the interviews Tom's life was made meaningful by "the work that I've done around here has given me a feeling in here (gestured to heart)". In addition to helping children and the "people that go through the door of the gym that make me feel useful", participating in this study contributed to Tom's meaningful life. Tom believed "if something I can say can change another person's rehabilitation in the future that I might never ever meet, something that I say can help them, without me knowing about it, still makes me feel good. To know if there is a possibility of something I say can help somebody stay off some of the pills that I was on, so much the better".

The Outcome: Living with the Pain

Participants described in a general sense where their pain and acceptance journeys have lead. Lyn acknowledged she does not struggle with her condition because "if I fought my condition and my pain and sat around and moped, and said 'I can't do it anymore.' If I gave into it . . . rather than fighting it I would be unhappy. I don't fight I just ignore it. I just tell myself it isn't important and people are worse". As far as her overall situation Lyn felt "pampered. I don't think I cried until about two years after [husband] died It was the pampering of home help and handibus that gave me solace. Anyway those are the two reasons why I think I am lucky. Perhaps my family and friends are closer because of my condition and I've always said the people around you who care is one of the greatest gifts".

At the time of the interviews Elizabeth recognized her life likely would have been very different if not for her condition and said she was, “thankful, I’m so thankful that I’ve come to this point in my life now, and its not five years from now, although I wouldn’t be around five years from now if I still felt the same way”. Elizabeth realized she started “looking for things to help myself, and I can see how much it can help others, and I’m really enjoying doing [participating in this study], and I love people, and it’s just all working for me. And I wouldn’t have been able to do it I hadn’t had this illness, and hadn’t experienced the pain that I felt”.

Janice was philosophical describing the changes she experienced. She thinks “life just changes how you think about things and how you approach things, so it’s really hard to say how much pain has changed that, because pain has made me who I am and without the chronic pain experience I’ve had I wouldn’t be the same person”. She acknowledged, “it hasn’t all been bad (laugh). I’ve had really good things happen to me too. But sometimes it’s hard to see them, and I think that’s a really important part of being able to look at things, all the good things that have happened”. Some of these good things in Janice’s life included being “married to a really wonderful guy and I have two wonderful kids and I live in a nice house and I have a great job right now and I’ve got lots of good friends and I guess just going through what I’m going through, you just have to try and find the positives and look at things that have happened”. Speaking about the challenge of her pain and acceptance Janice believed “a lot of it sort of centres around the belief that God’s not going to put me through anything I can’t handle” but Janice also recognized her role because “it’s more to do with that I try to look on the positive side of discovering who I am and what I can do and to just to look at it that I’m a better person”.

The outcome of accepting for Elyse surfaced through how she approached participating in activities she wanted to do. For Elyse “acceptance has probably had a positive impact in my life not only in terms of control but also not boxing myself into total restriction on activities I could and would like to try”. Acceptance “has probably taught me to think first before acting—always a good virtue to have in every aspect of life. Or if I stumble on that one and get a bit impulsive then I must expect the consequences”.

Sara reflected on the outcome of her pain and acceptance. She thinks “this injury has been a huge catalyst for positive change in lots of ways” and “so much positive has come out of this already”. Sara’s “sense of faith has increased since then. I am much more spiritual now than I was before I injured myself . . . My relationship with God is much stronger”. Sara’s “view of the world is quite a bit wider now. (Laugh) I’m not wearing near the blinders I used to, and I’m not judging everyone according to my standards”. More specifically, “I’m shocked at how self centred and self righteous I was before . . . I’m really glad I’m not stuck in those same thought patterns that I was in before. I’ve noticed that it’s helped me with my students. I’m a lot more tolerant of kids when things aren’t going well”. Sara predicted that without her pain and acceptance “if anything I would have gotten even more and more set in my very structured, high level functioning, ‘my way is the right way and the only right way’ thinking. I think I would have been less tolerant and more judgmental of others”. Overall Sara noticed she was “much more sympathetic and

empathetic and aware of what's going on around me, and compassionate, and more gentle . . . So I'm thankful for those changes. . . . Thankful I've grown as a person. I'm still not thankful for my injury, but I think that will come, too".

Participants discovered and developed ways to manage pain and to live with it. Sara was "still dealing with pain on a daily basis but I'm learning to manage it better". The prediction from Gordon's specialist was that "it's something that you are going to have to learn to live with". At the time of the interviews Gordon had "had [the pain] long enough now that I have sort of learned to live with it and I have sort of accepted that that's the way things are". Bea also realized that "it is just something that I am going to have to live with . . . I've realized that for the last over a year now. I've realized that my arm is never going to be right and that not only is there my arm but there is also the osteoarthritis. I have that in my hips and my back". With the realization that the pain is likely to persist Bea also concluded she will "just have to live with it" and she will "survive in the best way that you can". With this Bea said, "whoever bragged about the golden years was nuts (laugh) . . . you have hopes and dreams. I wanted to just retire and have some quality of life and it doesn't seem like that's going to be anything like that in the near future. We will just have to wait to see what happens I guess. Just trust in the good Lord above".

Janice succinctly summarized the significance of acceptance. For Janice "until you accept, it's never okay".

Impact of Participating in This Study

Participants were asked their thoughts about participating in this study, which has now become part of their acceptance experience. Tom said "to tell you the truth, can't really say I've learned, or realized a whole lot. You said there was some of the stuff that I've said has helped you understand my pain, where it's coming from. For me, I am still in the fight of my life". The fight that Tom was referring to was, of course, his ongoing litigation which was a sequelae of the motor vehicle accident which marked the beginning of his pain and acceptance experiences.

Like Tom, Lyn described an outcome from talking to me about her experience not shared by the others. Lyn commented, "because I have been analyzing myself for pain to answer your questions and that I have paid more attention to when my pain happens and what it's like I feel that I have experienced more pain". Lyn brought this to my attention as a way to raise a point about acceptance of pain that being "maybe mind over matter can be a very strong cultivated force [in the acceptance of pain]". Regardless of why the pain increased Lyn's plan was "to forge ahead with or without pain, so it had better climb back into the background".

Lyn summarized what she has gained from talking about acceptance. Lyn:

This self-analysis has taught me that I do one of several things all of the time. I force my mind to be busy so it can't interpret what my body is feeling. I often push myself to further my muscle strength where I have muscles, or endurance whether in fact some of the parts affected by neuropathy can take it or not and that is when I get zings . . . I often ignore the pain and grin and bear it. I refuse to let pain take command of my life. I'm likely better off than many seniors. I appreciate [city] health services for giving me home care and the city of [name] for giving me taxi

service. Without these aids to my daily living my quality of life would be far less . . . With the loving memories of my husband whom I adored and my loving supportive family, who cares about pain, I am a very lucky lady in my senior years.

Participants observed that participating in the study gave them an opportunity to reflect. This was the situation for Gordon and Wilson. Gordon noticed talking “about this situation has caused me to look back at what I’ve gone through and consider it maybe in some different ways in which I considered it before. There are a lot of things that I guess I had forgotten . . . in the process and this has caused me to think more clearly about what kind of a process I have gone through”. A benefit Gordon had through talking then was that it “has probably helped me to understand myself a little bit more”. The opportunity to reflect on his journey gave Wilson “assurance that I did make the right choices in regards to what I needed to do for me”. For Wilson the decisions “as hard as they were and as hard as it may be, those are decisions that I think were still positive more so than they were negative”.

Bea noted talking about the events that contributed to her pain and acceptance experiences has “just made me think about what I have actually went through. When I was answering the questions, when this happened and this happened, like I told you at the doctor’s and things like that, that brought it all back. It’s just a memory”. Rather than gaining insight as Gordon had, Bea’s review of events “just made me mad all over because those doctors should have been sued. I am getting the litigation from the fall but it is nothing what [doctors] put me through”.

Sara commented on the benefit of “this whole interview process” which she found to be “really good because it has given me the opportunity to really reflect on what it is I’ve gone through, and where it is I’m heading”. The benefits for Sara included the “chance to reflect on . . . all the good that’s come out of [the pain] so far. . . . Normally when I think about the past three years I tend to think about all the obstacles, all the negative, and instead this has really given me a chance to think about the positives that have come out of it”. Through the interview process Sara recognized “my own grieving process isn’t done. I need to talk about it, and discuss it, and it’s been a good opportunity for that. It means so much more when the person you’re talking to has a frame of reference and they know where you’re coming from. It just makes it seem like you’re really being listened to, and, and that’s important, that’s very helpful”. Sara found the interviews quite “emotional . . . to be honest. But it felt very good. It felt very therapeutic . . . I don’t get a chance to talk like this very often so this is good. It’s been very good for me”.

The benefit of talking about acceptance helped Elizabeth to “reinforce my own positive beliefs about myself and my values”. The benefits for Elizabeth continued after our conversations ended as she noticed “since we’ve spoken together, every once in a while something pops into my mind that refers to you and I speaking, or topics we were speaking about, and things have come to mind, or it’s helped me to remember some stuff. It’s been very positive”. Talking about her pain and acceptance for Elizabeth was also “almost therapeutic . . . to be able to speak about it to someone who’s interested, and especially someone educated . . . It’s an opportunity for me”.

Ginnie also observed the interviews were “like therapy” because “through talking I’ve sort of realized things I need to know”. One of the things Ginnie came to know was “okay this works, this doesn’t work, this makes me mad, this doesn’t make me mad”. She came to realize “why is it I’m so freaking stubborn about work? It is just way too much a part of what I am. I wouldn’t be me without it. So, I don’t have an option, unless I get into a wheelchair, which isn’t going to happen. So, I have to accept it and just quit thinking about it. That sort of self talk I have is, ‘stop your whining and carry on, because you’re not dead yet.’” Through the interviews Ginnie summarized the main components of her ability to accept her pain which included her “work ethic, the family support, and the idea that perhaps this treatment is working”. And finally, through putting her ideas “all together I can see the shape of what’s been going on. And how I have been dealing with it, and I think I’ve done pretty well. Quite impressed with myself actually And I’m really glad we’ve done this because otherwise I wouldn’t be able to see that”.

Summary

Participants described the present, their current situation, and where acceptance had lead them so far. In commenting on the stability of acceptance some believed their acceptance would likely remain stable even if their pain increased or their condition worsened. Others speculated they would be less accepting if the pain intensity increased to the point that it was unmanageable.

Participants talked about their futures with both hope and fear. They expressed hope their mobility would continue to increase, their situation would improve, and that neither the pain nor condition would worsen. Hope was also expressed for non-pain areas such as hope for acceptance as a writer and hope other life difficulties would improve. Participants strove to maintain a balance between hope and acceptance describing how hope was essential for acceptance: Hope the pain would improve in the future allowed for acceptance in the present.

Participants’ fears were in the same areas as their hopes. They held fear and hope their pain would change; they feared it would become worse while they hoped it would improve. Similarly, they felt fear and hope their ability to manage their condition would change Fear was felt particularly if there was no other treatment options. From the participants’ experiences it is evident that where there was hope there was also fear, along with acceptance.

An unexpected outcome of acceptance was strength to manage the unknown and uncertainty of the future with pain. Compared to the time before acceptance when the unknown created upset, anger, and stress, with acceptance participants spoke about the unknown and with calmness and confidence. In recognition that medical science does not hold all of the answers, a realization all participants experienced, some indicated the strength their faith provided in the face of this particular uncertainty.

Personal growth was another unintended outcome. During acceptance several participants achieved and reclaimed self esteem. Having chronic pain and nonacceptance delivered a blow to self value and self esteem, characteristics participants gradually strengthened with acceptance. Participants vividly described how their increased self-confidence enabling them to develop an inner trust and validation.

Confidence was displayed in how participants managed their pain and other aspects of their lives, and enabled them to establish and reach their goals.

Participants were all living with what each perceived to be a meaningful life. This was not unexpected since it was a study selection criterion. What was unexpected for many was that a meaningful life had developed *at all*, and how it had unfolded, given that each continued to experience pain. Resuming previously enjoyable activities, taking on new activities, helping others, and contributing to society were ways participants found meaning in their lives.

Participants talked about other outcomes of acceptance including developing closer relationships with family and friends. They acknowledged the importance and benefit of helping others. Others noted that the pain experience, while still difficult, had been the starting point for personal change and growth that may or may not have occurred if not for the pain. And participants observed they had developed strategies enabling each to live with pain.

Participants had an opportunity to comment on their participation in this study. Feedback included having no impact, noticing an increase in pain intensity during interviews, and feeling strong emotions. They acknowledged the therapeutic quality of participating in the study as the interviews offered an opportunity to reflect and be heard. Through talking about their experience and all that they had gone through, participants noted an increase in self-awareness and understanding allowing them to identify the direction of future healing. It was also an opportunity to validate decisions made and reflect on the positive aspects that have arisen from a difficult situation. Through participating in the study participants also realized how they manage their pain and identified their successes.

CHAPTER FIVE

DISCUSSION

Integration of Findings with the Literature

The purpose of this study was to explore the experience of the acceptance of chronic pain. Current treatment and interventions provide relief of pain for many but not everyone reaches the relief desired. Acceptance as measured with a questionnaire has been found to be positively related to improved quality of life and emotional status. However, existing literature could be enriched with an in-depth understanding of acceptance such as this study sought to provide. Study participants were ten individuals who had experienced chronic pain for at least six months, whose life had been impacted by pain, who were living a meaningful life with the pain, and who had accepted their pain as chronic. Participants lived in six Canadian communities located in three provinces in Central and Western Canada. Five themes emerged from the interviews: 1) The Essence of Acceptance, 2) Interpersonal Interactions and Acceptance: Help or Hindrance, 3) The Journey of Acceptance, 4) Choices and Changes on the Journey, and 5) Where the Journey has Lead . . . So Far. Given the qualitative nature of this study, the findings are not intended to be generalizable to the larger population of those in similar situations. However, it is likely the depth and richness of each theme is experienced. The published literature does not capture the complex and complete essence of each participant's experience but does support many of the ideas embedded within each theme.

Theme 1: The Essence of Acceptance

This first theme focused on attaining an understanding of the acceptance of chronic pain. In this way this theme serves as a foundation for understanding the remaining themes. Wright (1960) notes the "concept of acceptance" as related to physical disability "has also become a ready-made cliché purporting to guarantee adjustment, though if one becomes serious about the connection in the particular context, one often wonders what kind of acceptance and what kind of adjustment are meant" (p107). Reflecting on the essence of acceptance for the participants in the context of their pain involves careful use of the word 'acceptance'. This allows for clear communication and facilitates a rich and deep understanding of their experience.

Rather than a precise definition, participants described acceptance through metaphor or by outlining the function of acceptance in their life. This is similar to how pain is described and spoken about according to Katz (2004) who says that:

Although pain consists of a generally appreciated experience, pain remains a poorly communicated experience. Nowhere is this view of the instability of language underscored more heavily than in the attempts at the expression of pain. The communication of pain in no way approximates the mundane. Specifically, the language of pain is necessarily that of metaphor and metonymy (substitution or association). We are left to describe pain in comparative terms. We displace the language of pain onto the language of dysfunction (p. 60).

Participants used the following metaphors to denote acceptance: peace, freedom, going with the flow, and agreement. 'Doing all that could be done to manage pain' lead to a sense of peace even though the pain continued was voiced by one participant. Markway and Markway (2001) agree that acceptance is not denying the pain, but rather acceptance alleviates unnecessary suffering and can lead to peace and serenity in the midst of pain. Another said going with the flow of the pain rather than fighting it gave a sense of freedom and acceptance. Markway and Markway note the 'going with the flow' philosophy is a typically Eastern way of thinking which contrasts the Western 'fight to conquer' approach.

Each participant, in their own way, acknowledged an ability to continue living their life despite pain. For some, acknowledgment along with living a meaningful and full life defined acceptance. Anderson (1996), Campbell (2006), and McCracken (1999) agree that the defining aspects of acceptance are a willingness to live a satisfying life with pain rather than resignation pain is present. Anderson emphasizes acceptance also entails acknowledging the need to live a different kind of life than prior to the onset of pain. Letting go of the past life, as Campbell states, entails letting go of the person you were before pain. However, based on what the participants have said, acceptance entails giving up only a *part* of the person not all of them.

A glimpse into the time prior to acceptance, the time of nonacceptance, helps to understand acceptance. In contrast to the freedom and peace which characterized acceptance, nonacceptance, which ranged from months to years, was a time of great difficulty for the participants involving: searching for a cure or miracle which often entailed endlessly searching out health care providers, waiting for appointments, and experiencing the disappointment and frustration of no cure. Similar results were reported by Sofaer, et al. (2005) from a qualitative study with individuals aged 60 to 87 to explore the limitations they faced because of chronic pain and strategies they used to deal with those limitations. One of the two themes emerging was adaptation, with nonacceptance as a subcategory. The experience of nonacceptance for these older adults was similar to the nonacceptance for participants of this study. Both groups experienced nonacceptance as fighting the idea of having pain at all, and then searching out every possible way to find relief, which entailed dealing with the health system and experiencing disappointment when the system did not provide the miracle.

Feelings of anger, disappointment, worry, depression, hopelessness and helplessness characterized nonacceptance. These feelings are often the norm for such individuals whose lives have been thrown into turmoil and who have not yet accepted their pain. The Canadian Pain Society (2007) reported that 38 percent of individuals who reported chronic pain also experienced depression and anxiety. A study by Andersson and Hovelius (2005) with women between 25 and 64 on sick leave or otherwise absent from their jobs due to chronic and widespread pain, experienced similar thoughts and feelings about their pain. Participants completed questionnaires inquiring about health, stress, and coping. Responses revealed a range of psychological concerns including anxiety, anger, and uncertainty about the future. Similarly, those

who had entered treatment at a pain centre reported helplessness, fear of pain, and demonstrated passive coping strategies such as resting and worrying (Samwel, Evers, Crul, & Kraaimaat, 2006). Data analysis revealed these thoughts and behaviours were all related to pain intensity, disability, and depression.

At low points during nonacceptance participants described feeling lost, scared, and that the struggle was becoming too much. They felt like scum or garbage because they weren't responding to their treatments as predicted and were thus turned away from further services. At the lowest point, suicide seemed the only option. Many participants, in their own way believed their very existence was at stake. This was also the experience of 12 women with fibromyalgia who participated in interviews in Norway. Raheim and Haland (2006) told the stories of the women that pointed to a world experienced as changed by a body in chronic pain, and a struggle in which they felt their existence was at stake. Many people with chronic pain experience this changed body and struggle for existence.

Participants experienced acceptance as an ongoing process rather than a specified event or situation with a finite outcome. Bland and Henning's (2002) perspective on acceptance concur noting that "acceptance is a complex multilayered phenomena best understood as an evolving process that leads to new meaning (p.9)." As a gradual process, over time acceptance lead to changes in thoughts, behaviours, and emotions in generally positive, satisfying directions. Although McCracken and Vowles (2006) view acceptance as "a process of changing behaviour patterns so they are less tied to controlling the experience of pain as a primary focus and more directed toward elements of healthy living (p. 90)," participants would likely add that their changing thoughts and feelings are as important as their behaviour in the acceptance process.

The main point regarding the acceptance process is that participants themselves acknowledge the changes they continue to go through rather than viewing it as something finished and finite. Given that acceptance is a lengthy process, the question remains of how to best promote or facilitate its emergence. Several studies (Bach & Hayes, 2002; Hayes, et al 1999) report that acceptance-based programs, techniques, and approaches have demonstrated positive outcomes for individuals with chronic pain and schizophrenia. However, none of the participants in this study received any acceptance-based or psychological treatment focusing on acceptance. Therefore, it would seem that acceptance-based treatments or techniques can serve to create a foundation upon which participants then continue to grow and develop. This point will be accentuated in theme four, which discusses the invaluable growth and unexpected benefits that occur when a person moves onto the acceptance path.

Participants' language use as they described acceptance contributes further to understanding the essence of acceptance. The language participants used to describe their pain and the impact of the pain changed as acceptance came to play a role in their lives. The language conveying nonacceptance reflected judgment of self and others, struggle and blame, negativity and passivity. This was similar to women with chronic wide-spread pain whose written accounts used words of struggle, suffering, powerlessness, and feelings of being overwhelmed (Andersson & Hovelius, 2005). In contrast, the language of acceptance used

by participants in this study conveyed independence and confidence, non-judgment and calm in the face of uncertainty, control and responsibility, and most important, love, understanding, gentleness, and compassion for the self with pain.

Gordon (2007) speaks about the power of the language of acceptance in the contexts of acceptance of another person and language used by parents in child rearing. According to Gordon, most people think that if you accept children they will remain undeveloped, and therefore the best way to help a child grow is by communicating nonacceptance. Words of judgment, preaching, criticism, command and punishment are used by parents, by spouses to each other, by bosses to their employee, and in inner discussions to convey nonacceptance of a situation in the belief that this language will result in change. However, Gordon asserts, language of acceptance frees us to be open and to grow. A therapist's acceptance communicated to a client is one of the most important elements contributing to growth and change through therapy. Through acceptance a client comes to recognize that no attitude is too terrible (Rogers, 1942), no feeling too shameful, or no thought too wicked to bring to the therapist. In this way, clients come to accept themselves and use language of acceptance for their own growth and well-being. In this study, as participants integrated the language of acceptance and identified changes to be implemented, they grew more accepting of their pain, and themselves.

Anderson and Genthner (1990) present a guide for assessing the level of personal responsibility of patients with diabetes. The five levels start with the lowest in which patients feel overwhelmed, helpless, and hopeless, and proceed to the highest in which patients accept diabetes as a part of their lives and accept the responsibility for managing it. The areas assessed to determine the level are energy, focus, crisis management, and language. The criteria for level five is: "patients *accept* total responsibility for their lives (p. 274)" [emphasis added]. A patient's language at level one communicates no control or mastery over diabetes or self-care. The words "it" or "you" depersonalize the situation indicating 'the world is against you' or 'no one cares about you' rather than 'no cares about me.' At level two a patient's language is externally focused often blaming others for their condition. The word 'if' is commonly used as in 'if only the doctor would fix me.' Language at level three is split between the self and external forces indicating striking a balance between blaming others and with partial commitment toward personal responsibility. The word 'I' becomes prominent in level four as patient focuses more on self. Blame is absent and the patient starts to believe in taking responsibility, but they are not quite there. Finally, at level five patients accept total responsibility for their lives including their diabetes. Patients speak openly about themselves and their condition with less concern about what others think. Someone at level five might say 'diabetes has helped me rediscover how much I value feeling well and [has] given me the opportunity to make changes for my health' (Anderson and Genthner, 1990). Participants' language of acceptance in this study would likely be rated at a level four or five as they expressed hope, responsibility, control, and focus on self.

'Life goes on,' 'carrying on despite the pain,' 'focusing on the positive,' and 'doing the best I can with my pain' were some of the thoughts participants in this study expressed about their pain and

acceptance. According to the participants these thoughts influenced how they approached their pain, their feelings, thoughts, and actions, or what Caudill (2002) defines as their attitude. Specifically, attitude is a general posture or psychological characteristic enabling us to make decisions without consciously and intentionally weighing each decision, and which then influences behaviour (Caudill).

Acceptance, according to McCracken (1999) is “not simply a thought or a decision but an attitude that entails a range of overt and cognitive responses” (p. 99) which would encompass observable behaviours and internal thoughts. Markway and Markway (2001) describe acceptance as an attitude that directs how we look nonjudgementally at ourselves and the world around us. Campbell (2006) concurs that acceptance is an attitude and characterizes it as having realistic and optimistic qualities. The realistic quality focuses on accepting the illness or pain as a long-term, possibly lifetime condition which has changed their life rather than focusing on finding the miracle cure. At the same time, the optimistic quality encompasses a determination to improve and the belief that ways will be found to get better but through their own efforts and not through the efforts of somebody else (Campbell). The participants would likely agree that acceptance has this realistic quality. While some of them would agree that optimism encompasses a desire to improve and focus on the future, for others optimism provides confidence and peace in the present moment rather than in future. According to Kabat-Zinn (1990) the practice of being in the moment, or mindfulness, requires a number of attitudes, one of which is acceptance. The attitude of acceptance is more accurately comprised of qualities acknowledging reality and the present moment, while using optimism to live with the pain now and in the future.

All participants spoke about their ability to shape their attitude and the effort it took to assume an acceptance attitude. As observers of their attitudes, participants noted taking a positive stance toward their pain and their lives didn't come easy, that they reminded themselves to accept, and that acceptance took effort. Caudill (2002) notes attitudes are the result of multiple factors including familial beliefs, cultural influences, learned behaviours, and maybe genetics. From Kabat-Zinn's (1990) perspective the acceptance attitude is often taken on only after an emotion filled time of denial and anger. Moving toward acceptance came after a difficult time of nonacceptance which included anger and denial, for some of the participants but not all. And, the ones that did experience nonacceptance acknowledge acceptance takes awareness and effort.

To summarize, the essence of acceptance is multifaceted and best understood by looking at nonacceptance as well as the meaning, language, and attitude of acceptance. For the participants acceptance was the only way to live a meaningful, peaceful and free life with pain. As an ongoing gradual, lifelong process, acceptance was characterized, as revealed by the language of acceptance, by independence, responsibility, compassion, and self understanding. The attitude of acceptance, as expressed by thoughts, feelings, and behaviour, acknowledge the reality the pain will continue indefinitely, along with efforts and the will to remain positive and continue with life both in the moment and in the future. The attitude of

acceptance takes effort and awareness. Understanding acceptance from the perspective of the participants who have, and are accepting their pain, provides the foundation for understanding the remaining themes.

Theme 2: Interpersonal Interactions and Acceptance: Help or Hindrance

The second theme arising from this study involved relationships and interactions that helped or hindered acceptance. Participants spoke about the many relationships they were in, and numerous interactions that had occurred during their pain and acceptance experiences. It was particular qualities within the relationships and interactions including support, communication, momentous interactions, response to chronicity, being believed, and shared experiences, or combinations of these qualities, which were significant and influenced acceptance.

Interactions with family and friends, through faith, at work, and from professionals offered participants everything from strength and comfort to feeling alone, burdened, and distressed if support was absent or inadequate. The two basic types of support, according to Sylvain and Talbot (2002) are (1) practical support, which includes assisting with tasks, and (2) psychological support, which involves listening and understanding. Family and friends offered support to participants by helping with some of the tasks of daily living, reminding the person to rest or engage in self care, and being available to listen and sometimes challenge. The benefit of this support was feeling more comfort, less worry, a lighter load, facilitating independence, and sustaining dignity all of which facilitated acceptance. In contrast, when family support was absent, inadequate or inappropriate, participants' burden felt heavier. This made managing pain more difficult and acceptance more challenging.

A number of studies have been conducted which explored the role of support on acceptance and adjustment. Li and Moore (1998) report that social support from family and friends were found to play important roles in participants' acceptance and adjustment to disabilities such as mental illness, learning disability, and spinal cord injury. Forty percent of their sample of 1266 people reported chronic pain. In Thailand, Attawong and Kovinda (2005) completed a study showing the following key factors in accepting a spinal cord disability: social learning from family, disabled peers, friends, and the community; and emotional support which might, but not necessarily, come from formal counselling. One participant from Raheim and Haland's (2006) phenomenological study told of feelings of support by family including the sharing of practical responsibilities. She also described positive adjustments in her relationships which established mutuality, understanding, and a new common ground. Delmar, et al. (2005) also acknowledge the essentiality of help and support so a person with chronic illness is able to discover a new way of living and achieve harmony with their illness.

While the participants in this study validated the positive influence of support, McCracken (2005) reported the opposite effect of family encouragement to rest or offers to take over responsibilities. McCracken found a reduction in these assisting type behaviours to be associated with an increased acceptance score on the Chronic Pain Acceptance Questionnaire. More specifically Romano, et al. (1995) reported solicitous responses from a spouse involving offers to help to have a negative impact on the

physical disability of patients who were more depressed or who reported greater pain levels of pain than those with lower depression and pain scores. However, for the participants in this study regardless of emotional state or pain intensity, support from family and friends in the form of listening, helping out, or trying to understand, facilitated acceptance.

A relationship with God was a significant source of support for the participants who believed God would provide them the needed strength, that he was in control and that he would take care of the situation. Sofaer, et al. (2005) found participants used prayer to adapt to their pain; prayer was a source of inner strength and comfort through the belief that God would intervene. In general, spiritual strategies are a source of comfort and relief for individuals with chronic pain (Koenig, 2003) depending upon whether positive or negative strategies are used. Negative religious coping views God as absent or punishing while positive religious coping strategies look to God to provide strength, growth, and comfort. Positive strategies are associated with positive emotional affect (Bush, Rye, Brant, Emery, Pargament & Riessinger, 1999) and better mental health status. On the other hand, negative religious strategies are associated with higher pain intensity and compromised mental health (Rippentrop, Altmaier, Chen, Found, & Keffala, 2005) and depressive symptoms (Vandecreek, Paget, Horton, Robbins, Oettinger, & Tai, 2004). The study by Vandecreek, et al., found participants with few or no depressive symptoms used their religion in positive ways to cope with the emotional stress of rheumatoid arthritis.

Participants who were currently employed described their work situations as supportive. Support included accommodations, flexibility with timelines, offering patience, and understanding regarding moods and pain levels, allowing the employee to work within their limits, and benefits such as sick days and disability programs. The person involved in offering, or encouraging use of this support was typically a supervisor but co-workers were also supportive.

Several participants vividly described previous employment situations where support was absent or insufficient to allow the participant to continue employment. This was difficult, frightening, and challenging and similar to the experiences of the women in the Andersson and Hovelius (2005) study who told of employers ignoring or not adjusting their work leading to taking sick leave. Participants in the current study resolved these situations in various ways ranged from addressing the specific concern to finding other employment. Successful resolution of issues and support in the workplace allowed six out of the seven participants to work full or part time, while one of the three participants of retirement age continued to work part time.

Frank, et al. (1998) suggest that involving the workplace in negotiating accommodations or modifications is critical in assisting a person with work-related back pain successfully return to work. He asserts that if this is not done the return to work plan will fail. Siviter (2007) notes the time and effort involved in developing and implementing required accommodations. However, planning and effort are essential in order to ensure safety for all and to maximize the chance for a successful return to work. The outcome to date for the participants of this study at workplaces in which understanding and

accommodations were provided was that each was working in relatively satisfying employment, with stable job attendance, and fulfillment of, or exceeding job demands. In addition to allowing the participant to do their job, supportive employment enabled each to work. This is an important quality in living a meaningful life and acceptance. Regular attendance and job satisfaction was also found by Swedish women with fibromyalgia whose employers were willing to make personalized adjustments in the work situation including flexible hours and matching work demands to ability (Henriksson, Kiedberg, & Gerdle. 2005).

Support participants received from professionals, including physicians and mental health professionals, ranged from positive and helpful to not helpful and distressing. Not wanting to bother others including physicians who are viewed as being busy interfered with elderly participants accessing information and ultimately treatment (Lansbury, 2000). While the limits on time might be accurate, physicians themselves note a reluctance to provide ongoing care for patients with chronic pain because of the time and resources required (Tafor, Kern, & Oswalt, 2007). This impacted doctors' attitude, approach, and treatment of these patients. Regardless of the reason, one participant in this study left her appointments feeling alone with no direction or advice, which lead her to feel discouraged, bewildered, and unsafe with her pain. Unfortunately, this is a common outcome for people with chronic pain (Lillrank, 2003; Sylvian & Talbot, 2002; Walker, Holloway, & Sofaer, 1999) who look to professionals, particularly physicians for guidance, information, and understanding delivered with respect and trust (Delbanco, 1992).

When physicians and counsellors were understanding, encouraging, and gave direction, participants emerged with strength, confidence, and feelings of security and comfort which facilitated coping and their movement toward acceptance. It is precisely this type of support that promoted the transition from panic to well-being and control for women with fibromyalgia (Sylvian & Talbot, 2002). Support from professionals in an atmosphere of respect, dignity, trust, and co-decision making (De Ridder, Depla, Severens, & Malsch, 1997) where the needs of the person, regardless of age (Lansbury, 2000) are addressed, is the type of support which recognizes each as a human being and which guides each toward self-management and health (Sylvain & Talbot, 2002). Fortunately, many participants in this study received this type of support. Some received this support only after having negative experiences with professionals.

Participants identified the nature of communication as an important quality of personal interactions and relationships during acceptance. The benefit of conveying thoughts and feelings, openly, honestly, in a timely manner, and with awareness, however difficult, to family, friends and professionals, resulted in increased understanding and stronger interpersonal connections. Through verbalizing and sharing difficult experiences and sensitive topics, doors were opened for clarity. This helped dispel previously silent, yet powerful fears, and further developed connection and enabled support from the other person. An increased willingness and ability to freely express emotions to others was an important factor in feeling satisfied with support received for adults with rheumatoid arthritis (Holtzman, Newth, & DeLongis, 2004). Some participants in this study found that the stress of chronic pain combined with the intense emotions resulted in a breakdown of previously effective communication patterns. As they developed new

patterns the relationship was revived. Fernandez and Turk (1995) confirmed the pervasive anger associated with chronic pain interferes with communication, and hence connecting with spouse, family, friends, and health care providers is stalled or degraded.

The manner of communication from health care professions told participants whether or not they were believed, heard and, understood and also conveyed hope, caring, support, and offered connection. On the other hand, communication could also convey impatience, judgment, frustration, and disbelief. In contrast to personal relationships in which both parties benefit, communication and hence connection with professionals was typically unidirectional from professional to patient. Positive communications allowed the relationship to focus on the chronic pain, and made a positive contribution to acceptance. Non supportive communications resulted in an emotional response such as anger or sadness causing the participant to focus on the emotional response rather than on pain management. Bedell, Graboys, Bedell, and Lown (2007) identify this non supportive communication as 'language that harms' which is used in part because of general medical uncertainty. From the physician's perspective, the focus of communication often centres on conveying information and ensuring the patient understands instructions (Delbanco, 1992) rather than on connection. But from the perspective of the patient, connection and rapport through communication, and use of words that heal and which convey empathy (Bedell, et al.) is also important and is a significant contributor to patient satisfaction (Frantsve & Kerns, 2007), pain management (Lansbury, 2000), coping (de Ridder et al., 1997), receiving support (Widar, Ek, & Ahlstrom, 2007), and ultimately acceptance.

Physician's disbelief of one's pain was a powerful blow to the self esteem and integrity of participants. The response was typically anger, frustration, and sadness along with determination to be believed, validated, and taken seriously. When doctors communicate disbelief one's focus can change from productive coping, managing or accepting to a focus on efforts to be believed and credible (Werner & Malterud, 2003). The fear of not being believed and being judged is experienced by adults (Sylvain & Talbot, 2002) as well as children and their families (Carter, 2002) and is a difficult and stressful time. The power of a diagnosis in reassuring their pain was real, and that they were being taken seriously was a relief expressed by individuals with chronic back pain (Lillrank, 2003). Similarly, many participants with ongoing back pain feared the absence of pathological evidence, and hence no diagnosis, would imply their pain was in their mind and another way disbelief communicated (Walker, et al., 1999).

The significance of believing was noted by both the women with fibromyalgia and by health professionals in a study by Sylvain & Talbot (2002). The women rated being believed as the most helpful intervention, while health professionals recognized believing a patient was the most important attitude for a professional (Sylvain & Talbot). The opportunity to believe another's pain, emotional or physical, exists in many areas of health care. In psychology a client often comes with thoughts of doubt and mistrust of their experience and emotions. Through the therapy process, which involves validating and believing the client's

story including thoughts and feelings, acceptance and non-judgment are communicated. This enables the client to also come to believe, accept, change and grow.

Participants described momentous conversations with family and professionals that touched them in a variety of ways and influenced their lives with pain. One such conversation evoked outrage when the participant sensed he was being accused of not putting forth full effort in rehab and attempting to cheat the insurance company. Communicating disbelief of effort and intent evoked a similar response as when communicating disbelief of the pain. As mentioned not being believed is a common fear of people with chronic pain (Sylvain & Talbot, 2002).

Other conversations held significance because they indirectly or directly challenged the participant to think or act in a different way. Honest communication was significant, even if it was from a professional acknowledging limitations and uncertainty of effectiveness of treatment. This honesty helped build trust and enabled treatment to happen with no expectations other than being in the moment and being open to possibilities. Being challenged by concerned family to look at pain and life in a different way was significant, nudging the participant to think and act in ways that facilitated acceptance and living life more fully. Since these challenges by family came from a position of trust, love and care, there was no suspicion of ill intent. Lillrank (2003) would describe these events as turning point events because they prompted the participant to make a decision and take a different route than the one they had been traveling. These turning points can be seen as a turning point toward acceptance.

One of the most common interactions within the chronic pain journey was the physicians', general practitioners and specialists, responses to the participants' long term, sometimes unexplained pain. This interaction either concluded with comfort and hope along with feelings of support and encouragement, or lead to tears, frustration, collapse, and feelings of abandonment and aloneness. One participant thought doctors might also be frustrated with the uncertainty, chronicity, and lack of recovery or progress within the predetermined recovery time, characteristic of chronic pain. A physicians' frustration may evolve from the perception that their role is to cure rather than manage conditions (Lansbury, 2000) and when this cure does not occur both patient and physician feel defeat (Frantsve & Kerns, 2007) and disquiet with the uncertainty (Bedell, et al, 2007) of the condition.

Despite uncertainty, communication with professionals who conveyed understanding and acknowledged the pain, was found to be more productive and satisfying, enabling each participant to focus on the present moment which in turn opened the door to a future with acceptance. Professionals who provide care in the face of uncertainty must understand care as a process that facilitates the patient's acceptance of their condition (Koch & Kralik, 2001). The professional providing care for uncertain conditions such as chronic pain requires understanding of the process which facilitates patient acceptance of their condition (Koch & Kralik), upgrading their knowledge in chronic pain because many physicians acknowledge their knowledge is inadequate (Rich, 2000), using empathic language (Bedell, 2007), and developing an attitude of acknowledging uncertainty and that it is okay. For the person with chronic pain,

or other chronic illness, one of the challenges and often a difficulty is to find, and develop relationships with physicians and other professionals who are comfortable with uncertainty (Andersson & Hovelius, 2005; Campbell, 2006) and with whom you are comfortable with. And for other healthcare professionals, care must be taken when communicating with people with chronic pain and illness because what is said is influential, and carries a lot of power, to how individuals cope and maintain or achieve a valued self identity (Telford, Kralik, Koch, 2006).

Hearing and learning about the experiences of others proved to be an effective and powerful force toward acceptance for participants of this study for at least three reasons including: recognition that they weren't alone; the emergence of hope; and gained perspective. Sharing of experiences and lives occurred informally between co-workers, through self-disclosure by a professional, and while working with volunteers, and formally through organized groups such as support and psychoeducational groups. Realizing others experience chronic pain was powerful and significant for participants who had been blocked in their coping by thinking that no one else suffers chronic pain or could understand their experience (Lansbury, 2000; Roberto & Reynolds, 2002). Knowing others have survived hard times and that they understand the difficulties of injury and pain was significant and special connections were established. Establishing connection between group members was not the intent of a support group for individuals with chronic pain in the United Kingdom, but the outcomes of this medically established program included some increase in responsibility for self-management, a small decrease in anxiety, and that the patients themselves expressed satisfaction with the experience such that they established and continued on with their own self-help (Arthur & Edwards, 2005).

Attending groups and hearing the experiences of others with chronic conditions was helpful as it allowed participants to meet others they thought were worse off. Sofaer, et al. (2005) defines this viewing of others as worse off than oneself as downward comparison and found this perspective promoted a sense of well-being. Delmar, et al. (2005) notes that knowing someone else is suffering more than self can make accepting one's own situation easier. Participants in this study heard about the experiences of others who seemed to be ahead in terms of learning to manage and accept their situations, which planted the seed of hope; they realized they too could reach that point. It was the group members themselves who described what they had done to manage their condition to reach their current success. Keel (1999) concurs that hearing about the success of other group members is typically more encouraging and convincing than instruction from professionals for managing the condition. Participants noted readiness to attend any group was essential to benefit from the content and competent group facilitators essential to prevent downward spiral of participants' emotions. Despite these factors each participant was able to benefit from hearing the experiences of others, and gaining others' perspectives regardless of readiness and environment. Thus, the sharing of experiences is a key component of accepting disability (Attawong & Kovindha, 2005), chronic pain, and other chronic conditions.

Theme 3: The Journey of Acceptance

The third theme outlined significant qualities of the acceptance journey including; the beginning of the journey; aspects of the journeying process itself; and its' personal nature. The time element of acceptance was verbalized noting acceptance takes place over time, quite possibly lasting for the duration of life. As an ongoing, evolving life situation acceptance can be more accurately referred to as an experience on the move, or as a journey.

The participants' journey of pain began with an injury, accident, simply from life or the unknown. The journey of acceptance for many began with a decision. The decision to directly and consciously accept the pain was made by some participants while the more common route for other participants was to make other decisions which made unpredictable, unintended, yet invaluable contributions to their life, and unknowingly, to acceptance.

One participant decided to accept his pain when he realized a solution for his pain unlikely. Anderson (1996) similarly realized that despite the idea that hard work and determination will lead to success, that the decision to accept was the key to getting off the emotional roller coaster of fibromyalgia. Koenig (2003) argues that acceptance, one of four components of a spiritual attitude toward pain involves a decision to consciously bear the cross of pain one has been given. Kotarba (1983) notes the decision to accept pain is made when the medical system fails to alleviate the pain and occurs when a persons' belief system, most often through and in the form of organized religion, is such that emotional support and spiritual strength are available, and strong enough to support this decision. The decision to accept may also be made when a person feels safe psychologically (Anderson & Genthner, 1990) which could likely occur with appropriate therapy focusing on understanding, supporting, and validating the individual. In this study only one participant received such therapy while others wished they had. Some determined that spirituality was an important source of strength.

Participants made decisions other than to accept pain such as: reducing medication; taking steps to return to work; accepting the person in the mirror; finding ways to deal with the pain; having a baby; and going for a walk. These decisions were made for their own sake. It is only in hindsight such decisions were identified as precursors to acceptance. Similarly, Anderson (1996) decided how he was to live on a daily basis not knowing it was related to acceptance. Participants in a grounded theory study by Miles, Curran, Pearce, and Allan (2005) identified the decision to alter normal life caused by pain was key to accepting the constraint of pain. Paterson (2001) identified the shifting perspectives model of chronic illness which suggests those with chronic illness may focus on either illness or wellness and a decision to *consciously* engage wellness, or disengage illness, made the shift occur. The key to deciding to accept, or make any decision to live with pain, according to Kralik (2002), emerges when a person has come to terms with the reality of a changed life. This was the situation for several participants in this study.

The critical decision to accept the pain was the first of many steps participants took on their journey. They unanimously described acceptance as a process versus a moment in time event. While the overall direction of the journey was one of progress and improvement, some thought their movement was consistently in a forward direction while others noted it consisted of a back and forth quality. Participants agreed acceptance occurred step by step, and the necessity of all steps both forward and back. In this way each step taken built upon previous steps.

A review of existing research literature in the area of adjustment and acceptance of chronic conditions concur that acceptance is a process (Delmar, et al., 2005; Koenig, 2003; Kralik, 2002; McCracken, 2007; McCracken & Vowles, 2006; Paterson, 2001; Stanton, Revenson, & Tennen, 2007; Wright, 1960). Wright acknowledged the importance of "maladjustive reactions" (p. 107), described by participants and professionals as backward steps, as "important first efforts in the process of accepting one's disability and oneself (p. 107). Stanton, et al. emphasize the trajectory of chronic illness is neither "fluid, lockstep, nor linear" (p. 568) but is characterized by "twists and turns" (p. 568) and unpredictability. Both comments validate the bumps in the road to recovery and acceptance as expected and necessary. Acknowledging the conscious effort, discipline, faith, and trust required by individuals moving through acceptance (Koenig), and the sheer complexity of illness, pain, and people, Telford, et al. (2006) encourage healthcare professionals to listen to people's stories rather than pigeonhole them into stages as a way to facilitate adjustment. Listening to the stories and voices of people with illness and pain, emotional and psychological, is what psychologists do on a daily basis.

With the recognition that acceptance is a process, and for a process to unfold, time is required, it is almost redundant to discuss the time element of the acceptance journey. Anderson (1996), Li and Moore (1998), and Markway and Markway (2001) also recognize this. However, the time element is important to understanding the experience of acceptance, in the sense of recognition that time is needed for progress, adjustment, and acceptance to unfold, and that time passing is required for reflection. Participants in this study had been on the acceptance journey from between one and twenty years. Despite the passage of time, they also noted acceptance was likely a process which will continue for the duration of life. Because of the complexity of the acceptance process combined with the time it takes, it is important those offering treatment for a set period recognize the limits of their program. This includes programs that focus on pain management (McCracken & Eccleston, 2003), illness or mood management (Bach & Hayes, 2002; Teasdale et al., 2000), and stress management, with or without an acceptance focus such as acceptance and commitment therapy (Dahl, Wilson, & Nilsson, 2004; Hayes, Strosahl, & Wilson, 1999b) or mindfulness meditation (Kabat-Zinn, 1982; Kabat-Zinn, Lipworth, & Burney, 1985). While progress may be made during a treatment program, this progress may or may not translate into changed or improved quality of life, although it is possible. Lack of observable, measurable progress during a program does not necessarily indicate that progress is not occurring or that it will not happen in the following days, month, or years. Simply, it takes time for growth to happen and it is critical in any of these programs, in counselling, and

any helping situation that hope be facilitated and clients be encouraged to continue rather than giving up because evidence of progress is not observed.

Participants identified importance of the personal nature of acceptance. While each recognized how painful and difficult their journey had been, they realized the knowledge could not be purchased and nobody could tell them what to do. They also realized their outcome could be reached only by personally going through the experience. Although the meaning of the pain, its significance, nor influence on identity did not surface as strong findings in this study, this personal quality has been explored and reviewed by researchers (Anderson & Genthner, 1990; Delmar, et al., 2005; Kotarba, 1983; Dembo, Leviton, & Wright, 1956; Wright, 1960) in the areas of chronic pain, chronic illness, and disability. What remains significant is that while there are overlapping qualities, the essence of the journey is unique and personal for each traveler.

Theme 4: Choices and Changes on the Journey

Theme four presented participants' key choices and important changes as they moved toward acceptance. Learning and acquiring knowledge, and assuming or relinquishing responsibility were found to be important. Other significant changes included: recognition of choices, a change in focus, adaptation to limitations, and changes in relationships with self and with control. They also spoke about reevaluating values and priorities during acceptance.

Participants spoke of learning and acquiring knowledge from professionals and personal experiences. Professionals provided diagnoses, technical information about their specific condition, and theories about pain physiology. Each participant received a diagnosis labeling and explaining their pain. Some received diagnosis early in their pain experience, while for others this information came months or years after onset. Receiving a diagnosis was significant because it communicated their pain was real and they were believed. Similarly, diagnoses for women with chronic illness including diabetes and breast cancer helped them feel validated and believed (Kralik, Brown, & Koch, 2001). Diagnosis reduced the worry and uncertainty felt by some participants of this study as well as persons with AIDS in a study by Weitz (1989). For others in the current study, certainty of a diagnosis did not remove the worry or frustration as the diagnosis carried the message of a long-term condition rather than the anticipated cure. This was also the experience for the women with breast cancer and diabetes (Kralik, et al.). Participants in Weitz's study spoke about the dilemma of seeking a diagnosis to explain their symptoms preferring the uncertainty of not knowing to the certainty of a diagnosis of AIDS and what it meant for their future. A diagnosis for the participants of this study, and for many people with symptoms or concerns about their health, serves to provide direction and guidance for future decisions and management of the condition. According to Corbett, Foster, and Ong (2007) identifying and knowing what the pain is and that it is chronic are necessary for acceptance.

While a diagnosis was an important starting point participants described the importance of detailed information they could act on or apply to their daily living and acceptance. This information included:

treatment options; the predicted course and outcome of pain; instructions for management including an exercise program; and what outcome to anticipate. This information provided participants with direction, reassurance, and encouragement which reduced the worry and enhanced their efforts. At times participants questioned the information and lead some to ask questions or do their own research to find the answers. Keel (1999) agrees that information and education, including explaining pain theories such as the gate control theory, are important to assisting a patient become more motivated to engage in self-control techniques. Participants note information is generally helpful, however, one participant felt explaining the physiological theory behind pain invalidated her pain. Individuals with fibromyalgia found knowledge and education enabled them regain a level of control over pain and life (Sylvain & Talbot, 2002), reduced fear (Vlaeyen, et al., 1996) and lessened anxiety and depression (Strobel, Wild, Muller, 1998).

In contrast, the absence of adequate information resulted in feeling lost and vulnerable for women with chronic illness (Kralik, et al., 2001). For persons with post stroke chronic pain, inadequate information was incomprehensible, contradictory, or absent and contributed to a sense the health care professionals did not care (Widar, et al., 2007). In a study by Osborn and Smith (1998) participants described feeling ill-informed about their long-term back pain and an inability to influence the pain despite extensive contact with the medical system.

Participants in this study would agree contact with professionals does not equate to being adequately informed. They also learned by seeking out information from various sources as well as asking questions. Campbell (2006) suggests individuals learn all they can about their condition and this might in part come from trusted professionals. Widar, et al., (2007) describe continuity of care as significant to feeling cared for and a way to communicate knowledge to individuals with post stroke pain. Keel (1999) notes the objective of treatment from a pain management centre is for patients to “learn to accept the pain” (p. 498) and to convey information so patients can understand their pain and ultimately gain some self control over it. Kralik, et al. (2001) emphasize ongoing information is required so women with chronic illness maintain hope for their future. In this way, it is important people receiving time limited treatment from pain centres continue to receive support and information following discharge.

Knowledge gained through personal experience was likely the most beneficial and practical source of knowledge for all of the participants in learning to live with their pain. Through trial and error and attending closely to their pain they discovered what helped and what worsened their pain. Over time this learning reduced uncertainty and unpredictability of pain while increasing control. This contrasts with the negative impact of attention on pain on patient functioning and acceptance in a study by McCracken (2007) who studied 227 patients in a chronic pain management centre. Analysis of self report measures concluded that effective treatment methods should focus on helping patients decrease awareness and vigilance on their pain in order to improve daily functioning. Another treatment strategy proposed facilitated full awareness of pain while *continuing* with activity (McCracken). McCracken’s rationale for treatment contradicts contentions of participants in this study who note it is their attention and vigilance to their pain that is part

of learning of what helps and what doesn't, and this has enhanced their functioning. Further, participants in this study said they respect their limits because they have learned continuing with activities clearly increases their pain and is unhelpful. Learning through practice and discovery has also been helpful for individuals with depression (Mason & Hargreaves, 2001), chronic pain (Lansbury, 2000; Sofaer, et al., 2005), and chronic fatigue syndrome (Anderson, 1996). Participants were clear this type of learning can only come from doing and personal experience. Koenig (2003) adds the struggles, frustrations, and agony are an integral part of learning.

Participants' relationship with pain was like an interpersonal relationship, similar to that with a partner or friend; the longer they spent with their pain, the better they got to know it and its intricate nature. Learning when pain was worse and improved, when fatigue contributed, when happiness did its part, when a relapse was predicted, or simply acknowledging the pain intensity leveled off, and what to do with this learning enabled each to live fully. This learning only comes with time and experience. Participants in this study are similar to individuals with diabetes (Paterson & Thorne, 2000), depression (Mason & Hargreaves, 2001), and chronic fatigue (Anderson) who also get to know their condition and themselves. As Paterson, et al. (2001) note, learning by individuals with chronic conditions, physical and psychological, are unique and cannot be measured or interpreted by norms or textbooks.

The participants' intimate learning about their pain and their responses to it was an experience that usually occurred independent of professional influence. This was also the situation for persons with AIDS (Weitz, 1989), and for elderly persons with chronic pain (Lansbury, 2000; Roberto & Reynolds, 2002), even though pain clinics were available (Roberto & Reynolds). Telford, et al. (2006) acknowledge a strong focus on pain or illness fosters learning to live with it. Learning with minimal professional influence is self-management occurring because of the nature of the learning. That is, this learning does not follow prescribed protocol or textbook cases including the time lines often outlined by these sources. Independent learning is likely a factor on the time necessary for this learning to unfold. For participants in this study, learning has taken between one and twenty years, while for persons with AIDS, the learning was a minimum of a year (Weitz) and learning for those living with chronic fatigue occurred over several years (Anderson, 1996). Another possible reason for the learning to have occurred independently was that professional influence was not helpful. Participants described varying degrees of success with treatment such as surgery, physical therapy, TENS, chiropractic, acupuncture, and medication. This was in contrast with back pain patients who emphatically said treatment had not helped (Walker, Holloway, & Sofaer, 1999). Finally, this learning, if called self-management is the objective of the health care system; the goal is for those with pain or with illness to become as independent as possible while managing their condition effectively. It is evident this learning requires qualities such as responsibility, recognition of choices, taking control, and adapting (discussed later in more detail). However, Mason and Hargreaves (2001) suggest a change in attitude is required prior to embarking on this learning. Delmar et al., (2005), McCracken, Vowles, and Eccleston (2004) further suggest that some degree of acceptance is a required precursor to

change in this self-management approach. Sofaer, et al., (2005) think learning to live with pain and what can be done are all a part of acceptance. The participants in this study, based on what they have said, would agree with these views.

Assuming or relinquishing personal responsibility emerged as an important choice for participants and facilitated acceptance. Participants described their realization that no one else could make the pain better and that only they could make things happen to move forward. Participants took ownership and control of their pain in order to make the best of a difficult situation and to live a meaningful life by exercising, doing physical activity, getting out, socializing, completing tasks, and living life fully. The acknowledgment that living with the pain successfully had to come from the self was powerful and involved taking back the first person in life – the self. Taking responsibility is also noted to be important to living with diabetes (Anderson & Genthner, 1990; King, Carroll, Newton, & Dorman, 2002), heart disease, anxiety (Tacon, McComb, Caldera, & Randolph 2003), depression (Mason & Hargreaves, 2001), fibromyalgia (Campbell, 2006), and chronic pain (Dysvik, Natvig, Eikeland, Lindstrom, 2005; Roberto & Reynolds, 2002). Taking responsibility involves a shift from an external locus of control to an internal locus in which a person is more likely to engage personally in health-promoting (Tacon, McComb, Caldera, & Randolph, 2003) and pain managing behaviours. In assuming responsibility, participants both verbalized and demonstrated their willingness to adopt a self-management approach which corresponds to the action and maintenance phases of the Pain Stages of Change theory (Jensen, Nielson, Turner, Romano, & Hill, 2003).

One participant spoke about relinquishing personal responsibility of pain. Giving away responsibility might be interpreted in a negative way, but it can also be viewed as a way of surrendering nonproductive efforts at controlling the uncontrollable. In this way, the participant could channel efforts into areas in which assumed responsibility is helpful. Acknowledging the unpredictability of their pain lead women with chronic pain in a study by Roberto and Reynolds (2002) to “take it upon themselves to make adjustments” (p. 19). The participant in this study further explained how relinquishing responsibility was related to not taking on the blame for her pain and was helpful. This rationale is not uncommon Caudill (2002) states in that some people with pain believe that accepting responsibility for the pain and the way they feel is an admission of wrong doing and the equivalent of “giving in” both of which are erroneous (p. 112).

Participants in this study described the role of personal responsibility in living with chronic pain. Some were aware of the shift from an externalized to internal responsibility, while others felt the internal had never wavered. Participants who noted the shift described months and sometimes years of struggle before realizing that no one but themselves could make a noticeable difference in their lives. Experiencing the disappointment of unsatisfactory results with (typically) the medical system, although upsetting, seemed a necessary step toward assuming responsibility. This was also experienced others with chronic pain (Roberto & Reynolds, 2002), diabetes (King, et al., 2002), fibromyalgia (Anderson, 1996), and

depression (Mason & Hargreaves, 2001). Believing the medical system could provide satisfactory assistance, denial of the extent of the pain, and having a built in excuse for inaction were all reasons participants name for not taking responsibility earlier. Realizing these barriers and experiencing the growing desire to live a better life enabled participants take on the responsibility for managing their situation. Anderson and Genthner (1990) state "patients move to higher levels of personal responsibility naturally when they feel safe" (p. 277). Feeling safe, knowledgeable, and confident were likely all factors that contributed to assuming personal responsibility in this study.

Anderson and Genthner (1990) discuss two major types of personal responsibility, trait and state. Trait personal responsibility refers to one's ongoing worldview, which is embedded in personality and thus relatively stable. However, like other personality traits gradual change is possible. This is the type of responsibility referred to by a participant who spoke of those who blame others expecting them to fix their situation as a general approach to life. She thought such individuals might have difficulty accepting their pain. State personal responsibility, on the other hand, is situation specific and often temporary. A person in crisis, such as a relapse, may respond by assuming a lower level of responsibility than usual, and return to their former higher level once the crisis is resolved (Anderson & Genthner). Participants in this study who chose to assume responsibility for their pain may have been either reverting to their pre-pain level of responsibility, or perhaps their trait level had gradually increased. Regardless, maintaining or taking personal responsibility allowed participants in this study, along with others with anxiety, breast cancer, and diabetes to achieve and sustain a more positive outlook on life (Adams, 2007) while maintaining symptom control (Paterson, et al., 2001).

Recognizing available choices was another critical task taken by participants on the road to acceptance. Some were aware of choices already made and options available throughout their pain and acceptance journey. For others this awareness came after embarking on the acceptance journey. Still others thought they had no choice in areas such as having the pain, but believed they had choice in other areas such as how to manage it. For individuals whose awareness of choice came later, the road was tough, the journey frustrating, with feelings characteristic of nonacceptance prominent. These feelings included anger, fear, being trapped, uncertain, and hopeless. They were present prior to recognizing other ways to live with, and to respond to the pain other than the current 'no other option' approach which was largely unsatisfactory.

Participants seemed immobilized by what they perceived to be 'no other choice' with respect to litigation by believing the court case could absolutely not be terminated, decisions around employment including duties and taking time off, and toward finances including income and expenses. Beliefs one was incapable of working (Jensen, Thomsen, & Hojsted, 2006), questionable work conditions including work duties and autonomy (Raak & Wahren, 2006), involvement in litigating (Suter, 2002), and involvement in disability and compensation programs (Rippentrop, et al., 2005; Sofaer, et al., 2005) are all situations in which many individuals think their only choice is to continue a process to its completion. The negative

outcomes of this include increase in pain intensity, depression, disability (Raak & Wahren; Rippentrop; Suter), and increased life interference due to pain and poor mental health (Rippentrop). Being incapable of working, whether actual or perceived, is for many with chronic pain the "beginning of a social deroute" (p. 428) according to Jensen, et al. This in part explains the return to work focus for insurance, compensation, and disability programs.

Participants described their conscious, deliberate choice to accept the pain as well as other choices they made in conjunction with acceptance. These include, to name a few, choices to not let the pain interfere with life, to find ways to manage the pain, to end a court case, to change jobs, to end a marriage, to live on a lower income, and to live fully. Similarly individuals with diabetes described their conscious choice to avoid thinking about their diabetes and renal disease worsening (King, et al., 1990). Others with pain chose to become more active in their medical care and to participate in community activities (Borell, Asaba, Rosenbert, Schult, Townsend, 2006). Some of these choices were made by participants in this study when they realized the path they were following was doing harm, was too difficult, or that they no longer wanted to follow that path any longer. Believing there are no options, and therefore no choice, is the easier road because if no action is even possible then responsibility is not needed. The belief they are victims of circumstance may lead those with chronic pain or diabetes to adopt a victim stance. Because there is no choice they assign responsibility for feelings, thoughts, and actions to the condition (Anderson & Genthner, 1990).

Koenig (2003) states the tendency to become frustrated and angry is a choice. He notes that even not doing anything different is a choice. While that choice requires no effort, it usually leads to worsened pain. Many participants were unaware of the choices they had made such as the choice to eat out, buy ready-made foods, to take time off work, or to continue with litigation. As a psychologist I explore with clients their options, particularly when they feel they have none, and help them to become aware of their choices. However, with awareness of choices comes the challenge to then take responsibility for doing, feeling, or thinking in a different way, or at the very least acknowledge the choice to not change. Both ways are often difficult and require personal responsibility, but they can lead to freedom and increased control. One participant in deciding to live knew committing suicide would be easier. He also knew that choosing to live would require other difficult choices in order to live the way he really wanted to live, with or without pain. It was only he that could make that choice, and only he that could take on the responsibility and then assume the true benefit of this choice. Anderson and Genthner (1990) believe that no matter the circumstances, we have choices about how to think, feel, and behave. McCracken et al. (2004) state choices made in the context of acceptance allow patients to do what they value and to live meaningful lives with the pain.

Changing focus from the past, which couldn't be changed, and the present which was consumed by pain, to a focus on the future with pain was identified as an important component of the journey. This change in direction of life focus occurred while the participants were getting to know their pain by

attending to it, as previously described. The focus for participants during acceptance was no longer on finding a cure, which had been a primary goal and focus during nonacceptance. Instead, living with pain and reaching goals became their focus. One participant talked passionately about writing, teaching others to write, and playing in a band, while another described spending more time with their child. Campbell (2006) notes this focus is on feeling better and is directed to what a person with a long term illness is able to do, rather than what they are unable to do. This focus is also related to control.

When one's life focus shifted to include other areas besides the pain, setting and meeting goals became a part of living with the pain. Participants described how the relationship between setting goals and acceptance is interrelated with one influencing the other. However, one participant believed acceptance preceded setting long term goals because of the need to accept where you are in order to look forward. More important was awareness that setting goals was helpful in changing focus. The focus became directed to moving forward rather than on pain, fighting, anger, and the past which are all characteristic of nonacceptance. Raak and Wahren (2006) found working to be an important factor in helping clients focus on their abilities and future rather than on their inabilities and pain. Individuals who had returned to work six years after attending a pain rehabilitation program stated that focusing on work was a useful coping strategy (Raak & Wahren). Goal-directed behaviour including working, parenting, writing, studying, exercising, and other activities in which participants in this study were engaged, were found to be related to acceptance (Viane, Crombez, Eccleston, Devulder, & DeCorte, 2004). Viane, et al. conducted research with 501 chronic pain patients and members of a self-help group ranging in age from 25 to 92. Analysis of questionnaires and electronic diaries found those with a more accepting attitude reported a higher completion of daily activities, higher motivation, and greater participation in activities while attending less to their pain. Obviously, as difficult as it might be to return to work or engage in activities, the benefits include enhanced pain management, satisfaction, and acceptance.

The resolution of court cases emerged as influential in shifting focus and setting goals. The significance of litigation emerged with two participants on opposite sides of the litigation journey. One who was in the midst of a court case declared it was impossible to see any future until the case was resolved. Another recognized, with reflection, the power that her court case had in preventing her from seeing a future until it was settled. She also experienced the freedom of a future focus once she settled. She was aware that her entire focus during litigation was on proving her case. This involved maintaining a daily pain diary to record the severity of her pain. This preoccupation was not the same attention needed in order to learn about the pain as described. Zalewska, Miniszewska, Chodkiewicz, and Narbutt (2007) describe this as a constant preoccupation and concentration, resulting in uneasiness and passivity, which is not associated with acceptance. Any situation demanding attention to the pain detracts from a focus on the future with pain. The focus is on the present difficulty and the hopeless aspect. Such situations include insurance and disability programs or being on a wait list for diagnosis or treatment. These situations ought to be resolved as quickly as possible because the demands in these situations add to the difficulty of starting

and traveling the acceptance journey. Counselling may help those in these situations to recognize the conflict and to maximize acceptance in part by changing focus as much as possible until the situation can be resolved.

Participants adapted to limitations posed by their pain by changing the way they completed tasks and their attitude toward these modifications. Adaptations were another key element in the acceptance journey for participants of this study. One adjusted by typing with two fingers in order to continue her writing. Other adapted by increasing sleep, changing footwear, hiring personnel to do house hold chores, and discovering mutually enjoyable activities. Changing how they accomplished routine daily activities, such as sleeping on the floor rather than on a bed and altering house hold tasks, was the single most common way other individuals addressed their pain (Roberto & Reynolds, 2002). Participants said that adapting was a part of their journey. The precise relationship between adaptation and acceptance is mixed with some researchers describing adaptation as a component of acceptance (Raheim & Haland, 2006). Others report acceptance as a component of adaptation (McCracken, et al., 2004; Sofaer, et al., 2005) and possibly the first step of adaptation (Risdon, et al., 2003). Whatever the nature of the relationship, it is evident from participants' descriptions that adaptation and acceptance are related.

The terms adjustment, adaptation, and coping are used frequently and interchangeably in the chronic pain and acceptance literature. To clarify, 'adjustment' and 'adaptation' refer to the process of making a situation suitable while 'cope' and 'coping' refer to the process of managing or dealing with a situation successfully or effectively (Thompson, 1995). These definitions suggest that adjustment and adaptation refer to a process, while coping relates to an outcome. Researchers have various ways of interpreting these concepts. Esteve, Ramirez-Maestre, and Lopez-Martinez (2007) describe acceptance and coping as complimentary approaches. Acceptance was thought to be associated with coping with chronic pain (Briscoe, 2000) and as a part of adjustment (Nicholas & Asghari, 2006). Raak & Wahren (2006) found coping to facilitate adaptation to chronic pain. Participants in this study described their *adaptation* to pain in relation to their journey of acceptance. Whether called adaptation or adjustment, modifying how life is lived in order to have more predictability and stability while living with pain (Campbell, 2006) or a disability is a complex individualized process (Kralik, 2002; Wright, 1960) involving learning and time. Accommodating constraints of pain by adapting tasks and modifying goals was found to be one mode of acceptance resulting in maximized activity balanced with manageable pain (Miles, et al., 2005), minimized distress (De Vlieger, Van den Bussche, Eccleston, & Crombez, 2006; Schmitz, Saile, & Nilges, 1996), and increased well-being (Brandstadter & Rothermund, 2002).

Participants noted adapting involves both willingness and action. Willingness was identified as acknowledgment of limitations and a desire to find a new way to reach goals, if possible, or courage to change the goal. McCracken and Vowles (2006) note that "a spirit of willingness is a core feature of acceptance" (p. 91), referring to willingness to experience pain and have uncomfortable experiences. Campbell (2006) suggests willingness to adapt will be more useful and productive for managing symptoms

than anything a doctor does for a person. The experience of acceptance for participants in this study and their willingness correspond with Campbell's view since they have learned about their pain and taken responsibility for making the adaptations they feel necessary in order to minimize their pain.

The action component of adaptation involves the multiple ways participants have altered their lives in order to live with their pain. These are problem-focused coping strategies which tend to be associated with better psychological and physical functioning in contrast to emotional strategies (Jensen, Turner, Romano, & Karoly, 1991). King et al., (2002) contend that emotionally based strategies are appropriate and even required to help put an event, such as a trauma or bereavement, into perspective and into the past. This type of response, although commonly used, is not useful in situations for which there is no getting past, such as chronic illness and chronic pain. The calamity of continuing expression of emotional turmoil only serves to alienate the chronically ill from the healthy world (King et al.). This rationale explains why those with congenital disabilities adjusted better than individuals with an acquired disability (Li & Moore, 1998). The latter experienced personal loss and are likely to go through an emotional response until the journey of acceptance begins. Such people are likely to go through a similar experience to those with chronic pain, which are experiences the person with a congenital disability does not go through, at least not in the same way. Participants' own experience and the research indicate nonacceptance is an emotionally charged time, which is appropriate given the focus on 'getting over' the pain. However, once the acceptance journey begins and the focus becomes on taking control and living with the pain, problem focused adaptation becomes key.

As acceptance unfolded participants identified taking control of pain and related circumstances as important. The inability to completely remove pain from their lives was acknowledged, and countered with the belief that they had control over pain intensity and their response to it. Giving control to God was how those with these beliefs handled control. While those in litigation perceived lack of control in that area, they acknowledged control elsewhere in their lives. The search and then assertion of control was important for others with chronic pain (Anderson, 1996; Campbell, 2006; Lachapelle & Hadjistavropoulos, 2005), diabetic renal disease (King et al., 2002), AIDS (Weitz, 1989), and chronic illness (Paterson, et al., 2001). Similar to the participants in this study regarding pain, individuals with AIDS acknowledged inability to control their physical health but believed they could control their emotional health (King, et al.).

Strategies participants felt positively impacted and controlled their pain included writing letters, working, resuming a career, earning a university degree, staying active, and recognizing choices. These actions require a mind-set that control is possible in the many areas of life including the pain itself, at work and at home, and that it was up to the participant to take control. Anderson (1996) and Campbell (2006) used similar strategies to control lifestyle and maintain a positive spirit and hence control fibromyalgia and chronic fatigue syndrome, which increases confidence in managing these conditions. Residents of a nursing home who chose to exert control over day-to-day activities in their own way successfully managed their emotional health (Langer & Rodin, 1976). Taking control and realizing something can be done to alter the

pain experience is a way of unlearning learned helplessness, which Caudill (2002) notes is an attitude that develops when people are faced with uncertain and uncontrollable circumstances such as chronic pain. Participants emphasized the importance of adequate financial resources in order to live independently and maintain control. This was noted particularly by those depending on a pension. However, it is noted that not all participants of working age had these resources, or used them, and control was still possible.

Recognizing control is possible is not easy and in some situations required participant to settle a lawsuit prematurely, divorce a spouse, or change lifestyle but the eventual benefits outweighed the challenge. Working in a job with low control (Stansfeld, 2006), involvement in the legal, insurance (Walker, et al., 1999) and medical systems (Bartlett, 1990; Zalewska, et al., 2007) are potentially low control situations. But as the participants in this study indicated control is always possible, in some way, even if it is "finding ways at least to feel" (Weitz, 1989, p. 272) there is control in life.

The impact of learning about their pain and taking control of it and other life situations helped participants get back on their feet, enabling them to live independently and productively with pain. Taking control had a reciprocal and additive effect on the previously discussed choices and changes. Outcomes of taking control and making choices for individuals with chronic conditions included: facilitating adaptation and functioning (Cartwright, 2007; Sofaer, et al., 2005); reconstructing life and finding a place for illness (Kralik, 2002); sustaining control of symptoms (Paterson, et al., 2001); and reducing anxiety and achieving inner harmony (Delmar, et al., 2005).

The positive outcome of pain control and its role with acceptance described by the participants of this study and others just mentioned conflicts with the unhelpful role of control reported in a recent study by McCracken, Vowles, & Gauntlett-Gilbert (2007). These researchers had patients seeking treatment at a pain management centre complete the Chronic Pain Acceptance Questionnaire and other quantitative measures. McCracken, et al. found that attempts "to control pain, or seeking support or help" (p. 346) were associated with a decrease in functioning while an increase in control attempts were related to an increase in difficulties. Similarly, McCracken, Vowles, and Eccleston (2004) report cognitive control is unrelated to the total acceptance score and "strategies to control pain are often patently ineffective" (p.164). However, in a review article McCracken, Carson, Eccleston, & Keefe (2004) note control can be useful when it leads to an overall improvement, but that it can be problematic if the harmful effects of control outweigh the positive outcomes. Most important is what individuals with chronic pain say, which is that when it works control is beneficial, and only after a period of learning to find out what works and what doesn't. Bandura (1997) describes control as central to human lives. He states that what people believe about their ability to control has more influence on motivation, affect, and behaviour than what is found to be objectively true (Bandura). Psychologists may benefit people with chronic pain by helping them broaden awareness of areas in which control is possible, and strengthen their beliefs. The basis of Acceptance and Commitment Therapy (ACT) for pain (Dahl & Lundgren (2006) uses the analogy of 'taking back the driver's seat' for

taking control back from the pain. The aim of the ACT approach is to facilitate living with pain and taking control is one important component.

As the participants came to accept their pain they also noted inner changes and changes in their relationship with self. Participants described change within themselves in identity and values, while I as an outsider inquiring into their lives, could hear confidence and awareness in their stories. The sense of confidence, whether present all along or an outcome of the many changes and growth opportunities experienced, was particularly noticeable. This confidence was noted along with the adaptations made, level of control held, and the positive outcome of living a meaningful life with pain through acceptance. This confidence may be expressed through self-efficacy, which relates to perceptions of personal capability to exert control over life events (Bandura, 1997; Turner, Ersek, & Kemp, 2005). Self efficacy beliefs are constructed from vicarious and comparison experiences, social influence, and physiological and affective states, as well as mastery experiences which build confidence (Bandura). Higher levels of self-efficacy have been found to be associated with reductions in disease severity, depression, and pain intensity, but an increase in activity level and overall outcome for individuals with chronic pain, fibromyalgia, and disability (Attawong & Kovindha, 2005; Buchekew, et al., 1996; Turner, et al.). Attawong and Kovindha also found self-efficacy to be the most powerful predictor of acceptance of disability, while Li and Moore found self-esteem to be the most important predictor of acceptance (1998).

Recognition that participation in certain activities was no longer possible, lead participants to see themselves differently. This was particularly evident for a participant who could no longer run and another who had been out of the work force for a period of time. A changed identity was, with acceptance, a different identity. Other individuals with chronic pain describe the challenge to their identity particularly in the areas of: judgments by others, the ability to do things, and the physical changes which coexisted with the pain such as weight gain and loss of muscle mass (Miles, et al., 2005). Adjustments to challenges to identity were noted to be more difficult for those whose identity was based on performance and physical techniques (Miles, et al.). Hope helped individuals with back pain create a new identity (Corbett, et al., 2007), while participants in this study worked toward identity change through their choices to recreate a career and to discover other meaningful activities.

As participants came to accept their pain, many also came to a higher level of self acceptance. Prior to acceptance, several participants described a sense of being their own enemy by wanting to do more, not wanting to say 'no', placing undue pressure on themselves, and blaming themselves when healing and recovery did not occur. Terry (1994) explains that self-blaming surfaces in situations a person believes to be controllable which is characteristic of nonacceptance. Self blame also arises in situations in which control is known to improve a situation, but the confidence to take the control is absent. The common thought to this self-blame is self-punishment resulting in working harder and thinking negative thoughts about ourselves (Markway & Markway, 2001). But through the journey to acceptance and the taking of control, self-judgments were removed, or minimized, along with unnecessary pressure. These feelings were

replaced with kindness, patience, understanding, and acceptance of the self living with pain, in what Adams (2007) would call real self-acceptance because it involves acceptance of every aspect of the self. According to Wright (1960) a self accepting person has several qualities. These include one who assumes responsibility for behaviour and who does not deny any feelings, limitations, abilities or favorable qualities, but rather “accepts all without self-condemnation” (p. 134) including the chronic pain imposed on the self.

Chronic pain challenged participants’ long-standing core beliefs and values, leading to re-examination and change of some of these influences to acceptance. The challenge of living and working while in pain resulted in an evaluation of priorities, the role of societal pressures, and the emphasis on material possessions. Addressing these challenges necessitated recognizing a discrepancy between values and ability and was followed by a decision and a choice to live a different way. According to Campbell (2006) re-establishing priorities is important to living in general and particularly in accepting pain. Anderson (1996) notes making a decision to reset priorities requires discipline to not succumb to societal and familial pressures. As this study finds, acceptance of disability and pain is possible to the extent that a person recognizes those values that conflict with areas other than the disability itself (Dembo, et al., 1956; Wright, 1960). Similarly, McCracken and Yang (2006) found that living in line with one’s values in the areas of family, friends, intimate relations, health, growth and learning, was related to acceptance.

Along with shifting priorities and values relating to the external world, participants described evaluation of their beliefs impacting their internal world. In their internal exploration and evaluation participants challenged values learned from their family of origin. This exploration and subsequent recognition of choice made room for participants to move beyond family of origin rules which had kept them silent, suffering, and alone. With acceptance and all of the other choices and changes made, participants began to talk to family about negative and difficulty areas, including pain, which involved risking and surviving vulnerability. They also spoke about taking care of self by asking for help, seeking medical attention, taking time off work, and saying ‘no’. In all of these ways and through acceptance participants were able to join in activities and seek satisfaction in ways that befit their own characteristics, beliefs, and values “as a person rather than those of an idolized normal standard” (Wright, 1960).

Theme 5: Where the Journey has Lead . . . So Far

The fifth and final theme, portrays where the participants were at the time of their interview(s) in relation to acceptance of their pain. Participants talked about the stability or movement of acceptance and predicted how a change in pain intensity might influence it. They spoke about living with both hope and fear of their future with pain, while being able to live a meaningful life in the present. Unexpected positive outcomes of pain and of acceptance were identified, which included managing the unknown and personal growth. Finally, the experience, and the impact of participating in this study were revealed.

The participants were asked how their acceptance might change if their pain intensity increased following the interviews. This question was asked knowing that each participant, as a criterion for participating in this study, had in their own way accepted their pain. Some speculated that their acceptance

level would remain stable even though their pain might increase in the future. Others predicted their acceptance might decrease. None predicted that their acceptance would completely decline.

The interviews were carried out over a period of a few days to seven months, with three participants participating in three interviews conducted over a time span of more than five months. From the perspective of the researcher acceptance, as expressed verbally and behaviourally by the participants fluctuated during this time. Changes noted included an emphatic decision to not take time off work, increased frustration, increase in control and confidence, elevated mood, wider repertoire of coping strategies to adapt, and increased levels of self-acceptance. It is unknown how much the pain intensity changed, if at all, or in what direction, during the study period. In knowing that these reported and observed changes occurred for the participants who were all managing their pain without the assistance of pain management centres, and that the participants themselves speculate that their acceptance might fluctuate, it is critical that not too much emphasis is placed on scores from self-report measures such as the Chronic Pain Acceptance Questionnaire (CPAQ) developed by McCracken, et al. (2004) or that decisions not be singularly based on the CPAQ score. Use of the items on the CPAQ could, however, be useful to help clients with chronic pain in a therapy or counselling situation. A preliminary self-report measure was developed from the stories of these participants that more accurately reports and analyzes their acceptance experience, and that measures fluctuations in different areas. See Appendix G for a preliminary version of this measure.

In addition to accepting their pain, many participants spoke about their hopes and fears for the future. Some of these hopes and fears concerned pain directly, while others related to pain and general life circumstances. Hope was expressed that the pain would someday lessen on its own. There was also hope that it would improve due to the yet undiscovered treatments. Hope for a future without pain helped participants accept the present, making hope and acceptance inseparable, and acceptance a temporary situation. With acceptance and hope was also fear of worsening pain. With this spoken fear of the future was the unspoken implication that there would be no pain relieving treatment available and the pain would be unmanageable. Hope and fear are common in the experiences of others living with chronic conditions. Future speculation prevailed in interviews with individuals with low back pain who revealed worry and fear of the future as a central theme of their experience (Corbett, et al., 2007). Fear and doubt were also present for individuals who spoke about achieving harmony while living with a chronic illness including diabetes, colitis, and coronary occlusion, but hope and courage also arose as central elements of their experience with a sense that oscillation occurred (Delmar, et al., 2005). Acceptance of pain does not completely remove feelings of fear and hope. However, it seems acceptance diminishes the importance of fear and hope and makes oscillations less frequent.

Fear and hope also emerged in areas impacted by the pain and other life circumstances. Fear was expressed about the outcome should an infection occur with no treatment available to treat an immune deficiency condition. There was fear of the future of living with pain and disability forty years down the

road. More immediate was a fear expressed of possible decline in mental health if a leave was taken from work due to pain. With these fears was also hope that life would continue long enough to finish writing a novel and life would improve when a court case was settled. Findings show that where there is hope there is also fear. Hope and fear are intricately related to the point that either can be more prominent and powerful. Fear is seen to be the most significant hurdle to achieving hope (Groopman, 2005) and hope is also a critical antidote to fear (Jevne, 1991). While the complexity of hope and fear are beyond the scope of this discussion and are explored in the writings by Groopman and Jevne, acceptance is thought to be a prerequisite to hope according to Farran, Herth, and Popovich (1995). Acceptance is the starting point to imagining other possibilities. In contrast, Groopman thinks hope precedes acceptance but that acceptance need not eliminate hope. The process of acceptance as described by participants of this study indicate that the interplay between hope and acceptance is complex, non linear, and that the focus is on living with the pain and other life circumstances.

Chronic pain challenged participants to recognize uncertainty and the unknown, which were life realities that many seemed not to have recognized, or at least verbalized, prior to pain. Facing the unknown and uncertain with chronic pain, AIDS, renal disease, and anxiety is often a time of confusion, bewilderment, anger, fear, and sadness (Andersson & Hovellius, 2005; Corbett, et al., 2007; Grubb, 2006; King, et al., 2002; Markway & Markway, 2001; Mason, 1985; Ong, & Sim, 2006; Osborn & Smith, 1998; Richardson, Roberto & Reynolds, 2002; Weitz, 1989). These feelings arise because "human beings have a deep need to make sense of their world" (Mason, p. 1333). Uncertainty arises when people lack a cognitive framework for understanding their situation (Weitz) and hence cannot make sense of it. With this comes the realization of unpredictability and inability to control the outcome. The discomfort of realizing the pain experience is uncertain, conflicts with the certainty and therefore controllable world many believe exists.

As the journey toward acceptance unfolded and uncertainty persisted participants developed an increased familiarity and comfort with the unknown. Factors contributing to acceptance of the unknown were the combination of gaining knowledge and personal learning, the many ways adaptation occurred, recognition of choices, and believing that uncertainty need not mean difficult. All of these factors may also have decreased the uncertainty itself. Acquiring essential information reduced the uncertainty for individuals with diabetes (Mason, 1985). Similarly, uncertainty was reduced for individuals with AIDS in part because uncertainty had become "an accepted part of life" (Weitz, 1989, p. 277) and because many planned to commit suicide if warranted reducing the uncertainty of their death and maintaining a sense of control (Weitz). Practicing acceptance enabled individuals with anxiety to tolerate uncertainty (Markway & Markway, 2001). In accepting their pain participants continued to learn, hope, and live with pain while tolerating and living with uncertainty.

Personal growth accompanied and was an integral part of acceptance for several participants. With all of the choices and changes made toward acceptance, participants also saw a strengthening of their self-awareness, their confidence, and their value. They described trusting inner thoughts and feelings rather than

relying on others for validation and worth. They noted a strengthening of self-value and a return of self-esteem claimed by the pain and reclaimed with acceptance. Through reaching goals and managing pain the participants could celebrate their confidence. And, as previously described, self-acceptance was a part of pain acceptance. Koenig (2003) similarly describes how chronic pain challenges individuals to reach outward for assistance and look inward for strength. Gaining strength and confidence may be a further outcome of taking responsibility (Anderson & Genthner, 1990). Researchers noted personal strength and self-awareness evolved among individuals with fibromyalgia over a 14-month interview period (Sylvain & Talbot, 2002). This further indicates, as the data from this study have shown, that individuals with chronic pain change and grow even though the pain continues. Personal growth despite and with adversity such as the death of a friend or family member, illness, and chronic pain (Leonard & Burns, 2006) is not easy, but can be life changing and rewarding despite the challenges of the event precipitating it.

All of the participants were living a self-defined meaningful life along with acceptance, a criterion for participating in the study. Meaningful activities included the resumption or continuation of pre-pain activities and acquiring new activities to help them adapt. Giving to others and giving to self were two general ways participants' lives were made meaningful from acceptance and simply life events. Participants were giving to others by helping people with disabilities access resources, ensuring a clean floor space for babies, teaching others to write, raising their children, entertaining with a kitchen band for senior citizens, and participating in this study. Many provided support and care for friends and family, which contributed to living meaning lives. Older adults with chronic pain described helping others as a way of adapting to life with pain (Sofaer, 2005). Caudill (2002) says helping others is a part of healing and living a meaningful life.

Functioning with pain and contributing to society is often achieved through employment. The employment for participants involved teaching and helping others in many ways, and contributed to a meaningful life for them. One progressed from full time disability to full time employment. Individuals with Ehler-Danlos syndrome, a rare connective tissue disorder with chronic pain as one symptom, who were working full-time were found to have accepted their disability and pain to a greater degree than those on disability or sick leave (Berglund, Mattiasson, & Nordstrom, 2003), pointing to another benefit of work. A great source of meaning for one participant was the pride and accomplishment of writing and publishing. Returning to or continuing with pre-pain enjoyable activities such as dancing, cards and bingo, and attending church was meaningful for one participant, while another participated in physically challenging activities knowing she had strategies to manage the pain that would follow. A study rating the level of life meaning using the 'Life Attitude Profile-Revised' found that individuals with chronic pain who had a higher life meaning score also had less depression, lower levels of physical disability, and less pain (Park, 2003). While the participants in this study did not rate their pain, it is evident that living a meaningful life is an element of acceptance.

For participants in this study, the journey toward acceptance is challenging, difficult, and seemingly impossible at times. It is also a journey with an overall positive and unexpected destination. The participants philosophically recognized that life would naturally have changed them, but they also believed that pain, and particularly acceptance was a catalyst for change in a direction that would not have occurred if not for the pain. Acceptance reduced the struggle of living with pain. It also leads to increased strength, confidence, and freedom, while reducing the disruption and uncertainty pain brought. Increase in faith and feeling like a better person were other outcomes of acceptance. Participants spoke about feeling lucky for the support and grateful for the pain knowing that with acceptance life could be lived meaningfully with pain. These outcomes were similar to the outcomes reported by individuals with spinal cord injury who had accepted their injury and were living healthy, happy, and active lives (Attawong & Kovindha, 2005). Individuals with AIDS who came to accept their diagnosis and their life with the disease reported less stress, less uncertainty, and reduced fear as well as a focus to live for the present with a goal of living with pleasure (Weitz, 1989). Similarly, individuals with chronic illness described developing harmony with the self as a form of, and movement toward acceptance (Delmar, et al., 2005). Harmony, to the individuals with diabetes, colitis, and coronary occlusion, included hope, a spirit of living, and courage (Delmar, et al.). These important outcomes of acceptance show that the participants in this study have all learned to live with their pain—the task given to many of them by professionals—in their own time and way.

Given these outcomes of acceptance, the fluctuation noted by the participants in their acceptance, and the many changes comprising acceptance, it seems that development of a self-report measure that incorporates these ideas is needed. Such an instrument could then be used, not necessarily to measure acceptance, but as a way to facilitate further acceptance in areas appropriate and achievable for those with pain. This measure was developed based on the results of this study. See Appendix G for the first draft.

From the perspective of the researcher, an outsider, the outcomes of acceptance for participants in this study reaches beyond their responses. During interviews I heard about changed and stronger marital and familial relationships with more effective communication and greater understanding. I heard about establishment of other relationships, both professional and personal, many of which continue and which offer encouragement, support, and understanding. I heard about all that participants learned and had changed, leading to increased confidence, setting and reaching of goals, re-setting of values and priorities, and increased awareness of living in the moment rather than the future.

These outcomes of acceptance are, as identified by Hamburg and Adams (1965) encompassed by the essential adaptive tasks of adjustment to major life events, including pain and illness. The tasks fall into the areas of cognition, emotion, physical, and behaviour. Improved mental health and well-being, positive mood, and retaining purpose in life were identified as other positive outcomes of acceptance (McCracken, Vowles, & Eccleston, 2005; Raheim & Haland, 2006; Stanton, et al., 2007; Van Damme, Crombex, Van Houdenhove, Mariman, & Michielsen, 2006; Viane, et al., 2003).

Participants commented on participating in this study including review of their transcripts. The majority commented about the unintended outcomes of talking about their acceptance. Individuals in this study and those in a study by Sofaer, et al., (2005) described the interviews as therapeutic. Coyle and Tickoo (2007) acknowledge that a therapeutic feeling is a common outcome of the qualitative interview process. The outcomes of participating, which participants said mirrored therapy, included increased self-awareness, reinforced beliefs about self and values, and identification of strengths. Through talking about their challenges during acceptance participants gained appreciation for what they had gone through and their current situation. Talking about the experience brought back their anger, but it also allowed participants to see what they accomplished and to feel pride with this realization. For those in the study by Sofaer, et al. (2005) and for the participants in this study, this was likely the first opportunity to speak in-depth, frankly, and openly about their journey. For many it was a chance to share their success related to coping and acceptance with another person. One person noted an increase in pain while talking about her pain, but she knew that this would be temporary. All other outcomes of participating described were positive.

Significance of the Study

This study is significant for several reasons. First, it contributes significantly to the understanding of acceptance of chronic pain. Second, this study projects the voices, stories, and experiences of individuals with chronic pain who have accepted their pain and are living not just with their pain, but living meaningfully. Third, this study highlights the importance of interpersonal interactions and relationships on acceptance. Fourth, since none of the participants had or were currently attending a pain management centre, this study offers insight into a natural journey toward acceptance. Finally, this study makes a contribution to the base of qualitative, naturalistic, research on the acceptance of chronic pain.

First, this study presents an in-depth understanding of acceptance of chronic pain, the experience, and the outcome. Specifically, the essence of acceptance is that acceptance is a journey with a unique language and attitude. Interactions with family, friends, professionals, and others have the power to both facilitate and inhibit acceptance – to help and hinder. The journey toward acceptance takes time, perhaps a life time, and involves many steps which only each participant could take. These steps involve learning, responsibility, focus, adaptation, control, values, and the self. The outcomes of acceptance include living a meaningful life along with hope, fear, and uncertainty that pain and life presents. Confidence and experiential knowing that living with the pain is possible is another important outcome. This rich understanding of acceptance clearly contributes to the literature in this area.

Second this study has arisen from the participants themselves sharing their challenges and victories toward acceptance. It is hoped that these stories will reach others with chronic pain, providing encouragement, guidance, and hope. According to the Canadian Pain Society (2007), 33 percent of Canadians have chronic pain and are trying to discover how to 'live with their pain,' as many are directed to do from their physician.

Third, the influence of personal interactions and relationships on acceptance became apparent through the experiences of the participants. Interactions with family, friends, professionals, co-workers, supervisors, and many others were found to facilitate and also inhibit acceptance through support, communication, being believed, the response to chronicity, and sharing of experiences. Professionals are usually in a role to guide, encourage, and support, as opposed to family and friend who have other roles. It is hoped that an awareness of the power that their words as professionals hold in interactions with people with chronic pain might lead to more facilitative interactions. As an emerging psychologist, from this study and my own experience during internship at a rehabilitation centre, I have become aware and more responsible as to my choice of words.

Fourth, this study makes a unique, unexpected contribution to the knowledge base of acceptance since the sample of participants might be considered 'non-clinical'. None had or were planning to attend a pain management centre and for the most part had reached acceptance on their own. This was realized after data collection was complete. Of the ten individuals in this study only one had, or was, receiving treatment from a pain specialist. Participants in this study are among the 95 to 97.5 percent of people with pain who do not seek treatment from pain specialists (Turk, 2005). Given that many of the studies reviewed were based on individuals seeking treatment from pain management centres, this study makes a unique contribution to acceptance.

Fifth, the concept of acceptance of chronic pain is a growing area of research, and qualitative research is gaining popularity as an appropriate paradigm through which to explore it. Since there is an abundance of literature investigating pain and acceptance within the quantitative paradigm, this study contributes further toward the literature by presenting the experience of acceptance from a naturalistic base of inquiry.

Participants' Recommendations

Participants were asked what they would like to say to other people with chronic pain. Responses generally indicated that each person needs to move toward acceptance on their own time and in their own way. Ginnie emphasized the importance of having an understanding physician. Ginnie:

If there's anything about your medical professional people, whoever they happen to be, that is not quite feeling comfortable, then just go find somebody else that makes you feel comfortable and is interested in helping, not judging.

She added that having a physician who doubted her pain would lead to "a downward spiral especially if you don't have the greatest sort of ego in the first place. I would be folding up, quitting." This doubt might lead a person to "guess there is something wrong with me, or I am losing my mind because this professional says so. Well, no, that professional is an idiot, go find a good one."

Janice reflected on what would have facilitated her movement toward acceptance:

Looking back, I think I needed somebody to sit down and talk with me and say 'Yes, your pain is real, and let's talk about what we can do to help you learn to accept to live with your pain'.

Implications

This study makes a contribution to the field of health psychology in general, and to the treatment and management of chronic pain specifically. It has implications for health care professionals particularly psychologists, individuals with chronic pain, and for future research.

Implications for individuals with chronic pain

Several implications from this study emerged for individuals with chronic pain as well as other conditions for which there is no cure. First, this study provides support to individuals who are directed, or who realize on their own to 'learn to live with their pain' which many with chronic pain are instructed to do this (Kotarba, 1983; McCracken, 1998). This study provides insight of what this means and how this might be a way to live more meaningfully with their pain.

Another implication is that acceptance doesn't necessarily require one to give up searching and hoping for a cure for pain. Rather, acceptance allows a person to focus on the present, which is within their control, rather than on the future or the past, both of which are out of controls' reach. In this way, acceptance allows for life to be lived now, rather than when the miracle cure appears, which rarely happens.

The results of this study reveal the many ways the participants changed and the choices they had available to them when they decided to accept their pain. The significance of this finding is that each person, regardless of their situation or condition, has choices enabling each to have less overall suffering even if the condition or pain situation does not change.

Acceptance of chronic pain is clearly a long term, if not lifelong, process. To facilitate acceptance participants identified the importance of having supportive relationships with family, friends, and professionals who encouraged and validated. They also spoke about the learning, discovery, patience, and self-acceptance, which slowly evolved over months and years. The challenge with any journey is to keep the goal in mind and to maintain persistence. This often requires more than one attempt, and most often necessitates continuous moment to moment adjustments. Approaching chronic pain with these expectations will hopefully facilitate the journey.

Implications for Psychologists and Health Care Professionals

A number of implications for psychologists and other health care providers may be drawn from this study. One of the most important outcomes from interactions with professionals for those with pain relates to being believed, validated, and understood rather than judged. This stance provides the foundation for facilitating acceptance; only when one is able to acknowledge where they are, are they able to move forward with acceptance or any other change. Doubt closes doors while believing clients facilitates a relationship, which then opens the door for support, guidance, and encouragement.

Participants emphasized the importance of learning from others, including professionals, and from their personal experiences. Receiving a diagnosis is an important aspect of this learning (Kralik, et al.,

2001) and facilitates understanding and acceptance of the condition. Participants found explanations of the physiology of pain demeaning, but strategies focusing on the pain itself were helpful.

Acceptance of chronic pain requires a problem or solution focused approach (Dysvik, et al., 2005; King, et al., 2002; Lillrank, 2003) rather than an emotional response. This is because chronic pain is a condition for which there is no getting over. Psychologists are able to assist a person with chronic pain to acknowledge the emotional impact of pain and to gently guide the person toward a problem focused approach. Psychologists are in a position to encourage individuals to learn and develop ways of adapting to and managing their pain.

Recognition of options and the role of choice is an essential component of acceptance. Participants had difficulty identifying their choice and the role of decision earlier in their journey, particularly when they were in the midst of a lawsuit, disability claim, or receiving insurance or disability benefits. Resolution of these situations facilitated acceptance. Psychologists are able to help with identification of choices and encourage decision-making.

The idea that acceptance is a journey requiring time emerged both from the data and from the process of this study. During data collection there was a six-month time gap between interviews with one participant. Both the participant and the researcher observed significant changes and progress toward further acceptance, clearly demonstrating that acceptance takes time and is a process that needs to be experienced in order to benefit from the learning. Acknowledging the time factor has significant implications for pain management programs which are usually time limited, sometimes lasting a few weeks, and which then do not provide the client with ongoing support. A more beneficial program would include a brief period of intense education and orientation followed by months or even years of ongoing support. This support, according to Miles, et al., (2005) is essential to facilitating adaptation to the constraints of pain. The length of participants' successful but solitary journey is evidence of this time factor. Given that only one participant relied on government disability assistance for financial support it seems that acceptance facilitates maintaining employment status resulting in a cost benefit over the longer term.

Finally, it is essential that professionals understand acceptance as a process involving behaviour, thoughts, and emotions, and that can take months and years, not days or weeks. There might be the tendency for professionals to 'give up' on individuals because they are not 'getting better' or 'healing fast enough'. Understanding that acceptance is a journey of a series of required steps that take time to show progress may enable the psychologist to work with the person where they are, not where they want them to be.

Implications for future research

Several areas for future research emerged from this study. First, because the participants, as indicated, might be considered a 'non-clinical' population in that none had received treatment from a pain

management centre, future research might inquire about acceptance of pain from individuals who had received treatment in order to gain information on the influence of treatment on the journey.

Another area of research could focus on a similar population of individuals who have accepted their pain and include self-report measures to elicit a score of acceptance. These measures would include a self-report questionnaire on acceptance developed directly from this study (Appendix G), the Chronic Pain Acceptance Questionnaire, and a pain intensity measure. This direction for future research arises from the suggestion that the pain intensity and impact of pain for this 'non-clinical' population is not as severe as that of individuals who are actively seeking treatment. This suggestion may or may not be accurate because of the progress made by the participants in this study toward acceptance. However, future research might verify or discredit this idea.

Future research that focuses on specific groups, non-clinical and clinical, would yield further understanding of acceptance. As indicated, some of the participants were retired while others of working age. Research directed at both or either of these groups would add to understanding regarding developmental circumstances and acceptance. Five of seven participants of working age were working full time. Research inquiring into the employment status might identify factors that facilitate acceptance and maintain employment at a deeper level than this research revealed. Similarly, one participant was receiving full-time disability benefits. Another was working part-time and receiving part-time disability benefits which together resulted in full income. This income together with her workplace benefits facilitated acceptance for her, and she had no plans to alter this arrangement. Future research targeted at these groups would be helpful.

Research acquiring longitudinal data is likely to elicit further understanding of the evolution of acceptance as it is unfolding. Data from this study were acquired over a total of nine months, with individual processes including introduction, interviews, and transcript review spanning up to eight months. This unplanned, long-term process afforded participants the opportunity to note changes and advancement in their acceptance journey. Only one participant, noted significant progress toward acceptance during the study process.

Finally, research that expands on components of the journey identified in this study including choices, changes, focus, adaptation, and values would be of benefit. Expanding on the essence of acceptance such as the attitude and language of acceptance would contribute further to understanding acceptance, as would be a specific focus on the steps comprising acceptance.

Reflections

This final section offers me the opportunity to reflect on my research journey and how it has intermingled with the other parts of my life; coexisting journeys. I realized the many ways my journey has paralleled the participants' journey of acceptance. A major difference, of course, is that my research decision was preceded by the choice to pursue post-secondary education, but these decisions came out of my own pain experience. Participants did not choose to travel the pain journey, but they did make a

decision to move toward acceptance. Participating in this study evolved from their choice to accept. Each of their decisions to participate and share with me intimate details about the struggles and successes, the sad times, the angry, and the satisfying times, made this study possible. I am grateful for their trust, honesty, and willingness to tell their stories. I endeavoured to honour and respect each participant and their story to the highest degree possible and I hope that my writing reflects this intention.

The journey of completing this project was not a solitary one, even though it was I who wrote the words. As with the journey of acceptance for the participants, some of my relationships strengthened while others gradually dissolved as an outcome of my evolution as a person and a professional. Like acceptance there were particular interactions which impacted the process, including being contacted by persons to participate in the study, or so I thought, but realizing they were in fact seeking help with their chronic pain. Other interactions included spending time listening to the stories, receiving encouragement from committee members who never doubted I would finish even though it took a long time. Communicating my frustration, and acknowledging my fears to others, including committee members, although difficult, facilitated connection and ultimately completion.

This project presented me with many opportunities that have lead me to be the person I am today and contributed to my reaching this point. I constantly reminded myself that only I could complete this task and so it was my responsibility and my choice to assume such. As with acceptance, I learned through the formal channels of learning—reading and the writing. I also learned through personal experience, which included a one year pre-doctoral internship at an outpatient rehabilitation centre as a psychology intern. My personal learning came from the many days sitting before the computer, but also runs along the river, sometimes with my supervisor, sometimes not, in Saskatoon and Edmonton. During those times, my supervisor would reassure me that I was indeed ‘working’ on this dissertation along the way. Other learning venues were in coffee shops with my supervisor and committee members and in counselling rooms where I was doing my best to assist others.

The choices and decisions to be made were ongoing. Initially there was the decision to explore chronic pain and ultimately the decision to focus on acceptance. Once the study was underway, I made choices on how to carry out the interviews, by phone or in-person, where to meet the participant and how far to extend myself to have them participate. One requested I travel out of province to meet before agreeing to participate. Financial assistance allowed me to do this. When the interview process for this person extended to several months and receiving no reply to my numerous inquiries regarding the transcript review, I had a choice. My decision to stop pursuing this participant was guided by the ethical considerations of this study stating that participants were free to withdraw. After fourteen months had passed without receiving the transcripts, I concluded the participant’s actions indicated withdrawal from the study.

The many choices continued as the interviews were conducted and tapes transcribed all leading to data analysis. The use of a computer program greatly facilitated analysis, but I sensed all along that in

comparison to my master's thesis where I transcribed the tapes myself and analyzed the data without a program, I was somewhat removed from the data. Following computer analysis I decided to continue deeper analysis using the constant comparative method which lead to the results presented. This choice made the journey longer, but allowed me to maintain the integrity of my research to the degree I felt it warranted.

Throughout this process I was challenged with keeping my focus given the many opportunities for pursuing other challenges. These opportunities which necessitated choices included hiking, canoeing, traveling, pursuing employment, and life, all of which tempted me, sometimes successfully, to take my focus off this journey. This change of focus of course did not last and somehow, miraculously it seems, I held my focus long enough to get to this point.

As with the participants who grew in their self-acceptance and who re-evaluated values and priorities, I can see that this has also been an unexpected outcome of my journey. It is impossible to separate the changes of being in school and completing this research from where my life might have lead if not for an accident, and the decision to become a psychologist. Some of the changes I see in myself are noticeable externally while others are more subtle and private. For example, others will note that I now practice yoga and meditation, and I am a vegetarian as my heart will not allow me to eat anything that has lost its life to be on my plate. Family and friends also observe that my way of living is more focused on relationships not things, on being in the moment more than the future, and trying to see the best in others. Is this different? Maybe and maybe it has just become more obvious. From the inside I am more patient and understanding with myself. My confidence in certain areas has increased and it continues to develop in others—like a journey.

My own journey with pain and acceptance has also been influenced. I am able to identify the similarities between my journey and those of the participants, not because I told my story but because I listened to theirs. I know my pain better than ever to the extent that last summer I participated in one component of the sport (triathlon) I had given up a few years ago due to my injury. Participating in this race was made more memorable because my supervisor and a committee member also, coincidentally, participated in it. And, like the participants, I am not sure where my pain journey will go, but I know that it will come with me, not I with it.

The essence of qualitative research is that each person who reads this dissertation will connect with the findings in their own way and capture what is meaningful. I am proud to have worked with ten insightful and committed participants during the creation of this dissertation. I am humbled and thankful for their willingness to reflect and share with me their experience of acceptance.

REFERENCES

- Adams, L. (2007). *Accepting yourself as you are*. [Www.gordontraining.com/family-free-resources.html](http://www.gordontraining.com/family-free-resources.html).
- Adams, L. (2007). *Taking personal responsibility*, www.gordontraining.com/family-free-resources.html.
- American Pain Society (1999). *Chronic Pain in America: Roadblocks to relief*. Retrieved 28/08/04 from www.ampainsoc.org/whatsnew/forward_road.htm.
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., rev.). Washington, DC: Author.
- Anderson, D. (1996). Acceptance, Discipline & Hope: A Story of Recovery from CFIDS. *CFIDS Chronicle*, Winter, p3.
- Anderson, R. M. & Genthner, R. W. (1990). A guide for assessing a patient's level of personal responsibility for diabetes management. *Patient Education and Counseling*, 16, 269-279.
- Andersson, S. I. & Hovellius, B. (2005). Illness-related complaints in women with chronic widespread pain: importance of a contextual approach. *Stress and Health*, 21, 235-244.
- Aronoff, G. M. (1985). Psychological aspects of nonmalignant pain: A new nosology. In G. M. Aronoff (Ed.), *Evaluation and treatment of chronic pain* (pp. 471-484). Baltimore: Urban & Schwarzenberg.
- Aronoff, G. & Feldman, J. (2000). Preventing disability from chronic pain: A review and reappraisal. *International Review of Psychiatry*, 12, 157-169.
- Arthur, A. R. & Edwards, C. (2005). An evaluation of support groups for patients with long-term chronic pain and complex psychosocial difficulties. *European Journal of Psychotherapy, Counselling, and Health*, 7, 169-180.
- Attawong, T. & Kovindha, A. (2005). The influencing factors of acceptance of disability in spinal cord injured patients. *Nepal Journal of Neuroscience*, 2, 67-70.
- Bach, P. & Hayes, S. C. (2002). The use of Acceptance and Commitment Therapy to prevent rehospitalization of psychotic patients: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, 70, 1129-1139.
- Bandura, A. (1997). *Self-efficacy: The Exercise of Control*. New York: W. H. Freeman and Company.
- Bartlett, E. E. (1990). Putting patient education back into control. *Patient Education and Counseling*, 16, 185-186.
- Bass, C., Peveler, R., & House, A. (2001). Somatoform disorders: severe psychiatric illnesses neglected by psychiatrists. *British Journal of Psychiatry*, 179, 11-14.
- Bedell, S. E., Graboys, T. B., Bedell, E. & Bown, B. (2007). Words that harm, words that heal. *Archives of Internal Medicine*, 164, 1365 - 1368.

- Beisser, A. R. (1970). The paradoxical theory of change. In J. Fagan & I. L. Shepherd (Eds.), *Gestalt Therapy Now* (pp. 77-80). Palo Alto, CA: Science and Behaviour Books, Inc.
- Bellissimo, A. & Tunks, E. (1984). *Chronic Pain: The Psychotherapeutic Spectrum*. New York: Praeger Publishers.
- Berglund, B., Mattiasson, A. C., & Nordstrom, G. (2003). Acceptance of disability and sense of coherence in individuals with Ehlers-Danlos Syndrome. *Journal of Clinical Nursing*, 12, 770-777.
- Bland, E. & Henning, D. (2002). *Finding meaning in chronic pain: The dynamics of acceptance*. Paper presented to the Senate Standing Committee on Social Affairs, Science and Technology by the Ontario Psychological Association.
- Bogdan, R. C., & Bilken, S. K. (1998). *Qualitative research in education: An introduction to theory and methods*. Needham Heights, MA: Allyn & Bacon.
- Borell, L., Asaba, E., Rosenberg, L., Schult, M. L., & Townsend, E. (2006). Exploring experiences of "participation" among individuals living with chronic pain. *Scandinavian Journal of Occupational Therapy*. 13, 76-85.
- Bradshaw, M. (2001). Contracts and member checks in qualitative research in human geography: Reason for caution? *Area*, 33 (2), 202-211.
- Brandtstadter, J. & Rothermund, K. (2002). The life-course dynamics of goal pursuit and goal adjustment: A two-process framework. *Developmental Review*, 22, 117-150.
- Briscoe, D. E. (2000). The experience of coping with chronic pain: A phenomenological investigation. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 61(1-B), July, 522.
- Buckelew, S. P., Huyser, B., Hewett, J. E., Parker, J. C., Johnson, J. C., Conway, R., & Kay, D. R. (1996). Self-efficacy predicting outcome among fibromyalgia subjects. *Arthritis Care and Research*, 9, No.2, 97-104.
- Campbell, B. (2006). *The Patient's guide to Chronic Fatigue Syndrome and Fibromyalgia*.
www.cfidselfhelp.org/
- Canadian Pain Society (2006). *Establishing Acceptable Waiting Times for Treatment of Pain in Canada.. Brief Summary of the Findings of the Canadian Pain Society Wait Times Task Force October 19, 2006*. Whitby, ON., Canadian Pain Society. www.canadianpainsociety.ca/waittimes.
- Canadian Pain Society (2007). 1 in 3 Canadians now living with chronic pain. *News Release November 7, 2007*, www.newswire.ca/en/releases/archive/November2007/07/c5109.html
- Carter, B. (2002). Chronic pain in childhood and the medical encounter: Professional ventriloquism and hidden voices. *Qualitative Health Research*, 12, 28-41.
- Cartwright, T. (2007). 'Getting on with life': The experiences of older people using complementary health care. *Social Science & Medicine*, 64, 1692-1703.
- Caudill, M.A. (2002). *Managing Pain Before it Manages You (Rev. Ed.)*. The Guilford Press: New York.

- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA: Sage Publications Inc.
- Colledge, R. (2002). *Mastering counselling theory*. New York: Palrave MacMillan.
- Corbett, M., Foster, N.F., & Ong, B. N. (2007). Living with low back pain – Stories of hope and despair. *Social Science & Medicine*, 65, 1584-1594.
- Coyle, N. & Tickoo, R. (2007). Qualitative research: What this research paradigm has to offer to the understanding of pain. *American Academy of Pain Medicine*, 8, No. 3, 205-206.
- Creswell, J. W. (1994). *Research design: Qualitative and quantitative approaches*. Thousand Oaks, CA: SAGE Publications, Inc.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications Inc.
- Dahl, J. & Lundgren, T. (2006). *Living Beyond Your Pain: Using Acceptance & Commitment Therapy to Ease Chronic Pain*. New Harbinger Publications, Inc., Oakland, CA.
- Degood, DE, Kiernan, B. (1996). Perception of fault in patients with chronic pain. *Pain*, 64, 153-159.
- Delbanco, T.L. (1992). Enriching the doctor-patient relationship by inviting the patient's perspective. *Annals of Internal Medicine*, 116, 414-418.
- Delmar, C., Boje, T., Dylmer, D., Forup, L. Jakobsen, C., Moller, M., Sonder, H., & Pedersen, B. (2005). Achieving harmony with oneself, life with a chronic illness. *Scandinavian Journal of Caring Science*, 19, 204-212.
- Dembo, T., Ladiou-Leviton, G., & Wright, B. A. (1956) Adjustment to Misfortune: A problem of social-psychological rehabilitation. *Artificial Limbs*, 3, 4-62.
- De Ridder, D., Depla, M., Severens, P., & Malsch, M. (1997). Beliefs on coping with illness: A consumer's perspective. *Social Science and Medicine*, 44, 553-559.
- de Rivera, J. (1984). Emotional experience and qualitative methodology. *American Behavioral Scientist*, 27 (6), 677-688.
- De Vlieger, P., Van den Bussche, E., Eccleston, C., & Crombez, G. (2006). Find a solution to the problem of pain: Conceptual formulation and the development of the Pain Solutions Questionnaire (PaSol). *Pain*, 123, 285-293.
- Dougher, M. J. (1994). The act of acceptance. In S.C. Hayes, N.S. Jacobson, V. M. Follette, & M. J. Dougher (Eds.), *Acceptance and change: Content and context in psychotherapy* (pp. 37-45). Reno, NV: Context Press.
- Dysvik, E., Natvig, G. K., Eikeland, O. J., & Lindstron, T. C. (2005). Coping with chronic pain. *International Journal of Nursing Studies*, 42, 297-305.
- Eccleston, C., & Crombez, G. (1999). Pain demands attention: A cognitive-affective model of the interruptive function of pain. *Psychological Bulletin*, 125, 356-366.

- Eimer, B. N. & Freeman, A. (1998). *Pain management psychotherapy: A practical guide*. Toronto: John Wiley & Sons, Inc.
- Erlanson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). *Doing Naturalistic Inquiry: A Guide to Methods*. Sage Publications International Educational and Professional Publisher: London.
- Esteve, R., Ramirez-Maestre, C., & Lopez-Martinez, A. E. (2007). Adjustment to chronic pain: The role of pain acceptance, coping strategies, and pain-related cognitions. *Annals of Behavioral Medicine*, 33(2), 179-188.
- Farran, C., Herth, K., & Popovich, J. (1995). *Hope and Hopelessness: Critical Clinical Constructs*. Sage Publication, Thousand Oaks, CA.
- Fernandez, E. & Turk, D. C. (1995). The scope and significance of anger in the experience of chronic pain. *Pain*, 61, 165-175.
- Fishbain, D. A. (2000). Non-surgical chronic pain treatment outcome: a review. *International Journal of Psychiatry*, 12, 170-180.
- Fontana, A., & Frey, J. H. (1994). Interviewing: The art of science. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 361-376). Thousand Oaks, CA: Sage Publications, Inc.
- Fordyce, W. E. (1976). *Behavioral methods for chronic pain and illness*. Saint Louis, MO: The C.V. Mosby Company.
- Frank, A. W. (1991). *At the will of the body: Reflections on illness*. Boston: Houghton Mifflin.
- Frank, J., Sinclair, S., Hogg-Johnson, S., Shannon, H., Bombardier, C., Beaton, D. & Cole, D. (1998). Preventing disability from work-related low-back pain. *CMAJ: Canadian Medical Association Journal*, 158, 1625-1631.
- Frankl, V. E. (1959). *Man's search for meaning*. Toronto: Pocket Books.
- Frantsve, L. M. & Kerns, R. D. (2007). Patient-provider interactions in the management of chronic pain: Current findings within the context of shared medical decision making. *Pain Medicine*, 8, 25-35.
- Glaser, B. G., & Strauss, A. L. (1973). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine Publishing Company.
- Glesne, C., & Peshkin, A. (1992). *Becoming qualitative researchers*. White Plains, NY: Longman.
- Goetz, J. P. & LeCompte, M. D. (1984). *Ethnography and qualitative design in educational research*. Orlando, FL: Academic Press.
- Gordon, T. (2007). *The Power of the Language of Acceptance*, www.gordontraining.com/family-free-resources.html.
- Grady, K. M. & Severn, A. M. (1997). *Key topics in chronic pain*. Herndon, VA: BIOS Scientific Publishers.
- Green-Bush, E., Rye, M.S., Brant, C. R., Emery, E., Pargament, K. I., & Riessinger, C. A. (1999). Religious coping with chronic pain. *Applied Psychophysiology and Biofeedback*, 24, 249-260.

- Greenburg, L. (1994). Acceptance in experiential therapy. In S.C. Hayes, N.S. Jacobson, V. M. Follette, & M. J. Dougher (Eds.), *Acceptance and change: Content and context in psychotherapy* (pp. 53-67). Reno, NV: Context Press.
- Groopman, J. (2005). *The Anatomy of Hope: How People Prevail in the Face of Illness*. Random House: New York.
- Grubb, C. S. (2006) Uncertainty, disability and pain as predictors of worry and pain acceptance among chronic pain patients. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 67(2-B), 1148.
- Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage Publications, Inc.
- Hamburg, D. A. & Adams, J. E. (1967). A perspective on coping behavior: Seeking and utilizing information in major transitions. *Archive of General Psychiatry*, 17, 277-284.
- Hardy, P. A. (1997). *Chronic Pain Management: The Essentials*. New York: Oxford University Press.
- Hayes, S.C. (1994). Content, context, and the types of psychological acceptance. In S.C. Hayes, N.S. Jacobson, V. M. Follette, & M. J. Dougher (Eds.), *Acceptance and change: Content and context in psychotherapy* (pp. 13-32). Reno, NV: Context Press.
- Hayes, S. C., Bissett, R. T., Korn, Z., Zettle, R. D., Rosenfarb, I. S., Cooper, L. D., & Grundt, A. M. (1999a). The impact of acceptance versus control rationales on pain tolerance. *The Psychological Record*, 49, 33-47.
- Hayes, S. C., Stosahl, K. D., & Wilson, K. G. (1999b). *Acceptance and commitment therapy: An experiential approach to behaviour change*. New York: Guilford.
- Hayes, S. C., Stosahl, K. D., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., Polusny, M. A., Dykstra, T. A., Batten, S. V., Bergan, J., Stewart, S. H., Zvolensky, M. J., Eifert, G. H., Bond, Forsyth, J. P., Karekla, M., & McCurry, S. M. (2004). Measuring experiential avoidance: A preliminary test of a working model. *The Psychological Record*, 54, 553-578.
- Henriksson, C. M., Liedberg, G. M., & Gerdle, B. (2005). Women with fibromyalgia: Work and rehabilitation. *Disability and Rehabilitation*, 27, 685-695.
- Holstein, J. A., & Gubrium, J. F. (1995). *The active interview*. Thousand Oaks, CA: Sage Publication, Inc.
- Holstein, J. A., & Gubrium, J. F. (1998). Phenomenology, ethnomethodology, and interpretive practice. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 137-157). Thousand Oaks, CA: SAGE Publications Inc.
- Holtzman, S., Newth, S., & DeLongis, A. (2004). The role of social support in coping with daily pain among patients with rheumatoid arthritis. *Journal of Health Psychology*, 9, 677-695.

- Hutchinson, S., & Wilson, H. (1994). Research and therapeutic interviews: A poststructuralist perspective. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 300-315). Thousand Oaks, CA: SAGE Publications, Inc.
- Jacobson, N. S. (1992). Behavioral couple therapy: A new beginning. *Behaviour Therapy*, 23, 493-506.
- Jansen, L. A. (2001). Deliberative decision making and the treatment of pain. *Journal of Palliative Medicine*, 4, 23-30.
- Jensen, M. K., Thomsen, A. B., & Hojsted, J. (2006). 10-year follow-up of chronic non-malignant pain patients: Opioid use, health related quality of life and health care utilization. *European Journal of Pain*, 10, 423-433.
- Jensen, M. P., Turner, J. A., Romano, J. M., Karoly, P. (1991). Coping with chronic pain: A critical review of the literature. *Pain*, 47, 249-293.
- Jensen, M. P., Nielson, W. R., Turner, J. A., Romano, J. M., & Hill, M. L. (2003). Readiness to self-manage pain is associated with coping and with psychological and physical functioning among patients with chronic pain. *Pain*, 104, 529-537.
- Jevne, R. F. (1991). *It All Begins with Hope*. Luramedia: San Diego, CA.
- Kabat-Zinn, J. (1982). An outpatient program in behavioural medicine for chronic pain patients based on the practice of mindfulness meditation: theoretical-considerations and preliminary results. *General Hospital Psychiatry*, 4, 33-47.
- Kabat-Zinn, J. (1990). *Full catastrophe living: Using the wisdom of the body and mind to face stress, pain, and illness*. Bantam Dell: New York.
- Kabat-Zinn, J. (2002). At home in our bodies. *Tricycle: The Buddhist Review*, 46, 34-36.
- Kabat-Zinn, J., Lipworth, L., & Burney, R. (1985). The clinical use of mindfulness meditation for the self-regulation of chronic pain. *Journal of Behavioral Medicine*, 8, 163-190.
- Kabat-Zinn, J., Lipworth, L., Sellers, W., Brew, M., & Burney, R. (1984). Reproducibility and four year follow-up of a training program in mindfulness meditation for the self-regulation of chronic pain. *Pain*, 18, S303.
- Katz, J.D. (2004). Pain does not suffer misprision: An inquiry into the presence and absence that is pain. *Journal of Medical Ethics; Medical Humanities*, 30, 59-62.
- Keefe, F. J., Rumble, M. E., Scipio, C. D., Giordano, L. A., & Perri, L. M. (2004). Psychological aspects of persistent pain. Current state of the science. *The Journal of Pain*, 5, 195-211.
- Keel, P. (1999). Pain management strategies and team approach. *Bailliere's Clinical Rheumatology*, 13 (3), 493-506.
- King, N., Carroll, C., Newton, P., & Dornan, T. (2002). "You can't cure it so you have to endure it": The experience of adaptation to diabetic renal disease. *Qualitative Health Research*, 12 (3), 329-346.
- King, S. A. (1995). Review: DSM-IV and pain. *The Clinical Journal of Pain*, 11, 171-176.
- King, S. (2000). The classification and assessment of pain. *International Review of Psychiatry*, 12, 86-90.

- Knish, S. & Calder, P. (1999). Beliefs of chronic low back pain sufferers: A concept map. *Canadian Journal of Rehabilitation, 12*, 167-179.
- Koch, T. & Kralik, D. (2001). Chronic illness: Reflections on a community-based action research programme. *Journal of Advanced Nursing, 36*, 23-91.
- Koenig, H.G. (2003). *Chronic pain: biomedical and spiritual approaches*. The Haworth Pastoral Press: New York.
- Kotarba, J. A. (1983). Perceptions of death, belief systems and the process of coping with chronic pain. *Social Science & Medicine, 17*, 681-689.
- Kralik, D. (2002). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing, 39*, 146-154.
- Kralik, D., Brown, M., & Koch, T. (2001). Women's experiences of 'being diagnosed' with a long-term illness. *Journal of Advanced Nursing, 33*(5), 594-602.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: SAGE Publications, Inc.
- Lachapelle, D. L. & Hadjistavropoulos, T. (2005). Age-related differences among adults coping with pain: Evaluation of a developmental life-context model *Canadian Journal of Behavioural Science, 37*(2), 123-137.
- Langer, E. J. & Rodin, J. (1976). The effects of choice and enhanced personal responsibility for the aged: A field experiment in an institutional setting. *Journal of Personality and Social Psychology, 34*, 2, 191-198.
- Lansbury, G. (2000). Chronic pain management: A qualitative study of elderly people's preferred coping strategies and barriers to management. *Disability and Rehabilitation, 22*, 2-14.
- Leonard, R. & Burns, A. (2006). Turning points in the lives of midlife and older women: Five-year follow-up. *Australian Psychologist, 41*, No.1, 28-36.
- Li, L., Moore, D. (1998). Acceptance of disability and its correlates. *The Journal of Social Psychology, 138*, 13-25.
- Lillrank, A. (2003). Back pain and the resolution of diagnostic uncertainty in illness narratives. *Pain, 57*, 1045-1054.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*, Beverly Hill, CA: SAGE Publications, Inc.
- Markway, G.P. & Markway, B.G. (2001). *Painfully Shy: How to Overcome Social Anxiety and Reclaim Your Life*. Thomas Dunis Books: New York.
- Mason, C. (1985). The production and effects of uncertainty with special reference to diabetes mellitus. *Social Science Medicine, 21*, no. 12., 1329-1334.
- Mason, O. & Hargreaves, I. (2001). A qualitative study of mindfulness-based cognitive therapy for depression. *British Journal of Medical Psychology, 74*, 197-212.

- McCracken, L. M. (1998). Learning to live with the pain: Acceptance of pain predicts adjustment in persons with chronic pain. *Pain, 74*, 21-27.
- McCracken, L. M. (1999). Behavioral constituents of chronic pain acceptance: Results from factor analysis of the Chronic Pain Acceptance Questionnaire. *Journal of Back and Musculoskeletal Rehabilitation, 13*, 93-100.
- McCracken, L.M. (2005). Social context and acceptance of chronic pain: the role of solicitous and punishing responses. *Pain, 113*, 155-159.
- McCracken, L. M. (2007). A contextual analysis of attention to chronic pain: What the patient does with their pain might be more than their awareness of vigilance alone. *The Journal of Pain, 8*, 230-236.
- McCracken, L. M., Carson, J. W., Eccleston, C., & Keefe, F. J. (2004). Acceptance and change in the context of chronic pain. *Pain, 109*, 4-7.
- McCracken, L. M. & Eccleston, C. (2003). Coping or acceptance: What to do about chronic pain? *Pain, 105*, 197-204.
- McCracken, L. M., Spertus, H. L., Janeck, A. S., Sinclair, D., & Wetzell, F. T. (1999). Behavioral dimensions of adjustment in persons with chronic pain: Pain related anxiety and acceptance. *Pain, 80*, 283-289.
- McCracken, L. M., & Turk, D. C. (2002). Behavioral and cognitive-behavioral treatment for chronic pain. *Spine, 27*, 2564-2573.
- McCracken, L.M. & Vowles, K.E. (2006). Acceptance of Chronic Pain. *Current Pain and Headache Reports, 10*, 90-94.
- McCracken, L. M., Vowles, K. E., & Eccleston, C. (2004). Acceptance of chronic pain: Component analysis and a revised assessment method. *Pain, 107*, 159-166.
- McCracken, L. M., Vowles, K.E., & Eccleston, C. (2005). Acceptance-based treatment for persons with complex, long standing chronic pain: a preliminary analysis of treatment outcome in comparison to a waiting phase. *Behaviour Research and Therapy, 43*, 1335-1346.
- McCracken, L. M., Vowles, K.E., & Gauntlett-Gilbert, J. (2007). A prospective investigation of acceptance and control-oriented coping with chronic pain. *Journal of Behavioral Medicine, 30*, 339-349.
- McCracken, L. M. & Yang, S. Y. (2006). The role of values in a contextual cognitive-behavioral approach to chronic pain. *Pain, 123*, 137-145.
- Merskey, H. & Bogduk, N. (Eds.) (1994). *Classification of Chronic Pain, Second Edition, IASP Task Force on Taxonomy*. Seattle: IASP Press. Retrieved April 18, 2004 from www.iasp-pain.org/terms-p.html.
- Miles, A., Curran, H.V., Pearce, S., & Allan, L. (2005). Managing constraint: The experience of people with chronic pain. *Social Science & Medicine, 61*, 431-441.
- Millar, W. (1996). Chronic pain. *Health Reports, 7*, 47-53.

- Morley, S., Davies, C., & Barton, S. (2003). "Future possible selves": Conditionality and adjustment to chronic pain. *Anaesthesia*, 58, 936-940.
- Morse, J. M. (1994). "Emerging from the data": The cognitive processes of analysis in qualitative inquiry. In J. M. Morse (Ed.), *Critical Issues in Qualitative Research Methods* (pp. 23 -43). Thousand Oaks, CA: SAGE Publications, Inc.
- Morse, J. M. (1998). Designing Funded Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of Qualitative Inquiry* (pp. 56-85). Thousand Oaks, CA: SAGE Publications Inc.
- Moulin, D. E., Clark, A. J., Speechley, M., & Morley-Forster, P. K. (2002). Chronic pain in Canada: Prevalence, treatment, impact and the role of opioid analgesia. *Pain Research & Management*, 7, 179-184.
- Murphy, K. C. (1994). Chronic pain syndrome: What is it, and how can we help? *American Journal of Pain Management*, 4, 129 - 131.
- Murray, T. (2000). *Chronic pain study. A study for the Workers' Compensation Board Nova Scotia*. Retrieved September 28, 2003, from www.wcb.ns.ca/chresch.htm.
- Nicholas, M. K. & Asghari, A. (2006). Investigating acceptance in adjustment to chronic pain: Is acceptance broader than we thought? *Pain*, 124, 269-279.
- Osborne, J. W. (1994). Some similarities and differences among phenomenological and other methods of psychological qualitative research. *Canadian psychology/Psychologie canadienne*, 35 (2), 167-189.
- Osborn, M. & Smith, J.A. (1998). The personal experience of chronic benign lower back pain: An interpretive phenomenological analysis. *British Journal of Health Psychology*, 3, 65-83.
- Ospina, M. & Harstall, C. (2002). *Prevalence of chronic pain: An overview*. A Health Technology Assessment for the Alberta Heritage Foundation for Medical Research.
- Park, K. (2003). Meaning in life as a predictor of outcome in chronic pain patients: A quantitative and qualitative study. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 63(8-B), Mar, 3933.
- Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, 33, 21-26.
- Paterson, B. & Thorne, S. (2000). Expert decision making in relation to unanticipated blood glucose levels. *Research in Nursing & Health*, 23, 147-157.
- Paterson, B., Russell, C., & Thorne, S. (2001). Critical analysis of everyday self-care decision making in chronic illness. *Journal of Advanced Nursing*, 35(3), 335-341.
- Pruitt, S. & Von Korff, M. (2002). Improving the management of low back pain: A paradigm shift for primary care. In D. Turk & R. Gatchel (Eds.), *Psychological approaches to pain management: A practitioner's handbook* (pp. 301-333). New York: The Guilford Press.

- Raak, R. & Wahren, L. K. (2006). Health experiences and employment status in subjects with chronic back pain: A long-term perspective. *Pain Management Nursing*, 7, No 2 (June), 64-70.
- Raheim, M. & Haland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life. *Qualitative Health Research*, 16, 741-761.
- Rankin, H. & Holttum, S. E. (2003). The relationship between acceptance and cognitive representations of pain in participants of a pain management programme. *Psychology, Health, & Medicine*, 8, 329-334.
- Ray, M. (1994). The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 117-133). Thousand Oaks, CA: SAGE Publications, Inc.
- Rich, B. A. (2000). An ethical analysis of the barriers for effective pain management. *Cambridge Quarterly of Healthcare Ethics*, 9 54-70.
- Richardson, J. C., Ong, B. N., & Sim, J. (2006). Remaking the future: Contemplating a life with chronic widespread pain. *Chronic Illness*, 2, No. 3., 209-218.
- Rippentrop, A. E., Altmaier, E., M., Chen, J. J., Found, E. M., & Keffala, V. J. (2005). The relationship between religion/spirituality and physical health, mental health, and pain in a chronic pain population. *Pain*, 116, 311-321.
- Risdon, A., Eccleston, C., Crombez, G., & McCracken, L. (2003). How can we learn to live with pain? A Q-methodological analysis of the diverse understandings of acceptance of chronic pain. *Social Science & Medicine*, 56, 375-386.
- Roberto, K. A., & Reynolds, S. G. (2002). Older women's experiences with chronic pain: Daily challenges and self-care practices. *Journal of Women & Aging*, 14, 5-23.
- Rogers, C. (1942). *Counseling and psychotherapy: Newer concepts in practice*. Cambridge, MA: The Riverside Press.
- Romano, J. M., Turner, J. A., Jensen, M.P., Friedman, L.S., Bulcroft, R. A., Hops, H. & Wright, S.F. (1995). Chronic pain patient-spouse behavioral interactions predict patient disability. *Pain*, 63, 353-360.
- Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: SAGE Publications, Inc.
- Samwel, H., Evers, A., Crul, B., & Kraaimaat, F. (2006). The role of helplessness, fear of pain, and passive pain-coping in chronic pain patients. *Clinical Journal of Pain*, 22, 245 -251.
- Schmitz, U., Saile, H., & Nilges, P. (1996). Coping with chronic pain: Flexible goal adjustment as an interactive buffer against pain-related distress. *Pain* 67, 41-51.
- Schwartz, P. & Ogilvy, J. (1979). The emergent paradigm: Changing patterns of thought and belief. *Analytical Report 7, Values and Lifestyles Program*. Menlo Park, CA: SRI International.

- Seidman, I. (1998). *Interviewing as qualitative research: A guide for researchers in education and social sciences* (2nd ed.). New York: Teachers College, Columbia University.
- Siviter, B. (2007). I have my life back. *Nursing Standard*, 21, 20-22.
- Sofaer, B., Moore, A.P., Holloway, I., Lamberty, J.M., Thorp, T.A., Y O'Dwyer, J. (2005). Chronic pain as perceived by older people: A qualitative study. *Age and Ageing*, 34, 462-466.
- Stansfeld, S. (2006). Chronic pain, depressive disorder, and the role of work. *Journal of Psychosomatic Research*, 61, 661- 662.
- Stanton, A. L., Collins, C. A., & Sworowski, L. A. (2001). Adjustment to chronic illness: Theory and research. In A. Baum, T. A. Revenson, & J.E. Singer (Eds.), *Handbook of Health Psychology* (pp. 387-403). Mahwah, NJ.: Lawrence Erlbaum Associates. **(Get fr library)**
- Stanton, A. L., Revenson, T. A., & Tennen, H. (2007). Health psychology: Psychological adjustment to chronic disease. *Annual Review of Psychology*, 58, 565-592.
- Statistics Canada (2003). *Repetitive strain injury*. Retrieved April 19, 2004
www.statcan.ca/Daily/English/030812/do30812b.htm
- Strobel, E. S., Wild, J., & Muller, W. (1998). Interdisciplinary group treatment for fibromyalgia. *Zeitschrift fur Rheumatologie*, 57, 89-94.
- Sullivan, M. (2000). DSM-IV Pain disorders: A case against the diagnosis. *International Review of Psychiatry*, 12, 91-98.
- Suter, P. B. (2002). Employment and litigation: Improved by work, assisted by verdict. *Pain*, 100, 249-257.
- Sylvain, H. & Talbot, L. R. (2002). Synergy towards health: A nursing intervention model for women living with fibromyalgia, and their spouses. *Journal of Advanced Nursing*, 38, 264-273.
- Tacon, A.M., McComb, J., Caldera, Y., & Randolph, P. (2003). Mindfulness meditation, anxiety reduction, and heart disease. *Family & Community Health*, 26(1), 25-33.
- Tafor, S., Kern, T., & Oswalt, K. (2007). *Primary care physician attitudes toward managing patients with chronic pain*. Emerging Clinical Science from the 26th Annual Scientific Meeting of the American Pain Society, Washington, D.C. May 2-5, 2007 Abstracts and Expert Discussion of the Prospective Management of Refractory Pain, p17.
- Tait, R. C. (1999). Evaluation of treatment effectiveness in patients with intractable pain: Measures and methods. In R. J. Gatchel & D. C. Turk (Eds.). *Psychosocial factors in pain: Critical perspectives* (pp. 457 - 480). New York: The Guilford Press.
- Teasdale, J. D., Segal, Z. V., Williams, J. M., Ridgeway, V., Soulsby, J. M., & Lau, M. A. (2000). Prevention of relapse/recurrence in major depression by mindfulness-based cognitive therapy. *Journal of Consulting and Clinical Psychology*, 68, 615-623.
- Telford, K., Kralik, D., & Koch (2006). Acceptance and denial: Implications for people adapting to chronic illness: Literature review. *Journal of Advanced Nursing*, 55 (4), 457-464.

- Terry, D. J. (1994). Determinants of coping: The role of stable and situational factors. *Journal of Personality and Social Psychology*, 66, No. 5, 895-910.
- Tesch, R. (1990). *Qualitative research: Analysis types and software tools*. London: Falmer.
- Thompson, D. (Ed.) (1995). *The Concise Oxford Dictionary of Current English* (9th Ed.). New York: Clarendon Press.
- Turk, D. C. (2002a). Clinical effectiveness and cost-effectiveness of treatments for patients with chronic pain. *The Clinical Journal of Pain*, 18, 355-365.
- Turk, D. C. (2002b). Chronic non-malignant pain patients and health economic consequences. *European Journal of Pain*, 6, 353-355.
- Turk, D. C. (2005). When is a person with chronic pain a patient? *APS Bulletin*, 15, 2, www.ampainsoc.org/pub/bulletin/spr05/presl.htm
- Turk, D. C. & Okifuji, O. (2002). Psychological factors in chronic pain: Evolution and revolution. *Journal of Consulting and Clinical Psychology*, 70, 678-690.
- Turk, D. C. & Rudy, T. E. (1988). Toward an empirically derived taxonomy of chronic pain patients. *Journal of Consulting and Clinical Psychology*, 56, 233-238.
- Turner, J. A., Ersek, M., & Kemp, C. (2005). Self-efficacy for managing pain is associated with disability, depression, and pain coping among retirement community residents with chronic pain. *The Journal of Pain*, 6, no 7 (July), 471-479.
- Van Damme, S., Crombez, G., Van Houdenhove, B., Mariman, A., & Michielsen, W. (2006). Well-being in patients with chronic fatigue syndrome: The role of acceptance. *Journal of Psychosomatic Research*, 61, 595-599.
- Vandercreek, L., Paget, S., Horton, R., Robbins, L., Oettinger, M., & Tai, K. (2004). Religious and nonreligious coping methods among persons with rheumatoid arthritis. *Arthritis & Rheumatism*, 51, 49-55.
- Van Hesteren, F. (1986). Counselling research in a different key: The promise of a human science perspective. *Canadian journal of Counselling*, 20 (4), 200-234.
- Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: The Althouse Press.
- Viane, I., Crombez, G., Eccleston, C., Devulder, J., & DeCorte, W. (2004). Acceptance of the unpleasant reality of chronic pain: effects upon attention to pain and engagement with daily activities. *Pain*, 112, 282-288.
- Viane, I., Crombez, G., Eccleston, C., Poppe, C., Devulder, J., Van Houdenhove, B. & DeCorte, W. (2003). Acceptance of pain is an independent predictor of mental well-being in patients with chronic pain: Empirical evidence and reappraisal. *Pain*, 106, 65-72.

- Vlaeyen, J.W., Teeken-Gruben, N.J., Goossens, M.E., Rutten-van Molken, M.P., Pelt, R.A., & Heuts, P.H. (1996). Cognitive-educational treatment of fibromyalgia: A randomized clinical trial. I. *Clinical effects. Journal of Rheumatology*, 23(7), 1237-1245.
- Walker, J., Holloway, I., & Sofaer, B. (1999). In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain*, 80, 621-628.
- Weitz, R. (1989). Uncertainty and the lives of persons with AIDS. *Journal of Health and Social Behavior*, 30 (September), 270-281.
- Werner, A. & Malterud, K. (2003). It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors. *Social Science & Medicine*, 57, 1409-1419.
- Widar, M., Ek, A., & Ahlstrom, G. (2007). Caring and uncaring experiences as narrated by persons with long-term pain after a stroke. *Scandinavian Journal of Caring Sciences*, 21, 41-47.
- Wolcott, H. (1994). *Transforming qualitative data: Description, analysis, and interpretation*. Thousand Oaks, CA: Sage.
- Wright, B.A. (1960). *Physical disability - A psychological approach*. Harper & Row, Publishers: New York.
- Zalewska, A., Miniszewska, J., Chodkiewicz, J., & Narbutt, J. (2007). Acceptance of chronic illness in psoriasis vulgaris patients. *European Academy of Dermatology and Venereology*, 21, 235-242.
- Zettle, R. D. (1994). On the use of acceptable language. In S.C. Hayes, N.S. Jacobson, V. M. Follette, & M. J. Dougher (Eds.), *Acceptance and change: Content and context in psychotherapy* (pp. 46- 49). Reno, NV: Context Press.
- Zunker, V. G. (2002). *Career counselling: Applied concepts of life planning* (6th ed.). Pacific Grove, CA: Brooks/Cole.

APPENDIX A**POSTER FOR PARTICIPANT INVITATION**

I am conducting a research study on the Acceptance of Chronic Pain for my doctoral dissertation.

If you:

- are presently experiencing pain,
- have had the pain for at least six months,
- have had your life disrupted as a result of the pain,
- are living a meaningful life with the pain,
- have accepted your pain,
- and, would like to talk to me about your experience with the Acceptance of Chronic Pain.

Please contact me at:

Audrey Kinzel

Phone Number: (306) 653 1312 or (780) 492 0963

Participation in this research will involve up to 3 (1 hour) interviews. Interviews will be audio-taped.

APPENDIX B**INFORMATION AND CONSENT FORM**

My name is Audrey Kinzel. I am presently completing a Doctoral dissertation in Counselling Psychology in the Department of Educational Psychology at the University of Alberta. I am interested in learning about the acceptance of chronic pain. The title of the study that I intend to do is The Acceptance of Chronic Pain.

The purpose of the study is to explore, elucidate, and understand the experience of the acceptance of chronic pain. My hope is that this understanding of acceptance will a) provide insight into the experience of acceptance, b) allow for a deeper understanding of the meaning of acceptance of chronic pain c) be transferable into other areas in which acceptance may enhance life satisfaction and productivity, d) increase participants' understanding of their experience so that they are able to integrate and utilize this experience more fully and completely within their lives, and e) give voice to individuals who are living a meaningful life with chronic pain.

In order to gather the information required for this study I will be:

Conducting up to three audio-taped interviews with each participant, each interview lasting approximately one hour. Interviews will be conducted in-person at a mutually agreed upon site, or over the telephone.

This is to certify that I, _____ have been informed about, and agree to the following:

1. I have been advised about the nature and purpose of the study.
2. My participation in the study is voluntary. I may withdraw at any time.
3. Any information shared with Audrey Kinzel will be held in confidence. Quotations and/or summaries of what I say will only appear in the final thesis with my consent and may be published in an article or presented to a larger audience in the future. The use of a pseudonym will ensure my anonymity.
4. The interviews will be audio-taped and then transcribed. Audio-tapes, transcriptions, and any notes will be safeguarded and stored at the University of Alberta, and will be destroyed after the required 5 year time period has passed.
5. Interviews will be conducted at times and locations that are mutually convenient for myself and the researcher.
6. I understand that sharing any personal writings in the form of journal entries or other personal documents with the researcher is voluntary. This information will only be used in the dissertation with my consent.
7. In the event that I should need to speak to someone about my thoughts and feelings resulting from the interviews, the researcher will work with me to access appropriate professional assistance.

8. If I have any questions or concerns about my participation in this research, I may contact the following individuals:

Research Supervisor: Dr. Derek Truscott
Phone number: 780 492 1161

Researcher: Audrey Kinzel
Phone number: 780 492 0963 or 306 653 1312

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

My signature indicates that I have read and understand the content of this form.

Name of participant: _____

Signature of participant: _____

Phone number of participant: _____

Address of participant: _____

Signature of researcher: _____

Date: _____

APPENDIX C
GUIDING QUESTIONS

1. Context:

What are your thoughts regarding participating in this study?
(Prompt as necessary to elicit motivation for participation)

Describe your experience with chronic pain.
(Prompt as required to elicit present pain situation; past and present thoughts, feelings, beliefs; time frame, personal efforts to manage/cure pain; social and professional supports; past and present health service utilization; health/insurance coverage; receiving/received compensation or financial assistance - WCB, motor vehicle insurance, litigation, CPP, AISH, social assistance).

How does acceptance of chronic pain fit into your experience with chronic pain?

How has your life and life goals been impacted by chronic pain?

2. Details:

Tell me about your present life goals/life focus.
(Prompt to elicit details regarding a meaningful life with the pain)

What facilitated/promoted/lead to your present life focus?
(Prompt: what helped, what hindered or held you back? Time frame of acceptance)

Describe your experience towards this present life focus and acceptance of chronic pain.
(Prompt to elicit if a turning point event occurred when acceptance was realized or noticed, or if realization of acceptance occurred with reflection and hence hindsight)

What were and are some of your thoughts and feelings you have experienced during this time in your life?

Describe your attitude(s) toward yourself and others through the time of your pain and acceptance.
(Prompt: Attitude is comprised of beliefs, feelings, and thoughts)

Does the intensity of your pain change? If so, is there a relationship between the pain intensity and your acceptance of the pain?

3. Meaning:

What does acceptance mean to you?

What does acceptance of chronic pain mean to you?

How has your life been impacted by acceptance of chronic pain?

What have you learned or realized from your experience of acceptance of chronic pain?

What have you learned from your participation in this study?

APPENDIX D**DATA/TRANSCRIPT RELEASE FORM**

I, _____, have reviewed the complete transcript(s) of my personal interviews in the study The Acceptance of Chronic Pain, and hereby authorize the release of the transcripts and contents of the documents to Audrey Kinzel to be used in the manner described in the information and consent form.

I acknowledge that I have received a copy of this Data/Transcript Release form for my own records.

Participant

Date

Researcher

Date

APPENDIX E
APPLICATION TO THE UNIVERSITY OF ALBERTA
ADVISORY BOARD ON ETHICS

1. Name of Researcher(s) and Department(s)
Audrey Kinzel, Doctoral of Philosophy provisional, Department of Educational Psychology,
University of Alberta
Supervisor: Dr. Derek Truscott, Department of Educational Psychology, University of Alberta

2. Title of Study

The Acceptance of Chronic Pain

3. Abstract

The purpose of the study is to explore, elucidate, and understand the acceptance of chronic pain. The following research questions will guide the study: What is the experience of acceptance of chronic pain? What is the meaning of acceptance for the participant? What has facilitated the process of acceptance? What impact has acceptance of chronic pain had for the participant? A naturalistic inquiry is believed to be the most appropriate approach for this study. Individuals will be advised of the study and invited to participate through advertisements, posters placed at rehabilitation and counselling centres (self-help/support groups), and through personal contacts with professionals who work in health care. Participants will participate in up to three active/in-depth phenomenological interviews and will be invited to share personal writings and documents. Interviews will be transcribed. Data collected from the interviews and documents, will be analyzed using constant comparative analysis procedures. Such a procedure will allow categories and themes to unfold and emerge, thus facilitating an in-depth understanding of the acceptance of chronic pain

4. Funding

No grant or contract for funding has been awarded for this study.

5. Subjects

Participants will be selected using purposeful sampling techniques with an underlay of specific criteria. Participants who fulfill the following criteria will be considered for the study: (a) Individuals who are presently experiencing nonmalignant chronic pain. (b) Individuals who have had chronic pain for a minimum of six months. (c) Individuals who have had their life disrupted as a result of the chronic pain (d) Individuals who have a life focus other than chronic pain and are living a meaningful life with the chronic pain. (e) Individuals who are willing to participate in the study.

6. Method/Procedure

Participants will be asked to participate in up to three (1 hour) interviews. Guiding questions will be used (Appendix C). Interviews will be carried out in-person at a mutually agreed upon location and time, or by telephone. All interviews will be transcribed. Participants will be invited to share personal writings and documents.

7. Risk or deception

There is no deception in this study. In the event that participation in the study evokes emotional responses because of the nature of the subject matter, I will endeavor to assist the participant in securing appropriate support including professional counselling services.

8. Confidentiality

Confidentiality will be ensured in this by implementing several safeguards. All participants will sign an informed consent form. Anonymity will be upheld by using pseudonyms in place of participant names. Audio-tapes will be transcribed and coded with no identifying information. Excerpts of interviews to be included in the final written thesis will be used with the consent of the participant. All audio-tapes, computer disks, and copies of transcribed data will be destroyed following completion of the study.

9. Consent

Consent will be provided through the use of a consent form. Participants will have a clear understanding of the purpose of the study and their participation in it.

10. Debriefing and Feedback

Member checks will be employed throughout the data analysis procedures, so feedback will be given. Support and opportunities for debriefing will be offered through the research process.

11. Signatures

Audrey Kinzel, Doctoral Candidate, Department of Educational Psychology, University of Alberta.

Supervisor - Dr. Derek Truscott, Department of Educational Psychology, University of Alberta.

APPENDIX F
CHARACTER MAP: GUIDE TO THE PARTICIPANTS

Part'nt	Age	Dur' n pain	Dur'n accep.	Desc'n of pain, diagnosis, origin	Employment status	Support	Source of income	Meaningful life
Bea	65 yrs	1.5 yrs	1.5 yrs	Dislocated elbow from a fall,-osteoarthritis	Retired cook	Family, faith & physician.	Pension & settlement from litigation	Family, church, & activity
"Elyse"	early 40's	10 yrs	10yrs	Back pain from work place injury	FT Health care professional	Friends	Employment & benefits	Activities & career
Elizabeth	early 50's	20 yrs	2 yrs	Fibromyalgia & knee pain.	Unable to work	Family	Prov. Disability program	Helping others, family
"Ginnie"	mid 40's	3 yrs	2-3 yrs	Plantar fasciatus in both feet.	FT teacher	Family & friends	Employment & benefits	Family & career
Gordon	64 yrs	3 yrs	2 yrs.	Idiopathic sensory predominant polyneuropathy	Retired teacher, school bus driver	Family	Pension	Family & activities
"Janice"	mid 30's	15 yrs	7 yrs.	Back pain orig. with work place injury.	FT health care professional	Family & faith	Employment & benefits	Family & career
Lyn	74 yrs	10 yrs	10 yrs	Peripheral neuropathy	Retired volunteer, author/writer	Family & physician	Pension	Family, writing, perform in band,
"Sara"	late 20's	2.5 yrs	Approx one month	Reflexive sympathetic dystrophy (RSD) fr. running injury.	PT teacher/ PT disability	Husband, faith, support groups, counselor	PT Employment, PT disability, benefits, husband income & benefits	Faith & self-care
Tom	late 30's	7 yrs	1-2 years.	Back & legs originating from a motor vehicle accident	FT maintenance worker; former oil patch truck driver	Family	Employment , Litigation outcome pending	Helping children
"Wilson"	mid 50's	40 yrs.	Appro20 yrs.	Low back pain	FT Health care worker	Family	Employment & benefits	Family

Code: Full time - FT Part time - PT

APPENDIX G

CHRONIC PAIN ACCEPTANCE SELF RATING SCALE (CPASRS)

VERSION ONE

Please rate the following statements as they relate to your chronic pain. Indicate if this is a change from 6 months ago and what it changed from using a 'c'

Very false/False/True/Very true

1. My pain may never go away. VF-F-T-VT
2. I have lost hope for my future due to my pain. VF-F-T-VT
3. I am disappointed and angry that someone is unable to cure my pain. VF-F-T-VT
4. It is the responsibility of the health system to cure my pain. VF-F-T-VT
5. I am confident I can handle my pain. VF-F-T-VT
6. Even though I have pain I can make the most of my life. VF-F-T-VT
7. My attitude toward my pain is to carry on. VF-F-T-VT
8. My attitude toward my pain is to fight it and focus on finding a cure. VF-F-T-VT
9. I have some family/friends that I can count on to help me. VF-F-T-VT
10. I am hesitant to talk to others about my pain. VF-F-T-VT
11. I have a supportive workplace which enables me to continue working. VF-F-T-VT
12. My doctor and other health care providers believe me about my pain. VF-F-T-VT
13. I have at least one health care provider whom I can count on to help me with my pain. VF-F-T-VT
14. I have decided to accept my pain and get on with my life. VF-F-T-VT
15. The steps I have taken to deal with my pain have been necessary and helpful. VF-F-T-VT
16. Only I can make decisions about my pain. VF-F-T-VT
17. Pain information I receive from my doctor & other health care providers is helpful. VF-F-T-VT
18. I wish people would quit telling me what to do about my pain. VF-F-T-VT
19. I feel demeaned/ridiculed/put down by the information I receive about my pain. VF-F-T-VT
20. I have learned how to handle my pain through trial and error. VF-F-T-VT
21. Learning from doing helps me manage my pain. VF-F-T-VT
22. It is my responsibility to learn what I can do to manage my pain and then do it. VF-F-T-VT
23. Doing my exercise and other physical activity helps me manage my pain. VF-F-T-VT
24. Although I did not choose to have pain, I have options as to how to manage it. VF-F-T-VT
25. I have choices around work/finances and other areas of my life. VF-F-T-VT
26. My involvement with the legal/insurance/medical system is not my choice. VF-F-T-VT
27. I am living a meaningful life with my pain. VF-F-T-VT
28. My pain is the most important part of my life right now. VF-F-T-VT

29. I have goals I am pursuing. VF-F-T-VT
30. The changes I have made due to my pain have helped me learn to live with it. VF-F-T-VT
31. I can say 'no' to others' requests if I want to in order to help my pain. VF-F-T-VT
32. I am doing the best I can to manage my pain. VF-F-T-VT
33. I feel I can control the intensity of my pain. VF-F-T-VT
34. I am worried about my finances because of my pain. VF-F-T-VT
35. I have no control over my situation. VF-F-T-VT
36. My pain has lead me to evaluate what is important to me. VF-F-T-VT
37. My pain has resulted in me changing some values. VF-F-T-VT
38. I have hope and fear about my pain. VF-F-T-VT
39. I know I can handle my pain. VF-F-T-VT
40. There are meaningful parts of my life. VF-F-T-VT

Scoring: Very false (0), False (1), True (2), Very true (3)

Some items will be reverse scored.