The Hidden Pathways of Chronic Illness

Patient Engagement Research Study Report

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*Patients Matter: Engaging Patients as Collaborators to Improve Osteoarthritis Care in Alberta*

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# TABLE OF CONTENTS

Introduction ........................................................................................................................................... 3  
Background and Literature Review................................................................................................ 4  
Engagement Methods........................................................................................................................... 7  
Mind Mapping as an Engagement Method.................................................................................. 11  
Articulating Experience (Findings).............................................................................................. 13  
  1. Finding Yourself in an Alien Land......................................................................................... 14  
  2. Searching for Answers as a Way Out.................................................................................. 18  
  3. Finding You are on Your Own.............................................................................................. 23  
  4. Searching for Meaning........................................................................................................ 27  
  5. Presenting Your New Self..................................................................................................... 31  
  6. Understanding You are Your Own Boss............................................................................ 35  
Losses and Gains Along the Pathways....................................................................................... 40  
Summary.............................................................................................................................................. 44  
References........................................................................................................................................... 46

# LIST OF FIGURES

*Figure 1.* PER Research Methodology ............................................................................................ 9  
*Figure 2.* Mind Map 1, Mid-Portion ............................................................................................ 12  
*Figure 3.* Mind Map 2 .................................................................................................................. 12  
*Figure 4.* Mind Map 3 .................................................................................................................. 17  
*Figure 5.* Mind Map 4 .................................................................................................................. 27  
*Figure 6.* Mind Map 5 .................................................................................................................. 31  
*Figure 7.* Mind Map 6 .................................................................................................................. 35  
*Figure 8.* Mind Map 7 .................................................................................................................. 40
The Hidden Pathways of Chronic Illness

Introduction

This qualitative study has been undertaken to fulfill the requirements of an internship in the Patients Matter Project. Patients Matter is an innovative research project in which patients are taught to engage in qualitative research with other patients. As intern-researchers we initially worked as two separate groups, one exploring resilience and the other, the relationship between doctor and patient. During class discussions and practice focus groups we came to understand that our topics were very broad and needed to be focused more narrowly. And while the doctor-patient relationship was important, participants focused on what was the experience of the day-to-day living with ongoing chronic illness. They wanted to share their individual day-to-day experiences of finding ways to live a full life.

After the practice focus group we met as whole group to review what we had learned. One patient researcher showed us her journal in which she had written about her journey with Crohn's disease and then cancer. Writing about her life with chronic illness and adding visual expressions helped her to tell about her journey. We then tried creating maps to show our own experiences with our individual experiences of illness. We used colour, lines and words to tell about the important points along the way; we saw that we had experienced pathways that were hidden until we put them on paper.

Our research question emerged as we talked about our maps: How do patients make sense of living through chronic illness?

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1The Patients Matter Project has been completed in partnership between Alberta Health Services and the University of Calgary (Community Rehabilitation and Disability Studies and the Institute for Public Health). The project was funded through a two-year grant from the Canadian Foundation for Healthcare Improvement (CFHI).
We realized that we had a way to gather data about patient experiences of finding and making pathways through their chronic illness apart from their journey through the healthcare system and the clinical pathways.

Our mind maps showed similarities in how we each lived with illness. When we compared them, we recognized that with our diagnosis the world changed, our lives changed, nothing was the same, the future was unknown. We decided to plan a research project that would focus on and reveal the pathways of patient experience with chronic illness, pathways hidden from members of the medical community and from the patients themselves until they have the opportunity to uncover this experience in a peer-to-peer relationship with other patients.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study (Ethics ID number E-25196).

**Background and Literature Review**

The research question guiding this study is: *How do patients make sense of living through chronic illness?* The engagement with patients in conducting research means that patients plan the research study and collect data with other patients. This is in contrast to research which entails a top-down clinical engagement of medical personnel and professionals with patients.

Chronic conditions such as cardiovascular disease, diabetes, asthma, arthritis, Parkinson’s disease, Lupus, autoimmune diseases, mental illness, and some cancers are on the rise. These diseases affect Albertans and Canadians in general and have an impact on the cost of health care. According to the Alberta Health Services website (Grindle, 2011), 80% of Albertans over the age of 45 report having one or more chronic diseases or being at risk for developing a chronic disease.

Most of the current research on chronic illness management is in the context of clinical treatments, expert-driven self-management, evidence-based approaches and the effects of patient education. This research is largely based on quantitative analysis. Some examples of
this approach are studies of managing medication adherence across a wide range of chronic illnesses (Boskkovic et al, 2013; Simon et al, 2012), cost effectiveness and clinically-measured patients' outcomes through various interventions including self-management programs and lay-led supports (Kennedy, 2007; Lorig, 2008; Richardson et al, 2008). In addition, there is research on strategies for better coping with chronic illness which are evaluated by means of health care utilization outcomes (Lorig, 2001).

The expert-driven approach to design interventions and measure outcomes is reflected in education and training programs dealing with chronic illness management. An example is Flinders University (2010), where a focus is on increasing the skills of individual patients to be better self-managers so that they may have healthier lives in spite of a chronic illness (Battersby et al, 2010). Another expert-driven approach to research on chronic illness includes studies of psychosocial and cultural aspects (Cukor et al, 2007).

A particularly intriguing theory is Antonovsky's theory of salutogenesis (Antonovksy, 1987, 1996; Bahrs et al, 2003). Antonovsky defines salutogenesis as a study of the origins of health rather than the origins of disease as he presents the term salutogenesis in contrast to pathogenesis.

Some mental health research now shows individual narratives of chronic mental illness set out in the context of recovery (Amering & Schmolke, 2009; Ridgway, 2001).

Other research now includes the use of creative expression to seek out meaning-making (Stuckey & Nobel, 2010). These studies focus on the whole person not just on the sickness or medical treatments and include the use of creative expression such as visual art and music to reveal meaning-making (Stuckey & Nobel, 2010). The internet provides blogs where individual patients can tell their stories; the experience of individuals with chronic illness have been written and published in books such as Hidden Courage by Abigal Cashelle (2012) and A Day in the Life of Richard Cohen (Cohen, n.d.).

While little formal research has been done to explore patients' experiences of pathways that are largely hidden from view from medical personnel and sometimes from patients themselves, some studies are now opening a window into patient experience. A BMJ series
in 2004 calls for "giving patients time and space to talk about what happens to them" so as to "help to improve their experience of illness" (Lapsley & Groves, p. 582). The intention here is to "promote the importance of patients' voices and narrative based medicine" (p. 583). Pamela Ironside and her colleagues (2003) admit that "few studies have been conducted investigating now individuals experience living with chronic illness" (p. 172). Her study is conducted by clinicians working collaboratively with patients so the findings are "co-created."

Studies continue to arise from the efforts of medical professionals such as nurses to build relationships with patients so as to learn what can be done to improve nursing practice (Kralic et al, 2002). In addition, social work professionals such as Docherty and her colleagues (2003) acknowledge their "therapeutic alliance" with patients (p. 20) and the significance of Kleinman's "empathic witnessing" (p. 21). Research by patients with other patients remains on the margins in studies where the focus is on the "expert patient," as if some patients are experts about their experience of illness while others are not (Malcolmson et al, 2008, p. 670).

Some studies are interested only in the patient's experience of critical events such as the diagnosis (Kralic et al, 2001). One study focusing on "sources of hope" leans toward making sense of patient experience exclusively through spiritual and religious experience. The patient's spiritual or religious experience is not directly investigated. The patient's voice and construction of the experience is not central (Garrett, 2001).

Narratives have become a focus for data collection and are often centred on a single patient (Ekman et al, 2001), a small number of older patients (Docherty & McColl, 2003), a particular group such as women in mid-life (Kralic et al, 2002), or the elderly (Loeb et al, 2003). The study by Kralic and her colleagues (2002) encompasses a large number (81) of women in mid-life. It searches for understanding of the journey from diagnosis through "transition as a trajectory" from "extraordinary to ordinary" over a twelve-month period (p. 146). This study sees a cyclical process at work among patients, a process captured in narratives of illness and loss that can change into stories of "challenge and creativity" (p. 153).
The Hidden Pathways of Chronic Illness

The relationship between the stories of patients and the silences which can be found in the narrating of stories is the focus of the work of Kathy Charmaz with 140 interviews of chronically ill people. She seeks to understand both the stories and the silence and "what lies between them" (Charmaz, 2002, 302). Charmaz emphasizes that stories "emerge within social contexts and thus are historically, socially, and culturally specific” and "that any consideration of stories and silences must take these contexts into account" (p. 303). In her account of stories and silences Charmaz declares that "silence becomes a deliberate strategy when ill people reflect on possible actions" (p. 309). The silence continues among chronically ill patients seeking to be heard and it is for this reason patients conducting research with other patients is needed to bring to light the hidden pathways of chronic illness.

While there has been theory-making about phases and stages of chronic illness, little research grounded in the experience of patients has been done with and by patients. Albany Health Management Associates website offers Patricia A. Fennell's (2003) 4-phase model of Crisis, Stabilization, Resolution and Integration which is designed by clinicians and tested on patients. A website focusing on fibromyalgia draws on JoAnn LeMaistre’s (1995) six stages of emotional response to chronic illness: Isolation, Anger, Reconstruction, Intermittent Depression and Renewal. However, neither of these models is grounded in research carried out by patients with patients.

**Engagement Methods**

**The Patients**

Our research was an inquiry into the hidden pathways of chronic illness as a deliberate contrast to the clinical pathways delivered by the health system. Most of the patient engagement researchers engaged in this study have at least one chronic illness or have a relationship with a family member living with chronic illness.

There were 22 participants in this study, and all had been diagnosed with one or more chronic illnesses. This was our selection criteria as we searched for participants. The chronic illnesses were Crohn’s disease, diabetes, kidney disease, lung problems, COPD, rheumatoid arthritis, a thyroid condition, neuropathy, Parkinson’s disease, scleroderma,
chronic leukemia and other cancers, lupus, heart disease, allergies and asthma, and insomnia. The participants of the study were recruited using posters in doctors’ offices, the Kerby Centre, Wellspring Calgary, and through word of mouth from participants and researchers. Participants ranged in age from 50 to 81. There were two male participants. One male participant had a chronic illness; the other was a caregiver of a female participant with chronic illness.

Seven participants volunteered to take part in narrative interviews. The four interviewees were chosen at random from a list of those interested in following up on the focus group discussions. We interviewed participants in their homes where they would be the most comfortable. Interviews were recorded with digital recorders. The interviewer asked questions, and the process recorder wrote the answers. In one instance, there was an interviewer and two process recorders.

Table 1. Study Participants. Note: Initials have been coded to protect participant identity.

<table>
<thead>
<tr>
<th>#</th>
<th>Code</th>
<th>Session Date</th>
<th>Gender</th>
<th>Age</th>
<th>Chronic Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>TE</td>
<td>May 29, 2013 &amp; April 9, 2013</td>
<td>Female</td>
<td>&lt; 65</td>
<td>Neuropathy</td>
</tr>
<tr>
<td>2.</td>
<td>MH</td>
<td>May 29, 2013 &amp; April 9, 2013</td>
<td>Female</td>
<td>&lt; 65</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>3.</td>
<td>DK</td>
<td>May 29, 2013 &amp; April 9, 2013</td>
<td>Female</td>
<td>69</td>
<td>Rheumatoid arthritis</td>
</tr>
<tr>
<td>4.</td>
<td>EL</td>
<td>May 29, 2013 &amp; April 9, 2013</td>
<td>Female</td>
<td>&gt; 65</td>
<td>Thyroid condition and rheumatoid arthritis</td>
</tr>
<tr>
<td>5.</td>
<td>QQ</td>
<td>May 29, 2013 &amp; April 9, 2013</td>
<td>Female</td>
<td>63</td>
<td>Diabetes, lung condition and scleroderma</td>
</tr>
<tr>
<td>6.</td>
<td>LX</td>
<td>May 29, 2013 &amp; April 9, 2013</td>
<td>Female</td>
<td>54</td>
<td>Allergies and insomnia</td>
</tr>
<tr>
<td>7.</td>
<td>TBQ</td>
<td>April 24, 2013</td>
<td>Female</td>
<td>70</td>
<td>Arthritis</td>
</tr>
<tr>
<td>8.</td>
<td>QB</td>
<td>April 24, 2013</td>
<td>Female</td>
<td>67</td>
<td>Chronic condition not disclosed</td>
</tr>
<tr>
<td>9.</td>
<td>EF</td>
<td>April 24, 2013</td>
<td>Female</td>
<td>61</td>
<td>Heart disease</td>
</tr>
<tr>
<td>10.</td>
<td>XM</td>
<td>April 24, 2013</td>
<td>Male</td>
<td>57</td>
<td>Polycystic kidney disease</td>
</tr>
<tr>
<td>11.</td>
<td>TQ</td>
<td>April 24, 2013</td>
<td>Female</td>
<td>50</td>
<td>Diabetes</td>
</tr>
</tbody>
</table>
The Hidden Pathways of Chronic Illness

We have protected the confidentiality of the participants by assigning them code letters (Table 1). All identifying data, such as consent forms, demographic information and mind maps are stored separately from the raw data and analysis.

**Patient Engagement Research Framework**

As noted in the Introduction, we used the SET COLLECT REFLECT method as tested and set out in *Grey Matters* (Marlett & Eames, 2010). This method provides steps and processes for patients to come together as peers and become engaged in all phases of the research study. This distinct methodology is shown as follows:

![PER Research Methodology](image)

*Figure 1. PER Research Methodology.*
SET: A focus group was organized composed of participants with relevant patient experience. This format invited patients to become advisors and help SET the stage for the study. Participants refined and fine-tuned the questions to be used in the next stage of the research. We recruited six patients living with various chronic illnesses and conducted our SET focus group. This was an opportunity for discussion of our question, *How do patients make sense of living through chronic illness?*

We asked the SET focus group to try out the creative methods that we had created to uncover the existence of hidden pathways through chronic illness. We used a writing exercise in creating a definition of an unknown word. This was a success and was used in the COLLECT phase of the research. We also tested a creative exercise based on our experience of the mapping of pathways of chronic illness as a way to build trust among ourselves as researchers.

COLLECT: At this stage the main body of data is collected. The COLLECT focus groups enabled us to use the method approved by the SET focus group and to reach a larger number of participants and a greater range of conditions. In this phase we conducted two focus groups that provided a base to recruit four narrative interviews. At the end of each focus group we invited participants to indicate if they were interested in being interviewed by two or three of the intern-researchers. The purpose and procedure of the narrative interview was explained and written consent forms were explained and signed prior to the outset. The narrative interviews, enabled us to explore patient experience of chronic illness to a depth of detail that focus group discussion could not support.

REFLECT: Participants in the initial SET focus group are brought together again and offered an opportunity to consider and discern from the findings of the COLLECT phase what has emerged as main issues, inferences and recommendations.

**Creative Writing and Mind Mapping as Engagement Methods**

We have included specific information on the creative methods used for these offered a chance for each participant to reflect and share. After introductions were made, the participants engaged in a word game using the word "recondite." We asked participants to write a short
piece using the word "recondite" which they then shared. Not sharing was an option. We then
disclosed the definition of the word: obtuse or hidden. We then made the connection between
the word "recondite" and our research question focusing on "the hidden pathways of chronic
illness." This provided a link to the mind mapping section of the methods.

Participants were told that they would not be judged, that they could draw and write as
much or as little as they wished. We offered large newsprint sheets and dozens of different
colored wax sticks to make the mind maps and to encourage silent, personal time, we
played music as the participants worked on their mind maps. Almost everyone was
engaged in doing this for the full 25 minutes, including one woman who wanted to
participate but needed some assistance because she had limited use of her hands. We then
asked participants to present their mind maps and engaged in discussion about them. We
believe that by using this expressive and creative method to begin the focus groups we
made a safe space for experience to be shared with confidence. We reassured participants
that the mind maps would be shared only if each person gave consent to do so.

Participants offered comments on this aspect of our engagement method with remarks
such as: "the mind maps were very individualized and a good way to gain information and
understanding" (FG, 29.05.2013). Another participant said: "I have drawn me" (FG, 24.04.
2013). Many of the participants provided centers in their mind maps which we could see as
a starting point in "reading" the pathways they had drawn. Some had a name or a word
such as Life, Faith, God, the Self, Pain, Heart, and Death. Radiating from the centers were
lines or paths which led to repeated references to family, work, leisure activities, new
directions and choices. Along these paths were notations about feelings: depression, shock,
 hope, courage, patience, gratitude, stress and guilt. Some were extremely complex webs of
intersecting lines leading the eye into personal details such as names and places. Here are
two minds maps (Figures 2 and 3) showing two different expressive styles and two
different central concepts: in one centre is the disease; in the other is Death.

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2 Quotes are coded as either FG (focus group), or NI (narrative interview), followed by the date. Because of
the ethical requirements, we preserved the anonymity of participants' quotes.
Figure 2. Mind Map 1, Mid-Portion.

Figure 3. Mind Map 2.
Articulating Experience (Findings)

The shock of being faced with losing the life you expected to have is like finding yourself in an alien land. You are overwhelmed with raw emotions, afraid, angry and in pain. Once the shock begins to wear off, you rush into action to find a way out. You search for answers and throw yourself into following paths that claim to change your situation. You change your diet, you exercise, you meditate, and you search on the internet. For some of us, the way out works and a life style change reduces the symptoms, but, for most of us, the way out is temporary or a dead end. After long periods of hoping for a way out, you realize that you have exhausted ideas, family, and professional authorities, and you slow down, go inside, and get in touch with yourself and your illness. You face the fact that there is no way out, or away from who you are. Despite the willingness of family, friends and health professionals, you are the one who must deal with this new reality.

As you come to this new reality, you find the ability to re-engage with life and you find ways to know who you are and what you can give to others. You become more settled with who you are, you find it easier to interact with others. However, others are often not able or willing to interact with this new you and in order to re-engage with society so you are faced with modifying how you present yourself to others. You study what others need to hear and know about you, you morph into the perfect patient, the brave friend, the long suffering and supportive parent. While it works, you carry guilt about hiding who you are and feel sadness that you have to cover up your new self or modify yourself to make it easier for others to relate to you. Over time you compartmentalize who you are according to what groups of people need. You learn to identify what is worth holding onto, what is meaningful to you in this new life.

Finally you realize that you can take up the challenge to own your health and health care, engaging others in working with you to achieve and maintain health through all the inevitable setbacks, changes in directions and breakthroughs. You learn that conditions are unpredictable and you can process what life offers you. You are more than your condition. You can learn and be creative, cope and find others to help. You can find meaning and reason to continue to live.
The Hidden Pathways of Chronic Illness

The above summary was written after many sessions of sorting through the journeys and the paths that our participants travelled. These paths are not seen from the clinical pathway; they do not represent consecutive stages; they are pathways that no one can prescribe or predict. They are highly individual and can be retraced, interrupted and re-experienced at anytime. The six hidden destinations and their pathways that follow, each give a sense of place but each one also provides a way to keep moving, a way to resist shutting down to the self and the world, and a way to recreate a life.

The six hidden pathways are:

1. Finding Yourself in an Alien Land
2. Searching for Answers as a Way Out
3. Finding You are on Your Own
4. Searching for Meaning
5. Presenting Your New Self
6. Understanding You are Your Own Boss

1. Finding Yourself in an Alien Land

This is the first place patients describe. Patients tell of their pain, anger and fears at hearing a diagnosis and immediately finding themselves in a new and alien place. Here is Yvette’s journey into the findings about the patient experience in this strange and terrifying place and her description of this alien land.

Yvette’s Journey into Findings about the Alien Land

Picture this metaphor: You and your family have been away on vacation for two weeks and return to your farm in south eastern Alberta. The sight that awaits you is shocking and surreal. The entire landscape that was once flourishing with undulating green grain fields around the farm is now nothing but fields of pale brown earth with short straw stubble
everywhere. As you drive up the driveway toward your home, you are more shocked. The house and outbuildings look starkly naked as there is not a shred of colour visible where the trees, shrubs and garden had been lovingly planted. All that remains is a moonscape with some tree skeletons standing in the brown earth and the carcasses of hordes of grasshoppers. This scenario might be similar to those confronted with chronic illnesses. Life proceeded as normal and then one day a huge, foreign landscape was before them. I heard how participants found themselves after a diagnosis of chronic illness in a bleak, unknown territory.

Listening to patients telling about being suddenly thrown into a terrifying new place was a very different approach to research. I had not realized how much this method would challenge my prior understanding of what counts as research, having spent most of my career using quantitative methods. I can see that we can make a difference in our medical system by using this new method. Engaging with patients meant that I was not able to be in control or to predict behaviour or outcomes and I became more open to the "messiness" of human experience.

After their diagnosis our participants had many concerns about their illness and had no idea what to do next. Medical doctors recommended various treatments and that in itself was overwhelming. The future looks bleak and the situation impossible to understand. Patients with chronic illness can get stuck in this alien land and experience great difficulty finding a way out. Emotions such as anger and fear can threaten to consume the patient living with chronic and multiple illnesses.

**Trapped by Pain**

After the diagnosis of a chronic illness patients have names for the source of their pain, but knowing the name is not in itself helpful in making sense of an illness or in living day-to-day with chronic pain. One participant spoke of the pain of "loneliness" as a new state of mind, of "emotional dejection and withdrawal" (FG, 09.04.2013). The onset of depression "caused more pain and suffering than the physical ailments" said one participant suffering from RA (FG, 09.04.2013) and another participant agreed that her "arthritis was not as painful as depression" (FG, 09.04.2013). The experience of pain in this new landscape is
unpredictable: there are "cycles of pain, less pain, more pain..." (FG, 24.04.2013). One
participant said "people with chronic illness have an intimate relationship with their pain"
(FG, 24.4.2013). She added that "you get so used to pain that it would be weird not to have
it" (FG, 24.04.2013). Another patient spoke of pain taking her "inside herself" and looking
for ways to get to the outside instead of being trapped in an inner world where the pain
might take over (FG, 24.04.2013).

One participant spoke of having to face a "dark past" when she entered this new landscape

Others took on pain as a companion. The pain of a chronic illness "stays with you when you
go to bed at night" and "it's there when you get up in the morning." Pain "comes on
vacation with you and it's there when you go to work" (NI, 02.05.2013).

**Naked Anger**

One participant told of being angry about the "loss of quality of life, loss of driver's license"
and that she now "has to wear braces [on her legs]." She feared this anger would "grasp
her" and that "she could easily get stuck in her box" (FG, 24.04.2013). She now "has to rely
on someone to get her from point A to point B." When she needs to be bathed, she has
"some young girl standing over her naked old body" (FG, 24.04.2013). Another participant
spoke of wanting "to give up." She was angry at "everything and everyone" (NI,
13.04.2013). Another participant wondered why this was happening to her because she
"did everything she was told" (NI, 13. 04.2013). For one participant anger took a strong
hold on the whole family: her husband became violent which led to police involvement and
then to divorce (NI, 13. 04.2013). The experience of anger leading to losses was repeated
many times over among the participants in this study.

**Filled with Fear**

Fear was a common thread in the narratives and focus group discussions. One participant
described the fear she experienced upon getting the diagnosis of neuropathy as a state of
self-doubt: "you question your mental faculties as much as you question your physical
capabilities" (FG, 29.05.2013). Another participant spoke of "beating myself up" for not accepting her changed life (FG, 29.05.2013).

Fear can build to a level of panic: "I have fear, my heart constantly flutters, it makes me want to run to the doctor but I have to learn not to panic" (FG, 24.04.2013). Being in an alien land can engender fear about daily living such as falling with the accompanying anxiety about the consequences of a fall (FG, 24.04.2013).

One participant feared she was worthless because her illness seemed to arouse doubts in others about her abilities: she came to feel that she was inadequate as a human being, that she now had to prove she was "worth more" and not less because of her illness (FG, 29.05.2013). Many participants agreed that, as one woman said, fear prevented her from talking about her illness. She pointed out that with this opportunity to participate as a chronic illness patient in this project she could reveal that being able to talk about the fears has meant she is "now able to face her fears." In talking with other chronic illness patients she has discovered that she no longer has to live in silence and "stuff the fear anymore" (FG, 29.05.2013).

Figure 4. Mind Map 3.
2. Searching for Answers as a Way Out

We listened to the patients’ experience of pain, anger and fear in the alien land and we heard participants describe how they looked for answers. As the mind map shown above demonstrates, there are main routes and branching pathways that can be seen as representing a search for answers. We heard that participants were like shoppers in a market place looking along the rows of tables displaying exotic treasures. Among the crowds of other shoppers they pushed forward to grasp at the items displayed on the rows of tables searching for something that would be an answer to pain or anger or fear. For some participants the answers did help to ease the pain and anger and fear, but the disease did not go away. Here is what Cyrene found as she lived this search herself and as she moved through the findings.

Cyrene’s Journey into Findings about Searching for Answers as a Way Out

I come to this section on findings as a widow who lost a husband to cancer. Like many cancer prognoses, ours was accompanied by a death sentence. If the tumour could be surgically removed, we would have 2 to 4 years. If not, we had 8 to 9 months. My husband’s surgery was not successful. An aggressive protocol of radiation and chemotherapy was administered but left him depleted and emaciated. The cancer did not respond.

My long days in hospital were spent trying to understand this beast that was in front of us. I was convinced that if we educated ourselves about our opponent, we would outsmart him. Everywhere I turned, I was greeted by survivors, many of whom were given the same sentence as much as thirty or forty years ago. The resources in the Tom Baker library were invaluable in my quest for answers. With the help of skilled librarians I was directed to reliable websites. All kinds of money-making products and services flood a cancer search online. It is easy to be seduced by false claims and testimonials.

Wellspring Calgary was an oasis: my husband and I sampled energy sessions which opened doors to well being and immensely relieved the effects of strong medications. For a couple of days after a simple foot massage my husband told me he was pain-free.
Diet and exercise are two primary life style changes that are common recommendations or answers within the medical community. For many conditions such as heart problems, diabetes, arthritis and others, changes in diet and activity have been either an answer or a partial answer, motivating people in doing what is good for their bodies and their condition. People do reduce toxic foods from their diet, eat healing foods, exercise and build resistance, and reduce stress. Some people stop smoking as an answer to what they perceive to be the cause of their condition.

During this time and for the first time in my life I came to realize how food affects the body and every single cell in it and that emotions also affect the body. Our family came to know the power of nutrition through our struggle to understand and contribute to healing cancer. We went through our surgery and treatments in the hope that we would have a full and complete recovery. As we know, this is not always the case. Chronic illnesses seldom go away completely and often get progressively worse. In our case we first addressed the physical symptoms, then studied the impact of environment, and ultimately fumbled our way into our inner selves and into an expanding spiritual dimension.

The search for answers is a common reaction when families find themselves overwhelmed by the diagnosis of a chronic illness. The first answer we look for is to make sure that there wasn't a mistake and that takes time to process. There is also a period of trying to keep busy, looking normal, going about your daily business as you try to find out what you are meant to be doing as a family with cancer living with you. We also rely on distraction to take away the focus on the illness, to buy time while we sort out what we are to do.

In the findings that follow we show how some participants searched for a safe place to talk about their experience of chronic illness. We also found that some experienced benefits from exercise, changes in diet and attention to nutrition. Others found help through peer support and community resources. Changing the pace of their lives and learning to problem-solve were other directions for some of our participants. Many participants searched for and found an array of answers: as one participant told us, instead of pills she tried "heat, meditation ... massage, acupuncture" (FG, 24.04.2013).
A Safe Place to Talk

One patient living with Parkinson's disease told of her decision to go for counselling. With the help of the Parkinson's clinic she was referred to a psychiatrist and "he did an assessment and confirmed my self-diagnosis that I'm not depressed." She added, "I go to counselling to allow me to have a safe place to talk about things that concern me, to have as sounding board and someone who can give me good advice on how to deal with other people. Because very often it's not how I deal with my disease, it's how other people deal with my disease" (NI, 02.05.2013). This patient emphasized that the "disease isn't who I am, it's just part of what's going on in my life." She has learned to "set up boundaries" with family members around time and activity and advice-giving. Family relationships improved as she learned through counselling how to manage relationships living in her new world of chronic illness.

Another patient told of the help she had from a counsellor to get through a divorce which was "a nightmare." The counsellor showed her "another way of life" so she could get through the difficulties she faced now being on her own (FG, 20.04.2013). Another patient knew she needed counselling so asked her doctor how to get it: "it changed my life" she said. She has gone through a divorce and found that experience was "worse than having cancer" (FG, 20.04.2013).

One patient spoke of how chronic illness "changed her life plan" and working hard to "gain identity or get a new one." She saw a counsellor to help her work on building a new life (FG, 29.05.2013).

The Benefits of Exercise

One patient spoke of walking a lot. Though she had heart disease and lived with fear because of having almost died "3 times," she was excited that she was able to go "zip-lining in St. Lucia" because "it was something I had to do" (FG, 24.04.2013). Another told of getting out with her dogs: they "force me to get out every day and help me to meet people" (FG, 24.04.2013). Yet another patient praised the Living Well program she attended and said "exercise helps so much, it helps in many areas, sleep, digestion and mobility" (FG 24,
One patient told of the benefits of yoga (FG, 20.04.2013) and another got her exercise by gardening and landscaping (FG, 09.04.2013). One patient told of running "three times a week" in spite of her illness (FG, 09.04.2013).

In one focus group a patient put her attitude toward physical activity this way: "When I choose to be happy, I put on the radio, dance or exercise or garden. It is a great step for me to keep in a positive way" (FG, 29.05.2013). Another pointed out that exercise is a way of moving out of isolation: "Walk, talk it out, exercise. Move in some way and don't shut yourself in" (FG, 29.05.2013). One participant confined to a wheelchair spoke of "doing a five-km roll" (FG, 24.04.2013).

**Part of the Journey: Peer Support and Community Resources**

Several participants named the Chronic Pain Centre in Calgary as a valuable community resource (FG, 29.05.2013). One participant said, it was a "blessing to get support which was missing for 7 years" (NI, 13.04.2013). Other participants stressed the support provided by the Living Well Program offered by Alberta Health Services: information is provided about many chronic illnesses, and workshops offer learning about problem-solving (FG, 29.05.2013). Some participants found peer support through their churches: one church in Calgary offers sessions based on the 12-step program and acts as a Christian peer support group (FG, 29.05.2013).

One participant noted that massage was an effective way to manage pain (FG, 24.04.2013). She has a housekeeper and a massage once a week but recognizes that "not everybody has the financial wherewithal to do all of these things but there are resources available ... to get free massages ... free counselling" (NI, 02.05.2013). While family may be a source of support for some chronic illness patients, some participants emphasized that having friends who accept you and understand you is very important (FG, 24.04.2013). One patient praised the HandiBus: it's "wonderful" she said, and she added that the "Kerby Centre has resources and books" (FG, 24.04.2013).

One participant spoke of peer support as "part of the journey" and that because of peer support she can "still put her big girl boots on and walk down the road" (FG, 20.04.2013).
One participant told of sexual abuse as a child and how she had shut down emotionally. She has seen a psychiatrist and has had 10 surgeries. For the first time, she told us, because of the peer support available to her through being a patient participant in this research project, she "feels free" (FG, 20.04.2013).

**Lowering Stress Through Diet and Nutrition**

Several participants mentioned changing their dietary habits: one person told of switching to organic foods (FG, 24.04.2013). One woman told of going on a regime of "eating a balanced diet with lots of fruit, veggies and legumes" (NI, 02.05.2013) and found that eating properly helped to lower her stress levels. Another participant told of taking homeopathic supplements (FG, 09.04.2013). Another spoke of resorting to "biologics" which she said are "very hard on the system, but I didn’t want to be in a wheelchair!" (FG, 29.05.2013). One participant spoke of "seeing a naturopath as well as my own doctor" (FG, 29.05.2013), and another patient spoke of adding ginger and Chinese oil to her diet (FG, 24.04.2013).

**Learning to Live One Day at a Time**

Many participants spoke of needing to pace themselves as an answer to managing their chronic illness. One participant had to remind herself constantly not to "over-schedule" her life (FG, 29.05.2013). This participant described how she struggled with "learning to accept that it changes day-to-day" and talked of having "high expectations" and not being able to "keep up" (FG, 29.05.2013).

One participant reflected on learning not to overload "my time commitment with more than I am capable of doing at that time." She found that her "perfectionism" or "all or nothing attitude and behaviour" did not help. She had to change her "view and expectations" to a new reality (FG, 29.05.2013). Another participant acknowledged that she experienced fatigue easily and needed to "rest and sleep a lot" (FG, 29.05. 2013). In a summarizing statement another participant asserted that the chronic illness patient must "learn to pace herself. If you don’t pace yourself you’ll suffer the next day" (FG, 24.04.2013).
Learning about the Disease

One participant spoke of doing "information research" about her illness (FG, 20.04.2013) and another told of "dealing with the experts ... but feeling something is not right" (FG, 20.04.2013). She learned to listen to her body. Other participants told of "getting to know the disease" (FG, 20.04.2013) and learning that "fears are dispelled by education" (FG, 24.04.2013). One patient spoke of learning about "triggers" that made the illness worse. Some participants were able to obtain very specific answers for the management of chronic illness: one woman learned that quinine would help with her seizures; another found that lying on a cold floor helped her leg cramps; a third person discovered that silk was both warm and light and easy on her body (FG, 24.04.2013).

3. Finding You are on Your Own

We imagine this place as a swamp with stagnant and brackish water. As you come to this place you might find your feet are getting bogged down in the muck and mud at the edge of the swamp, but you might get out of the mud for a time and find a fallen dead tree to sit on. As you sit, you stare at the motionless water. If you watch quietly, you can see the movement of a small animal – a frog or a turtle. You can see the little black flies and mosquitoes buzzing and humming around you and over the still water. In some swamps you might even find a wild orchid. In this place where it is quiet, you can rest from your search for answers and go within yourself.

Dorett searched the data for findings about how our participants experienced this pathway.

Dorett's Journey into the Findings about Being on Your Own

I have learned that our healthcare system is based on an acute care model, that doctors and technology are in control and that the patient can be viewed as the "passive recipient of pharmacological miracles and technological triumphs" (Mills, n.d.).

I have worked with groups of clients with chronic illness for many years and understand what they have experienced in our healthcare system. My work involves providing a home for people with mental illness, ages from 20 to 60; many of these patients have been
homeless so I provide a stable environment, a place where they are safe and warm and have a room of their own. Some have multiple chronic illnesses and require complex medication regimes. Since most have been homeless, the connection with families has been severed; they have lost much in the way of support and emotional care.

They are truly on their own. Safe housing and treating them with respect helps to work against their sense of being on their own.

With this experience I chose to be one of the researchers for the Hidden Pathways of Chronic Illness and the topic, Finding You are on Your Own with Chronic Illness. With my background as a Social Worker with a Bachelor of Arts degree in Behavioral Science and a Diploma in Social Sciences, I have more than 10 years of experience providing housing for chronically ill patients. The methods we used in this project helped me to see that there may be patients who experience mental illness but remain undiagnosed for years.

Our methods provided a safe place for patients to listen to each other and tell of their struggles. Again and again I heard our participants tell of being on their own.

The focus groups have given me additional knowledge of how patients with chronic illness feel as they move along in their journey with chronic illness. This was a very different kind of journey for me working as a researcher. There were ups and downs and many learning curves. I have gained experience and come to know my own strengths and weaknesses. I also see that not much is done for some and sometimes not much can be done for some patients, that some are always going to be on their own.

The patient participants of the Hidden Pathways of Chronic Illness research focus groups who have found themselves on their own, found that they are at pause searching for answers and that all the answers out there aren’t enough. They are on their own because chronic illness is deep in their body and souls.

This Illness is My Journey

Coming to understand that you are on your own with a chronic illness was marked for one participant this way: "This illness is my journey, now that I am on my own. I will be my own
counselor and take it into my own hands" (FG, 29.05.2013). For one chronic illness patient the period of realizing she was on her own is immobilizing: she "would not get out of bed, would not shower, would eat junk food" (NI, 15.04.2103).

Another participant spoke of feeling unsafe and judged because of having a chronic illness. She added that it took five years to get an MRI. Another told of having a physiotherapist tell her "If you see a chiropractor, I won't see you." Yet another told of not being able to go on to Blue Cross because she had "too many complex needs" (FG, 29.05.2013).

In a narrative interview we heard how one woman with a chronic illness became a single mother living alone with her child and no support. She spoke of being depressed and having "suicidal thoughts" because she was on her own. "I had no self-esteem. It disables you completely" (NI, 15.04.2013).

Another participant spoke of her experience of being on her own as being at a "very low point ... life was about doctors' appointments, treatment and pain" (NI, 13.04.2013). Another told of added stress as she went through the experience of being on her own because her "husband had short term memory making it hard to rely on him" (FG, 24.04.2013).

One participant told of coming to a point of "understanding it's out of your control, let it go because you can't change it ... It'll happen the way the way it's going to happen" (FG, 24.04.2013). Finding you are on your own can be "draining ... both mentally and physically" and people just "assume all you have to do is change the attitude." "Take a pill and you'll be fine," said another participant (FG, 29.05.2013).

Two participants described long periods of being on their own. One "became 85 lbs" and came close to death because, she alleged, her husband was unwilling to help her. She was given "final blessings" and at the "weakest point" she somehow rebounded and found the strength to live. Another told of sexual abuse as a child and shutting down emotionally (FG, 20.04.2013). These women have had to live for significant periods of time on their own with chronic illness.
Deciding How You are Going to Feel about "Stuff"

Many participants told of seeing a new way forward in their lives while they were in the swamp of being on their own. One participant spoke of coming "up with my own plan" and doing "a lot of research." She asked questions and decided not to "let everyday be run by others." She got her weight back to normal and got on with building a new life (NI, 13.04.2013).

One participant said, "I will fix myself" (NI, 15.04.2013) while another told of deciding "how you want to live your life" (FG, 29.05.2013). Another participant told of her husband wanting to "do things for her" but wanting to "ask for help if I need it" (FG, 24.04.2013). Yet another marked her realization of being on her own with starting a support group and changing her attitude on "how to be independent." She began to use her walker and learned to "ask for help" and was able to teach others about her disability (FG, 24.04.2013).

With the realization some came to new awareness: one participant told of new friends and learning to dwell on positive actions, learning "to understand her illness and take control" (FG, 09.04.2103). One woman who knew her husband was in a relationship with another woman, faced up to the situation, moved out of her home and sought a divorce. She then moved to Calgary and made a new life (FG, 20.04.2013).

One participant learning to live with Parkinson's disease told us that being on your own can be a liberating experience. Her kids "hired a personal trainer" and began to research her disease to find what might help with the symptoms. She continues to be employed in a challenging job but is adamant that "You have to decide how you're going to feel about stuff and walk down that path."

As the mind map that follows shows (Figure 5), it is possible to build a new life and new awareness.
4. The Search for Meaning

This pathway shows us a place where the sky is wide and high and the rolling hills seem to go on forever. A stand of poplars offers shade from the sun and wind, a place to sit and look out over the rolling hills. You might even find you can hum a tune in this place and enjoy the vibrations in your throat as you watch a hawk wheeling on an updraft high above in the sky. You know that in this place at night you could see the stars and they would give you a sense of hope even in the darkness.

On this pathway patients move from the realization that they are on their own into an exploration of finding or making meaning as they continue living with chronic illness. Heather has a long and deep experience of this pathway.
Heather’s Journey into Findings about the Search for Meaning

It is a very solitary and hidden pathway for those of us who have chronic illnesses even if we have good healthcare and are surrounded by family and friends. This is why I am so interested in this topic – searching for meaning. It is the “practice of making health” that is our challenge and this practice is linked to finding meaning. This search took many forms for me. One form of meaning was coming to know my own inner strength in the face of my illness.

As one participant said: "In some ways it is better. I’ve grown; it’s made me stronger" (FG, 04.24.2013). I found just as one participant said: "Friends are my strength – wonderful friends – shared so much – had fun too" (FG, 09.04.2013). One individual "met wonderful people through the illness ... learned a lot about myself ... opened new doors by having the illness" (FG, 24.04.2013).

I find strength from church and choir and the friends there. It helps me to answer the questions: Who am I? Who loves me? I saw among our participants that finding meaning was a way into a life of believing and that many participants had a belief in God or a higher power. They found that self-worth comes through faith and faith becomes a cornerstone of meaning.

For many people nature adds meaning: one participant spoke about loving life and walking her dog and another spoke of her love of landscaping. It was her "gift" (FG, 09.04.2013). Another told of changing her yard, planting trees. "That was a healing thing for me (NI, 15.04.2013).

I found that listening and helping others had meaning. This makes us look deep inside and offers us a way to cope with CI. This researcher has worked as a volunteer on health care advisory groups for almost twenty years. Even though I am not paid for it, it gives me satisfaction to know that I am helping others who are in similar situations. "When you do the things you love to do, there's a healing process ... [you can] and make the most of that day" (FG, 29.05.2013).
One participant spoke of how meaningful it would be for her if information from this research project could be brought to doctors so they could know how much work patients do to find ways and means to practice being healthy in spite of their chronic illness. There was mention of bringing this information when doctors do their "grand rounds" (FG, 29.05.2013).

I heard participants speak of music bringing joy. I have had chronic illnesses since my mid-twenties and if I did not have music in my life, it would be difficult to cope. My choir keeps me focused and gets my mind off myself and my illness. It is a form of meditation and can keep depression at bay. I believe as one participant said that "music takes you outside of yourself. I sit back, close my eyes and get into a restful state with music" (FG, 24.04.2013). I also saw that meditation can be in the form of prayers or journaling.

A sense of humour is vital in living with illness. "You can't always make jokes about illness but one feels that humour has really helped ... laugh at yourself, what else can you do?" (FG, 24.04.2013).

I personally find meaning in the statement "I have never felt totally comfortable sharing my hidden stories and I don't think I've ever shared them – except in my journal" (FG, 29.05.2013).

**Finding Meaning By Giving Myself in Service to Others**

Some participants spoke of bringing new meaning into their experience of living with chronic illness through volunteering: one spoke of being "devoted to volunteering" (FG, 24.04.2013) and another spoke of running a support group as a volunteer. "Being around others that are helping themselves is inspirational" she said (FG, 24.04.2103). One participant spoke of helping others as a way to keep her out of depression: "I get a new perspective ... focus on my own life." "In spite of my own issues and chronic illness, I can still be productive and worthy" (FG, 29.05.2013). Yet another participant said, "Volunteering has many benefits. Too often we are overly focused on our 'self' and our issues. Helping and working with others takes the focus away, helps put our situation in perspective, focus on more positives, working towards a dynamic ... self ... gets us out moving, thinking and contributing" (FG, 29.05.2013).
Of her experience of volunteering one participant said: "We take our experience, strength and share it with other people. Others can do what we have done," and she went on to add, "share, be inspiration and find inspiration" (FG, 29.05.2013).

**Finding Meaning Through Faith and Meditation**

Many participants described how their belief in God or a higher power helped: "My centre is my God and Saviour. I want to find a breakthrough and be positive" (FG, 09.04.2013). Another spoke of "the importance of faith in my journey" (FG, 09.04.2013) and another participant spoke of "God giving her a second chance." She asserted that she "needs to make the most of it" (FG, 09.04.2013). Several participants spoke of learning to meditate (FG, 24.04.2013).

**Finding Meaning through Creative Expression**

One creative project that showed how much life can be altered but for the better was a house renovation described by a participant. She had plans to do this prior to her diagnosis but was spurred on to complete the project when told she had a chronic illness (FG, 29.05.2013). Several participants spoke of gardening and landscaping as ways to create meaning. One participant described how she had been depressed for years because of her experience of abuse and depression; then she took one step to begin gardening and later in life launched a career as a landscaper. She has come full circle from the alien land to a life of creating beauty for others.

Though perhaps not an obvious creative activity, for one patient living with chronic illness, riding her motorcycle was a meaningful experience. When she is not riding, she can visualize riding; when the pain is bad, she "can control pain that way" (FG, 09.04.2013).

One woman who remained isolated because of her illness enjoyed music and read (FG, 24.04.2013). Several other participants also told of music and reading as meaningful pleasures. Two participants spoke of journaling as a source of creative energy and a way to give meaning to their experience of living with a chronic illness (FG, 20.04.2013; FG, 29.05.2013).
One woman described how she followed a course called The Artist’s Way and "had business cards made up that said Writer, Facilitator." It took "a lot of work to gain identity or get a new one" because "everything in life had changed." This participant volunteers for the Neuropathy Association and is now a working writer and facilitator (FG, 29, 05, 2013).

**Figure 6. Mind Map 5.**

**5. Presenting Your New Self**

Join me in a place which sits in isolation far out in the ocean, but sharing the place with many other species. You'll need to figure out who's your friend and who's your enemy. At first you'll find living here is difficult but as time goes by you learn new skills and your days get easier. Learning to be a chameleon in this place of diversity is a challenge. You keep one eye out for predators and one eye out for a mate, and you're having to pay attention to each step. One misstep may cause you to stumble. It's difficult to thrive in this environment with
other competing species and the weather forever changing. You realize that if you were to try to return home, you'd never be the same anyway. This island has changed you forever. This place of presenting a new self shows that people diagnosed with chronic illness can move into a new relationship with self and with others. But it is a bit like learning to be a chameleon. You may have to learn not to speak about your illness with some and hide it from others. As the mind map above shows, a new self may be an opening into a new life. Sandra knows this pathway well.

**Sandra’s Journey into the Findings on How to Present Your New Self**

This hidden pathway is of interest to me as I have had to learn new strategies in order to navigate my relationships while living with a chronic illness. At 18 I went from being an athletic healthy young woman to being very ill. At the time I was attending a post-secondary institution, had a boyfriend, was engaged in athletic activities and an active social life. I found myself in situations where I was unsure how to handle myself. I tried humor but there were times when I would avoid situations because I could no longer trust my body. I was diagnosed with Crohn’s disease at an age when your peers are not too interested in discussing health issues. The diagnosis changed my world. My boyfriend decided it was all too much for him and left. I began to see that the outside world was seeing me differently, even though, in my mind, I was the same person. I learned that I would have to become a chameleon in order to fit in. I educated myself so that I could educate others. I had five older brothers and they had a hard time hearing about their little sister’s illness. Instead of expecting them to shift their perspective of me, I shifted my perspective. I watched their reactions when I spoke of my illness and started to protect them from what they did not want to hear. I tried to maintain the image of a healthy and happy-go-lucky younger sister. It took time for some of them to get used to my having this illness.

At this point I became more involved with healthcare professionals; I wanted to be part of the team. This was difficult as I seemed to have to present myself at all times with the right amount of assertiveness, humor, respect and knowledge. Even when I got it right, some medical professionals were not interested in being on the team.
I started to see my new self through other people’s eyes and adjusted my persona depending on the situation and the people in it. I took one approach with medical personnel and another with family, friends and employers. This experience was described many times in our focus groups.

It’s rare for us, patients with chronic illness, to be in a situation where we are able to completely let our guard down even with family and friends. We’ll often "sugar coat" the seriousness of the chronic illness. When given the right situation, a person with a chronic illness is able to express himself or herself openly and honestly. We were privileged as researchers to witness this happening during our focus groups. We had experienced similar struggles and were able to speak openly about our experience of living with a chronic illness in a safe environment. We were clear that we are not therapists which allowed the participants to express and then move on. Through observations and feedback it was apparent that we could let down barriers and just "be ourselves."

Those of us with chronic illness learn to adopt personas as coping mechanisms. When we’re forced to put up barriers, we’re left feeling frustrated, rejected and alone. We learn to counterbalance these feelings by being humorous, being a teacher or an advocate, and we’re left to figure out when and with whom to share our vulnerabilities, insecurities, anger or bluesy moments. There seems to be a fine balance needed when we are constantly walking that tight rope in order to "fit in."

Learning about how patients live with the experience of chronic illness has some life-changing lessons for all of us. There’s no going back to who we were before the chronic illness so we figure out what works or does not work. Many of us struggle to navigate this pathway. If we are able to develop the strength and courage to "test our new selves" and dare to hope that we may receive some positive reactions and experiences, we may find a pathway to independence, self-advocacy and being our own boss.

**Ways of Presenting Ourselves**

Humor is just one way a chronic illness patient may choose to present himself or herself. One participant who depends on homecare for necessary daily activities told of learning to
laugh. Even with a loss of dignity and privacy, she saw the humor in her situation: "Laugh at yourself, what else can you do?" (FG, 24.04.2103). Humor can also be useful when speaking with medical professionals, family, friends and even in the work environment.

Becoming a teacher about an illness helps us to better understand our own situation as well as help others. One participant showed how she took on this role. She gave a detailed description of her early experience with Parkinson’s disease, told of having a sore shoulder, then going for a cat scan and finally seeing a neurologist. Through her own learning she became a teacher of how to present your new self as a person living with a chronic illness. She told us how she educated her mother: "When my mother started saying, 'you should do this, and you should do that,' I talked to her [pause] she needed to stop and think that I have probably thought about everything she has to say plus a whole bunch more because it’s in my face, not hers, all the time" (NI, 02.05.2013).

Being an advocate for oneself is especially important when navigating the medical system. It can also be a little tricky as you risk being seen as difficult or non-compliant. One of our participants explained that she wanted to take an active role in making decisions about her health and her body but her doctor did not seem interested in what she had to say. She said to him "I am over 18 ... I can make my own decisions, you just give me advice" (FG, 09.04.2013).

Another participant spoke of having to hide her chronic illness. She was told the illness was "all in her head ... take a pill ... you'll be fine." She told of the lack of validation for women with Workers Compensation. She was told to "just go home and look after your kids." Fighting back was one way to present herself to get what she needed but having to fight caused stress (FG, 29.05.2013).

Another participant spoke of having to deceive people about his illness. He described his difficulty getting hired when he told the truth about his chronic condition. The condition would not interfere with work but no one wanted to hire him because of the condition. He hates being deceitful but finds that, if he is honest, he has to work hard to convince people that he will be able to come to work every day (FG, 24.04.2013).
The most difficult masks to wear are those of vulnerability, insecurity and anger. Most people are uncomfortable with being presented with these strong emotions. One participant told how she had hidden the story of childhood abuse until coming to a focus group. She has struggled to hide this experience from everyone; her husband who was also a participant told of a new appreciation of her experience of chronic illness now knowing what she has been hiding (FG, 20.04.2013).

Figure 7. Mind Map 6.

6. You are not the Boss of Me

Imagine imposing wooden doors opening into a long light-filled room. On the south wall floor-to-ceiling windows open onto a garden. Along the north wall are bookcases from floor to ceiling: there you can find CDs, DVDs and books – including electronic books – about an array of subjects. Scattered about the room are groups of comfortable chairs encircled
about tables. Men and women of all ages are seated about the room in groups of three or four or five; many are deep in conversation as they lean back on big cushions. On the two remaining walls to the east and the west hang paintings by the Group of Seven: landscapes of rocks and lakes, pines and firs, maples, birches and aspens, some with blue sky, some with storm clouds yet all painted in a riot of yellow and orange, red and green, blue and black.

This is a place where people speak and act with confidence because they know they are in charge of their lives. This is a place where patients talk openly about illness, where they can have a mutually beneficial conversation with medical practitioners as well as other patients. Here you can become the leader in your own life because you are building relationships that help you to live a healthy life. You learn to be the boss with your healthcare providers here, and, in this comfortable setting, you can be fearless in telling family and friends what you need.

As the preceding mind map shows it is possible to see how to live a healthy life even while you live with chronic illness.

Chris tells of his journey along a path to this place.

**Chris’s Journey into the Findings of You are Not the Boss of Me**

With my professional experience in Human Resources, this topic resonated personally with me. I have spent countless hours with employees, employers and boards endeavoring to strengthen leadership processes and turning individuals into the leaders they need to be. In many ways my personal journey was one of not finding a way, not being shown the way, not being told what to do, but creating my own pathways through chronic illnesses. Creating these pathways has only served to strengthen me.

Many of our participants told compelling stories of changing dynamics with healthcare professionals, with family and friends, with strangers, and most importantly with themselves, while learning how to regain control of their own lives. Gaining the
understanding that "you are not the boss of me" and the corollary that "I am my own boss" is a phenomenon that represents a hidden pathway.

Some research is helpful in understanding the need to become a leader in managing a chronic illness. I was struck by the following in one of the articles I read:

"Meichenbaum and Fitzpatrick (1993) postulate that 'how individuals and groups engage in narrative construction is critical to their adjustment to stressful events' (p. 712). Diagnosis of a chronic illness or the onset of a disability is indeed a stressful event. The transition from well to ill, able-bodied to disabled, represents a challenge to the beliefs many of us operate under at some level, namely, that we are invulnerable, that our lives are predictable, that life has meaning, and that we are worthwhile. The onset, sudden or otherwise, of a chronic illness or a disability calls all of those beliefs into question." (Docherty & McColl, 2003, p. 20)

It is through calling these beliefs into question that our participants demonstrated how they chose to ignore old patterns of life and old bosses, how they chose to reframe themselves and their lives. After the shock of the diagnosis of chronic illness faded, they found internal strengths – far beyond what they had initially believed – to take control, alter their state, their condition, their situation, their reality, and, in fact, become the boss of their illness.

We were privileged to hear participants tell how they transitioned along the hidden pathways to take charge of their illnesses. We heard stories that demonstrated Antonovsky’s sense of coherence factor of manageability, the theory that you can develop the skills, the ability, the support, the help, the resources necessary to take care of things, that life can become manageable and within your control even when you live with an illness. (Antonosky, 1979).

**My Disease is Not My Boss**

Many participants told of learning to distinguish themselves from the disease. "I view myself as having the disease not being the disease. The disease isn't who I am, it's just part of what's going on in my life." This same participant stressed how a chronic illness is with you all the time, that you can never forget you have it (NI, 02.05.2103).
Another participant spoke of being "in victim mode until 2010" when a Freedom Sessions workshop, a version of a 12-step program, "snapped me out of it." She told of feeling "crippled" and explained that these sessions have helped her to take charge of her illness and of being "much healthier now" (FG, 09.04.2013). At a subsequent focus group one participant declared that "it is really important to take charge of your own treatment. They [health care providers] are not always right." She went on to say: "we know our own bodies better than somebody sitting on the other side of the table," and added, "learn to listen to your body" (FG, 20.04.2013).

One woman with seriously impaired vision spoke of being "grateful for not being totally blind" and then told us "when I'm on a trip I take it all in, live in the moment and then when I get home I try to remember everything." She loves to travel and relives each experience and enjoys being her own boss in relation to her illness (FG, 24.04.2013).

Another participant added a sticky note to our flip chart notes, as we invited all participants to do. It read, "I strongly believe one should have the right to make informed choices. I will stand firm on my beliefs and convictions that if I am diagnosed with an illness that is progressive and will leave me in a total state of disability I will certainly choose ... to prolong my life" (FG, 29.05.2013). She was stating, as many others had, that she and no one else was in charge of managing her illness.

**Leading Through Educating**

Educating those who are in the role of educating the patient can prove to be a challenge. Several patients referred to their changing leadership dynamics with the variety of healthcare professionals they met. Learning to be assertive and even confront healthcare professionals was an important step for many participants. As one participant put it: "I am the expert of me." She told her doctor, "You do not understand! You aren't dealing with the illness. We need to explain what we deal with on a daily basis" (FG, 09.04.2013).

Manageability of an illness for some participants meant not so much schooling themselves, but schooling others that they needed help and how they can be helped. Educating others about their illness became a way to lead others into new understanding. One participant
admitted that she needed "to go to the lowest" to see her own strength but she has found the strength to tell others what she needs (FG, 20.04.2013).

A few participants spoke of building a team to assist with the management of the illness. One participant spoke of how good it was to have "nurses in different places" and "professionals in different places" who would provide the care she needs (FG, 09.04.2013). Another participant told of setting up a "Team Network" and of having rules for her team. This participant stressed that she is "extremely independent. If I can do it myself, I will do it myself." She has built a health care team that includes the right doctors including specialists and considers community services as part of her health care team as well as family and some friends (FG, 29.05.2013).

**Drawing on Past Experience to Be the Boss of Your Illness**

Illness in the family at an earlier time set the stage for one participant's journey into chronic illness: "I certainly have had periods of my life of great grief but the reality is that when my daughter passed away at 10 years of age, that was very, very difficult ... So when she died, that was probably the lowest point I’ve ever been in emotionally in my life ... This [her chronic illness] is a piece of cake compared to that” (NI, 02.05.2013). "If I can deal with everything that went on in that experience parenting a child who is terminally ill who is progressively deteriorating, and who eventually died at the age of 10, this is pretty darned easy" (NI, 02.05.2013).

As the following mind map shows (Figure 8), chronic illness does not mean that your life is over; indeed life can be full and meaningful even in the face of all the losses that may be experienced.
Like a mighty river running through and across the places we have named as hidden pathways, losses and surges accumulate and build. Throughout our focus groups and narrative interviews participants spoke of the losses and gains that became part of their entire journey, part of their learning, part of their search for meaning. Gloria searched the data for the losses and gains that have been experienced all along the pathways by our participants.

**Gloria's Journey into Findings about Losses and Gains**

I understand that chronic illness is persistent and long-lasting in its effects and that the term, chronic, is usually applied when the course of the disease lasts more than three months. Most seniors have at least one chronic disease. Many of the losses relating to chronic
illness can be permanent as I have learned. Having difficulty with mobility I am unable to continue to hike or golf and any employment that requires travel. This has meant losses involving social relationships and interaction with others including supportive relationships. In the past I have taken up the caregiver role and now find it disheartening to find myself as a recipient of care.

My personal gains are spiritual and emotional. Faith and the ability to experience gratitude for what I can do are strong gains. I realize that as an individual I can continue to make a contribution to society even with a chronic illness. The experience of being engaged as a patient researcher with other patients has been helpful in showing new ways to be a contributing member of society. I see that by engaging in this research I am able to provide research data to health professionals and the medical system as a whole, research which may help other patients living with chronic illness.

While many of our participants disclosed the permanent losses, they also told of gains. Gains included acceptance and the experience of generosity of friends, the joy of children and grandchildren. Insight can be developed: discovering who I am and learning that I can choose my attitude. You can learn to listen to your body and learn how to help others.

I found the theory of salutogenesis helpful in an understanding of the experience of losses and gains with chronic illness. Participants spoke of stress: managing stress is part of this theory. Antonovsky's (1979) formulation of "generalized resistance resources" helped me to see that many of our participants had made gains in learning how to access and develop their resources to resist stress. One participant spoke of new insight. Some found inner strength they did not know they had. Some began to see their illness as an opportunity to learn about their bodies and others spoke of taking control of their lives. One statement that was said again and again was that you may not be able to control what is happening to you but you can choose how you react to what is happening

**Loss of Relationships**

We were all struck by one participant’s admission that the focus group was her first "social outing in 10 years." She was not sure if she could participate "too much" (FG, 24.04.2013).
This participant has a relationship with her daughter and granddaughter which she really enjoys but she has lost all contact with any friends she might once have had (FG, 24.04.2013).

Many participants spoke of the difficulty of planning social gatherings. One participant described the loss of social relationships this way: dinner parties have to be cancelled because "sometimes you are tired on a 'cellular' level and your body requires you to rest – friends need to understand that" (FG, 29.05.2013). Another participant added that "people don’t want to hear about it [chronic illness]. You look fine so 'what’s your problem'?" Many people "stay away because they can't deal with it" (FG, 29.05.2013).

One of the most difficult losses is the dissolution of marriage. With the loss of marriage comes the loss of intimacy: one woman spoke of wanting to be "normal again" that she needed to be seen as "whole and sexy" (FG, 09.04.2013). With the loss of marriage comes also the loss of financial support: one woman spoke of "huge financial issues" (FG, 09.04.2013).

One woman told of being diagnosed with uterine cancer at age 22. She moved to Alberta and married and worked two jobs so her husband could go back to school. She became pregnant and the cancer returned. She then moved to Calgary only to hear her husband say to her one day "It’s over." She "did not see light for a year" (FG, 09.04.2013).

Loss of Work, Career and Identity

One narrative interview opened up into a depth of disclosure about losses. At age 30 this participant had been employed, active and married with two children. She suffered a sports injury playing soccer which triggered a series of losses: she became divorced with no income and then was rear-ended in a car accident resulting in permanent nerve damage to her right arm. She could no longer ski or swim. In spite of these losses, or maybe because of them, she returned to university and completed a Master’s degree which gave her a feeling of self-worth (NI, 13. 04.2013). A second accident sent her into another long recovery period. This woman experienced a loss of identity but fought her way back to regain faith in herself and eventually a new identity.

The challenge of recreating a sense of identity was expressed by one participant this way:
"The disease is what I have, not what I am" (FG, 20.04.2013). Another participant lost her identity as a wife when her husband died and then experienced another aspect of identity loss when she could not longer work as a nurse because of her illness. One woman who had been a bank manager found she was unable to get out of bed one day: she was unable to walk. The bank did not want her back and she lost her job (FG, 29.04.201).

**Gains**

Throughout all the focus groups and the narratives interviews, gains were named. We heard participants speak of gaining a sense of what is safe and unsafe for them as they learn to live with their chronic illnesses (FG, 09.04.2013). One participant in an early discussion noted that she had gained a new self-awareness: this included a new appreciation of others, of becoming more of a "giver than a taker" (FG, 09.04.2013). Another participant spoke of how she had learned to "challenge herself away from fear" (FG, 24.04.2013). One woman talked of learning to adapt, that she was able to see that she could still have a life, a life that might even be better in some ways: "I've grown, it's made me stronger" and there are "not too many things I couldn't take on." This participant told of gaining new tools "to adapt to things" and how she has "met wonderful people through the illness." She "learned a lot about herself (FG, 24.04.2013).

Learning to live in the present was a gain for some participants. "It is so freeing. Yes, I am living in the present] and have found that I don't have the fear and anxiety and worry anymore" even though "it was a struggle to live in the present" (FG, 29.05.2013). One participant said: "If we see ourselves as victims – we are. Everyone has some burden to carry" (FG, 29.05.2013). One participant acknowledged that she has learned to make "self-affirmations." "My mind might know it is safe but my body doesn't know it is safe, so I tell my body that it is safe" (FG, 29.05.2013).

Another spoke of deciding to be positive: "it's not that I don't from time to time ... have negative feelings, I do, there are times that I like everybody else have black clouds over my head, but I am vigorous in saying to myself ... think again, do not think this way, think differently, and so I do because I truly do recognize it's about choices" (NI, 02.05.13).
Summary

We conclude here that this research project validates the concept that chronic illness is an entity in its own right and, as such, that chronic illness needs to seen as a common category or sphere of patient experience that can provide new and valuable knowledge about the care and management of chronic illness. The experience of patients living with chronic illness needs to be brought to light and understood as having unique qualities. The similarities and connections between patient experience of living with chronic illness shown with this project indicate a need to keep a focus on the human experience of chronic illness.

Antonovsky’s theory of salutogenesis provides a way to see this more clearly. The pathways described here in this report can be seen as illustrations of how chronically ill patients comprehend, manage and give meaning to their lives not in spite of the illness but because of it. The hidden pathways can be seen in the light of patients seeking a sense of coherence even as they live with illness: as patients struggle with the stressors encountered while living with chronic illness, most are able to discover and/or build resources that act as resistors to stress. However, further research by patients and with patients is needed to come to an understanding of the complex nature of the experience of chronic illness and the stressors encountered by patients. More research on hidden pathways in the light of Antonovsky’s theory will not only enrich our understanding of the experience of chronic illness, but also contribute to knowledge of how to support patients to build resources to resist the stress of chronic illness that is encountered throughout a lifetime.

We see also that further research into the patient experience of these hidden pathways will show how reliance on silos of medical expertise may work against effective management of chronic illness. A strategic need appears to be what we could call ongoing consultative communication between medical professionals and patients. There is a critical need to listen to and understand the patient’s experience of his or her illness. Clinical pathways are designed to treat a specific illness, but the hidden pathways of chronic illness as revealed by patients speak to the need to understand that the patient is not the illness. Patients want
to be seen as whole human beings who have the illness rather than hosts of an illness that is somehow treatable as an entity separate from their whole selves.

We see a strategic and continuing need to address the treatment of chronic illness as an entity, but we also see a strategic need to invest resources in patient engagement research. The engagement of patients with each other to provide knowledge about their individual patient experience could prove to be invaluable for more effective management of chronic illness.

This research shows that patients do make their own pathways as they live with chronic illness, that they actively engage in seeking wellness and health, that they do not and cannot rely on technical and rational medical treatments rooted solely in a pathological perspective. Patient engagement suggests what the health care system at present cannot. Additional research into understanding, managing and making sense of living with chronic illness will support the patients’ desire to live a healthy meaningful life rather than one lived in the long shadow of unmanageable and incurable illness.


