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**FACULTY OF GRADUATE AND
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Chronically Ill Patients' view of Health, Illness and the Healing Relationships in Integrative Medicine

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PROPOSED TITLE:

**CHRONICALLY ILL PATIENTS' VIEW OF HEALTH, ILLNESS AND THE
HEALING RELATIONSHIPS IN INTEGRATIVE MEDICINE**

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Abstract

The increasing popularity of integrative medicine requires that we understand the meaning that patients attribute to their treatment experience. This project was a phenomenological study that sought to understand how nine chronically ill patients perceived their experience of living with illnesses and the treatment process at the integrative clinic. My findings reveal that their illnesses disrupted their life and were a threat to their self. An impetus combined with the influence of the social sphere led patients to join the clinic. The relationship with caregivers at the clinic was an important component of the treatment process and provided participants with the knowledge necessary to manage their illnesses. The positive interaction with caregivers enhanced patient empowerment and improved patient participation. Following treatments at the clinic, the majority of participants felt that their health had improved and that they had returned to their old self. Many had set future goals.

Chapter 1: Introduction

Increasing longevity rates due to health care advances and an aging population have resulted in an increased number of individuals suffering from chronic illnesses. Eighty percent of Ontarians over the age of 45 currently suffer from chronic ailments, and of those, seventy percent suffer from multiple morbidities (Tsisis & Bains, 2008). Previous research has demonstrated that patients' perception of their chronic illness experience influences their selection of a coping strategy. Similarly, physician-patient relationships can significantly impact how patients perceive their illness, and hence, their choice of coping strategy. There is limited research to date on the influence of practitioners within the context of integrative medicine, an approach to the delivery of medical services that combines alternative and conventional medical treatments by one's physician. Integrative medicine's emphasis on wellness and the treatment of the whole person (bio-psycho-socio-spiritual variables), and the holistic approach that is adopted by integrative clinics represents an attractive treatment modality for patients seeking complex care (Bell *et al.*, 2002).

The growing popularity of alternative medicine within conventional care requires that we understand the meaning that patients attribute to their experience of living with a chronic illness and the different aspects of their treatments within the context of other health care models. Patients are increasingly incorporating alternative treatment modalities such as herbal remedies and massage therapy within their treatment regimen. Up to 73 percent of Canadians are reporting that they are using alternative medicine and that number is expected to increase as the population ages and the number of chronic illnesses rises (Hollenberg, 2006). The healing modality offers many benefits to chronically ill patients including improved patient compliance and the inclusion of benefits from each healing therapy (Boon

& Kachan, 2008). Physician-patient relationships play a central role in the treatment process in integrative medicine—treatment sessions aim to not only address somatic difficulties, but also lifestyle choices, health promotion and patient participation (McCaffrey, Pugh, & O'Connor, 2007). Examining the meaning of living with a chronic illness and the aspects of the healing relationship that impacted how patients perceived their treatments can provide lessons that will serve to draft policies on how to better meet the needs of our chronically ill patients.

Herein, I aim to illustrate how patients perceived their experience of living with a chronic illness as well as the elements that made their integrative treatment process meaningful. As such, the purpose of this project is to answer the following research question: how do patients experience their chronic illness and the process of receiving integrative medicine treatments? More specifically, I am examining:

- 1) How patients experience their health and illness before and after their treatments;
and
- 2) How they view their relationship with the integrative physician at the integrative clinic and the impact of this relationship on their treatment, health and healing

As the integrative staff works closely and often with the patients, the patients describe their appreciation for the work of the integrative staff members and that of the integrative physician in particular.

Health and illness are lived experiences that are characterized by “perceptions, beliefs, skills, practices and expectations” (Benner, 1985). Health psychologists have recently acknowledged the importance of understanding how participants make sense of their

experience (Leventhal, Diefenbach, & Leventhal, 1992). Interpretative Phenomenological Analysis (IPA) is a qualitative research method that seeks to portray the meaning of lived experiences through the study of the particular and rich descriptions. The approach requires both the narrative contribution of the participant and the interpretative approach of the researcher (Smith *et al.*, 2009). IPA is an attractive method because of its ability to link the understanding of participant experiences to theoretical frameworks. Furthermore, IPA is a valuable method when the phenomenon that is being studied is complex or new. The novelty of integrative medicine makes IPA an appropriate method for this study. IPA has been used extensively in psychology but has recently been adopted by the fields of social science and health science (Smith *et al.*, 2009).

In the next sections, I will review the existing literature on patient experiences of chronic illness, self-management and physician-patient relationships. Although the purpose of the study is to understand the patient experience, I will link my research to existent literature on chronic illness and physician-patient relationships because my findings address these issues. Nevertheless, these topics have not been examined extensively in integrative medicine. As Lopez & Willis (2004) encourage IPA researchers to extend the interpretation of their findings to meanings for practice, research and policy, I included a section on implications for medical practice, policy and research. It is important to note that the opinions presented by the participants do not necessarily reflect the opinion of the author. Participants' views presented in the thesis should not be interpreted as medical evidence or a prescribed course of action for others. Patients that require medical attention should seek care from a registered health professional.

Chapter 2: Review of the literature on the experience of living with a chronic illness, and the physician-patient relationships

This chapter examines findings from previous studies on the experience of living with a chronic illness, self-management procedures and the elements of the physician-patient relationship that affect patient care. The experience of living with a chronic condition influences the adoption of self-management procedures. A positive physician-patient relationship has the potential to modify how patients perceive their condition, and hence, how they manage their illness. These past studies are important in determining the areas of research that have been covered in conventional medicine. Since integrative medicine is a relatively new field, few studies have examined the physician-patient relationships within the context of integrative medicine, and this one focused on the experience of chronically ill individuals. Other studies have yet to examine it within the context of chronic care and integrative medicine.

Chronic Illnesses and the Self

Chronic diseases are caused by irreversible pathological alterations that are permanent and often disabling (Whittemore & Dixon, 2008). Chronic illnesses result in poorer quality of life, poorer levels of effective functioning, “loss of independence, pain, emotional distress and changes in self-identity” (Whittemore & Dixon, 2008). The consequences of chronic ailments are further compounded by the fact that patients can suffer from more than one chronic condition at a time.

At a systematic level, chronic illnesses such as heart disease, diabetes and asthma impose a significant burden on the health care system. In Canada alone, costs incurred in order to

treat chronic ailments account for 55 percent of all health care costs (Tsasis & Bains, 2008). In terms of health resources, individuals with chronic illnesses use homecare and hospital services to a greater extent than other patients (Broemeling, Watson, & Prebtani, 2008). The present health care structure is built to address acute rather than chronic care needs—with greater emphasis placed on treating the immediate (and urgent) needs than on disease management and prevention (Bodenheimer, Wagner, & Grumbach, 2002). As a result of this structure, most patients suffering from chronic conditions do not receive the resources or the time necessary to properly manage their condition, and as such, receive substandard care (Bodenheimer *et al.*, 2002).

On an individual level, chronic conditions alter the personal life story of the people that they affect. It is what Öhman *et al.*, 2003 call a “break with the past” and the revision of future life goals (Öhman, Söderberg, & Lundman, 2003). In his study of the chronically ill, Bury (1982) describes how participants experienced a ‘biographical disruption’; due to their illness participants had to reconstruct their life story and modify how they perceived their self (Bury, 1982). Chronic illness, therefore, creates a sense of disorder in the life world and renders the individual vulnerable. The impairments that arise of these conditions require significant adjustments in daily living and force the individual to learn to cope. As Charmaz (1983) has described in a previous study, the physical and emotional consequences of the illness, and the demands of the treatments can negatively influence social activities. Social withdrawal, depression and feelings of becoming a burden can threaten the self, “the organization of attributes that have become consistent over time” (Charmaz, 1983).

Self-Management Procedures and Illness Representation

Self-management procedures have recently been introduced as a tool to improve the health outcomes of chronically ill patients and to reduce the burden on the health care system (Whittemore & Dixon, 2008). Self-management techniques are defined as the dynamic learning, practicing and discovering of skills that are utilized by patients to cope with their condition (Whittemore & Dixon, 2008). Self-management programmes call on patients to take-on a more active role in making health care decisions, and as such, require proper support from caregivers, including their physician. They have been shown to reduce the number of visits to physicians and to improve decision making. Furthermore, patients report reduced pain levels, improved quality of life and health outcomes. Proper self-management techniques are crucial steps in maintaining or improving the health status of individuals suffering from chronic ailments. An example of a self-management programme for chronic heart failure includes the following: patients must follow a strict drug regimen and low sodium diet (Horowitz *et al.*, 2004). Patients are also advised by their physicians on how to monitor their health for any signs that would indicate water retention (and therefore health deteriorations), and on how to respond to these changes. The response may include adjusting their daily medical dose.

Several studies have examined the impact of illness representation on self-management procedures. Horowitz *et al.* (2004) examined the illness representation of 19 patients with congestive heart failure in order to understand what prevented them from adopting a proper treatment regimen. Although therapy for congestive heart failure has been shown to improve survival and quality of life, health outcomes for the condition have not improved (Horowitz *et al.*, 2004). Seventy-five percent of men and 62 percent of women die

within 5 years of diagnosis. Patients often fail to engage or maintain in self-management procedures that would improve health outcomes. Interviews conducted by Horowitz *et al.* indicate that patients failed to recognize the chronic nature of their illness due to a lack of information on the symptoms and the causes of their illness, and did not have the tools necessary to manage their condition. When their symptoms worsened, patients had difficulty accessing their physician. Guidelines for the treatment of congestive heart failure recommend that patients obtain a solid understanding of the condition that extends beyond the knowledge that is gathered from the physician.

A study investigating the illness representation of depressive patients has found that patients who adopt proper self-management techniques have fewer symptoms and a better quality of life (Brown *et al.*, 2001). Patients who possessed a good understanding of depression and its consequences were capable of selecting the appropriate coping techniques and adhered to the recommended medical procedures. Similarly, a study aiming to develop and implement a self-management programme for asthma patients found improvements in self-efficacy and quality of life (Smith *et al.*, 2007). ANOVA tests (Group x Time F) on key outcome variables indicate that the intervention produced significant improvements in medical adherence (3.95), asthma self-efficacy (4.76) and quality of life (4.00). By examining both the Time F and Group x Time F columns, however, only improvements asthma self-efficacy and quality of life are significant. Nevertheless, patients who were able to identify problematic areas in their health were capable of producing strategies to help resolve key issues in their health.

Patients' positive perception of their self and self-management procedures can be reinforced by patient centered care. Patient centered care is defined as providers sharing

control of the consultation with their patients and decisions regarding the treatment process, and as such, good physician-patient relationships are required (Kvåle & Bondevik, 2008). Patient participation can lead to patient empowerment if the practitioner takes the time to listen to patients and makes them feel valued. Patient empowerment is perhaps best described as “the connection between a sense of personal competence, a desire for and a willingness to take action” and as a process of “gaining control over one’s life” (Peterson, Grippo, & Tantleff-Dunn, 2008). Factors that patients described as empowering have been documented in previous studies. Maizes and Victoria (2009) describe patient empowerment as follows:

Patients become empowered when they have the “knowledge, skills, attitudes, and self-awareness necessary to influence their own behaviour . . . to improve the quality of their lives.” Empowerment arises from the relationship between clinician and patient. It is less a transfer of power and more a symbiotic process where power is created and grows through the relationship.

Access to lay information is another essential component of patient empowerment. Lay information provided by caregivers allows patients to become experts in their condition and to control their illness.

Physician-Patient Relationships in the Context of Chronic Illness

The physician-patient relationship is a central element of living with a chronic illness in Charmaz’s (1983), Öhman *et al.*’s (2003) and Bury’s (1982) studies. Charmaz (1983) reports that the role of the physician becomes an important part of the chronic illness experience, especially in cases where social withdrawal exists. Öhman *et al.* (2003) explain that patients who received help felt that they had more control over their daily life. In

addition, patients experienced confusion when the physician provided them with information that did not correspond with their individual perception of their condition. On the other hand, patients felt relief when the explanations fit within their perceptions. The overall message is that patients need explanations to make sense of their experience and the improper delivery of these explanations may lead to feelings of uncertainty. Bury (1982) describes similar findings. Providing patients with access to medical information allows them to separate their self from their illness (Bury, 1982). Moreover, medical information provides patients with a legitimate reason to engage in socially undesirable behaviour (e.g. social withdrawal) as the symptoms that they are experiencing fall within an established diagnostic and this also provides them with a valid reason to seek clinical care. Finally, poor communication practices and inappropriate treatments on the part of caregivers may create a sense of disappointment in patients who initially had high hopes of the ability of medicine to treat their condition.

The effects of physician-patient relationships on patient care have been examined by other authors within the realm of conventional care. In their qualitative study, Haugli *et al.* (2004) examined the aspects of the medical encounter that were meaningful to patients with rheumatoid arthritis and non-specific inflammatory conditions (Haugli, Strand, & Finset, 2004). The findings indicate that patients with rheumatoid arthritis wanted to be seen more as individuals than a disease entity. Similarly, they wanted their physicians to acknowledge that patients were experts on their life. This, in addition to accepting the patients' perspective was seen as contributing to the development of a supportive physician-patient relationship. The availability of the physician when patients felt that their symptoms were worsening also contributed to a strong relationship. Providing patients with information on

their condition and their prognosis were important elements of the medical encounter as well. Interestingly, patients expressed more trust in a physician that was willing to admit that he didn't have an answer to a problem.

In their study of the physician-patient relationship in Irritable Bowel Disease, Goldring *et al.* (2002) reported that the management of a chronic illness requires that patients and physicians work in a partnership. Patients need to be capable of exploring options with their physicians in order to determine the solution that will maximize the patient's health. The options must be consistent with the patient's opinions and preferences. Patients must likewise receive clear and consistent information. The study concludes that more involved patients adhere and engage in more health promoting behaviour.

Wasson *et al.* (2006) describe the effect of physician-patient relationships specifically within the context of collaborative care (Wasson *et al.*, 2006). Collaborative care is a partnership between patients who manage their condition and their physician. In order to involve patients in the management of their condition, physicians must provide sufficient information for patients to make decisions regarding their health. Positive physician-patient interactions have been associated with improved patient self-care, better clinical outcomes and reduced medical costs.

Fuertes *et al.* (2007) describe similar findings in their study of 'working alliances', the cognitive and emotional elements associated with physician-patient relationships in conventional care (Fuertes *et al.*, 2007). They report that good working alliances have positive effects on patient adherence and satisfaction. Patients that participate actively in health decisions are more likely to follow their physician's recommendations and to value their treatments. In addition, they demonstrated a link between self-efficacy and

adherence—patients who feel that they can follow their treatment are more likely to adhere to it.

Parchman *et al.* (2005) found that chronically ill patients experienced less ‘hassles’ while seeking care if a high level of co-ordination and communication was established with their physician (Parchman, Noe□1, & Lee, 2005). A high level of interpersonal communication between the physician and the patient reduced hassles. Similarly, in their study of physician-patient interactions, Kaplan *et al.* (1989) found that the relationship is important for the transfer of information to patients and that it encouraged patients to follow a treatment regimen (Kaplan, Greenfield, & Ware Jr., 1989). The findings demonstrate that the communication of more information resulted in better health status. The physician and the patient’s ability to express affect were likewise associated with better functional status and subjective evaluation of health care services.

The above review indicates that the physician-patient relationship has been studied extensively in the context of conventional medicine. Few research studies, however, have examined the relationship within the context of integrative medicine. The study by Koithan (2007) performed in the outpatient clinic of the Program in Integrative Medicine (PIM) at the University of Arizona’s College of Medicine in Tucson, examined the care experience of clinic patients using two cancer focus groups and a non-cancer group. Results indicate that the physician-patient relationship was the most important part of the treatment process (Koithan *et al.*, 2007). The elements that patients identified as crucial for a good physician-patient relationship are the following: 1) listening and taking into consideration patient and family concerns, 2) showing respect, 3) spending enough time with patients, 3) taking into consideration bio-psycho-social variables, 4) treating the patient as a partner and 5)

empowering them. Patients rated their experience at the clinic as favourable, although the effects on outcomes, costs, and quality of life have yet to be determined. The health care delivery service approach described in this study is similar to the integrative clinic in my study and the physician-patient relationship was an important element of the treatment process.

In summary, chronic illnesses disrupt the life story of individuals and create a sense of disorder. Patients often experience social withdrawal and feelings of becoming a burden. As a result, the physician-patient relationship becomes extremely important. Although several studies have examined the relationship within the realm of conventional medicine, few have examined it within the context of integrative medicine. In addition, the majority of the studies use quantitative approaches and do not examine the meanings that patients attribute to their experience. The following study will attempt to examine how patients experience their chronic illness and their relationship with caregivers at the clinic.

Chapter 3: Methods

My study investigated how chronically ill individuals perceived their illness and health before and after beginning treatments at the integrative clinic, and how they viewed the impact of the healing relationship on their treatment, health and healing. I wanted to examine the health and illness beliefs of patients and the factors that they perceived as contributing to the success (or lack thereof) of their therapy. I used interpretative phenomenology, an analytical approach that is derived from Heideggerian philosophy to guide my research methods. In this chapter, I discuss the philosophical underpinnings of my methodological approach, my stance as a researcher, my research design, my study questions, and my approach to data collection and data analysis. Finally, I discuss the different validation techniques for qualitative research and the limitations of my study.

Philosophy:

Phenomenology is both a qualitative research approach and a philosophy that was developed by Husserl (Lopez & Willis, 2004). Heidegger broke away from Husserl's descriptive approach to develop an interpretative approach to inquiry. Contrary to Husserl who focused on the nature of knowledge, Heidegger examined the nature of *being* (Smith *et al.*, 2009). Interpretative Phenomenological Analysis (IPA) is concerned with understanding the meaning of individual experiences or phenomena from the perspective of the participants.

Three tenets characterize Heideggerian phenomenology (Lopez & Willis, 2004). The first is that individuals and their world are co-constituting, also referred to as *being-in-the-*

world or *Dasein* (Smith *et al.*, 2009). The individual and its world coexist as a single entity and they are linked together by dialogue—the meaning of a person’s existence stems from the world surrounding the individual. The *Dasein* appears through interpretation as hidden elements are uncovered. The analysis should aim to bring to light the activities and relationships that make the world appear meaningful to us (Singer, 2001; Smith *et al.*, 2009). The interpretation occurs through the process of *hermeneutics*— the aim of the method is to uncover human experiences by relating the part to the whole. As such, parts of the text are examined with respect to the whole text and texts are compared to other texts. This allows the researcher to develop an awareness of key structures within the data and to thoroughly understand the context.

The second tenet of Heideggerian phenomenology is the notion of the *Lebenswelt*, the lifeworld (Lopez & Willis, 2004). The *Lebenswelt* is the everyday world of the individual, as seen through direct and immediate experience. This life world may not be a reflection of the objective reality, but rather, it is the reality as perceived by the individual (Smith *et al.*, 2009). As it is tied to its context, it is constantly changing, resulting in characteristics that are both dynamic and organized. The notion of *Lebenswelt* serves to demonstrate that the focus of the hermeneutic inquiry should be on discovering the meaning that individuals place on their experience. Idiography, the study of the particular in IPA, adds depth to the analysis and allows researchers to understand how an experience is seen from the perspective of a specific individual within a specific context. Idiography hence allows researchers to comprehend the *Lebenswelt* of an individual.

The final tenet of Heideggerian phenomenology is that the researcher is involved in the interpretation of the participant’s experiences (Lopez & Willis, 2004). The goal of the

interview is to engage with the participant in order to gain a thorough understanding of their experience. Nevertheless, the researcher should be aware of any preconceptions that arise during the research endeavour. A theoretical framework may be used in interpretative phenomenology to guide the analysis.

Phenomenology rejects the concept of cause and effect and replaces it with the notion of structure. Phenomena may manifest themselves differently according to variations in the philosophical lenses of different individuals and their “life situations”. Although there may be variations in how the phenomenon appears, it is said to have the same meaning when a consistent pattern is perceived over time, in different situations.

Researcher’s stance:

In IPA, the researcher contributes to the analysis and “makes the inquiry process a meaningful undertaking” (Lopez & Willis, 2004). The researcher’s experiences, personal knowledge, and understanding of the literature contribute to the formulation of a research topic. As Packer (1985) states, “we understand human action — and act ourselves — within a background of practices (bodily, personal, and cultural) that is always present, although it can never be made fully explicit”, and as such, understanding the background knowledge of the researcher is important in the interpretation portion of IPA (Packer, 1985).

I have had an interest in medicine and its related fields since I was young. I am a curious person by nature and I am always interested in individual’s narratives. I have travelled extensively and I had the opportunity to see life from different cultural perspectives. Stories on how people find solutions to everyday problems have always caught my attention. It has also led to what some call my “non-traditional way of thinking”.

In high school, I had the opportunity to follow naturopathic treatments and I found the experience really beneficial and intriguing. I went on to study health from a conventional perspective when I began my Bachelor of Health Sciences (Faculty of Medicine) at the University of Calgary. Along with my biological understanding of diseases, my knowledge base also includes sociology, psychology and economics. I learned about the concept of integrative medicine while completing an assignment for a research design class during my Master's. I found that the concept of merging conventional and alternative medicine was interesting for several reasons: 1) it allowed physicians to spend significantly more time with patients, 2) it allowed the physicians to monitor patients' intake of prescription medication and alternative treatments and 3) it provided patients with a wider range of treatment options. I was also curious about how integrative medicine could combine two very different health philosophies: the very technology driven and specialized conventional medicine versus the holistic approach undertaken by alternative medicine. Unfortunately, I have likewise seen the plight of individuals with chronic illness as they try to navigate through society. My decision to examine how chronically ill patients viewed their illness and aspects of their integrative treatments arose from my review of the literature. The concept of integrative medicine is a relatively new concept (MEsH term as of 2009) and there were no studies that examined the self and healing relationships within integrative care. The self and the impact of healing relationships have been examined fairly extensively within the realm of conventional medicine and I was curious as to whether similar elements would be cited by patients from the integrative clinic.

A phenomenological, qualitative research design:

The aim of IPA is to examine people's experiences and/or their understanding of phenomena (Smith *et al.*, 2009). The approach is concerned with the process by which individuals make sense of an experience within a specific context. It is hence an open ended method. Common features of an experience within a specific context are emphasized in the study. Since IPA seeks to explore the meaning that individuals attribute to a phenomenon within a context, individuals who have experienced it are sought out. Due to the idiographic nature of IPA, sample sizes remain small and homogenous. Homogenizing the sample, either through social or theoretical factors defines the boundaries of the study and allows for subsequent research endeavours. In cases where the number of individuals have experienced a phenomenon is small, researchers can be more selective as to what factors they want to utilize to make their selection. Smith *et al.* (2009) recommend that 3 to 6 individuals be selected for a student project.

Phenomenology is essentially a qualitative approach. Qualitative methods present several advantages including the study of phenomena within their natural settings, the 'local groundedness' of the study, the richness and holism of the data, and the flexibility of the research design (Miles & Huberman, 1994). The study of a situation within its natural setting allows researchers to obtain an understanding of "what real life is like" while the 'local groundedness' approach provides the opportunity to examine the underlying context in which specific situations take place. The holistic procedure allows for an understanding "from the inside" and highlights the complexity of the situation. The flexible study design allows qualitative researcher to adapt the methods to the needs of their project. Qualitative research approaches such as phenomenology have been described as human sciences

because of their emphasis on understanding human experiences and the meanings assigned to them (Munhall, 1989). In the flow of experiences that surrounds every individual, qualitative researchers are interested in the factors that render an experience more conspicuous than others to an individual (Smith *et al.*, 2009). Hence, IPA researchers attempt to engage with the participants' reflections on what makes the experience significant.

According to Munhall (1989), the world that is perceived by the individual constitutes reality—it is the meaning that the individual attributes to an event. Consequently, the different perceptions lead to different actions by individuals (Munhall, 1989). As such, edifying our knowledge base on what makes an experience significant may provide insight on the thought process of individuals experiencing the event and their possible future actions. Furthermore, qualitative approaches are useful in cases where there is little information on the domain, such as the field of integrative medicine. The purpose of qualitative research is not to attempt to modify the practices of individuals, but rather to inform subsequent theories, policies or implementation guidelines. In addition, Annells (1996) cites more practical reasons for undertaking an IPA project such as understanding different levels of meaning and comprehending how patients really perceive interventions that can be costly to society (Annells, 1996).

The following section provides a detailed overview of the methodological approach that was used to complete the study. It reviews the research questions, research settings and context, data collection, data management and data analysis procedures. The last section concludes with the validation techniques that were utilized to establish the trustworthiness of the data.

Research Question:

The overarching question for my study is: how do patients experience their chronic illness and the process of receiving integrative medicine treatments? More specifically, I am examining:

- 1) How patients experience their illness and health before and after their treatments
- 2) How they view their relationship with caregivers at the clinic and the impact of this relationship on their treatment, health and healing?

Research Settings:

The study took place at an integrative clinic in a large metropolitan centre in Canada. I obtained access to this clinic by contacting the physician-owner and explaining the purpose of my study. The concept of integrative clinics is relatively new and few clinics in Canada offer such care. The clinic offers a unique combination of conventional and alternative medicine, as well as chelation treatments. (Chelation treatments are “intravenous infusions of ethylenediamine tetraacetic acid (EDTA) in combination with oral vitamins and minerals” [Anderson *et al.*, 2003]. At the clinic, chelation is generally used to supplement conventional treatments for patients with coronary heart disease or diabetes. More research, such as a randomized clinical trial, is needed to better assess whether chelation therapy is beneficial for heart disease and type II diabetes). In Canada, routine conventional medical services such as blood tests are covered by the provincial insurance programme while alternative medicine services are covered by private health insurances or are paid out-of-pocket. Patients pay \$130 for each chelation treatment.

The clinic is owned by a physician who practices integrative medicine. In addition to the integrative physician, the clinic is operated by a team of five internationally-trained physicians (M.D). One of the caregivers is an internationally-trained medical doctor (M.D) and an ayurvedic (a form of alternative medicine) practitioner. All members of the health care team are completing training in order to receive a board certification or a licence to practice in Canada. The integration of the two treatment modalities occurs at the level of the physician—he is certified to deliver both conventional (M.D.) and alternative medicine. The integrative physician completed training for a medical degree (M.D) as well as acupuncture and Chinese medicine in a Canadian University. He subsequently furthered his training in Chinese Medicine in China. He is the author of several studies on alternative and integrative medicine. In addition to his practice and his research, the integrative physician is a lecturer in the faculty of Medicine at a Canadian university, and is a current invigilator for several colleges.

A typical clinic session:

In order to gain a thorough understanding of the context in which participants received care, I asked patients during the interview to describe a typical clinic session. Typical sessions involve a lengthy and thorough process. Assistants first meet with the patient and undertake a complete physical examination of the patient that includes details of the family and medical history, current treatments and life style habits. Notes are taken during the examination and handed to the physician prior to his meeting with the patient. The physician subsequently reviews any symptoms that the patient brings up during this meeting and answers any questions that the patient may have regarding their condition or

treatments that they would be receiving at the clinic. The physician also takes care to correct any incorrect medical beliefs that the patient may have regarding their condition. During the session, the physician might attempt to correct any ailment that can be easily addressed.

The physician will ask many questions of the patient and will thereafter chart a course of action for the patient. The physician will take notes for himself and the patient while discussing the course of action with the patient. Patients report that the integrative physician resorts to different methods of communication to help patients understand their condition and the treatments that they will be receiving. This will be explained in more detail later. The physician may review the progress of the patient during another session. The treatment may be modified if the patient is not improving. Some patients will require less contact with the physician. The progress of their health condition is the key determining factor in the number of sessions that will be held with the integrative physician.

Sample:

The participants for the study were purposefully sampled— all were chronically ill patients and were receiving treatments at the integrative clinic. Participants that were interested in participating had to meet the following inclusion criteria:

- 1) They were patients at the integrative clinic,
- 2) They received alternative medical treatments on a regular basis,
- 3) They were between the ages of 18-80, and
- 4) They agreed to provide written-informed consent.

A recruitment letter was posted at the front desk of the clinic. The letter indicated that the researcher was seeking approximately 10 patients to participate in a study. Patients

that responded to the letter and that met the eligibility criteria were chosen on a first-come first-served basis and gender did not factor into the selection process. Patients were assured that their participation (or refusal to participate) would not impact delivery of care and that the results of the interview would be kept confidential. The patients that agreed to participate were then assigned an independent study number and the name of the patient was not used.

The participants represented a homogenous group of patients. All were Ontario residents from a large urban area. All participants were Caucasian, employed and in their middle age or seniors. The nine participants selected for the purposes of the study consisted of eight men and one woman. The ages of the participants and the length of time that they have been at the clinic is listed in Table 1. Names of the patient, staff members and of the clinic were changed in order to maintain anonymity. Patients are listed in the order that I interviewed them.

Table 1: Description of Participants				
Patient	Age	Chronic illness	Length of time at the clinic	Frequency of time at the clinic
Cynthia	49	Type II diabetes, hypothyroidism	More than a year	Once a month
Marc	59	Angina, partially functioning heart following a heart attack	4 months	Once a week
Allan	77	Type II diabetes, heart palpitations	5 months	Once a week
David	65	Type II diabetes, hypothyroidism	3-4 years	Once a month
Daniel	62	Clogged arteries, high iron levels, type II diabetes and parasitic flu	3-4 weeks	Twice a week
Andre	70	Hypertension, shoulder pain	1 month	Once a week

Michael	60	Hypertension, previous heart attack	2 years	Twice a week
Robert	70	Hypertension, high levels of heavy metals	3 months	Once a month
Adam	67	Type II diabetes, hypertension	5 months	Twice a week

Procedure:

The study received approval from the University of Ottawa’s Research Ethics Board. A copy of the recruitment poster and the informed consent letter are located in Appendix A. Data collection took place at the integrative clinic between the months of April and August, 2009. The time period was selected in order to satisfy the researcher’s availability. A pilot project was conducted in February and March to test the interview guide questions. Although the initial focus of the project was on health outcomes, the focus was later re-oriented towards health, illness and healing relationships in chronic illness in order to be responsive to the participants’ narratives.

Participants were interviewed in a quiet, private area at a time that was convenient to them. Interviews lasted between 30 minutes and an hour. Interviews are what Smith *et al.* (2009) call a “conversation with a purpose and allow the researcher to see the lifeworld of the participant. An interview guide was used to help patients recount how they experienced their illness and the healing relationship between them and the integrative physician’s approach (c.f. Appendix A). The guide covered the following global topics: 1) what factors led patients to attend the clinic, 2) how they perceived their health, 3) how they experienced receiving treatments at the clinic and 4) how they viewed their relationship with the staff at the clinic, 5) how they perceived the outcome of their treatment. Although an interview

guide was used during the study, participants were free to describe the important elements of their experience at the clinic. All interviews were audio-recorded.

Data management:

Audio-recorded interviews were transcribed into a digital print format by a professional. Pages of the transcripts were dated and identified by their patient number. Patient numbers were later replaced by pseudonyms. Margins were widened to allow the researcher to note any comments. I noted additional observations from the interview process in a notebook and I kept a hard copy of the transcripts and the notebook in a secure area.

Data analysis:

Although several methods for IPA exist, they share common processes and principles. The first is that researchers move from the particular (idiographic) to common trends among experiences (Smith *et al.*, 2009). The second is that researchers seek to uncover the meaning that participants attribute to their experience by engaging in a dialogue between the data and their knowledge base. Data collected from the interviews was analyzed using Interpretative Phenomenological Analysis (IPA) as described by Smith *et al.* (2009). Data analysis began during the interview process when I was actively listening to the participant. I then immersed myself into the data by first listening to the audio-recordings at least once and by actively reading the transcripts. This step ensured that I focused on the participants. Moreover, active reading helped me observe the initial patterns that can start to emerge from the data and allowed me to note any contradictions. I subsequently isolated meaningful statements from each interview to remove any out of

context comments. The second step involved noting initial thoughts on interesting language patterns or meanings. The notes contained descriptive and interpretative comments, and the identification of key elements from the participant's experience. These notes were used to divide the text into meaning units. The third step involved data reduction by seeking the emergent themes that arose from the meaning units. Once I had developed emergent themes, I went back to the transcript to verify the validity of the themes. In order to find patterns between themes, I followed the following steps. From all the interviews, I collected all the meaning units that had the same emergent theme and I organized them according to the topics that I had covered in my interview guide. I printed the documents and condensed the themes using the technique of abstraction. Abstraction is a procedure that combines "like with like [in order to develop] a new name for the cluster" (Smith *et al.*, 2009). These clusters form what are called sub-ordinate themes. The themes were subsequently modified to better represent the data. For example, I initially had two sub-ordinate themes for the section on the impact of integrative staff-patient relationships on patient illness representations and self-management procedures and I combined them into one—relationship building. To facilitate the development of a narrative account, I created a table with the sub-ordinate theme and its respective emergent themes. Table 2 lists examples of statements extracted from the interviews along with their meaning.

Table 2: Examples of statements extracted from patients at the integrative clinic, and the meaning unit, emergent code and sub-ordinate theme

Patient	Statement	Meaning unit	Emergent Code	Sub-ordinate theme
Marc	Early December, I started having passive angina when I went to go to bed. I'd wake up with tightness of the chest and everything.	Deteriorating health condition	Stimulus	Impetus for seeking integrative care
Allan	I thought, well I should look into this too because I didn't seem to be getting any better doing what I was doing with the normal physician	No improvement in their health condition	Stimulus	
David	the diabetes seemed to be worsening	Deteriorating health condition	Stimulus	
Daniel	[influence to come to the clinic] my wife	Family influence	Information-social	
Michael	[heard about the clinic] I read about it in [an] investment letter.	Media influence	Information-social	
Adam	then one of the people who was working said to me, [...] you should go see [the integrative physician] to do chelation	Colleague influence	Information-social	

Assessing validity and quality:

Smith *et al.* (2009) recommend that researchers use four criteria to assess the validity and quality of IPA studies (Smith *et al.*, 2009). The first criterion is sensitivity to context. Sensitivity to context can be demonstrated in the following ways: an engagement to the study of the particular (idiography) and good interviews in which participants are at ease and the researcher shows empathy. Furthermore, the use of a good number of verbatim extracts allows readers to check the interpretation of the findings. An awareness of the literature (through literature reviews) illustrates an awareness of existing knowledge. Sensitivity to

context was demonstrated in several ways in this study. First, information on the participants' age, condition(s), frequency and length of time at the clinic were collected, and pseudonyms were used to highlight the personal experiences of each participant. Second, the interview data was good and it is apparent from the transcripts that participants were at ease. One of the participants felt comfortable enough to remove his construction boots in order to show me how his foot was healing. Many more used humour consistently throughout the interview.

The second criterion is commitment and rigour. Commitment is demonstrated by the attention that is paid to the participants during the data collection (interview) and data analysis process. As I stated earlier, participants felt at ease during the interview process and I invested a significant amount of time in order to follow proper data analysis process. Rigour refers to the thoroughness of the research process. Researchers must take care to ensure that their sample is carefully selected and homogenous, and that the quality of the interview is good. For larger studies (i.e. more than six participants) like this one, verbatim extracts from a number of participants should be used. The quotes that best illustrate the theme should be selected and the analysis should always be verified against the data. I met the rigour requirement by selecting participants that had a chronic condition and that had received treatments at the integrative clinic. The participants also represented a homogenous group of the population. I used verbatim extracts from all participants in the final report. I also asked two independent researchers who had a background in qualitative research to review two of the coded interviews in order to have an independent audit. The independent reviewers had a qualitative research background and experience in health research. They

read and coded the transcripts independently. We then compared our results and discussed any discrepancies. Any discrepancies were then resolved.

The third criterion is transparency and coherence. Transparency and coherence allude to how clearly the stages of the research process are detailed. This includes providing information on how participants were selected, the interview guide, the interview process, steps in the analysis and tables. All of this information was presented in the methods section of this report.

Finally, the last criterion is the impact and importance of the study. Researchers must demonstrate that their findings are important and useful. I met this criterion by including a section on contributions and implications in the conclusion section of this report.

Chapter 4: Results

The examination of the transcripts revealed similarities in the patients' representations of their health, treatment and relationship with the integrative physician.

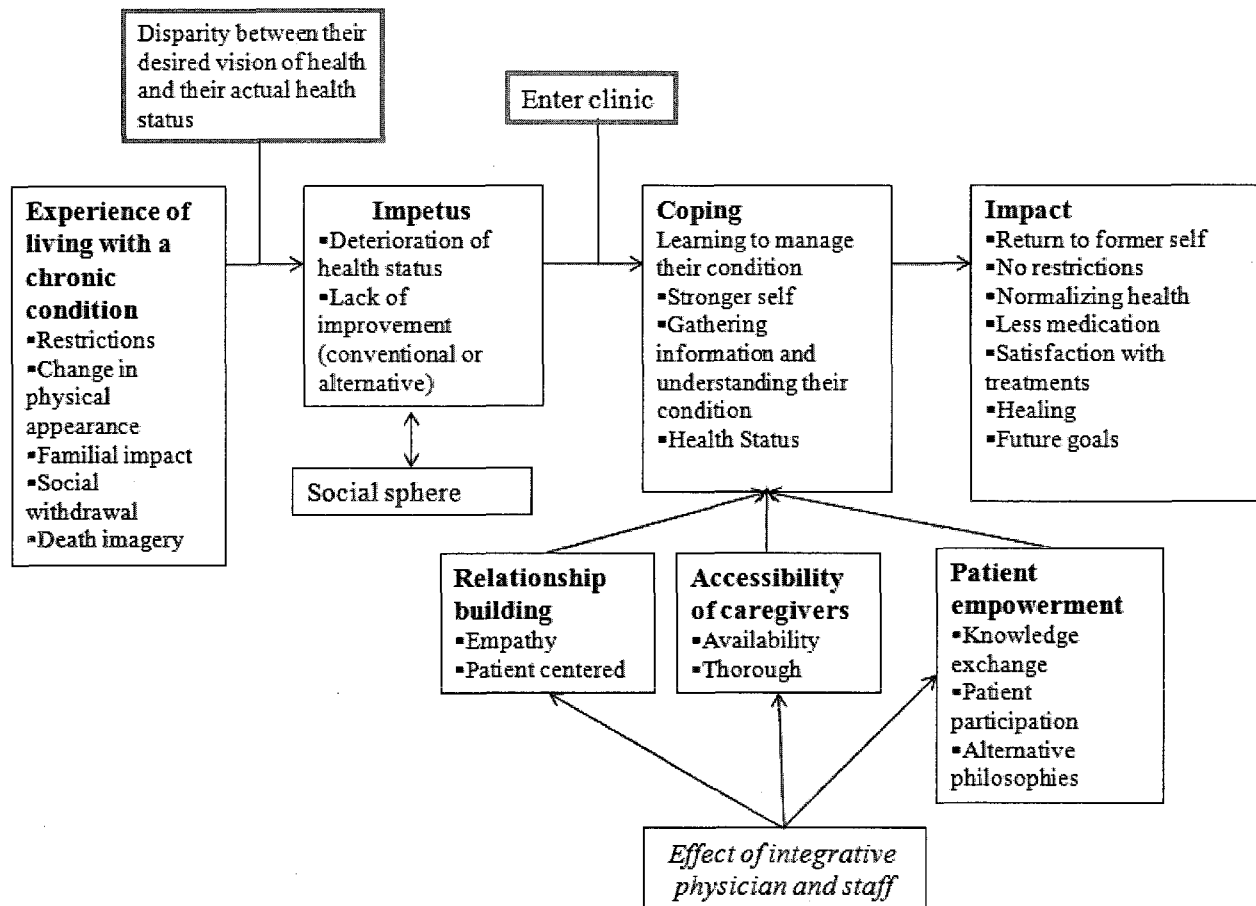


Figure 1: Healing process before and after receiving treatment at the integrative clinic

The process that illustrates the changes that occur in how patients perceive their illness and their health before and after receiving integrative care, and the influence of the integrative staff on the process is illustrated in Figure 1. Prior to joining the clinic, patients describe the experience of living with a chronic condition negatively. A disparity between their desired and current health status, combined with the influence of the social sphere leads

patients to join the clinic. At the clinic, the relationship with the integrative physician and his staff, their accessibility and patient empowerment allows patients to learn to cope with their illness. Patients describe improved health outcomes as a result. The themes presented in Figure 1 are elaborated in the following sections.

Part I: Patients' view of their chronic condition prior to seeking integrative care

Patients describe how their chronic condition has affected their daily life. The disease has had a physical and emotional impact that has resulted in restrictions and the incapacity to fulfill duties. An impetus served to encourage patients to seek care at the integrative clinic. The impetus was derived from the patient's medical condition and from members of their social sphere.

The experience of living with a chronic condition

Patients described the impact that their chronic condition has produced in their life prior to entering the clinic. The chronic condition had impacted significantly their activities and had affected how they perceived themselves. Patients suffering from more severe forms of chronic illnesses exhibited greater concern for their health and were more aware of the impact of the condition on their activities. Patients reported experiencing restrictions in their daily activities, a sense of suffering and a decrease in their quality of life. For the majority of patients, the inability to complete routine activities such as performing household chores, working or driving, was the most common complaint. Furthermore, restrictions in daily activities often reflected the lack of control that patients had over their condition. Adam

relates how he could no longer work for as long as he did in the past. As a self-described workaholic, the disease imposed a significant change in lifestyle:

I was a workaholic all my life. I worked 20 hours a day, or about 18 hours all my life. When I turned 60 I said to myself, [...] oh maybe I've made a mistake. Then [at the age of] 63, 64 [I started] to feel bad. And it got to the point where I had to go home [at] 4:30, 5 o'clock.

This forced time restriction in his daily work was further compounded by the fact that he could not complete tasks at work. In the case of this patient who performs construction work, the disease impeded his ability to perform his work tasks on several occasions. There is a sense of a loss of control in this patient's response:

I do emergency work on the highway [...]. One morning I'm having breakfast with my wife, she gave me cereal and I'm not feeling good [...]. And she gave me oatmeal and then oh, the blood sugar would go up way high [...]. So anyway, I had an emergency so take off, go, on the road I had to stop, my sugar was so high, my vision was blurry, I [didn't] feel good.

For many, the disease's biological consequences undermined their physical appearance or physical abilities. Adam referred repeatedly in the course of the interview to the loss of hair on legs, a change in his physical appearance. He describes how he had lost hair on his legs and arms, and how his hair had turned white.

Because I went to the point my hormones were low, I lost the hair from my leg. I didn't have [...] hair on my leg. [...] I was white, my hair went really, really white;

For Cynthia, the disease affected both her physical appearance and her physical abilities. As a result of a thyroid condition, she had to buy wider shoes and she suffered from pain in her feet on a regular basis:

I used to have a lot of problems with my feet where I couldn't walk, where I was in a lot of pain. [...] I don't have the issues that my feet are bothering me. I used to have to buy shoes that were more on the wider side. Now, I don't have to worry about that.

The incapability to fulfill spousal responsibilities also challenged the image that participants had of themselves within the familial context. Hence, the patients' frustration also stemmed from the negative impact that their disease had on loved ones. The feelings of frustration within the familial context arose from the incapacity to meet spousal demands and to spend time with family. Patients were forced to limit their familial engagement, and to restrict their accessibility. Daniel explains how his disease had created friction with his wife and how he was unable to see his children often:

I've just been married for two years now and so we've redone the house and it's been a real drag to be doing it because lack of energy. So I've gotten in trouble a lot because of lack of energy, like well why didn't you do this or that. Well I can't. [...] I have three kids so my youngest would be [...] 35. And then I have two other daughters and four grandchildren so I haven't been able to do much with them and they don't live handy so it's a bit of driving there as well. [...] I can drive it but I can't drive it like I used to because it takes everything out of me to drive it. So it cuts back on my activity going down there.

As patients experienced restrictions in their daily lives, their focus shifted overwhelmingly from other undertakings to the disease. Marc describes how he had to forego chasing women, an activity he clearly enjoys, following his last heart attack:

I had to give up a lot of things after the last one. Like chasing women was one of the things that just broke my heart. It was terrible.

Restrictions in daily activities likewise resulted in social withdrawal. The disease had curtailed his ability to be active and had introduced the potential for embarrassment. He could no longer enjoy one of his vices and he was now forced to stay put at home. His fear of being found dead in a snow bank, illustrated well his withdrawal and the potential fear of embarrassment of being found dead. The potential for embarrassment appears to impose a greater level of restriction on his activities.

I find the hardest time of the year for me is the Winter time. It's cold and windy. I can't go for a walk. It's maybe okay if you're healthy but trying to go for a walk when you're like me. I don't want to be found like a popsicle in a snow bank someplace. [...] When you sit around all winter long while snowflakes are falling, you don't do much, it gets to you after a while. I can't chase women anymore, not for a few months at least. I don't have any vices that keep me percolating, right? [...] I don't have much of a personal life to be honest.

The idea of withdrawal due to life restrictions was also voiced by Adam. He did not have the patience to maintain social relationships.

Terrible, terrible life. No energy, no self... You lose the pride to life, you lose the [...] joy of life [...] You lose, you, everything is a chore and when it comes to the end of the day you say to yourself, to all the people, don't call me anymore please, lose my phone number. Need a friend, get a dog, but don't call me. If I hear you bark I'll listen, [I] just don't want to [speak to you]. You have no patience to talk to anybody.

Images of death are likewise very prevalent in this patient's discourse. The disease had made death appear as a better outcome than his health condition. The image of what he would become in the future simply did not correspond to the image of himself as a strong and vibrant man. His condition significantly threatened how he perceived himself in life. Death appears to be better than the future consequences resulting from untreated diabetes.

I was so bad last winter that I redid my will [...]. I had my own plot and everything, ready to die in the summer. I was ready to go away this summer, I figured I was dying. You lose your wanting to live, your energy.

Later:

When I came here I was a dying man, I'm telling you I was a dying man, I was. I figured a few months, I'm done. When your feet start to fall apart, you know [an] amputation is around the corner. Could you see a man, a vibrant man like me in a wheelchair? [...] Over the bridge buddy. Just don't want to do this. And we're so used to be, like I'm an inventor, I'm a constructor and I'm so used to being vibrant and efficient in my life; all of a sudden it's not there anymore. We're done, we're done.

Death imagery is also present in Marc's discourse, a patient who has received extensive conventional treatments. Death was perceived as a more desirable fate than the quality of life that resulted from living with a chronic condition. The notion that animals are not left to suffer while humans are forced to endure their burden is presented.

Because there are worse things in this world than dying. You know what I mean. To live life when you're like a vegetable or can't get around. What good is quality of life like that. If you get a dog like that, you put him down. But humans we don't.

The experience of living with a chronic illness was portrayed negatively by all patients. The disease threatened the self-concept of patients, "the organization of attributes that have become consistent over time" (Charmaz, 1983). The emotional and physical changes that were induced by the chronic illness appear to have had undermined the self of many patients. Difficulties performing tasks were seen as a factor that required patients to reconsider a self that they had assumed for a large portion of their life. For some patients,

the threat to their self came from the incapacity to perform work to the same extent. For others, it was the incapacity to fulfill their familial role or to pursue activities that they enjoy. Restrictions in daily living could result in social withdrawal. As it will be discussed in subsequent sections, the relationship with the physician can become very important. Finally, for some patients death was seen as a better outcome than the quality of life that can be brought on by the disease.

Patients' initial impetus to join the clinic

The impetus to join the clinic is related to the medical condition of patients and to individuals that belong to the patients' social surroundings. The impetus can be the result of a lack of conventional alternatives, a deteriorating or non improving health condition and the influence of social factors. For a few patients, the integrative treatments offered at the clinic are their last resort to improve their health. They have exhausted all other possible conventional treatments. As such, the integrative treatments provide hope that they will be able to rectify their current health status. For Marc, the integrative clinic is truly his last option. His health condition has already forced him to attempt clinical trials that were deemed risky, and eventually failed.

And this is the only alternative I had. I can't go back to surgery. I'm toast there. I was in a clinical [...] study to study your DNA where they would draw your blood out, inject it with a whole bunch of hormones and then put it back into your heart. It was in your chest wall. And that got stopped in a hurry because it was deemed to be cancer causing, I think. It would take tumours in the body and cause them to grow, from what I understood anyways. So this is why I'm here.

Several patients likewise described how they were frustrated because their health was not improving even though they were following the required conventional treatment regimen. The lack of improvement was a concern to patients who feared further health deteriorations. Michael illustrates his concern over the fact that the conventional therapy was not lowering his blood pressure:

Over a period of time I realized that [...] despite the medication that I was using, my blood pressure, instead of the medication maintaining at what is considered an optimum level, 120 over 80, it started escalating. [...] that concerned me. I'm taking what is supposed to maintain it at a proper level and instead of it staying there, over time it started escalating.

The sentiment is echoed by Adam who was initially very sceptical of the ability of the integrative physician to improve his health condition. His scepticism, however, later turns into a sentiment of regret for not having joined the clinic sooner.

So I said to myself, I don't want to see another quack; I've been seeing doctors for two years and I just feel like hell. But I'm in such a pain and agony [...] that maybe I'll try it, I'll try it, I'll call anyway. [...] It's too bad I lost so many years of my life before I came here because when I was 50, I started to do high blood pressure, I should have started to come here. And then you have to bypass all of this, you know, because he tells you that your veins got plugged. When your veins get plugged, the holes that the insulin go through your body are plugged. You make insulin but it ain't working, so this helps, this really helps.

The lack of progress in the patients' condition also served as an incentive to seek alternative care. A few patients had received extensive care within the frame of conventional medicine. Nonetheless, the care that they received within conventional medicine did not appear to translate into any results, inciting them to pursue other care

avenues. Allan recounts how he decided to join the clinic after his health condition did not appear to improve.

I thought, well I should look into this too because I didn't seem to be getting any better doing what I was doing with the normal physician so [the integrative physician]'s theory made a lot of sense to me. [...] A year ago last July I was diagnosed with pneumonia, sugar diabetes and heart [palpitations] all at one time. And of course I guess leading up to my going to the hospital was the fact that I was feeling so bad that I thought, well I better go and get checked out. So this is what they found; I was in the hospital for eight days and then given the various prescriptions and so forth. But wasn't necessarily feeling any better.

Daniel experienced a similar lack of progress, albeit with alternative medicine. He had attempted to treat his medical condition with herbs, but the lack of progress prompted him to seek care at the clinic. It seems as though the benefits he felt he was obtaining from his herbal treatments had reached their limit. In addition, he appears to feel that conventional medicine will not offer solutions to his problems and that he will eventually be told by physicians that they cannot help him:

We had been going to another doctor and we were treating it herbally but I wasn't getting many results. So we changed to here to try and get some results. Because it was stupid to have an hour and a half's energy and then you were done, [it] just didn't work. [...] I did herbals before and my regular doctor basically was at her end and she said I had to go on [...] insulin. Because that was all that was left. And after being here and talking to quite a few patients and a lot of them were like my brother in law, where they went to a doctor and they needed a triple by-pass and they had the triple by-pass and they came back and they had the same problem again and the doctor said, well there's nothing more I can do for you.

Deteriorations in their health condition led the majority of patients to seek medical help at the integrative clinic. The worsening health condition of patients led many to believe that their health would only go downhill from there and this factored into their decision to find a solution. Marc describes what led him to join the clinic:

I was having angina pain. The diabetes seemed to be worsening. You just knew you had to do something to get control. [...] I knew I had to do something. I guess I had reached that stage where now was the time and so I took that step at that point.

He recounts how the symptoms that he suddenly began to experience created fears that served as an incentive for him to seek care at the integrative clinic.

Actually in December, early December, I started having passive angina when I went to [...] to bed. I'd wake up with tightness of the chest and everything. So that kind of scared the crap out of me so I decided I'd better do something. So the next day I called [the integrative physician] and got in for an evaluation.

As mentioned previously in the first theme, individuals that surround the patient and social elements can impact how patients perceive their condition. Family members such as significant others, children and siblings were cited the most often as factors that incited patients to join the clinic. At times, these family members serve to provide patients with information regarding the existence of the clinic. Such is the case for one of the patients, who heard about the clinic from her sister. Another patient heard about the clinic when his daughter started receiving treatments at the clinic herself. In other instances, family members are seen as providing support and guidance to encourage patients to receive treatments at the clinic. Similarly, individuals belonging to the social environment of the

patient may simultaneously represent actors from different areas of the social sphere—such as a family member and a medical authority. David brought his son, a medical doctor to his first appointment with the integrative physician. Within the context of familial relationships, his son’s medical knowledge and his acceptance of the integrative therapy reinforced his decision to seek care at the clinic. He explains that:

I have a son who’s a doctor and so we came in, I made an appointment, we came in and I brought my son with me. And we sat down with [the integrative physician] and we chatted for a long time, I mean [the integrative physician] spent more time with my son than he did with me, [...] explaining the protocol and the rationale [...] behind what he was doing. And afterwards we went away and my son said, “Absolutely do it.” And so that’s how I got started.

It is also important to note that David’s son is a conventional physician that has trained in alternative medicine and that prefers alternative treatment modalities. This may facilitate his acceptance of different treatment modalities, and hence, integrative medicine.

He’s much the same as [the integrative physician]. He prefers alternative medicine for his [practice]. He actually went back and he also became a naturopathic doctor as well.

Colleagues and friends can also influence patients in their decision to seek care at the clinic. Marc heard about the clinic from a “client of [his] who’s come here and taken the chelation because he had bypass surgery”. Patients also report that colleagues suggested that they join the clinic after seeing that they were not feeling well. Adam recounts how one of his colleagues suggested the clinic:

I was doing a job one day - I do environmental work - I was doing a job and then I told the environmental people that were there, I said, I’m going to go home, my sugar is so high, I’m not

feeling well. Then one of the people who was working said to me, he said, you should go see [the integrative physician] to do chelation.

Colleagues of patients can likewise simultaneously represent different actors in the patients' social sphere such as a friend and as a medical authority. Marc heard about the clinic through a nurse friend who encouraged him to seek treatments at the integrative clinic. More importantly is how the nurse friend is described by the patient as someone who "thinks outside the box". Since all conventional treatment possibilities had been exhausted for this particular patient, the ability to think outside of the box may have encouraged the patient to listen more attentively.

Family members and colleagues, however, play another important role in how patients perceive their illness. The majority of patients report that changes to their health since they have begun treatments have been noticed by others around them, and this serves as an encouragement to continue their treatments. Individuals thus serve the role of confirming that progress is being made and that the patient should continue receiving treatments. Moreover, individuals from the social sphere may reinforce the self of patients and contribute to their ability to feel that they can control their condition. One of the patients described how his wife thought he had lost his mind because he regained all of his previous energy. Cynthia spoke of the reaction of her family and colleagues:

Everyone actually has a made a comment. Especially for those who haven't seen me for a while. They notice a big difference in me. [...] They just say you look great. Keep it up.

In addition to family members, colleagues, medical authorities and other patients, patients' cognitive representation of their illness is affected by the social media.¹ Patients report having read interviews in the local newspaper that were conducted with the integrative physician and having used Google to access information regarding chelation. Robert cited an investment letter as a factor that contributed to his decision to attend the clinic. He was further encouraged to attend the clinic when he discovered on the internet that the integrative physician was also a reader of this investment writer.

I read about it in a [...] investment letter. [...] I read the [...] letter and I went on the Internet and I saw that [the integrative physician] was also a reader of [the investment letter] and he was the only doctor [...] that I could see that, is sort of close to me that did this.

Two main elements factored into the patients' decision to begin treatments at the integrative clinic. On one hand, an impetus that arose from their current condition served to encourage them to look into joining the clinic. This impetus was at times characterized as a measure of last resort for patients that had exhausted all other medical options. The lack of improvement or deteriorations in their health conditions led other patients to seek integrative care. On the other hand, elements of the individuals' social sphere were factored into their decision to join the clinic. These elements include family members, friends and colleagues, medical authorities and the social media.

In summary, prior to joining the clinic, patients have very negative views of their condition. Patients describe living with a chronic illness negatively. The physical and emotional consequences that arose as a result of their condition challenged the patients' self.

¹ For the purposes of this paper, social media will refer to any means of communication that is accessible to a large number of people.

In addition, their condition has led to become socially withdrawn. All patients experienced an impetus that led them to join the clinic. The impetus may have arisen from a change in their physical condition or may have been mediated by members of the individual's social sphere.

Part II: Impact of the integrative staff-patient relationships on patient illness representation and self-management procedures

Building a meaningful relationship with patients was the cornerstone of the treatment process at the integrative clinic. Time and accessibility of the integrative clinic staff were important factors in building a relationship. Moreover, they facilitated the process of information gathering and allowed for patient empowerment.

Relationship building

Patients perceived that the integrative physician and his staff impacted their illness representation and self-management procedures by fostering a healing relationship and empowering the patients. The healing relationship with the integrative staff stems from the empathy that is demonstrated by all staff members. Time and the accessibility of the integrative physician and his staff facilitated the exchange of information with patients. Hence, patients consider that the relationship with the members of the integrative staff significantly affects how they perceive their illness and their ability to control their condition. In addition, patients appreciate the integrative physician's ability to consider philosophies that fall outside conventional medicine and his use of natural treatment modalities. Patients feel that the cost of the treatment is well worth it and may, in fact, be

cheaper for the health care system as a whole. As the integrative staff works closely and often with the patients, the patients describe their appreciation for the work of the integrative staff members and that of the integrative physician in particular.

Patients cited that empathy was an important component of the relationship between them and the caregivers. Patients recall that empathy at the integrative clinic is perhaps best demonstrated by the allocation of care resources towards patients. Interestingly, patients ascertain that efforts to deliver patient oriented care start with the person overseeing the clinic, specifically, the integrative physician. Marc highlights how patient centered care begins with the integrative physician.

They actually seemed to be concerned with your well-being here. And I think that comes from the top down. I think if you get the chance to sit down and talk to [the integrative physician], you realize that you're not just a number to him.

Andre explains that he sees all of the integrative staff as following the integrative physician's approach to the delivery of health care services.

I see the [the integrative staff members] here that I interact with as following in [the integrative physician]'s footsteps, by way of being of caring, very knowledgeable and interested in helping you. And that goes for all of them, without exception.

Patients also feel that staff members exhibit empathy when they make an effort to learn more about the personal situation of the patients. The attention that is provided by staff members allows patients to feel valued and to feel that their distinct conditions and needs are recognized. As a result, patients have a greater sense of respect from staff members and this enables the development of a meaningful healing relationship. Moreover, the healing

relationship with the integrative physician is extremely important for the self of patients.

David stated that he respects the members of the integrative staff because the care is directed towards the patient:

It's so personal and directed towards you as the patient and, I mean they ask you about all kinds of questions every time you come in here. [...] And they try usually [...] when you come in one of them will try to maybe remember and come back to you so they can build a rapport. So from that aspect it's very directed towards you as an individual and you feel that, I mean you respect them for reading a little bit before they come and see you and just go over your issues and whatnot. Because when I first came in that's, and they had never seen me before, the first thing they started doing was starting to read, to find out, okay who is this person and what have they been doing sort of thing.

Along with directing services towards patient care, patients feel that staff members attempted to build a healing relationship with them. Staff members try to not only learn about their medical condition, but also to develop a more personal relationship. Patients described that personal relationship development arises from conversations on everyday and trivial events. Robert reports that staff members always remember the last conversation that they had with him. Patients find this effort remarkable as it is a skill that they do not possess themselves. Furthermore, the ability of the staff to remember conversations is seen by patients as proof that staff members are interested in their life story and that they are attempting to build a meaningful rapport.

They see so many patients and they still remember what the conversation was last time you were here and I find that amazing. Three days later I won't even remember the conversation you and I had, specifically, and Alex will come in and say, [...] is your right ankle still bothering you?

Patients referred to the relationship that formed between them and the integrative staff. The relationship provides patients with the confidence necessary to manage their disease. In addition, patients feel that staff members believe in their ability to treat themselves and find this reassuring. Patients likewise feel that they are part of the programme rather than feeling like the treatment is imposed upon them. The positive relationship that is formed between the integrative physician and the patient reinforces the self of the patient. Marc describes the relationship between him and the staff at the clinic, and the importance of having the confidence necessary to manage his condition:

Instead of a doctor-patient relationship it's more like a human to human relationship. I don't have to knock at the pearly gates to get in here to talk to anybody. They actually talk to you like you're a human being. [...] I'm much happier I think. [...] They think that you have a brain first of all. They tell you what to do and how it's going to affect you. [...] If you need to get more information, they tell you how to get it. I just feel like I'm part of the programme here as opposed to [conventional clinics].

Time and accessibility of the integrative clinic staff

Time and accessibility are two concepts that patients describe as helping to solidify their relationship between them and the integrative staff members, including the physician. Accessibility to care is characterized by the ability to obtain help from the integrative physician and his staff. Patients feel that they are not fighting their disease alone and that they are well supported throughout the treatment process. The accessibility of the integrative physician also reinforces the trust that the patients have in him. David explains how the accessibility of the integrative physician reinforces his trust in him:

It's good to know that he's available, that you can make an appointment and come and talk to him if you need to. You know, it's not just you're in, he gets you hooked and he's taking your money and you're on your own. No, it's not like that, he's always here for follow-up and he's always made that clear, that he's here for follow-up with him, just make an appointment. His next trip or whatever's convenient for both of you, you could see him.

For Adam, a patient who expressed difficulty reading written material, the time that the integrative physician and his staff are capable of spending with him allows him to understand better his condition. His interactions with conventional physicians appear to be negative and may have undermined the positive image of his self. Conventional physicians may have caused him to reflect negatively on his self by making him feel like a burden and by making him feel like he is unable to take care of his condition. His comparison between the delivery of information at the integrative clinic with that of his conventional clinic highlights how he appreciates the dedication of the integrative staff members.

[The integrative physician] will speak to you and explain things to you; your family doctor or your specialist, if you exceed four minutes in his office, you should be out of here buddy. You're taking my time, you're wasting my space, you're breathing my air; take this and go. You don't know what you're doing. [...] They speak to you every time, they have the time to sit there and speak to you. Because [...] we're going nowhere, I'm illiterate. I come from - I was raised in the bush in Québec. But here they teach you.

The clinic's approach to care is often contrasted by the patients with the approach taken by conventional clinics. Although patients understand that conventional physicians "are all under pressure", the proper management of their condition requires more time and resources. The time restrictions experienced by patients in conventional clinics is often

described negatively. Patients feel like they are simply a number. Patients describe the delivery of health services at conventional clinics as a process that resembles a mass production chain and a factory assembly line, where patients come in and out quickly in order to maximize cost efficiency. Conventional clinics are also described as exhibiting concerns only for the amount of money that chronically ill patients are costing them. Patients believe that they are seen as a burden and that they will not receive attention unless their health condition has deteriorated severely. As a result of these factors, patients do not feel that they are receiving an optimal level of care and this may undermine their self as well. David explains how his interaction with conventional physicians has made him feel like a number. His frustrations with the clinic are likely the result of poor interactions with the conventional physician and unmet expectations.

The other places you're a statistic, a number, and you're almost made to feel you're lucky to get in here and what not. [...] But certainly in the family doctor now that I have [...] It's one of those clinic situations where you're basically just a statistic, [...] sort of in and out, in and out. [...] I'm certainly not impressed with the, maybe I'm not in a great one but not impressed with the level of care. [...]It's less personal, it's, you come in and they basically say, well what are you here for? And it could be that you're there for a follow-up, and you're thinking to yourself, well why the hell didn't you read before I got in here? And you almost have to ask them, do you think we could do this or that or wouldn't it be a good idea if we checked this out? You very much have to be very directive as to what you want to do. I find that they just don't necessarily, unless you're, you know, half dead on the floor, they're not too interested in trying to determine what's really wrong with you. It's more, here take this and please don't come back too soon because it's costing us money now.

The time that is available is important to patients for another reason. Patients feel that time allows the integrative physician to be thorough in his assessment and diagnostic.

The thoroughness with the delivery of health services is comforting to patients because it confirms that they are well looked after. The thoroughness of the integrative physician is important to patients as they feel that conventional physicians sometimes forget reasons for their visits. Allan demonstrates this idea by comparing the integrative physician's method and relating an incident that occurred during one of his visits to his GP.

He just goes over everything, he writes it down on a piece of paper. He addresses each issue as you go along and then he asks questions to see if you have any other problems [...]. And he's just very thorough. [...] The last time I was at my doctors I was supposed to go in for a flu shot and she forgot all about it. [...] She basically ended the appointment and I was out the door and never got the flu shots and everything else. So his method and that seems to be very good and he has his other assistants that follow up on everything and he has it written down and they just follow the schedule.

Similarly, patients decry the perceived lack of feeling by conventional physicians. Following his father's death, Marc recalls his anger at seeing his father's physician express no feelings. Failing to express feelings and to demonstrate empathy prevents the development of any human to human relationships between physicians and their patients.

I understand that they lose patients. It's like a poker player. You're going to lose some hands, you're going to win some hands. But he was so removed from any feelings. I felt like reaching across the desk and hitting him, slapping him in the head.

Facilitating the process of information gathering and patient empowerment

In addition to providing support to patients, the accessibility of the staff at the integrative clinic facilitates the process by which patients can gather information on their condition, on their treatments and on other illnesses. Patients admire the knowledge of the

integrative staff members and the physician in particular, and appreciate their willingness to share information with them. Cynthia describes the staff at the integrative clinic as “very good at what they do”. David states that “it’s great to know that [the integrative staff] are very, very knowledgeable”. Many patients perceive the staff’s great source of knowledge as an asset in their goal to improve their health. The staff’s knowledge becomes a tool that patients can use to learn more about their condition and their treatments. As Daniel patient explains, “they’re very knowledgeable and very helpful. It’s nice to see that because you’re certainly looking to get things done”.

Patients regarded the willingness of the staff at the integrative clinic to share information with patients regarding their condition and their treatments as another factor that strengthened the relationship between them and the caregivers. Information that is accessible at the patient’s level of understanding forms an important cornerstone of all communication within the integrative clinic. Patients believe that communication is crucial for self-management procedures as it allows the integrative physician to transmit information to them regarding their care. Cynthia explained that the integrative physician “basically has a great way of explaining things in very simple terms. He’s excellent at sharing knowledge”. By using simple language and images, the integrative physician is capable of transmitting important information as to the goal of the treatments. An example of how the integrative physician can transmit information in simple terms comes from how the physician explained to Marc that his overall health had to improve before his heart could function properly.

Because the way [the integrative physician] explained it to me, your heart is like a piece of vegetable soup. If it’s floating in a contaminated bowl of soup, it’s not going to be very good. So what we want to do is we want to get the soup broth better and then your heart will get better.

[...] When I talked to him, he said basically what we got to do is we got to make your arteries to

the point where when you get nutrition in there, it stays in there. It doesn't leak out. This doesn't happen and that doesn't happen. So that your heart ends up in a better bowl of soup than when you started out.

Patients also found that the different means of communication employed by the integrative clinic to be interesting. Patients report that the integrative physician uses a website, non-commercial documents and books to teach them about their condition and their treatment. The physician likewise provides diet books that patients can return once they have used them. As a consequence, patients feel that the diet book allows them to modify their eating dramatically. In some instances, the integrative physician also provides patients with drawings. Andre was impressed with the physician's method of communicating information:

He has and not only commercial [readings], I'm talking about articles, like the reprints. The shelf that you see he has out there. He's not the greatest artist, however [...] he tries to give you even sketches so that it's not just the theory. He approaches you from different modalities so you can read the material

Other patients rely on written material that is provided by the clinic and made available to all patients. As David explains, patients appreciate having the ability to learn more about the treatment process to expand their knowledge of health in general.

I think you like to be able to read what the process is, in addition to what you've been told. Certainly it's more in depth than what somebody can sit down and tell you in five minutes, you can read quite a bit more about it and other alternatives. And it's always interesting to read about other problems and not necessarily your own personal problems [...]. It's more knowledge; I enjoy that part of it.

Information is seen by patients as a tool to improve their health. By providing patients with adequate and accessible information, the integrative physician and his staff members and the patient can, along with the patient chart out a strategy to improve the patient's health. Nevertheless, the purpose of improving patient knowledge is to encourage participation in the treatment of their condition. Marc describes what is expected of the patient after their first session with the integrative physician.

When you sit down the first session, you really have to go home and do your homework. It's like a piano lesson, he gives you the work to take home and get better at it. So I took it home and played the CDs, read the Southbeach diet. All kinds of things. Tried to make myself better informed. [...] And as you become more informed you become a better patient. And I think as you become a better patient... [...] I [pause] actually feel like have some control over my life. It's kind of like not being the backseat driver.

It is clear from the statement above that patients are expected to adopt an active role in their health management. As patients explain, the integrative physician wants his patients to be educated on their condition. Patients perceive the integrative physician's desire to educate them as a mean to involve them in the treatment process and hence they feel that they have more control over their lives. Moreover, the physician's willingness to involve them enhances their trust in him. The ability to be involved in the treatment process is empowering to patients who feel that they have the skills necessary to make decisions about their health. Cynthia states how the integrative physician helped to educate herself on her condition:

He gave his website. If you had a condition he gave you books to read on, websites to go to. He wanted to ensure that you were also educated on what your symptoms were. So that you can

make the choices. [...] I feel more empowered. I'm more trusting of what his recommendations are too.

Patients believed that staff at the integrative clinic encouraged them to manage their condition by enhancing their awareness. By creating greater awareness about their disease, patients learn how certain factors can benefit their health. The physician, however, may at times be very straightforward about the state of a patient's condition. Nevertheless, the integrative physician's honesty with regard to the patient's condition, only serves to reinforce their confidence in him. As Andre stated, "he looks at what is best for the patient, and that causes me to have greater trust and confidence in him". Allan describes how the integrative physician affected his awareness and the impact this has had on the management of his condition:

[The integrative physician] said something to me in the initial interview that had quite an impact. Because whenever I'd go to any doctor and they give you a full physical [...] you're in great shape. [...] I asked [the integrative physician] the same question and he said, well right now you're not in good shape, there are problems here. And he said, I think you're probably going down 20% a year. Well that was quite a shock because I heard 20% a year, in five years I'm gone. [...] I certainly think I have now a keener sense of what I need to do and I'm more conscious, I guess you'd say, of my medical condition and the fact that there are things that I can be doing through diet or through exercise that are going to be beneficial.

The sentiment that patients know more about their condition is echoed by others who feel that they can be in control of their health condition. This idea is supported by Andre who states that:

In light of the fact that I understand more what's going on, I'd like to think that, gee I'm in control of improving my situation. And in that I understand what's going on better, then I'm in a position to evaluate whether or not what I am doing is beneficial.

Finally, patients report that the integrative physician impacts their participation by assisting in helping them modify their life style habits. For Daniel, the integrative physician provided him with the necessary tool to modify his diet dramatically and therefore to lose weight. The tool in this case is a simple recipe book that can be returned to the clinic once the patient no longer needs it.

They changed my diet dramatically which has caused the weight loss [...] And in this diet they give you alternatives to what you have. [...] It's not the same but it's close. It's fine, very palatable and that. [...] [The recipes are] in a book that they promote. And even at that the book is reasonably priced and if you don't mark it up or anything you can bring it back and they give you your money back. Can't beat that.

The integrative physician's philosophy may also differ from conventional medicine. Adam remembers his surprise when he discovered that the integrative physician's philosophy was entirely different than that of the conventional Diabetic Clinics:

His method of curing things [...] works. He teaches you how to handle diabetes by rearranging a diet. The diet that he gives you is totally different than the Diabetic clinic. He takes you off the carbs, which I'm off. [...] At the Diabetic Clinic, well they tell you the opposite of what [the integrative physician] says. I went in there and I took picture of the food they told me I could eat, I get the picture enlarged and I brought them in and I gave them to [the integrative physician]. He says, totally opposite of me

The patients admire the integrative physician's ability to use philosophies that are not advocated in conventional medicine. The integrative physician's approach to treating health conditions is seen by many patients as revolutionary. Cynthia and Marc were impressed by his ability to "think outside the box". Similarly, patients appreciate his willingness to question traditional ways of thinking. Cynthia describes how the integrative physician refused to believe the conventional diagnostic:

I believe [the integrative physician] is the type of individual that thinks out of the box. He asks a lot of questions. He's great at diagnosing what the real problem is. He was never judgmental. I found him very open in regards to a lot of your health issues are because of weight. He didn't think that at all. He said there's obviously something wrong here. [...] He identified that I had a thyroid condition. Where no one else would've picked up on it. The blood work was coming back saying that I didn't have a thyroid condition. [The integrative physician] said "I bet you do!". [He said] check your body temperature and I did. I was at 35 and you're supposed to be at 37. He really helped me with my thyroid there.

The combination of healing modalities is one of the elements that were attractive to patients at the clinic. As Cynthia exclaimed, "I love the fact that he combines Eastern plus Western medicine". Patients believe that the integrative physician's combination of Eastern and Western medicine also reflects an inclination to utilize different healing approaches. David explains that "it's a totally different concept in treatment". In some instances, the physician prescribes natural supplements to address nutritional deficiencies such as low Omega-3 levels. In other cases, the integrative physician uses natural ways to address health conditions. The use of natural therapies is important for patients who do not wish to increase

the amount of prescription medication that they are taking. For David's thyroid condition, the integrative physician suggested the use of natural hormone:

You just knew you had to do something to get control and find some other alternative other than more pills and more pills and more pills. [...] [The integrative physician] will answer anything that basically that you ask him. If you ask him something about diet, whatever your concerns are he will try to address it and he'll find natural ways to do it. One of the things I had asked about was thyroid and he suggested going on to a natural thyroid hormone.

Another patient reports the same treatment approach. The integrative physician not only finds natural alternatives for ailments that he identifies, he also replaces conventional medication for natural treatment modalities. The use of natural alternatives to treat conditions is hence appealing to patients who wish to reduce or eliminate the amount of prescription medication that they are taking. Patients' wishes to reduce the amount of medication that they are taking may stem from the fact that some, such as David, believe that conventional medication was "treating symptoms rather than underlying causes and not with necessarily great outcomes". This desire to determine the root cause of the problem is appreciated by patients that feel that they can better address their problems. Andre expresses his appreciation of the integrative physician's method:

One of the things about [the integrative physician] which pleases me very much, it's not good enough for him to say, 'okay I'm giving you the treatment'; [...] he looks for the root cause. [...] and as a result of knowing the root cause then I feel one can eliminate the problem. Because you're not just addressing the symptoms.

Patients also associate conventional medication with negative side effects that make patients question whether the medication is working. Adam relates how one of his conventional medications caused him to experience significant side-effects:

The diabetic doctor gave me a pill called Diamacron, I thought my heart was going to come out of my chest. They tried to stimulate the flow, force the blood into your vein. You know, it just doesn't fly, [it] does not fly

In fact, many patients express distrust in conventional physicians that prescribe many pills. Prescription pills are seen by many as a corruption of modern conventional medicine. Pills also become a vehicle to express the feeling that physicians are not as concerned as they should be about the well-being of their patients. Marc recounts an experience with his conventional physician:

Whereas in the medical profession, I remember once I pissed off my cardiologist by suggesting to him that maybe he had a conflict of interest by taking a free trip from [a pharmaceutical company] over to the Nappa valley to go through the wine vineyard in the fall on a free trip with him and his wife. He didn't like that very much. What are you going to do?[...] Whereas the mainstream medical profession today they just prescribe you a pill and if it works great and if it kills you ah well. On to the next patient.

Other patients believe that the benefits of the integrative physician's approach extend past the reduction of prescription medication. These include perceived cheaper treatment costs for the medical system as a whole and the possibility for patients to avoid surgeries.

Adam explains:

There's another doctor that comes in here, another guy comes in here, he had a heart attack last November, and he was supposed to go for the bypass. He comes in three times a week, he's not getting [a] bypass [...]. The bypass will cost, would generate \$100,000 for the medical profession,

this will generate, \$15,000, \$20,000. And you don't get all cut up. Every time you cut it takes a while to heal after that.

The costs of the treatments, however, elicited different responses from the patients. For some patients, the realization of the treatment costs initially engendered concern. Nevertheless, as Cynthia explained, she felt that it was worth paying the cost of the treatment if she could improve the state of her health.

I was looking at first at the cost factor because it's a lot of money upfront. But he did make a point. He goes if your roof went in your house, would you have to pay for that to get it repaired? I go "yes definitely". He goes well don't you think your health is important? I go "yes it's true". So, with regards to the cost of the treatment, I no longer look at that.

For Adam who is well off, the cost of the therapy has never been a concern. The benefits that he believes that he gained compensate for the cost.

I've probably spent \$12-14,000 here now, but what a gift, because I want to feel good. [...] Whatever the cost is, it's, to me it's nothing.

For Marc, improvements in his health would be the 'real' test—the one that would determine whether chelation was effective. He states that since he has to pay for the service, it is a good indication that he is satisfied with the outcome. Marc explains his reasoning:

I'm paying for this. If I wasn't getting good service, I wouldn't be paying for this. It makes a big difference when you reach into your own pockets and pull out that money every week to pay for this treatment. You want to make awfully sure that you're getting is what you're getting. As opposed to...Every time in the hospital, I was in so many studies. They give you placebo they give you this, they give you that. I know they have to do blind studies, but here this is where my

old coach used to say this is where the rubber meets the road. Either get better or get out. So I'm in the programme here and I'm going to feel better. And I'm going to live long enough to get my old age pension cheque. And then I'll feel much, much better.

The approach of the integrative physician and his staff can be described as patient centered. Clinic resources are directed towards the well-being of the patient. Time and the accessibility of caregivers cemented the relationship between patients and caregivers. The physician-patient relationship enabled patients to take control of their health and to participate in health care decisions. The accessibility of the integrative clinic staff facilitated the exchange of knowledge. Patients are impressed by the knowledge of all personnel members at the clinic and their willingness to share information. Patient empowerment at the clinic encompasses a number of key elements including patient education and participation and having the ability to modify life style habits. Educating patients to encourage them to become active participants in their treatments is another important element of patient empowerment. Patients appreciate the ability to take a more active role in their health and are more trusting of the integrative physician's recommendations. The incorporation of traditional and non-traditional treatment modalities is also attractive to patients. Patients likewise believe that these non-traditional modalities are significantly cheaper than conventional approaches. Nonetheless, the impact of the staff at the integrative clinic reverberates past the treatment process and life style changes. Finally, it is important to note that patients often compare their experiences at the integrative clinic to those at their conventional clinic.

Part III: Patients' view of health and their chronic condition following treatments at the integrative clinic

Following treatments at the integrative clinic, patients report that they have detected changes on an emotional and physical level. These changes sometimes reflect a return to a self that patients associate with their life prior to the onset of their condition. All patients have set future goals in their treatment process.

The majority of patients report that they have detected changes in their health condition following the beginning of treatments at the integrative clinic. The level of changes detected depends on the severity of the patient's chronic illness. Other detected changes included levels of well-being, control over the management of their disease, and reductions in the amount of medication taken. Although patients are still afflicted with a chronic condition, improvements in their health condition have allowed them to perceive their health in a more positive light.

Discussions among patients in the clinic and patient attitudes were factored into their assessment of their condition following treatments. The evidence that treatments are improving the health of patients can be confirmed by different members of the social sphere. David reports that improvements in his health condition were confirmed by both his Endocrinologist (a medical authority) and his family members. The progress in his condition serves as an encouragement to keep pursuing integrative treatments and may also indicate a resolution in how he perceives his illness. He perceives changes in his health in terms of reduced symptoms and improved function. His outlook on his condition is more positive and indicates that he has a more positive view of his self. The progress is consistent with how he describes the healing process.

[Healing is] feeling like you felt when you were at a much younger age and being symptom free and without limitation. [...] And of course your expectation that you're going to live longer. [...] My last visit to the Endocrinologist, I was going every three months. She said, I don't need to see you for six months. It was normal (pause). So to me that's a good measurement, things are working. So that kind of outcome, that's the sort of thing that you're looking for is, you know, as normalized as you can possibly get and that keeps me coming back here as well. [...] My wife, my family, my son [noticed changes]. They can just see that, you know, that you've got your energy back and we're able to do a lot more things together that we weren't doing before.

For Adam, the treatments at the clinic produced significant physical changes. Progress in his health is therefore described in terms of reduced impairment, fewer symptoms and improved function. The state of his feet were a particular concern for two reasons: 1) as a diabetic patient any further health deteriorations would have forced him to undergo an amputation, 2) he is in the construction business which requires that he be on his feet for long periods of time. The ameliorations in his health are therefore reassuring. In addition, progress in his health follows his vision of healing. His view of healing reflects a return to his former self—a younger, more energetic self that could work long hours.

Healing means that you regress, [to] go back to being 40 again. [...] You see, this thing here cures the problem; it doesn't hide the symptoms [...] that's my approach. [...] When I came here I had lost skin on one of my toes, my big toe was so dead I could take a needle, prick it, and I wouldn't feel it. Now, the health is back in my feet. I can walk without pain in my feet, without pain in my legs. I can last... I'm a contractor, I can last many days, I can have a 16 hour day.

Weight loss is another important outcome of the therapy that he follows at the integrative clinic. The weight loss that has occurred once again reinforces his conviction that the treatments are beneficial.

I used to weigh 325 pounds and in the last two and a half years I lost 75 pounds. When I came in here I weighed 262, dressed up. My home scale, 252. And I've lost, in the last four months I've lost four inch of waistline. The other thing I can say it's a miracle cure, it's a common sense cure, it's an old cure. [...] it's a gift from the gods, I'm telling you

The progress in his health condition is important for another reason—it represents a return to his perceived self prior to the onset of the chronic illness. In this case, the growth and change in colour of his hair can come to symbolize a return to youth and his former self. Similarly to the healing that has occurred in his feet, the return of his hair is convincing him that the treatments are effective.

I didn't have a hair on my leg. All the hair [came] back. [It] started to grow back inside a little bit now. My knuckles; see that? It's all back there. [...] Look at all the new hair growing inside the arm, all the black hair, that's all new growth. So something's got to be right. [...] Oh I couldn't believe, in the last six weeks another phase has changed. My beard got dark, it used to be white like a piece of paper. My wife says, the back of your hair is darker. It was white, white, white, white, white.

For other patients, regaining the ability to be more active is another outcome of the therapy. Patients express happiness at regaining their ability to perform more daily activities. The progress in Daniel's case is hence described in terms of regaining function.

I've had a business of my own and I also work full time for a company. [...] I went the whole day yesterday and then I went, I have a dog also so I went out and walked her last night and that

and didn't feel the cold or I didn't feel the lack of energy and that. So it was really good so I'm improving.

David expresses similar feelings by stating that he is no longer bound by any health limitations. The changes that he perceives to have occurred highlight a return to his former self and a more positive self-image.

For me I like to basically cycle, that's one of my really enjoyable things at this stage in my life. [...] You have so much time to do certain things and always like to exercise. [...] I have no limitations no, I can do anything. Exercise, treadmill, cycling, you name it. Golf.

Robert and Michael describe how they did not detect changes in their health status. Nevertheless, as Robert explains this is not necessarily a negative fact: "that's not a bad thing because I haven't noticed any deterioration either. [...] I don't have major problems". Robert believes that he hasn't noticed any major changes because his health condition is not as severe as some other patients at the clinic, and as result, he is less likely to perceive significant changes.

Patients likewise report a greater sense of well-being. These changes have taken place at a physical and emotional level. Marc explains how the changes in his health condition have also made him feel younger and more energetic. The changes that he has described are also consistent with his vision of healing—the removal of limitations that threatened his self:

[Healing is] being able to get up every morning and doing what you want without fear or restrictions or whatever. [...] I think my brain works better. It's hard to say. But I don't seem to be depressed. This was one of the best winters I've ever had as far as depression goes. [...]

I feel better generally, right. I haven't really done anything physical other than at home when I do laundry and I go up and down 3 or 4 flights of stairs and I do it probably 6 or 7 times in a day. But I don't have any shortness of breath. I don't have any angina. And besides I feel younger. Because I haven't had Spring fever for about 20 years. This spring I'm really feeling it.

Other patients explain that they generally feel better. Though the concept of feeling better is very broad, patients cite it as an important component of the healing process. Patients also admit that they have difficulty expressing how they feel when they are asked by medical professionals. Allan explains the dilemma by saying that he believes that his health is progressing but that the outcome of his treatments will appear later.

The point about feeling better and of course this is the first question you always get from the medical people is, well how are you feeling? And I think for most people it's really hard to say. In a general health wise sense I am feeling better. But I'm not feeling better in leaps and bounds, like there's no... But the rationale is that it all developed, your problems, very slowly so why would the recovery be fast? It's probably faster than the debilitating things that were happening to you so I just generally feel better and feel that I'm making progress.

Gaining the ability to control their health condition was the most common cited change. Cynthia explains how the integrative physician has helped her manage her disease:

Basically he got my myxedema under control. My thyroid is under control now. And my diabetes is under control. Which were my three major concerns.

Andre concurs that he has better control over his disease. He likewise obtained relief from a nagging shoulder problem.

You think in terms of healing taking time, over time. With the frozen shoulder that was instantaneously I got relief. With the hypertension, [the integrative physician] has changed my medication, part of my medication, and along with that change I've noticed better control of the hypertension. [...] I've also noticed that there has been an improvement, a general improvement. [...] I've noticed general improvement by way of the hypertension that I'm focusing on now. The measurements that are taken are better under control. Instead of peaking all over the place, it's on a steady basis.

In addition, improvements in the health condition of patients have allowed them to use less prescription medication. As many patients associate prescription medication with side-effects, the reduction in the amount of medication that they take is an important outcome of their treatment. Daniel describes how he able to reduce the amount of prescription medication that he was taking:

It's also, and here's another factor, gotten me off of a lot of drugs the regular doctors were prescribing to me. So I've cut down from all they were giving, well not all but the ones for the diabetes they've cut me down to one and then they've given me a couple of little pills to take.

Along with the changes that have occurred to their personal health situation, patients can assess how they perceive their illness and the management of their condition within the context of the community spirit that is present at the clinic. The interesting set up of the clinic allows patients to discuss amongst them while they are receiving treatments at the clinic. Their discussions impact the patient's assessment of their condition and of the treatments that they receive. Marc stated that these discussions reinforce his faith in the treatments that he receives since patients who experienced problems would tell the others immediately:

The fact that I'm sitting here with my peers and other people that have similar problems as me. And we're all comparing those, right. And you can't sit here and have bullshit floating around with that many patients out there without someone saying, hey this isn't working or this isn't happening or this isn't going the way I thought it was going.

It is important to note that the patients express satisfaction with the services that they receive at the clinic. Satisfaction with services at the clinic is asserted by Adam who believes that the physician is “phenomenal” and that “chelation is a “gift from the gods”. Marc echoes Adam’s though stating that he would recommend a clinic to somebody else because he believes that the care is genuine and of high quality:

I sell hope. I sell real estate, right. When you sell hope like I do, you realize when you people are genuine and forthright and straightforward as opposed to people who are trying to blow happiness up your skirt. I appreciated that with him. [...] The care. If I was talking to you as a real estate agent, I'd tell you get more here for your buck. But from one person to another, I'd say, it's the care but it's the quality of care that you get.

All the patients expressed a desire to attain future health goals. Goals can be mediated by personal objectives or can be influenced by members of the social sphere. Aims to reduce prescription medication further were a common goal as well as the desire to satisfy members of the social sphere. Patients stated that they were still working towards improving their health. Several patients aimed to reduce the amount of prescription medication that they were taking. Cynthia described the personal goals that she had set for herself now that progress was being made.

It's been a 100% turnaround. I've got the thyroid under control. The diabetes is under control. I still have a ways to go. I'd like to be off the medication because right now I'm on Metformin.

So I'd like eventually down the road be off that. I've lost a lot of weight. Still have more to go. But it's just 100% turnaround. It's just amazing.

Marc's goal is very straightforward. Though his focus is still on achieving personal goals, the emphasis has been placed on longevity rather than on medication. His focus on longevity stems from his desire to collect what he believes to be rightfully his—the fruit of many years of labour.

So I'm in the programme here and I'm going to feel better. And I'm going to live long enough to get my old age pension cheque. And then I'll feel much, much better.

Nevertheless, desires by patients to achieve better health may be mediated by a desire to please individuals from the social sphere. Individuals from the social sphere hence serve as indicators that the health condition of the patient is improving and as an impetus to get better. Marc explains this gauge of success as follows:

I think the big startup is going to be when the golf season starts. There's probably people saying, golf geez. But let me tell you if I didn't have golf, I don't think I would have gotten over my last heart attack. That's basically because my buddies, I remember when I was in my hospital room, I was in pretty bad shape, came in and they said to me. And I don't know what it's worth to you, but a bunch of the guys at the golf course got together and we paid your membership this year. And it's no small fee at the golf course where that I belong too, we're talking thousands of dollars. And I thought to myself, I can't let them down. I've got to get better. So I busted my ass and got better. As far as the social life goes, I'm looking forward to the golf season so that I can get out there with my buddies. Not have angina and not be worried every time I go out on the golf course whether it's my last trip around the course or not.

Similarly, David stated how he wanted to keep improving his health so that he could spend more time with his grand-children. His desire to become healthy stems from his recollection of a time when he had fun watching his own kids growing up.

I've got seven grandchildren and, you know, I thought to myself, I got to be around, I want to see these kids grow up, because we had so much fun with our own growing up and whatnot. So I just wanted to feel healthy, I wanted to be active and I wanted to get off as many drugs as I could.

Several patients report significant changes following the onset of therapies at the integrative clinic. Some patients described regaining the capacity to perform more physical exercises. On the other hand, some patients stated that few changes had occurred. They explain, however, that their health condition was better than some other patients. Patients report having a greater sense of well-being and better control over their disease. Similarly, some patients were capable of reducing the amount of medication that they were taking. Finally, patients appear to be satisfied with the services at the clinic. Patients set future health goals that were at times motivated by personal objectives such as losing more weight or reducing the amount of medication that they are taking. In other instances, individuals from the social sphere contributed to their desire to get better.

Summary of the Findings

Before beginning their treatments at the integrative clinic, patients described their condition in negative terms. The disease imposed significant restrictions and had threatened their self-concept. Their medical condition and the influence from members of the social sphere factored into the participants perception that their health status required attention, and hence,

served as an impetus for them to join the clinic. The relationship between the staff and the patients reinforced the patients' positive view of themselves, their condition and their ability to manage their disease. The good relationship between patients and caregivers was important to patients because they felt that it was based on a human to human connection and that caregivers believed in their ability to self-manage their condition. The accessibility and thoroughness of the integrative staff strengthened the patients' trust in caregivers and allowed them to feel that they were well looked after. In addition, the relationship between caregivers and patients facilitated the process of information gathering. Patients were impressed by the knowledge of the caregivers and believed that they could use it as a tool to improve their health. Moreover, patients appreciated the integrative physician's ability to communicate important information using lay language and multiple communication modalities. The opportunity to gather more knowledge on their condition was seen by patients as an encouragement to take an active role in the treatment process. Patients also believed that their newly gleaned knowledge could help them evaluate whether there was progress in their health status. Patients admired the integrative physician's adoption of alternative health philosophies and his use of natural supplements. Many patients wished to reduce the amount of prescription medication that they were taking and saw pills as a corruption of conventional medicine. Following the start of their treatments at the integrative clinic, patients described having experienced several physical and emotional changes. Patients felt that these changes represented a return to their former self—their self prior to the onset of their illness. Many also reported using less prescription medication. All patients set future health goals.

Chapter 5: Discussion

The purpose of the study was to illustrate how patients perceived their experience of living with a chronic illness and their integrative treatment process. I tied my research to existing literature on chronic illness and physician-patient relationships in conventional medicine because my results address these particular issues even though they have not been examined extensively in integrative medicine. The meanings of the findings for this study extend to implications for medical practice, policy and research, and will be discussed in the Conclusion. It is important to note that the opinions presented by the participants do not necessarily reflect the opinion of the author. Participants' views presented in the thesis should not be interpreted as medical evidence or a prescribed course of action for others. Patients that require medical attention should seek care from a registered health professional.

The process that highlights the patient experience prior and after joining the clinic is illustrated in Figure 1. All patients perceived their health condition negatively prior to entering the clinic. The lack of improvements in their health condition or further deteriorations served as the impetus, or in other words, as the 'trigger' to seek integrative care. Members of the patients' social sphere likewise played a role in encouraging them to join the clinic. Patients perceived that the impact of the integrative physician arose from his approach to care. The healing relationship that is fostered at the clinic as a result of the accessibility of the integrative clinic staff and the time spent with patients, allows patients to control their condition better. Patient empowerment was hence enabled. After receiving care at the clinic, many patients report improvements to their health and the desire to attain more goals.

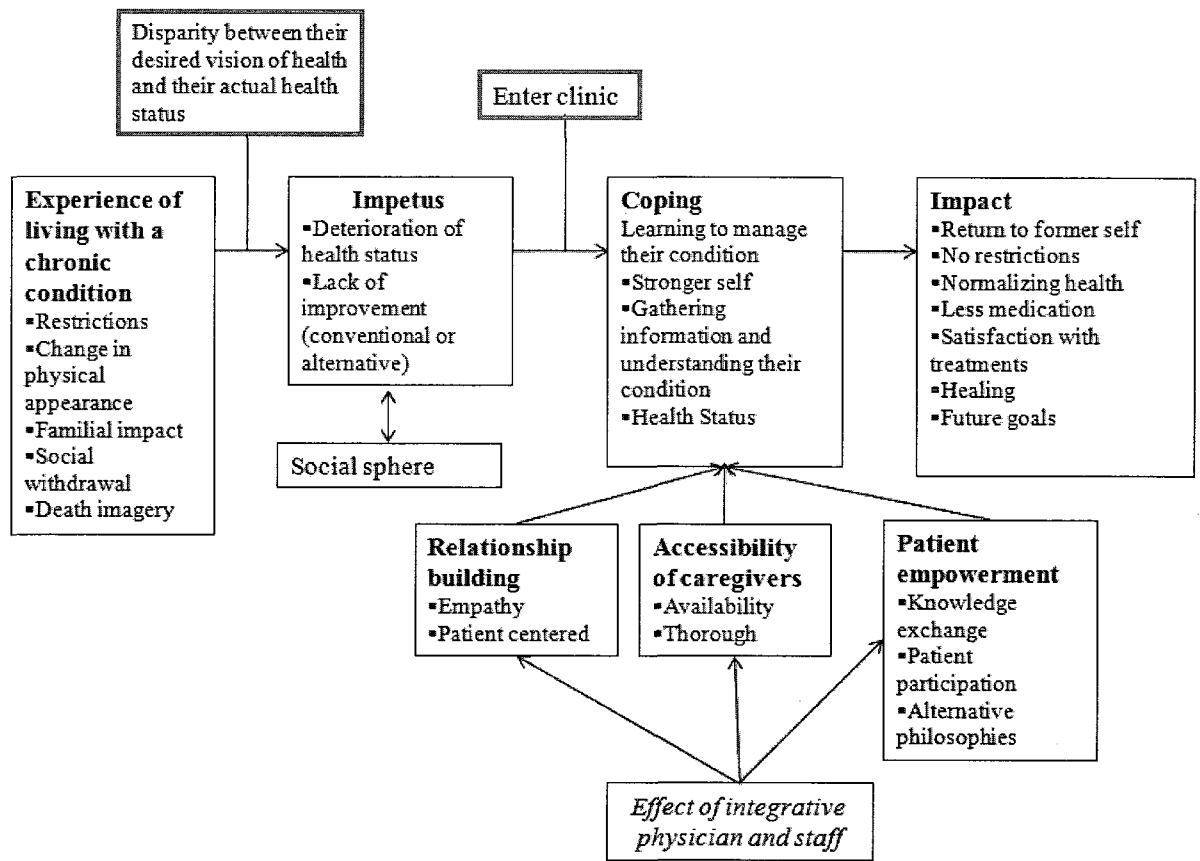


Figure 1: Healing process before and after receiving treatment at the integrative clinic

Patients reported on their experience of living with a chronic condition and the impetus that led them to join the integrative clinic. They then describe how they learned to cope with their condition while at the clinic and the effect that the integrative staff had on their coping strategy. Finally, patients reported on the impact of their treatments and on their future goals. This chapter will highlight similarities and differences with the existing literature.

The experience of living with a chronic condition

Patients explained how they viewed their health and their ability to manage their condition before and after receiving treatments at the integrative clinic. All patients perceived their health condition negatively before starting treatments at the integrative clinic. Individuals that suffered from more severe chronic illnesses tended to exhibit a greater concern for their health and demonstrated an enhanced awareness of their limitations. Feelings of suffering, loss of control and daily living restrictions were prevalent within the patients' responses of their experience living with a chronic illness prior to receiving integrative care. Participants reported that their condition had limited their ability to fulfill their spousal or familial roles and therefore had a negative effect on these relationships. Patients had been unhappy with the negative changes in their physical appearance that resulted from their health condition. Patients' account of their experience with chronic illness is consistent with Charmaz's (1983) and Bury's (1982) research demonstrating how chronic illnesses threaten the individual self and biography (Bury, 1982; Charmaz, 1983).

Prior to receiving treatments at the clinic, patients reported that the emotional and physical consequences of their chronic illness had undermined their self by forcing them to reconsider how they had perceived themselves for a large part of their life. Their past self may have revolved around their work, physical, familial or social activities. The consequences of chronic illnesses had made patients aware of the fact that their daily lives had become more restricted. For some more chronically ill patients, the daily restrictions in their lives caused them to withdraw from society. For one of the patients, social withdrawal arose out of the fear that he would be found dead, while another patient lacked the energy necessary to maintain a social relationship. The findings are also consistent with Suchman's

(1988) description of patients suffering from chronic illnesses. Suchman describes how chronic conditions may interfere with patients' ability to maintain control in their life and may lead to social withdrawal (Suchman & Matthews, 1988). Pain and daily restrictions likewise contribute to the social withdrawal of the patient. In addition, the patients' coping mechanisms may be insufficient to deal with their condition.

Impetus for seeking integrative care

The patient's negative perception of their condition is therefore the result of a disparity between their desired vision of health and their actual health status. This disparity eventually translated into an impetus to join the integrative clinic—the impetus arose from the medical condition of patients and from the influence of the individuals that belong to their social surroundings. For some participants, joining the integrative clinic was seen as a last resort for a health condition that could not be treated by conventional medicine. For other participants, a health condition that wasn't improving with conventional or alternative treatments encouraged them to seek integrative care. Finally, others had decided to join the clinic once their health condition had deteriorated and the symptoms that they were experiencing became a source of anxiety. Patients often cited family members, friends and colleagues as factors that encouraged them to join the clinic. The findings are consistent with Zola's (1973) study on what leads individuals to seek medical care (Zola, 1973). Zola's review of the literature highlights contradictory patterns on care seeking and demonstrates that symptoms on their own may not be a strong enough impetus to encourage individuals to seek medical attention. Those who experience more severe symptoms are not always the ones seeking care, and therefore, other elements must serve to convert a person to a patient.

Although Zola's research dates back to the 1970s, his work is still relevant to today's health care challenges (Williams, 1996).

Many patients in my study who had experienced severe symptoms reported that their family was a strong influence for joining the clinic. Hence, it seems as though symptoms by themselves were not enough to seek integrative care. The study demonstrated that interference with social or personal relationships was a factor in seeking care. The findings highlight how family members can serve as a driving force to seek care and places the concept of health and illness within the realm of a social phenomenon.

Patients also report that individuals that represented medical authorities such as physicians and nurses also impacted their decision to obtain care at the clinic. In addition to factoring into patients' decision to enter the clinic, members of the social sphere reinforced the patients' perception that changes had occurred in their health. The results derived from patients' account support findings in the study by Berkanovic *et al.* (1981) that investigated the impact of social networks on care seeking behaviour. The study shows that patients with greater networks and contacts were more likely to follow advice to seek care and use medical services (Berkanovic, Telesky, & Reeder, 1981). This was especially true if members of the network encouraged the individual to seek medical attention. Finally, social media served to encourage patients to join the clinic by providing patients with information on the integrative physician and the treatments that he offered.

Learning to cope with a chronic condition

Patients learnt how to manage their condition as they began to receive treatments at the integrative clinic. Patients stated that they became better patients as they gathered more

knowledge on their health. Participants reported that the integrative staff had a strong influence on their choice of a coping strategy. The effect of the physician-patient relationship arises from three factors: 1) relationship building, 2) the accessibility of caregivers and 3) patient empowerment.

1) Relationship-building—patient centered care and empathy

Patient centered care is an important component of integrative medicine (Maizes, Rakel, & Niemiec, 2009). Patient centered medicine can be defined as the delivery of health services with an added emphasis on patient-oriented care, agreement over health care goals and the development of personal bond between physician and patients (Mead & Bower, 2000). Patient centered care can facilitate the self-management process (Maizes *et al.*, 2009). Two factors have been identified for successful self-management procedures in integrative clinics: 1) continuity of care and 2) communication (Maizes *et al.*, 2009). The relationship between patients and staff members at the integrative clinic formed the basis for allowing patients to improve how they manage their condition. Patients appreciated the effort made by the integrative staff members and the integrative physician to build a relationship that extended beyond their disease and encompassed their personal life situation.

Empathy was an important component of the relationship that developed between caregivers and the patients. Empathy is defined as the power of understanding and sharing of another person's feelings (Squier, 1990). Patients felt that caregivers at the integrative clinic demonstrated empathy by showing genuine concern for the well-being of the patients and by attempting to establish a rapport with the patients. The factors cited by the patients have been documented in other studies. Scott (2008) reports that physicians can exhibit

empathy by creating an environment in which patients feel comfortable telling their story, by demonstrating curiosity and by being 'present'. In order to be 'present', the physician must engage in active listening, and must accept the patient's illness experience (Scott *et al.*, 2008). Empathy has been shown to be important in helping patients manage fear and establish a stronger self, resulting in greater motivation and better coping strategies (Squier, 1990). Moreover, physician-patient relationships that emphasized the empathetic component of the relationship resulted in increased patient participation and satisfaction. In addition, physicians who were able to demonstrate empathy were able to gain patients' trust and involvement to a greater extent.

2) *Accessibility and thoroughness of caregivers*

The accessibility of caregivers enabled the development of a healing relationship between caregivers and patients. Two elements factored into the accessibility of caregivers: their availability and their thoroughness. Availability is best described as the amount of time that patients could spend with caregivers. Patients felt that the availability and the thoroughness of caregivers strengthened the healing relationship. As a result of the availability of caregivers, patients were more trusting of the integrative physician and appreciated the fact that staff members had the time to explain their condition to them. Patients also felt that the caregivers were able to respond to their unique needs and that they were thorough. Patients reported that the thoroughness of the integrative physician and his staff reinforced the belief that their health was being carefully looked after. Interestingly, patients contrasted the thoroughness of the integrative physician with that of their conventional physicians. The thoroughness of the integrative physician serves to highlight

frustrations with the conventional system that is seen to mimic a factory assembly line. The push to encourage conventional physicians to adopt holistic practices is reflected upon in Egnew's (2009) essay. Egnew explains that physician's are increasingly faced with the task to help chronically patients overcome suffering and that they can become holistic healers by helping patients transcend suffering. Transcending suffering implies that patients are able to reconnect with themselves and find meaning in their experience. Physicians can aid patients in transcending suffering by "normalizing" the patients' feelings and behaviours towards the illness. Patients believed that the integrative physician helped them transcend suffering by allowing them to understand their condition. A good healing relationship which is characterized by warmth, genuineness, and empathy, is also crucial in aiding patients reconnect with the world from which they may have withdrawn (Egnew, 2009). As this study demonstrated, chronically ill patients often experience social withdrawal and physicians can help patients reconnect with the world. Patients in this project report that empathy and empowerment were important elements of the healing relationship and gave them the confidence necessary to manage their condition. Moreover, good healing relationships result in better physician-patient communications, an enhanced perception of the physician's expertise, greater trust in the physician's abilities and greater overall satisfaction (Kim, Kaplowitz, & Johnston, 2004).

3) *Patient empowerment*

a) Patient participation

Participants report that patient empowerment was enabled by facilitating the exchange of knowledge between caregivers and patients, by encouraging patient

participation and by using alternative treatment modalities. Patients felt that staff members were aiming to encourage their participation in the treatment process. Patient participation in the treatment process was encouraged by teaching them about different available coping strategies and by showing them the milestones that had to be reached in order to improve their condition. The results reflect earlier studies on physician-patient communications. Bartlett (1984) demonstrated that good physician teaching improved lesson recall and learning (Bartlett *et al.*, 1984). Hall (1988) likewise found that patients were happier when physicians communicated with positive affect (Hall, 2005). Good physician-patient communication can result in better patient participation and patient empowerment (Bartlett *et al.*, 1984). As a result of the healing relationship that was created between the caregivers and the patients, patients felt that they had more control over their condition and could participate to a greater extent in the treatment process.

Patients also reported feeling more empowered and in control of their life. Patients' trust in the integrative physician is reinforced because they believe that he has a desire to educate them. In addition, patients stated that they were allowed to become better patients. A review of the literature on approaches to health care delivery has found that empowered patients are more satisfied with the services that they receive and are more likely to follow their treatment regimens (Grol, 2001). The results of this study are consistent with a study by Aujoulat (2007) that found that three factors were necessary for patient empowerment: 1) the education of patient focuses on reinforcing patient skills to control their condition, 2) the focus of the education is patient centered and encourages learning by experience, 3) the patient-physician relationship is continuous and involves both the patient and the physician (Aujoulat, d'Hoore, & Deccache, 2007).

It is interesting to note that the concepts found in the study by Aujoulat (2007) have been advocated by other researchers in the past. Funnell (1997) promotes patient education as a mean to improve self-management of diabetes and patient participation. He states that education can enable patients to take control of their condition (Funnell *et al.*, 1991). Firstly, education should focus on allowing patients to recognize and to enhance their individual strengths so that they may make informed choices and set goals. Secondly, physicians and patients should aim to become equal and active partners in the treatment process. While the physician may be an expert on the disease, the patient is an expert on their life. Finally, emphasis should be placed on the whole person (bio-psycho-social) rather than only on the disease.

b) Knowledge exchange

Consistent with Kim's (2004) studies, patients reported that the positive relationship that they had with caregivers at the integrative clinic facilitated the exchange of information (Kim *et al.*, 2004). Similarly, patients saw the knowledge of the integrative physician and his staff as a tool to improve how they manage their condition. Many patients perceive the staff's great source of knowledge as an asset in their goal to improve their health. The physician-patient relationship is very important in chronic care and as Charmaz (1983) remarked in her paper, patients are not always given enough information by their physicians on how they could participate in life. Patients at the integrative clinic appreciated the attempts by the integrative physician and his staff to build a meaningful relationship with them and their willingness to engage them in the treatment process. In accordance with Charmaz's findings, the relationship with the physician can strengthen or weaken the self of

the patient. By engaging the patients in the treatment process, the patients in this study felt that they had the confidence necessary to manage their condition. Many patients admired the integrative physician's ability to convey information in very simple terms and through various modalities. Patients appreciated the fact that health information was easily accessible and fit their level of understanding.

Different communication modalities were made available to facilitate the transfer of information. Although the integrative physician utilized multiple communication modalities, few studies have examined the impact of using drawings and a summary of the session, to reinforce self-management procedures. Nonetheless, a randomized double-blind study examining the use of initial audio-taped consultations demonstrated that patients who audio-recorded their session were more satisfied with the consultation and the level of care than the patients who did not record the session (control group) (Ong *et al.*, 2000). Moreover, audio-tapes facilitated information recall on a long-term period. Since information is seen by patients as a tool to improve their health, access to clear and understandable information was an asset to the management of their condition and the information allowed them to become better patients.

c) Alternative philosophies

Patients believe that the integrative physician's knowledge is best demonstrated by his inquiring attitude and his ability to think outside the box. Patients appreciated that he was capable of presenting solutions that conventional medicine could not offer to patients and that multiple options existed to treat their condition. His quest for finding natural solutions to health problems resonates well with patients who sometimes fear side effects

that may be caused by conventional medication. Side effects that are caused by conventional medication is a well-known barrier to self-management procedures (Leventhal *et al.*, 1992). In addition, some patients believe that the current conventional system has been corrupted by pharmaceutical companies and that treatments at the integrative clinic could benefit the health system as a whole by reducing costs.

Patients' preferences for integrative medicine are consistent with the study by McCaffrey (2007) in which patients stated that they preferred integrative medicine. The study examined the response of 37 participants that were divided into 6 focus groups. All participants were regular users of integrative medicine. The study was undertaken using grounded-theory. The participants stated the following reasons for using integrative medicine: 1) patients believed that the blending of alternative and conventional therapies is more beneficial than either alone, 2) health evaluations include bio-psycho-social variables, 3) patients are reluctant to utilize prescription medication, 4) they need the guidance of an integrative physician on how to combine the two treatment modalities, 5) the accessibility of the integrative physician is important, 6) they want an opportunity to participate in the treatment process (McCaffrey *et al.*, 2007).

Impact

The confidence that patients gain during the treatment process provides them with a positive and stronger view of their self. Many believe that they have regained their physical capabilities, and are hence, able to perform activities that they enjoyed in the past. For patients who had experienced difficulty managing their condition, the ability to control it also brings a sense of relief and enhances their confidence levels. The changes that are

described by patients fit within their perception of healing. All patients set future goals to achieve. Although the patients still suffer from a chronic illness, their health appears to have improved.

The findings are consistent with the notion of health within illness. Lindsey (1996) states that health and illness form part of the same concept (Lindsey, 1996). Patients can participate in their health by owning the healing process and by becoming the authors of their health experience. Studies have demonstrated that chronically ill individuals rate their health as good or excellent. Caregivers must be aware of the potential to enhance health within illness and adopt a model of care that promotes health and healing. Lindsey's study of health within illness with chronically ill individuals reveals that six elements were important for participants: 1) honouring the self, 2) seeking and connecting with others, 3) creating opportunities, 4) celebrating life, 5) transcending the self and 6) acquiring a state of grace. In honouring the self, participants spoke about being in control and having the ability to make decisions. Participants also described the importance of forming social relationships and creating opportunities. This is consistent with the results of this study. Similarly to the findings of this study, patients felt more alive and experienced more energy. On the other hand, patients did not describe transcending the self or acquiring a state of grace. This may be due to the fact that patients did not suffer as much from a painful disability, but rather from chronic illnesses that produce symptoms in certain situations (e.g. shovelling).

Chapter 6: Conclusion

Part I: Contributions

IPA is a useful research method that provides the opportunity to understand the meaning of lived experiences of chronically ill individuals as they receive treatments at the integrative clinic. It likewise provides the researcher with the opportunity to participate in the interpretation process. This study will contribute to our understanding of the experiences of chronically ill patients, including the despair and the fear that patients may feel when their condition is not improving or is deteriorating. It also provides insight into why patients seek integrative care and why they believe that they can benefit from the combination of alternative and conventional medicine. In addition, it highlights how patients believe that a good physician-patient relationship is central to the treatment process and to the improvement in their health. Setting the study within the context of integrative medicine likewise provides us with information on how patients reflect on practices adopted by integrative clinics. Since chronically ill patients require more time and resources, the findings of this study could be applied to conventional medicine.

Part II: Implications

Medical Practice

Integrative medicine emphasizes the bio-psycho-social elements of health and illness. The delivery of health care services that is described by patients in this study is consistent with the literature on integrative medicine. McCaffrey *et al.* (2007) state that the physician-patient relationship and patient participation are important elements in the delivery of health

services in integrative medicine (McCaffrey *et al.*, 2007). Maizes *et al.* (2009) describe similar components of the delivery of health care services in integrative medicine:

- 1) Physicians and patients are partners in health
- 2) Health and illness encompass bio-psycho-social elements
- 3) The body's natural healing response should be emphasized
- 4) Natural and less invasive solutions should be used whenever possible
- 5) Practitioners of integrative medicine should serve as role models for their patients

The findings from this study suggest that a strong healing relationship between physicians and patients can improve how patients view their illness and improve the management of their condition. The healing relationship at the integrative clinic is derived from the patient centered care and by the empathetic relationship demonstrated by the clinic staff. The strong healing relationship facilitated the exchange of knowledge between patients and caregivers and allowed for patient empowerment. The approach adopted by integrative medicine could provide useful solutions on how to humanize conventional medicine.

Howard *et al.* (1977) identified how conventional medicine can dehumanize patients: objectifying patients, exhibiting coldness and indifference, and limiting the freedom of patients (Howard *et al.*, 1977). Similarly, Howard Leventhal reported that patients are dehumanized when their psychological and physical self are split (Howard *et al.*, 1977).

Howard named the conditions necessary to humanize medical care:

- 1) Patients must be perceived as unique and irreplaceable and worthy of the caregivers' time
- 2) Patients must share decisions with caregivers

- 3) The patient-physician relationship should be an equalitarian, not a patronizing one
- 4) Patients should be able to function autonomously within the limits imposed on them by their condition
- 5) The healing relationship should be based on empathy and warmth

The integrative physician at the clinic was seen by patients to humanize medical care.

Patients state that the human to human relationship reinforced their self and provided them with the confidence necessary to manage their conditions. Similarly, patients report that the integrative physician educated them on their condition in order to encourage their participation in the treatment process.

Barry *et al.* (2001) likewise recommend that physicians rely more on the patient's lifeworld. The lifeworld of the patient can be defined as the biographical and social situation of patients. Focusing on the patient's lifeworld allows patients to produce accounts that are more meaningful and more coherent. The integrative physician and his staff make an effort to tap into the patient's lifeworld by spending considerable time with patients and by extending their focus to include psychological and social elements.

Policy

Approximately 80 percent of the Ontarian population over the age of 45 currently suffer from chronic ailment and 70 percent of them have two or more chronic conditions (Tsasis & Bains, 2008). The prevalence of chronic illnesses in Canada alone requires that we revise the health care delivery system in order to ensure continuity of care along clinical settings. As efforts are being focused on helping patients manage their condition, there is a need to integrate care services so that patients can receive treatments for multiple chronic

disorders. The adoption of the Expanded Chronic Care Model (CCM) has shifted the focus away from the health provider's need to the patient's need by emphasizing self-management procedures and taking into account social and economic factors (Tsasis & Bains, 2008).

Nevertheless, more needs to be done to facilitate patient centered care. The institution of a community organisation that is capable of co-ordinating the social and medical needs of its patient is the first critical step in the implementation of a successful long-term plan for chronic care management. These community organisations could adopt a model that is similar to that of integrative care clinics where the emphasis is on patient centered care and on providing services for multiple conditions. Nonetheless, integrative clinics offer another advantage over conventional clinics by offering alternative medicine services under the supervision of a conventional medical specialist.

Furthermore, incentives to dedicate more time to chronically ill patients should be worked into the system. Moving away from a fee-for-service towards a capitation system may allow conventional physicians to dedicate more time to their patients. As the results of this study indicate, time and accessibility to the physician are crucial in the development of a meaningful healing relationship. A strong healing relationship facilitates knowledge exchange and allows for patient empowerment.

Finally, providers must allow patients to feel a sense of control over the treatment of their disease. Community groups should aim to introduce education programs that provide patients with the skills and understanding necessary to deal with their disease. Patients should be taught about how to manage their condition and how fostering stronger social networks. By providing patients with the opportunity to have greater control over their

disease, patients will be capable of setting their own goals and to identify barriers, thus achieving a healthier lifestyle.

Research

This study examined how the patients' representations of their health, illness and treatments were affected by their relationship with the integrative physician and his staff. Since this research project examined only the patient perspective, future research projects should include the integrative physician's perspective. The perspectives of the physician and of the patient should likewise be compared. As the study was conducted only at one integrative clinic with a small number of patients, it would be interesting to study the impact of communication on self-management in other care clinics, both in conventional and integrative settings.

This research project also demonstrated that physician-patient relationships and communication were important in helping patients manage their condition. Further studies examining how to improve the healing relationship would prove useful. These could include studies on how to teach patients how to communicate more effectively with their physicians, and how physicians can improve their communication skills. Similarly, the impact on self-management procedures that results from the use of different information modalities during consultations has yet to be studied extensively.

Part III: Limitations and Areas for Future Research

My study design has a few limitations. Although my sample was purposive for participants that suffered from chronic illnesses and received care at the integrative clinic, I interviewed mostly men. Women may have different treatment experiences than men and

subsequent studies should aim to seek more of their input. Similarly, participants came from a Caucasian background and additional research should try to incorporate the perspective of members from more diverse ethnic groups. In addition, the personal costs incurred from accessing services of the clinic limits who can become a client at a clinic; this, in turn, may limit the transferability of the study's findings to those who cannot afford such services. Future research should seek to examine the impact of income on accessibility to services and its impact on patient's experiences with chronic illness. The research project was likewise conducted in only one integrative clinic and other studies should aim to determine if common patterns exist across integrative clinics. Specifically, additional studies should investigate whether the patient-physician relationship and high levels of patient empowerment result in improved patient outcomes. In addition, my study did not seek the perspective of the caregivers. Further studies should examine the perspective of caregivers to see if there are common points between them and the patients.

Concluding remarks

Given that health and illness play a major role in how individuals view themselves and their quality of life and given the increasing popularity of integrative medicine, it is incumbent upon researchers to understand how patients experience health, illness and healing modalities. This study moves in this direction by exploring the lifeworld of chronically ill patients within the context of integrative medicine. I hope that future studies will seek to explore different aspects of integrative care including healing modalities in other clinics, health outcomes and the role of the integrative physician.

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Appendix A

**Participants needed for:
Research project on integrative clinics**

Dear patients,

A Telfer School of Management researcher from the University of Ottawa will be conducting interviews with patients at the clinic in August 2009. The research project is for her Master's thesis.

As a participant, you will be asked questions on: 1) why you came to the clinic, 2) your views on health, 3) and the factors that lead you to consider a treatment to be successful. The interview will take no longer than 1 hour.

The purpose of the research is to determine how patients evaluate their treatments so that proper evaluation measures can be established for integrative clinics. Measures are used in health care to determine whether a treatment provided benefits to patients.

Appropriate measures for integrative clinics could provide these long-term benefits.

- Help determine whether a treatment is successful or not
- Improve practices in all integrative clinics
- Eventually, may allow patients to access more health care services
- Provide physicians and complementary and alternative medicine practitioners with a better understanding of how patients view their treatment and provide them the opportunity to improve their services

To qualify as a participant, you must meet the following criteria:

1. Be a patient at the clinic
2. Be receiving complementary and alternative medicine treatments on a regular basis
3. Suffer from one or more chronic diseases (e.g. heart problems, diabetes, hypertension, arthritis...)
4. Be between the ages of 18-80
5. Be fluent in French or in English
6. Be able to provide informed consent (permission)

If you are interested in participating in the study, please contact Nathalie Richard at _____ or one of the doctors at the clinic. I am seeking approximately 10 patients that meet the criteria mentioned above for the study. Participants will be selected on a first-come first-served basis.

Sincerely,

Nathalie Richard
M.Sc. Health Systems candidate

This study has been reviewed by, and has received ethics clearance through, the Review Ethics Board, University of Ottawa.

Title of the study: Establishing health outcome measures for integrative clinics

Investigators:

Nathalie Richard (M.Sc. Health Systems Candidate), Telfer School of Management, University of Ottawa; Dr. Doug Angus, Telfer School of Management, University of Ottawa; Dr. Ivy Bourgeault, Department of Health Sciences, University of Ottawa.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

Invitation to Participate

I am invited to participate in the above mentioned research study conducted by Nathalie Richard, Dr. Doug Angus and Dr. Ivy Bourgeault.

Purpose of the Study

The aim of this study is of two parts. The first part involves obtaining a better understanding of why patients chose to receive treatments at an integrative clinic (a clinic that combines conventional and alternative medicine) and to understand how they view health. The second part involves determining the factors that patients use to evaluate the treatments that they receive. The factors identified by the patients will be compared to existing guideline measures to determine if the current measures incorporate elements that are important to patients.

Participation

My participation will consist essentially of participating at a one-hour interview during which I will answer the questions asked by Nathalie Richard. I will be asked to review the pooled results of the study to determine whether the summary of the project accurately reflects my experience during another one hour session.

Risks

My participation in this study will entail that I provide information regarding my treatments and my views on my decision to attend the clinic. This will involve releasing personal information, and this may cause me to feel uncomfortable. I have received assurance from the researcher that every effort will be made to minimize these risks. The researcher has authorized me to answer questions within my comfort level and I may choose not to answer a question (or questions). I may decide to stop participating or to withdraw from the study at any time without suffering any negative consequences. I can withdraw from the study by

asking the researcher to stop the interview or to destroy the information that she has collected from my interview. I may also ask the researcher questions about the study at any time. I may ask to review the interview transcripts. If I choose to do so, I will provide the researcher with information as to how I can be contacted. This information will only be seen by the researcher and will be kept confidential.

Benefits

My participation in this study will help identify factors that can be included in guidelines for the evaluation of integrative clinics. These factors will help improve practices of clinics that incorporate alternative medicine and will ensure that patients are receiving the best care.

Confidentiality and anonymity

I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that a summary of the information collected during the interviews will be used only by the researcher in order for her to complete her study. My confidentiality will be protected as only the researcher and her supervisors will have access to the data collected during my interview.

Anonymity will be protected in the following manner: I will be given an independent study number and my name will not be used. Only the information related to the context under which I decided to become a patient of the clinic and on my views of the treatments that I am receiving will be used in the study. The clinic name will not be included in the final project.

Conservation of data

The data collected will include a recording of the interview, a transcript of the interview and notes made during the session. The data will be kept in hard copy and in an electronic format that will be kept in a secure manner in a safe compartment in the office of one of the research supervisors. Only the researcher and her supervisors will have access to the data.

Voluntary Participation

I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, all data gathered until the time of withdrawal will be destroyed by the researcher.

Acceptance

I agree to participate in the above research study conducted by Nathalie Richard of the M.Sc. Health Systems, Telfer School of Management at the University of Ottawa and her supervisors Dr. Doug Angus and Dr. Ivy Bourgeault.

My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project and agree to participate as a subject. In no way does this waive my legal rights nor release the investigators or involved institutions

from their legal and professional responsibilities. I am free to withdraw from the study at any time without jeopardizing my health care

I understand that the interview will be audiotaped and I agree to let Nathalie Richard record our conversation. There are two copies of the consent form, one of which is mine to keep.

For further questions concerning matters related to this research, please contact:

Nathalie Richard

Dr. Doug Angus
Dr. Ivy Bourgeault

_____	_____
Participant's Name	Signature and Date
_____	_____
Witness' Name (needed in the case where a participant is illiterate, blind, etc.):	Signature and Date
_____	_____
Researcher's Name	Signature and Date

The University of Ottawa Research Ethics Board has approved this research study. If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 159, Ottawa, ON K1N 6N5

Tel.: (613) 562-5841
Email: ethics@uottawa.ca

Integrative medicine questionnaire (IMQ):

Hello. My name is Nathalie and I'm doing a Master's project with patients at integrative clinics to determine the elements of their treatment that are important to them. I would like to tape-record our discussion so that I don't miss any important elements or risk the chance of changing your words somehow. Do you have any questions for me before we start?

I. Context

- How did you hear about the clinic?
- How often do you come to the clinic?
 - Probe: since when have you been coming?
- What is it about you that led you to join the clinic?
 - Probe: medical conditions/family/friends/biomedical experience/values
 - Probe: your situation, your personality, your desires

II. Perceptions of health and healing

- What does it mean to live life fully to you?
 - Probe: positive/negative vision; disease/well-being; give me an example
- What does healing mean to you?
 - Probe: what do you value the most about health?; e.g. activities, meaning of life?
- What was the most important element in this process?
- How do you see your role as a patient?
 - Probe: responsibility, team with physician, setting goals
 - Probe: changes over time
- What changes, if any, have occurred since you have joined the clinic?
 - Probe: role as patient
 - Probe: empowerment; control; resources

III. Features of intervention is holistic

- Imagine I was present at one of the sessions, what would I see going on? Describe what I would see.
 - Probe: what elements are examined during a session?; with whom?
- Who are your main caregivers at the clinic?
- How would you describe your relationship with the caregivers at the clinic?
- How do the treatments that you receive at the clinic differ from the treatments that you receive in a conventional doctor's office?
- How, if anything, has this affected your satisfaction with the care that you receive at this clinic?
- What elements encourage you to keep coming back to the clinic?

Before I move on to the next set of questions, let me make sure I've got everything you said about why you chose to receive treatments at the clinic and on your perceptions of health. Before I ask you questions about the success of your treatments, are there any additional comments that you would like to make?

IV. Success of treatment

- Give me examples of changes that have occurred since your treatment began.
 - Probe: mental/physical/affective/in your environment
- How have these changes impacted your personal life?
 - What has been the most significant change?
- How do others see these changes in your life?
- Suppose I was a friend and that I was looking for recommendations for a clinic like this one. What would you base your recommendation on?

V. Factors that increased or decreased the success of the intervention

- Suppose that you were asked to determine whether your treatment was successful. On which elements would you base your response?
- What aspects of your treatment are you satisfied with?
 - Probe: clinic
- What aspects of your treatment are you less satisfied with?
 - Probe: clinic
- What expectations do you have regarding the role of [the integrative physician] in terms of the treatments that you are receiving?
- What expectations, if any, do you have regarding the role of the other doctors in terms of the treatments that you are receiving?
- What are your expectations, if any, regarding the role that you play as a patient?
- What are your expectations regarding the treatments that you receive at the clinic?
 - Probe: types of treatment, power, resources, relationship with caregiver
- How have these expectations changed over time?
 - Probe: elaborate; give me an example; how did it affect your perception of the services that you received
- What impact do you think these expectations had on your satisfaction with the services that you have received/receiving?
 - Probe: positive: met expectations; negative/not meeting expectations; process verses outcome
 - What role?

Well we are about to end the interview. Things went very well and I learned a lot from our discussion. Is there anything you would like to add?