“Until you’re there… you don’t know how you’ll be”

A phenomenological study of the influence of lived experiences on beliefs and attitudes about being a patient.

By

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A Thesis

Submitted to the Faculty of Graduate Studies

In Partial Fulfillment of the Requirements

For the Degree of

Doctor of Philosophy

Faculty of Pharmacy

University of Manitoba

Winnipeg, Manitoba

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ABSTRACT

Canadians are worried about the future of the health care system, and provincial governments are questioning the ability of the existing system to support Canadians health care needs in the 21st Century(Industry Canada, 2011). Health care providers and system administrators are both driving and experiencing a paradigm shift; moving away from paternalism and toward an egalitarian approach. In order to practice patient centredness, health care providers must prioritize patient needs; provide information regarding treatments while taking patient preferences into account (Romanow, 2002). While there is a growing body of literature regarding patient centredness, there is scant information from the patient perspective. If the most effective and acceptable health services are those that realize the expectations of the users, this is an important area of study. Using phenomenological research methods and the theory of planned behaviour as a theoretical framework, the purpose of the study was to explore the influence of beliefs, attitudes and experiences on behaviour from the perspective of patients in primary health care or stroke rehabilitation. A second purpose was to explore the degree to which beliefs, attitudes and behaviour were similar between clinical contexts. The theory of planned behaviour was unsuitable for understanding peoples' beliefs, attitudes and behaviour about being a patient. Being a patient was not a single, observable behaviour, but rather a set of contextually dependent strategies patients' directed at a particular goal. The goal for each participant group was different; rehabilitation patients focused on the specific goal of recovery and discharge, while PHC patients focused on a broader goal of accessing and receiving best health care possible. These goals were reflected in their respective approaches to accessing health care services, an experience they described as socially oriented, governed and reinforced. Although patients described themselves as actively engaged, they did not approach each interaction with health care with a set of behavioural beliefs about being a patient. During the course of their participation, patients identified, developed and adopted strategies to assist in achieving the target; and evaluated those strategies more positively.

CHAPTER 1

Introduction

Health care has become a steadily rising concern for many Canadians. In the year 2000, 50% of Canadians identified health care as the most important issue (over unemployment, the economy and education), which was up dramatically from 1% in 1990 (Mendolsohn, 2002). The Canadian health care system is publicly funded (over $54 billion annually) providing health care to over 30 million citizens. Over 740 000 Canadians are employed by the health care system, including those that work in more than 1200 hospitals nationwide. The health care system is governed by the *Canada Health Act*, built upon the principle of universality; guaranteeing care to all Canadian citizens (Industry Canada, 2011)

When the plan for comprehensive medical care was introduced in 1962 it was greatly debated and criticized. In the fifty years since however, health care has become a pillar of the Canadian identity. The ability to access health care has become a perceived right of being a Canadian; as demonstrated by a 2002 study which found that 93% of Canadians agreed with the statement "health care is a right of citizenship" (Abelson, 2004; p.189). Mendolsohn (2002) noted that 88% of Canadians believe that a strong, publicly funded health care system is important to them; and that the health care system is symbolic of Canadian values.

Despite a commitment to the current system, Canadians have noted that the quality of the health care system is deteriorating; particularly in terms of timely access citing wait times and access to primary health care services (Mendolsohn, 2002). Canadians are worried about the future of the health care system, and policy makers are becoming increasingly cognizant of the need to structure the health care system in a way that meets the public and patients' needs. Provincial governments are questioning the ability of the existing system to support Canadians health care needs in the 21st Century and determined that a new set of principles and criteria must be developed and implemented to be representative of the new environment (Industry Canada, 2011).

Health care providers and health system administrators are both driving and experiencing a paradigm shift. The traditional view of the patient – health care provider relationship is undergoing significant changes. Long standing patterns of interaction between patients and health care providers have been paternalistic or hierarchical; essentially a physician- or health care provider- centred approach. This hierarchical approach fosters demand rather than self-reliance in patients. Instead of being treated as responsible, autonomous adults capable of making informed decisions, patients have been treated like children who require guidance and reassurance regarding their health and wellness. Paternalism is recognized to create passivity in patients and dependence on health care providers, which in turn decreases their confidence and ability to cope with their health concerns (Auerbach, 2001; Coulter, 2002). The health care system is moving to an egalitarian approach; researchers (Feeley & Gottlieb, 2004; Sullivan, 1998) have suggested that the rise in health promotion and changes in health care delivery processes have been significant drivers of this paradigm shift. These changes have resulted in the need to educate patients in appropriate use of health care services leading to a more patient centred approach (Hibbard, 2004; Sullivan, 1998).

Moving Away from the Medical Model

The distinction between health and disease has never been clear; and societies have tried to find ways to categorize these concepts (Engel, 1977). Medicine as discipline, evolved as a response to the need to identify diseases, providing corrective measures. As taxonomies were developed and physicians started applying the scientific methods, in an effort to understand and treat disease, the 'biomedical model' of medicine evolved; a concept of illness that excludes psychological and social factors. It includes only biological factors to understand a person's medical illness or disorder (Engel, 1977; MediLexicon, 2011). The biomedical model requires that diseases be dealt with as an independent entity from social behaviour, with the goal of treatment being the correction of the biological or physiological 'malfunction' leading to a cure of the disease. Recognizing the need to address the psycho-social aspects of illness, without sacrificing the advantages of the biomedical model, Engel suggested a new model; a "bio psychosocial" approach. He suggested that this would provide practitioners with a basis to understand the determinants of disease and arrive at treatments taking into account the social context of the patient.

David and Holloway (2005) noted that the biopsychosocial model has not been widely accepted, and Biderman, Yeheskel, &Herman (2005) suggest that although the biopsychosocial model has been put forth as the ideal, physicians have not been trained to apply it. Joseph Herman (1989) blamed the slow uptake on the fact that the model is difficult to teach and apply in a clinical setting. Epstein and Borrell-Carrio (2005) and McLaren (1998) ask whether Engel's approach is more aptly described as a vision, a theory, a philosophy or a clinical method. They also suggest that there is a missing link between the intent and the clinical reality; perhaps taking a biopsychosocial approach is more appropriately a process rather than an outcome.

Patient Involvement in Health Care

The involvement of patients in the planning and delivery of health care services at both the individual and systemic level, is another significant shift in the health care system; “the active patient concept is part of a dialectic that has waxed and waned for two centuries, with broader societal interests in autonomy, self-direction, and personal responsibility” (Roberts,1999 p83).

Prior to 1900 many people were wary of the medical profession and as a result the ill were tended by their families. After the release of the Flexner Report (1910), medicine was widely recognized as a scientific profession. As a result, and together with early scientific and technological advancements, people came to rely on physicians as the expert from whom they sought advice for problems that were once managed by lay people. As Steele and colleagues stated “by the 1920’s, the discovery of various vaccines, sera and medications… cemented physicians’ power and authority. For the next twenty to forty years doctors enjoyed unparalleled dominance, medical authority was seldom questioned, and patient acquiescence was assumed” (cited in Roberts, 1999 p. 83). This authority was exposed at its extreme during the Nuremberg trials and subsequently, the doctrine of informed consent was drafted; patients were to receive adequate information about treatment. This was the impetus for the development of patients’ bills of rights.

A number of countries (New Zealand, the United Kingdom, Australia, and Norway) have introduced patients' bills of rights and responsibilities or patient charters; some legislated; others as non-binding policies. These initiatives often provide for collective rights such as equal access to health care, as well as individual rights that pertain to the relationship between patients and health care providers or institutions. Examples of individual rights include: giving consent to treatment, participating in health care decisions, receiving information about treatment options and medical procedures, being assured of privacy and confidentiality, receiving dignified and respectful patient treatment, and having a complaint investigation and resolution process.

A 2001 paper (Flood & Epps) noted that a patient bill of rights could improve patients' ability to deal with health care providers. Smith (2002) presents a comparative overview of the patient bill of rights in Canada, which is less developed than in a number of other countries. Only since the late 1990's, have proposals to create such bills been discussed. To date, the majority of Canadian proposals for patients' bills of rights have focused on certain collective and individual rights in relation to the provision of health care services. Collective rights are those broad principles that relate to the societal obligation to make access to health care available for all Canadians. Individual rights refer to the application of the health care system to the individual patient or consumer what people are entitled to and can expect when they interact with health care services and professionals. In Canada, these rights include access to information, expectations of privacy and confidentiality as well as the requirement for consent to treatment. In addition to outlining specific patients' rights, the bill lists three health care responsibilities *of patients*:

- provide health professionals with full and accurate information relating to their health and the public health services they have received;
- cooperate with health professionals and to either follow their advice or indicate when they have not done so; and
- 'exercise due economy' in using health services.

Patients' bills of rights may well be part of the future landscape of the Canadian health care system. Whether developed through legislation or as statements of government policy, they can serve as an important tool for recognizing patients' rights, defining health care objectives, and emphasizing the complementary nature of the rights and responsibilities of patients and health care providers.

Regardless of the process, many policy makers and health care administrators have agreed that it is important to move patients toward being more active in their own health care delivery which in turn should support improved quality, system efficiency and health outcomes for patients. Crawford, Rutter, Maley, Weaver, Bhui et al (2002) conducted a systematic review of the effect of involving patients in the planning and development of health care systems and services. They found 337 articles about involving patients in planning and health care but excluded 294 for not adequately describing the nature of the involvement. The remaining 42 articles, published between 1966 and 2000, described the involvement of patients as active participants in the monitoring and development of health services for patients. From the review of included papers, they reported that (a) patients appreciated being involved and reported that their self-esteem improved as a result of their involvement; (b) staff involved in the initiatives found the programs as rewarding, (c) one of the most commonly reported affects was the production of new or improved sources of information for patients and (d) that new services were developed as a result of requests by patients (including advocacy, complementary medicine, and crisis services). The most significant finding of this study however, was that although involving patients in the planning and delivering of health care programs was recommended, limited information was available about the effects of involving patients. Crawford et al, cautions that the absence of evidence should not be mistaken for an absence of effect; there is a need for a better evidence base to persuade providers to elicit input from patients when making decisions about health programs and services.

Canadians want the health care system to provide timely access to high quality sustainable services. Agreeing that reform is necessary, the public has supported new public investments targeted to achieve this goal (Health Canada, 2003; Mendohlson, 2002). In September 2000, the Provincial First Ministers signed an accord to ensure that all Canadians have timely access to health care services; that health care services available are effective, patient centred and safe, and that the health care systems is affordable and sustainable. This required a commitment to health system renewal and the First Ministers agreed upon a vision, a set of principles and a commitment to a ten year action plan. As the first stage, the federal and provincial/territorial governments commissioned a number of task forces and studies that reflected the views of Canadians.

In 2002, Roy Romanow, the former premier of Saskatchewan, was commissioned to engage in discussions with Canadians regarding the future of Canada's health care system, and to recommend policies and measures necessary to ensure the long term sustainability of a universally accessible, publicly funded health system. Commissioner Romanow's report: *Commission on the Future of Health Care in Canada: Building on Values,* states that "Canada is a diverse country, and that diversity should be reflected in our health care system"… and that "the care we deliver should match the needs of different groups of Canadians, from men and women, to new Canadians, to visible minorities, people with disabilities and others" (p. 31).

In his proposed Health Covenant for Canadians, Commissioner Romanow reminded readers that Canada was founded on the principles of co-operation, perseverance and mutual respect; characteristics for which Canadians continue to be recognized throughout the world; presenting patient centred care, a respectful ethical system and public input as being essential in shaping our health care system. Additionally, the report states that Canadians are entitled to make informed decisions regarding their personal care, and to receive all information and medical documentation related to them, while respecting the judgment and expertise of health providers. Health care providers have a responsibility to (a) ensure that the health care system places the highest priority on the concerns and health needs of patients and (b) to provide information to patients on treatments, related services, and available alternatives, while taking into account the preferences of their patients. By doing this – the necessary relationship for patient centred care can be developed. If patients are to be simultaneously active members of the team and recipients of the team care, it is necessary to determine the best way to engage patients as active collaborators in the planning and utilization of health care services and programs, if they want to participate at all.

The new Canadian emphasis on providing information to patients is similar to the German concept - the “modern patient”. The modern patient, sometimes thought of as the ideal ‘patient’, is built upon the ideology of the ‘modern citizen’; an individual with self-determination, autonomy, self-responsibility and freedom of choice. In her article: *The modern patient – threat or promise?* Dieterich (2007) states that for the modern patient, having influence and participation in the health care system is a basic right – and in order for this to happen, modern patients must be afforded the opportunity to participate in a respectful partnership with their health care providers.

Although there is a significant amount of literature specific to patient centredness (Schneider, Wensing, Quinzler, Bieber and Szecsenyi, 2007; Lancaster, 1982; Waterworth&Luker, 1990), there is a paucity of information reflecting the stated interests, beliefs and needs of the patients themselves. Little, Everitt, Williamson, Warner, Moore, Gould et al (2001) recognizing this, emphasized that the patient is the best place to collect this information. Most of the available literature emphasizes the organizational, or clinician/administrator perspective and does not account for differences in patients’ expectations, experiences and needs. Available research tends to focus on the influence on patient expectations on physician prescribing and participation in decision making (Britten, Ikoumunne&Boulton 2002; Gleason, Harper, Eggley et al, 2009; Goldzweig et al, 2010; Schwartz, Soumerai, &Avorn, 1989).

Janzen, Silvius, Jacobs, Slaughter, Dalziel & Drummond (2007) developed a conceptual model focused on people’s health and health care expectations. A health expectation is the prediction of consequences of health related phenomenon which can be focused on treatments, interventions as well as health status, and presence or absence of diseases. Health expectations are socially and culturally contingent; governed by one's perceptions of the social world. In health care, it is more important to understand the process by which an expectation is formed and how it may relate to prior attitudes and behaviour as well as to future ones. Angela Coulter, editor of *Health Expectations*, states that public and patient expectations of health care services and providers is often seen as problematic by clinicians and policy makers but that "understanding how expectations are formed and how they affect health attitudes, behaviours and outcome assessment is crucial for consultation behaviours, health related lifestyles, patient assessed outcomes, patient satisfaction, patients' preferences, informed choice, shared decision making self care and self management," (2007; p1). If the most effective and acceptable health services are those that realize the expectations of the users, with increasing social expectations of health care services, this is an important area of study.

Research Purpose and Objectives

There is a paucity of information reflecting the beliefs, expectations and needs of the patient themselves from their own perspectives. Van Dulmen (2003) stated that "the meanings and effects of patient centredness may perhaps only be assessable by inquiring about each patient's individual needs, expectations and preferred level of activation and decision participation prior to entering a medical treatment and, subsequently, by evaluating visit and health outcomes in relation to these a priori assessed measures" (p.196). Little et al (2001) also emphasized that the patient is the best source from which to collect this information; unfortunately most of the available literature is from the clinician/administrator perspectives and does not account for the differences in patients' experiences and needs.

Patient experience is an aspect of patient centeredness, one of six health care quality aims proposed by the Institute of Medicine (2001) which seeks to understand what patients did or did not experience in their interactions with health care providers and the health care system. It has been well documented that a good patient experience has a positive relationship to other aspects of care quality (Brown, Roseman, Shaller & Edgman-Levitan, 2010). Therefore, measuring patient experience is essential if policy makers want to understand and improve the quality of care for patients.

My research was designed to address the need for data on the effect of beliefs, attitudes and experiences on people's engagement or behaviour as a patient from their own perspectives. Specifically the objectives of this study were:

- To gain insight into the separate experiences of being a patient in the rehabilitation context and a primary health care setting.
- To elucidate patients' common beliefs, attitudes and expectations regarding the experiences and understand the influence of these factors on patient behaviour.
- To identify similarities and differences between the experiences of being a patient in different clinical environments, assessing if patient beliefs, attitudes and behaviour is consistent from one health care context to another.

CHAPTER 2

Literature Review

"In grounded theory studies, case studies and phenomenological studies, literature will serve less to set the stage for the study" Creswell (2003) (p. 30); rather, the literature becomes an aid at the conclusion of the study, once patterns and categories have been identified in the study data. Reviewing the literature at the end of the qualitative study is recommended, as it uses the literature inductively, ensuring the researcher has learned from the participants rather than answering questions from their own perspective. Interpretive phenomenologists, however, believe that it is impossible to ignore prior knowledge and assumptions about a topic. Rather this knowledge will help to guide the research questions and therefore a review of some literature will help serve as the foundation for the research design. My study is grounded in hermeneutic phenomenology, and therefore an initial literature review provided a foundation for the research design; additional literature was reviewed at the conclusion of the study grounding the results in the literature.

The majority of this chapter is a presentation of relevant literature on collaborative care, patient and patient centred health care. The remainder of the chapter focuses on several concepts relevant to my study and the chapter ends with a discussion of the Theory of Planned Behaviour as a theoretical framework for the study.

Literature regarding patient engagement and participation in health care is contained within several inter-related concepts or clinical applications: (a) collaborative care, and (b) patient centred health care, centred on the principles of:

i) The notion of patient empowerment: within this conceptualization, patient centred health care is both a way of viewing health and illness that affects a person's general well-being and an attempt to empower the patient by expanding his or her contribution to the consultation (May and Mead, 1999).

ii) The premise that the patients' knowledge will guide the encounter: patient centred health care is predicated on an understanding of the patient as a unique human being and refers to a style of doctor-patient encounter characterized by responsiveness to patient needs and preferences, using the patient's knowledge to guide actively the interaction and information giving and shared decision making (Mead and Bower, 2000; Laine and Davidoff, 1996; Stewart, 2001); or

iii) collaboration between the patient and the health care providers (Brown, 2004): patient and family centered care places an emphasis on collaborating with patients and families of all ages, at all levels of care, and in all health care settings (IHI-FCC, 2006)

Overall, the core aspects of collaborative patient centred practice are group oriented (health care providers) interactions designed "to promote the active participation of several health care disciplines and professions. It enhances patient, family, and community centred goals and values, provides mechanisms for continuous communication among health care providers, optimizes staff participation in clinical decision making (within and across disciplines), and fosters respect for the contributions of all providers" (Oandasan, 2004). Successful health care often relies on collaboration, requiring a variety of health care providers to interact with patients, their families and the community. The patient is at the centre of the interactions, yet being a full-fledged partner in the collaboration (Health Canada).

Collaborative Care

Collaborative care has been identified as a potential model for Canadian health care renewal, particularly in primary health care services (Reeves, 2006). In collaborative care, health care providers work together and with the patient to ensure comprehensive and coordinated care, as the needs of patients often extend beyond a single discipline. For health care providers to meet the full scope of patients' needs, a patient centred service requiring interprofessional collaborative care is often required (Commission on the Future of Health Care in Canada, 2002; Freeth, 2001; Health Council of Canada, 2005).

The focus of a collaborative relationship is for one individual to help the other to grow and develop (Mayeroff, 1972) supporting a person's efforts to take control over their own health. Both participants acknowledge the knowledge and expertise of the other, recognizing that it is different than theirs and therefore essential. The collaborators respect each other and benefit from the relationship as it allows them to learn, gain and grow from the relationship (Feeley & Gottlieb, 2004; Halstead, Wagner, Margo, & Ferkol, 2002). Patients and professionals entering into collaborative partnerships should be flexible, respecting the other's contributions and expertise, and be willing to share information. (Potvin, Cargo, McComber, Delormier, & Macaulay, 2003).

Miller, Kessler, Peek and Kallenberg on behalf of the Agency for Healthcare Research and Quality (2011), presented a series of papers supporting a research agenda in collaborative care. They noted during discussions regarding the development of a research agenda, a persistent lack of clarity regarding the term ‘collaborative care’. A host of terms have been used to describe collaborative care including “integrated care,” “shared care,” “co-located care,” “primary care behavioral health,” “integrated primary care”. These terms and many others have developed from different clinical areas and different disciplinary perspectives almost as though they are “dialects of a more general language loosely understood by insiders or “native speakers” in that field” (p.26). Although conceptual confusion is normal when a field of inquiry and practice is evolving, the individuals (health care providers and patients/family member) engaged in collaborative care require a lexicon. The inconsistency in terminology is not just a theoretical concern - it has very practical implications; clinicians, policy makers and patients need to have a clear and common conceptualization of the approach if they are to advocate and redesign health care services accordingly.

Way, Jones, and Baskerville (2001) defined collaborative care as “an interprofessional process of communication and decision-making that enables the separate and shared knowledge and skills of care providers to synergistically influence the client/patient care provided” (Appendix Z, p.2). Feeley and Gottlieb (2004) describe the model of collaborative practice as based on a philosophy of caring and a set of beliefs that values a nurturing approach including: (a) the sharing of power between partners, (b) the pursuit of goals that are the result of discussion and negotiation, and (c) active participation and involvement of the partners in the process of working together.

Oandasan, Baker, Barker, Bosco, D’Amour et al. (2006) state that collaborative practice is inherently patient centred, as it promotes the participation of many disciplines, interacting to enhance patient goals while encouraging patient participation in the care process. Oandasan et al (2004) explains the connection between the terms 'patient centred health care' and 'collaborative care':

> "Although available evidence to date is limited, it is mounting: collaborative practice does enhance patient outcomes. Patients are thus at the center of collaborative care since they are the very reason behind the interdependency of the professionals. This explains the terminology of "Collaborative Practice - Patient-Centred Care Practice" … patients are simultaneously active members of the teams and recipients of the team care".

A Shift to Patient Centredness

In *The Commission on the Future of Health Care in Canada,* Commissioner Romanow reminded readers that Canada was founded on the principles of co-operation, perseverance and mutual respect; characteristics for which Canadians continue to be recognized throughout the world. Commissioner Romanow presented patient centred care, a respectful ethical system and public input as being necessary in shaping our health care system. In his report, these terms and concepts were defined as follows:

- *Patient-centred Care***:** The direction of our health care system must be shaped around health needs of individual patients, their families and communities.
- *A Respectful, Ethical System*: Our health care system must be based on the highest ethical standards, and must recognize the worth and dignity of the whole person including biological, emotional, physical, psychological, social and spiritual needs.

- *Public Input*: Public participation is important to ensuring a viable, responsive and effective health care system.

Additionally, the report states that Canadians are entitled to make informed decisions about their care and to receive all information and medical documentation related to them, while respecting the judgment and expertise of health providers. Health care providers have a responsibility to ensure that the health care system places the highest priority on the concerns and health needs of patients and to provide information to patients on treatments, related services, and available alternatives, while taking into account the preferences of their patients. By doing this – the necessary relationship for patient centred care can be developed and take place.

The recent emphasis on egalitarianism and patient centredness specifically, implies that this is a new phenomenon; however, patient centredness is not a new concept. Dr. Michael Balint, a psychoanalysist in the United States was the first to explore the patient–doctor relationship specific to general practice in his seminal 1957 work, *The doctor, his patient, and the illness.* Balint's work engaged general practice physicians in explorations regarding the nature of the doctor–patient relationship and the impact this interaction could have on diagnosis, treatment, and subsequently patient outcomes. Michael and Edith Balint (his wife and collaborator) are known for their contribution to the development of "whole-person medicine", through their original research, seminars and training groups, as well as their prolific writings (Lau, 1987). It is particularly noteworthy that Dr. Balint and his colleagues were the first to introduce the term patient centred medicine in 1969 and thereafter the term patient centred care was presented by the Picker Institute in 1988 (Conway, et al 2006).

Britain was the first formal systematic driver of the patient centred concept. In 2000, the British government made improving patients' experiences in health care the central theme for its plan for the National Health Service (NHS) (Coulter, 2002). This commitment on the part of policy makers and administrators was to ensure that health care services were shaped around the needs and preferences of individual patients, their families and their carers, treating them as individuals. This commitment solidified the movement toward patient centredness.

At the same time, The Bristol Royal Infirmary Inquiry was conducting an examination of the higher than average mortality rates on a pediatric cardiac surgical unit. The 530 page report containing 198 recommendations was produced by Professor Ian Kennedy. A key recommendation was the "the notion of partnership between the healthcare professional and the patient whereby the patient and professional meet as equals with different expertise, must be adopted by health care professionals in all parts of the NHS, including healthcare professionals in hospitals". (Bristol Royal Infirmary Inquiry, 2001).Further recommendations urged doctors and health professionals to:

- Keep patients informed and involved in treatment decisions
- Improve communication with patients including the ability to engage with patients on an emotional level, listen and assess how much information a patient wants to know, conveying information with clarity and sympathy.
- Provide patients with counseling and support and elicit feedback from patient listening to their views

Although not meant to be a follow up assessment of the progress of the NHS, an international study by the Commonwealth Fund of New York (2004) surveyed 8672 patients selected randomly across Australia, Canada, New Zealand, the United Kingdom and the United States. The survey focused on the patient's experiences in primary health care. They found that although British patients were more positive about their health care systems than other patients in other countries, patient centred health care was not the norm. The United Kingdom also scored much lower on aspects related to shared decision making, information about medication and preventative strategies as well as management of chronic diseases (Coulter and Rozansky, 2004).

The terms 'patient centred health care' and 'patient centredness', have become common in the literature (Brown, 2004; Kinmonth et al, 1998; Mead and Bower, 2000; Morris et al, 2007)but are a poorly understood concept in medical practice and education(Stewart, 2001; Tsimtsou, Kerasidou, Efstathiou, Papaharitou, Hatzimouratidis, &Hatzichristou, 2007). There have been many attempts to define the concept of patient centred health care and identify the attributes of patient centred care (Sidani, 2008; Stewart, 2001); however there is a lack of consistency between authors, policy makers and health care administrators regarding terminology. Stewart (2001) noted it may be easier to identify what patient centred care is not: patient centred care is not technology centred, disease oriented, physician centric, or hospital focused.

Hughes, Bamford and May (2008) conducted a literature review regarding the inclusion of 'centredness' in the health and social literature. Their review, found that 'centredness' at a conceptual level, contained ten central themes which formed the basis of five types of centredness:

i) *Client Centred:* Focuses on three ‘necessary and sufficient’ conditions for a therapeutic relationship – empathetic understanding, unconditional positive regard and therapeutic genuineness.

ii) *Family Centred*: Primarily used in paediatrics – focuses on mutually beneficial interactions between clinicians, family and patients.

iii) *Patient Centred*: Stemming from the work in general practice and described as understanding the patient as a unique person – has focused on fostering a joint understanding of illness and its management

iv) *Person Centred*: The term is used primarily to emphasize the importance of communication and the relationship between clinician and individual.

v) *Relationship Centred*: Affirms the centrality of the relationship in health care, suggesting that patient centred is not inclusive enough

Hughes et al, noted that although there are several types of centredness, which may affect the way health care professionals work, there are no significant differences between the types at the conceptual level. The different types may however “represent a corrective to the more blinkered approach to how professionals should interrelate with their patients or clients” (p.461). Most importantly, they noted that that the different types of centredness are essential in the different contexts they are implemented in, and that the attention to centredness demonstrates a move from the biomedical model to a broader view of the people accessing health care services.

Patient Centred Health Care as Conceptual Framework

Mead and Bower (2000) present patient centredness as a conceptual framework. They note that patient centredness evolved from the limitations of the biomedical model and encompasses five key elements; i) biopsychosocial perspective, ii) the patient as person, iii) sharing power and responsibility, iv) therapeutic alliance, and v) doctor as person. These five elements are the areas of difference from the medical model, and although they have their origins in the social and behavioural sciences, much of the development of patient centredness in the health care context has evolved from general practice (primary health care).

Patient Centred Health Care as Clinical Approach

As one of the Health Canada commissioned papers for background information regarding Interprofessional Education for Collaborative Patient Centred Practice, Brown (2004) provided a discussion regarding a previously developed, patient centred clinical method and approach (Stewart et al, 1995). This clinical method was identified as a central aspect of the national IECPCP initiative, as the patient is at the centre of the initiative:

> “Patients want patient-centred care which: (a) explores the patients' main reason for the visit, concerns, and need for information; (b) seeks an integrated understanding of the patients' world - that is, their whole person, emotional needs, and life issues; (c) finds common ground on what the problem is and mutually agrees on management; (d) enhances prevention and health promotion; and (e) enhances the continuing relationship between the patient and the doctor" (Stewart, 2001, p 445).

The first component of the clinical method involves the assessment of both disease and illness experiences. It is important to note that effective patient centred care focuses equally on the personal *experiences* of illness as much as the disease. The second component is the ability to integrate the individual's experience of disease and illness as it relates to the whole individual including personality, individual's life experiences, life cycle, family history, family dynamics and spirituality. Other work has indicated that appreciation and respect for the person's culture and health care practices, working as equal partners and negotiating a plan of care that takes these beliefs into account have been reported to be the significant features of successful patient centred initiatives (Potvin, Cargo, McComber, Delormier, & Macaulay, 2003).

"Finding common ground" between the patient and the health care provider is the third component; requiring open communication and identification of the roles that each individual (patient and provider) will assume during the interaction. The fourth component discusses health promotion and disease prevention. Specifically focused on the interactions between the patient and the health care provider, the emphasis is on the determinants of health for the individual, the person's potential for health and their present/potential disease, as well as their experiences of health and illness. This is all examined in the context of the individual and their relationship with their health care provider. The fifth component of the method focuses specifically on the relationship between the patient and their health practitioner and the significance of the relationship. Brown describes this relationship as the foundation for the patient centred clinical method. The sixth and final component discusses pragmatics – the need to be realistic when trying to implement patient centred clinical practices.

Shared decision making has been proposed as the ideal model of communication between patients and physicians (Schneider et al; 2006) as it is the middle ground between paternalism and informed choice. This model requires that treatment decisions are based on the provision of evidence based information and the clarification of patient preferences. Stewart (1995) conducted a review of articles published between 1983 and 1993 to determine if physicians and patient communication regarding treatments had any influence on patient health outcomes. Of the 21 studies that met criteria for review – 16 reported positive results that the quality of communication between patient and physician influenced patient health outcomes.

Charles et al. (1997, 1999) proposed a model of shared decision making that was originally designed for acute care settings but has subsequently been refined for application in both primary health care and the management of chronic diseases. The model focuses on doctor–patient communication and how selection of a treatment is determined from a list of potential treatments. Of particular noteworthiness is the level of partnership and joint initiative undertaken by both the patient and the physician at all levels of the decision making process, culminating in a true joint decision.

What is not clear however is whether patients always want to be involved in decision making. This may vary depending on the level of impact the decision will have on health outcomes or if the decision is based on uncertainty or lack of clinical knowledge (Lancaster, 1982; Waterworth & Luker, 1990). A study conducted in primary care offices assessed patient preferences for involvement and found that younger age, female sex, higher economic status, better health status and being single were associated with higher preferences for involvement in decisions (Schneider et al, 2006.). Individuals with minor complaints had more preference for involvement than those with chronic or severe diseases. In another study, older adults with more than one chronic condition were more likely to feel enabled if they had been actively involved in primary care consultation (Wensing, Wetzels, Hermsen and Baker; 2007).

A study by Schneider, Wensing, Quinzler, Bieber and Szecsenyi (2007) attempted to assess the impact of preference for involvement in treatment decisions with patient adherence to asthma medications. Although patients' participation preference was quite low overall, patients with a higher level of interest in participating in treatment decisions reported lower adherence rates and demonstrated a greater desire for self-management techniques. Schneider et al noted that although these results might indicate that patients want to actively participate in treatment decisions, it may also suggest that patients would like to decide whether or not they use medications at all. Further work exploring patient preferences for treatment decisions and how these relate to health actions (self-care) is needed.

Measuring Patient Centredness

Coulter and Ellins (2007) conducted a systematic review and concluded that it was difficult to select evaluative criteria for patient centred initiatives, as most studies used different outcomes measures, making it difficult to compare study results. Based on their review, most of the included studies showed positive results in the following areas:

i) Improved health literacy: A patient's ability to obtain process and understand health information provided to them by health care providers is related to health status, utilization patterns and medication adherence. Information (paper and electronic formats), education and support services are all interventions that can help to improve health literacy levels, although much work is still needed.

ii) Improved clinical decision making, shared decision making, or concordant relationships. Allowing treatment decisions to be guided by patient preferences, which are based on the sharing of information between patient and health care provider.

iii) Improved self-care and self-management: providing patients with education programs and access to their own health records enhances patients' knowledge and sense of control. No evidence however, was provided regarding long term outcomes, cost effectiveness and which types of interventions are most successful.

iv) Improved patient safety: the role of patients in promoting safety has only recently been acknowledged and limited research exists. Patient safety will only be maximized however if the patient involvement is recognized as being essential to the process.

Mead and Bower (2000) sought to understand the relationship between the concept of patient centredness and the measurement of the concept. They conducted a review of quantified measurements of patient centredness and found that studies employed two methodological approaches, utilizing either physician self-reports or observational assessments of the consultation process. Only quantitative studies were reviewed as the focus was on measuring patient centredness that may be part of initiatives for professional evaluation and that monitor quality. Most of the studies they reviewed conceptualized patient centredness as a clinical approach evident by the number of studies utilizing an observational approach. Several studies (Winfield, Murrell, Clifford and Farmer, 1996; Langewitz, Phillipp, Kiss, &Wossmer, 1998) reported positive associations with patient satisfaction after the consultation; however Mead and Bower noted that the pattern of findings was inconsistent and that the discrepancies between patient perceptions and the measures of patient centredness may reflect a methodological issue. It is known that patient preferences for consultation styles vary greatly; often based on age, gender, social class and presenting concern. Winefield, Murrell, Clifford & Farmer (1996) suggested that future work should examine what factors influence the goal setting and behaviours of the participants in the clinical consultation, rather than focusing on the measurement and validity of the instruments.

Zwarenstein, Reeves, Russell, Kaszchuk, Conn, Miller et al (2007), building on evidence that interprofessional collaboration can affect the delivery of health care services, sought to determine the effect of practice-based interprofessional collaboration interventions on patient satisfaction and effectiveness or efficacy of health care. They found only five studies that met their inclusion criteria; the authors determined that due to the small number of studies, it was difficult to determine the key elements of interprofessional collaboration and the associated effectiveness.

Lewin, Skea, Entwistle, Zwarenstein& Dick (2001) noting that patient centred health care is increasingly advocated by health care providers and consumers alike, conducted a systematic review to determine the effect of interventions directed at health care providers in order to promote patient centered health care approaches. They found great variety in the health concerns on which the interventions focused and within the interventions themselves; which were primarily focused on general practitioners in community or outpatient settings. Evidence suggested that interventions may lead to significant increases in the patient centredness of clinical care and some improvement in patient satisfaction. There was limited evidence on the effect of the interventions on health status or patient behaviour.

Barriers and Dilemmas in Patient Centredness

The lack of consensus regarding the terms used to describe actively involving patients in the provision of their own health care services is significant. Although each conceptualization is centred on the active engagement of the patient; not all patients want or are able to actively engage in their health care delivery. This section will outlines some of the barriers and dilemmas in patient centredness.

The Institute for Family Centred Care and the Institute for Healthcare Improvement collaborated on the ‘Partnering with Patients and Families to Design a Patient and Family Centred Health Care System’ initiative (2006) identifying three primary areas that barriers to collaboration fall within: attitudinal, educational and organizational. Attitudinal barriers include fear, preconceived ideas and the need for evidence. Many clinicians have reported fears that patients suggestions and demands will be unreasonable, or that patients may compromise confidentiality. Other fears include the amount of time and resources required for patient centred practice. An unfortunate preconception is that many patients are too poor, too violent, too cognitively impaired, or too uneducated to be involved in their own health care (Coulter, 2002). Some clinicians believe that patient centred care is unnecessary; they believe that their own clinical roles are sufficient for knowing what is best for the patient, or that satisfaction surveys is a sufficient way to collect information and feedback from patients. The final attitudinal barrier is represented by the clinician or administrator who insists: “show me” substantial evidence regarding the benefits and utility of the patient centred method. This reliance on evidence is problematic as there is insufficient information regarding the benefits of patient centredness, and no cogent evidence.

Organizations must be willing and able to provide training and support to clinicians as well as patient and family for this barrier to be overcome. Patients who are to be treated as co-producers need to be given the tools for the job. When patients are provided with unbiased, evidence based information about treatment options, likely outcomes and self-care, they usually make rational choices that are often more conservative and involve less risk than their doctors would choose. For example, American patients given full information about the pros and cons of screening for prostate specific antigen to detect prostate cancer are less likely to undergo the test than those who were not fully informed. Appropriate and cost effective use of health services could be encouraged by investing in tools to help patients make evidence based decision (Coulter, 2002). Coulter identifies several ways that patients can be empowered to participate in their own health care:

- recognize patients’ expertise, values and preferences
- offer informed choice, not passive consent
- training in shared decision making
- evidence based decision aids for patients
- public education on interpreting clinical evidence
- patient access to electronic health records

Organizational barriers typically relate to the culture within which patient centred initiatives are expected to occur. Organizational buy in must occur at all levels.

Top down leadership for patient centred initiatives must be cognizant of building commitment at all levels and ensuring buy in from all those affiliated with the program. Bottom up initiatives require leadership and adequate support (including resources) to build programs.

Gagliardi, Lemieux-Charles, Brown, Sullivan and Goel (2008) conducted an exploratory study to determine what barriers existed to patient involvement in higher level health service planning and evaluation. There was variable patient interest in participating, health professionals preferred patients to take a more consultative role in the planning process, and there was a lack of knowledge and awareness regarding the methods of patient involvement. Many administrators believe that assessing satisfaction is a sufficient method of including patients. However, it is not enough to ask patients about their level of satisfaction – such tools are often conceptually flawed and measure items of administrative importance rather than topics important to patients (Sitzia and Wood, 1997). The NHS has adopted a more focused approach and hope that better data collection approaches will engage health care providers to act on results to improve quality of care (Coulter, 2002). The work of Gagliardi et al supports the NHS approach but cautions that health care professionals do not feel that patients should have the final say on performance indicators and that further education of both administrators and patients regarding this process is required.

Despite the evidence that patient centred health care can lead to improved communication and patient involvement in their care, the patient centred approach may not be appropriate for all patients at all times. Not all patients want to be engaged in patient centred care. Swenson, Zettler, White, Delaney, Ruston, et al, (2004) assessed which style of communication patients preferred: patient or doctor centred. They found that older patients and those with lower levels of education preferred the physician centred approach. Coulter (1999) also found that older patients may be more comfortable and prefer a more paternalistic approach to their health care. Patient centredness was associated with greater patient satisfaction when they present in primary care with a psychosocial concern – however those individuals with very straightforward or very complex concerns were less satisfied with a patient centred approach (Winefield et al, 1995). Individuals requesting prescriptions may prefer a directive approach from their primary care physician (Jones, 2003). Other patients, may want information about their health concerns but do not wish to be engaged in their own care all the time. Degner et al (1997) conducting a study of people with cancer, found that one third did not wish to make treatment decisions, deferring to their physician.

Not all decision can be made in collaboration; in some situations, the evidence clearly points to a treatment and the physician is likely to suggest a course of action. Shared decision making works when there may be a suite of treatment options that are equally acceptable (Elwyn, Edwards, Kinnersley, Groll, 2000). The opposite situation may also be the case, where the physician attempts to dissuade patients from undergoing unproven treatments or therapies (Jansen, Kievit, Nooij de HaesOverpelt van Sloten et al, 2001). In this instance as well, the physician will not be engaged in shared decision making, rather exerting their professional expertise.

Patient Expectations

Studies have outlined a variety of methods for assessing patients' expectations of care. There is however, a lack of available information on the advantages and disadvantages of the different approaches (Kravitz, Callahan, Azari, Antonius & Lewis, 1997). Kravitz (2001) noted that meeting patients' expectations will foster greater satisfaction with the clinical care, support adherence to medical advice, and reduce 'doctor shopping'. Patient expectations are culturally, contextually contingent and are affected by socioeconomic status; patient satisfaction declines modestly as patient's income rises (Hall & Dornan, 1990). Patient expectations can influence the clinicians' behaviour both objectively and subjectively (Britten, Ukoumunne&Boulton, 2002), and have been shown to affect the likelihood for receiving treatments (Haggerty, Tudiver, Brown, Herbert, Ciampi&Guibert, 2005)

Jansen et al (2006) developed a conceptual model, focused on people's health and health care expectations; a health expectation being the ability to predict the consequences of phenomenon on the psychological or physiological condition of the body. Health expectations can be focused on treatments, intervention, as well as health status, presence or absence of diseases. Health expectations are socially and culturally contingent (governed by one's perceptions of the social world). The authors noted that it is important to understand the process by which an expectation is formed and how it may relate to prior attitudes and behaviour as well as to future ones.

Angela Coulter, states that public and patient expectations of health care services and providers is often seen as problematic but that "understanding how expectations are formed and how they affect health attitudes, behaviours and outcome assessment is crucial for consultation behaviours, health related lifestyles, patient assessed outcomes, patient satisfaction, patients' preferences, informed choice, shared decision making self-care and self-management," (2007; p1).

Self-Efficacy and Locus of Control

The concepts of self-efficacy and locus of control are particularly relevant to the discussion of patient experience and patient centredness. Self-efficacy, as described by Bandura (1977; 1994) is a person's beliefs about their ability to produce an effect or achieve an outcome; affecting all aspects of people lives, how they feel, think, motivate themselves and behave. Patients with a strong sense of self efficacy will approach difficult situations as challenges to be mastered, rather than shying away. People with high efficacy believe they can exercise control over threatening situations; failures are attributed to insufficient efforts, inadequate knowledge or an indication that additional skills were required. People with high efficacy are less vulnerable to stress and depression, and tend to achieve personal accomplishments.

Bandura (1994) identifies four primary sources for the development of self-efficacy beliefs. The first is through mastery experiences; achieving success builds a sense of efficacy. The second method is through observing other's experiences. Positive role modeling, by individuals perceived to be similar, can raise an individual's perception that they too have the capabilities required to achieve the desired outcome. If the models are perceived as being very different from themselves, self-efficacy is not influenced by their behaviour and subsequent results. Social persuasion is the third way in which people develop self-efficacy beliefs. Verbal encouragement that they possess the capabilities to succeed can propel individuals toward skill development and success; however it should be noted that it is more difficult to build self-efficacy through persuasion that it is to undermine it. The final method comes from the individual's own somatic and emotional responses and by reducing the stress response to the situation.

Positive moods will promote self-efficacy and consequently negative moods diminish it. It is important to note that people with high levels of self-efficacy will view the emotional arousal as an energizing force for their behaviour while individuals with low self-efficacy, will see this energy as a debilitator.

Self-efficacy beliefs help determine how people feel, think, motivate themselves and behave as it relates to their health. Self-efficacy has been demonstrated to influence motivation, and health behaviours, by focusing the goals patients set, as well as determining how much effort people exert in achieving the goals and their resilience when facing a challenge (Dixon, Thornton, Yound, 2007). A study by Lee, Hwang, Hawkins, &Pingree (2008) examined the interplay between emotions and self efficacy. They found that in patients with high health self-efficacy, negative emotions were positively related to the amount of information about their conditions and treatment was sought, whereas people with low health self-efficacy, the negative emotions were negatively related to the amount of information sought. There is a growing body of literature that suggests an optimistic sense of personal efficacy is associated with better health status, and lower costs to the health care system (Cross, March, Lapsley, Byrne, & Brooks, 2006; Sarkar, Fisher,Schillinger, 2006). Bandura notes that the everyday world is “strewn with difficulties… full of impediments, adversities, setbacks, frustration and inequities. People must have a robust sense of personal efficacy to sustain the perseverant effort needed to succeed” (1994; p.76). It is also important to note that perceived self-efficacy changes as we progress through the life course from childhood to old age (Bandura, 1994; Berry & West, 1993). Each of these life stages and the normative changes influence how efficaciously people manage their lives. The competencies required in each life stage changes, and therefore, the nature and scope of self-efficacy also changes.

Locus of control is a personality construct and refers to an individual's perception of the locus of events as determined internally by their own behavior versus external circumstances. This construct is derived from Rotter’s social learning theory (1966) and has received much attention in the area of behavioural research. One of the earliest studies, conducted by Seeman and Evans (1962), found that patients with an internal locus of control asked more questions of their physician, knew more about their conditions, and expressed dissatisfaction with the amount of information they received in comparison to patients with an external locus of control. Wallston and Wallston (1978) conducted a review of the literature to determine if there was any link between locus of control and prediction of health behaviours. They found relevance between the concepts and suggested that scales measuring locus of control may be useful; health educators may want to tailor programs to individuals’ expectancies regarding locus of control. The concept of health locus of control and the assessment instruments have been widely used to help understand and predict a wide range of health behaviours such as adjustment to injury (Waldron et al, 2010); and patient self-management (Sloan, 2009). Other researchers have sought to explore the link between locus of control and patient independence (Hughes, 2004) and how the construct may relate to patient – provider relationships (Brincks et al, 2010). Wallston and Wallston presented the notion of ‘powerful others health locus of control ‘to explain why patients decreased internal locus of control; perceiving a health care provider as being in a position of authority may influence a person’s interactions with their health care providers. Further to this, Brincks et al (2010), found that patients who had high levels of ‘powerful others locus of control’ reported higher levels of trust in their physicians.

McCombs, 1991 suggested that what underlies the internal locus of control is the concept of "self as agent." An individual’s thoughts can control their actions and that when they realize this executive function, people can positively affect their beliefs, motivation, and academic performance. "The self as agent can consciously or unconsciously direct, select, and regulate the use of all knowledge structures and intellectual processes in support of personal goals, intentions, and choices" (p. 6). McCombs asserts that "the degree to which one chooses to be self-determining is a function of one's realization of the source of agency and personal control" (p. 7).

Theory of Planned Behaviour

The theory of planned behavior was first described by IcekAjzen in 1985, and is now one of the most popular models in the social-psychological literature. The theory of planned behaviour (Ajzen, 1988) grew out of previous work done by Ajzen and Fishbein (1980): the Theory of Reasoned Action (TRA). Ajzen (2011) indicates that TRA is a form of the theory of planned behaviour (TPB) as the TPB extends the theory of reasoned action. In TRA, it is assumed that people have control over the behaviour of interest and that they are aware of their capability to perform the behaviour should they choose. TPB added the perceived behavioural control element to address situations where individuals may not perceive that they have the ability to act upon their intentions.

An individual’s actions, when applying the TPB, is influenced by three factors: i) their attitude toward the behavior, (positive or negative evaluation of the behaviour) ii) the subjective norms regarding the behaviour (perceived social pressures to perform/not perform the behaviour) and iii) perceived behavioural control (whether people believe they have the capability to perform the behaviour). These three factors work in combination to form an intention for behaviour - generally, more favourable a person’s attitude and subjective norms, combined with a high degree of behavioural control, should lead to an intention to perform a behavior (Ajzen, 1988). The three predictors as determinants of intention may vary based on population or even behaviour of interest (Ajzen & Gilbert, 2008). When people have a sufficient amount of control over the behaviour, people are expected to fulfill their intentions when the opportunity arises. There is, however, a lack of information about what may facilitate or hinder actual performance of the behaviour in question. Please see figure 1 for a visual representation of the TPB and Table 1 contains a description of each element of the TPB.

Figure 1.
The Theory of Planned Behaviour (adapted from Ajzen)

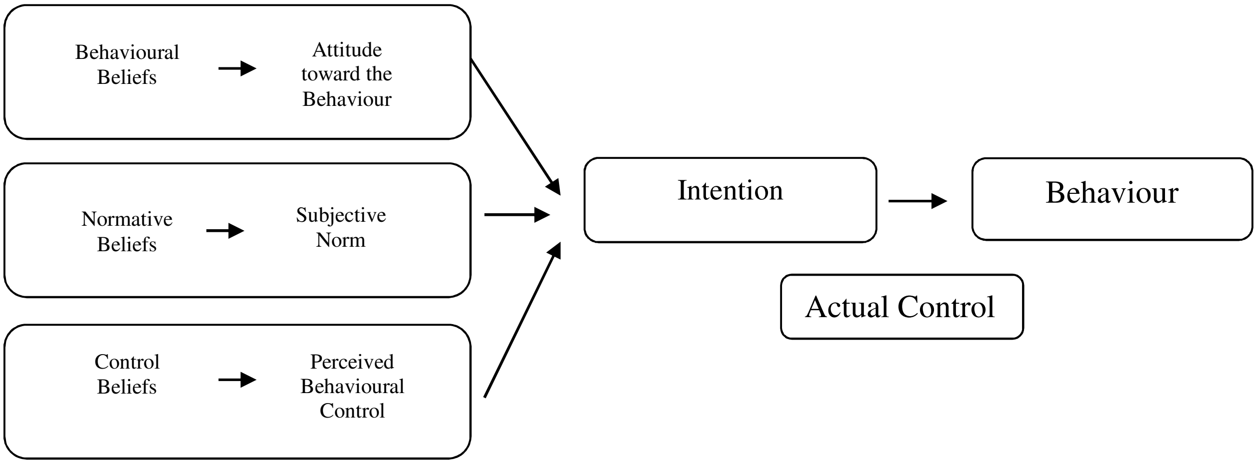


Table 1.

Description of the Elements of the Theory of Planned Behaviour

Element of the Model	Description
Behavioural Beliefs	Describe an individual's beliefs about the consequences of the behaviour linked to outcomes.
Attitude toward the behaviour	The positive or negative evaluation of performance – also whether the performance is positively or negatively values.
Normative Beliefs	The perception about a behaviour as influenced by significant others
Subjective Norms	The social normative pressures regarding the behaviour
Control Beliefs	the perceived presence of factors that may facilitate or impede performance of the behaviour
Perceived Behavioural Control	the perception people have regarding their ability to perform the behaviour
Actual Control	the extent to which the individual has the skills, resources or other pre-requisites to perform a given behaviour
Intention	the indication of readiness to perform a given behaviour
Behaviour	The actual observable response in a given situation

The standard approach to the application of the TPB is quantitative in nature, although Ajzen notes that the part of the methods that requires qualitative research is the identification and coding of accessible behavioural, normative and control beliefs. This was the approach taken for my research. For my study, the TPB was used as a framework guiding the research questions, data collection and analysis and as a lens through which the findings are viewed.

Information was collected from participants regarding their beliefs and attitudes regarding health care globally, and about being a patient specifically. Attitude is the evaluation of a physical entity, an institution, a policy, an abstract concept, or any other aspect of a person's world and there are two types of attitudes, i) global attitudes and ii) attitudes toward a behavior. Global attitudes do not necessitate specific action toward an object of interest, and therefore cannot be reliably used to predict behavior.

Evidence demonstrates that global attitudes can’t predict specific behaviours, regardless of whether explicit or implicit measures of attitude are used and irrespective of social desirability concerns or the controllability of the behaviour.

An exploration of patients’ beliefs using the TPB as a guiding framework allowed for an exploration of patient beliefs and attitudes specific to the behaviour of *being* a patient. From the data, it was possible to identify each element and examine the behavioural beliefs about the consequences of being patient, whether those behaviours were positively evaluated or not, what significant others and the broader community felt about being a patient as well as the perceptions about ability to engage in the given behaviour.

CHAPTER 3

The Research Methods

LeVasseur (2003, p. 408) noted that “traditional science has not been concerned with the lived experiences of individuals because these are largely unmeasurable and difficult to appreciate through sensory observation. However, clinicians must contend with and respond to their patients’ lived experience of health and illness”. This need to understand the lived experience extends to health researchers and policy makers alike. The presented research was concerned with people’s experiences in health care, seeking to understand how these lived experiences influence behaviour, so selecting an appropriate research approach and methods was essential. This work used an interpretive phenomenological approach, based on the belief that the truth can be discovered in peoples’ lived experiences. Additionally, patient’ experiences, explored from their own perspectives is a relatively unstudied topic, and as Carpenter (1995) noted, Phenomenology is well suited to holistic questions or to phenomena that are not well understood.

Role of the Researcher

In interpretive research, the findings that researchers arrive at are a blend of meanings presented by both the researcher and study participants (Lopez & Willis, 2004) as each bring different backgrounds, assumptions, ideas, meanings and experiences to the interaction. The interpretations are subsequently bound by the individual and the combined horizons of the participant (Geanellos, 1998).

The role of the researcher is particularly important in the conduct and reporting of interpretive qualitative research. The researcher is the originator of the research idea, develops the methods to address the question, serves as the data collection instrument and is the primary mechanism for interpreting the data. Therefore it is essential that researchers explore and understand their own subjective reality (Munhall, 1994) before arriving at interpretations. By understanding the meaning of the phenomenon of inquiry personally, the researcher is better able to understand the influence their perspectives may have on the research process and/or findings. Van Manen (1990), argued that although researchers attempt to ignore or supersede their own experiences, they might find that "the presupposition persistently creeps back into" their reflections (p. 47).

One recommended strategy, consistent with the interpretive phenomenological approach is to compose a statement at the beginning of a research program outlining the researcher's preconceived ideas, biases, and notions regarding the phenomena so they may recognize where their impetus for the research question, as well as identify any influence they might have on the interpretation of study results. Prior to engaging in any data collection, I took some time to think about my own experiences with health care, and what I believed about the experience of patients in health care. Following is a compilation of excerpts from those notes:

I have been a patient. Health care to me is one of those quintessentially Canadian things – we all have access and have used the services when necessary although I don't think people use it mindfully. I think you only really think about it when you have to use it – otherwise it is a taken for granted "thing" in the background of our lives. I speculate that I have a different perspective on heath and health care *than many Canadians, as I have worked in a variety of health related settings (primary health care, community, long term care and rehabilitation). I recognize that my perceptions of health care and probably my use of the services have been shaped by these personal and clinical experiences. I am not intimidated by my physician, but respect their knowledge and expertise. I understand how the system works, and what I can and cannot ask for of my doctor. Is this a benefit of my collective experiences or do others have this same perspectives? Am I receiving different or better care because I am a knowledgeable consumer? What do others think about health care? Do they think about it at all?*

I recognize that as a result of my experiences and the time I have spent thinking about these topics, I bring certain preconceived ideas to the study. Although I will make every effort to pursue objectivity, these perspectives will inherently shape how I view and interpret the data that is collected. I start this study with the perspective that people have conflicting perspectives on health care services, and that indeed many people have not thought about the health care system broadly, nor have they reflected on their needs from the system. Based on my previous interactions with people in various health care contexts, I suspect that many people feel that they have little or no control over what happens in the health care system and do not feel that they are in fact the "co-creators" of the system.

I start this research program with the idea that patient's behaviours are different in different health services environments – how people behave in the hospital will be different than accessing health promotion or primary health care services (PHC). In my personal experiences as a patient with PHC, emergency departments and surgical *program, I behaved very differently. In the emergency room and surgical program, I was very willing to hand over control and decision making processes in the desire to "get better". I just wanted someone to "fix it" so I could go back to my regular activities. I speculate that for others, like for me, it would have to do with the severity of illness and physical ability to be a patient. I wonder how the type, frequency and the nature of the interaction with health care services shape people's perspectives. I would guess that they have some influence but am unsure of how.*

All of this comes together though in my questioning how to engage the patient or elicit the patients' needs for patient centred health care. Is there a time and place to assess people's participation? Do these beliefs about health care transfer from one context to another? If we understand what people need in one health services setting, can we extrapolate this to another? I have talked a lot about what patient centred health care is, but feel like I really need to know what it is like to be a patient before I can conceptualize how to address their needs, concerns and preferences in a health care setting.

Over the course of conducting this study, I continually reflected on what I thought I was hearing from the study participants and assessed whether the themes were emerging from the data, or if my preconceived ideas were being superimposed onto the results. By identifying my preconceived ideas, beliefs, and experiences with the phenomenon of accessing and utilizing health care services, I was able to recognize where my beliefs and the emerging themes converged or diverged. Further details regarding this can be found in the chapter section on ensuring methodological rigour.

The Iterative Research Paradigm & A Qualitative Approach

The interpretivist paradigm developed as a critique of positivism in the social sciences. In general, intepretivists share the following beliefs about the nature of knowing and reality (Berger &Luckmann 1967; Glaser & Straus, 1967; Guba & Lincoln, 1994):

- knowledge is a natural phenomenon that occurs in a variety of subjects with a shift from absolute knowledge to a contextual or situational knowledge
- there is no objective reality, knowledge is created as the investigation of a phenomenon proceeds
- we cannot be separated from what we know: who we are and how we view and understand the world is fundamental to how we understand ourselves and others.
- meaning is constructed by people based on the context of their experiences and how they approach the world they are interacting with and interpreting.

The values of researchers working in the interpretive paradigm are particularly important and are inherent in all stages of the research process, with the expectation that these values are made explicit. Interpretivists acknowledge that research findings emerge from interactions between a researcher and participants and that subjectivity is a valuable aspect of the study process. The interpretive methodology (how we explore the world) relies heavily on naturalistic methods such as interviews, observations and examining existing texts or materials.

Qualitative research involves investigating social situations, people and events in a natural setting, attempting to bring meaning of these events through the researcher's interpretation (Lincoln and Denzin, 2000). Qualitative research has been used by researchers in psychology, sociology, anthropology and even biology, when investigators seek to understand how social experiences are created and given meaning. Researchers using qualitative methods function as the data collection and analysis instruments, giving voice to participants' perspectives. Interpretation of qualitative data involves looking for common themes which leads to a conclusion or broad interpretation of the event under study. Although objectivity and truthfulness are essential in both quantitative and qualitative research, the evaluation criteria differ for these constructs. The focus in qualitative methods is to ensure that the data is believable. Believability is based on trustworthiness and credibility through verification, rather than traditional validity and reliability measures. The goal of generalizable findings does not translate to qualitative methods where the goal is to demonstrate what was done, and what the findings indicate, in order to resonate with the audience (Rossman and Rallis, 1998; Creswell, 2003).

Table 2
Characteristics of Qualitative Research

	Characteristic
1	Occurs in natural settings, where human behaviours and events occur.
2	Uses multiple interactive and humanistic methods.
3	Captures and gives voice to the participant's perspective of the event or occurrence.
4	Emergent – the research focus and data collection methods may change and develop as the researcher learns and refines the boundaries of the study.
5	Fundamentally interpretive and descriptive. The researcher interprets the data for themes, working toward a conclusion or broad interpretation of the event.
6	Researcher reflects on their role in the inquiry and is sensitive to the effect their perspective may have on the results.
7	Researcher adopts and uses one or more strategies of inquiry as a guide for the procedures.

*Note.*Adapted from Creswell (2003) and Rossman& Rallis (1998).

Phenomenology

Immanuel Kant was the first to describe the phenomenological view as the study of ‘phenomena’ or of ‘things’ (Cohen, 1987), although Edmund Husserl is considered the founder of the philosophy known as phenomenology. Greenfield (1974) said, “it (phenomenology) has its origin in the distinction Kant drew between the noumenal world or ‘the world as it is’, and the phenomenal world or ‘the world as we see it’. Phenomenology as a research approach explores and describes what participants have in common regarding a shared experience or phenomenon. By collecting data from people who have experienced the phenomenon, the researcher can identify and start to understand the essence of the experience. The focus on the lived experience of several individuals facilitates the understanding of the common or universal essence of the experience. Presenting the essence of the experience as a composite is meant to serve as a description, not as an explanation or analyses, sharing what the individuals have experienced and how the phenomenon was experienced. Phenomenologists attempt to understand how people create meaning, focusing on the concept of intersubjectivity, the idea that people experience the world with and through others and that meaning is created based on human action and interaction.

Types of phenomenology

Phenomenological approaches can be broadly categorized as, i) descriptive (eidetic) phenomenology and ii) interpretive (hermeneutic) phenomenology. Lopez and Willis (2004) noted that primary differences between the approaches centre on “how the findings are generated and in how the findings are used to augment professional knowledge” (p.727).

The Descriptive Approach to Phenomenology

Descriptive phenomenologists focus on the subjective information people perceive, as they believe this serves as the foundation for human motivation and subsequently behavior. In order for researchers to take a phenomenological standpoint, or focusing not on the things themselves, but on peoples' consciousness of things; they must "bracket out" everything that is not essential. Bracketing requires researchers to suspend questions of truth or reality and describe the contents of consciousness. Asking open ended question, listening carefully and accepting these reports uncritically is the process required to gain direct access to subjectivity (Ritzer, 1992).

Bracketing, phenomenological reduction or the epoché, are synonymous terms central to descriptive phenomenology, means setting aside all our usual, "natural" assumptions about the phenomena. This means putting aside biases, prejudices, theories, philosophies, religions, even common sense, and accepting the phenomenon for what it is; ultimately suspending one's beliefs in the existence or non-existence of the phenomenon.

Interpretive Approach to Phenomenology

Hermeneutics is defined as the process of interpreting or clarifying messages normally hidden in human experiences (Spielgelberg, 1976). Solomon, as cited in Lopez and Willis (2004) states that "in relation to the study of human experience, hermeneutics goes beyond mere description of core concepts and essences to look for meanings embedded in common life practices. These meanings are not always apparent to the participants but can be gleaned from the narratives produced by them. The focus of a hermeneutic inquiry is on what humans experience rather than what they consciously know" (p. 728). Interpretive phenomenologists describe the meanings of the individual's being in the world and how these meanings influence the choices they make; and it is this connection to the broader contexts that is essential to interpretive phenomenology.

A significant point of dissention between descriptive and interpretive phenomenologists is the role of the researcher. Descriptive phenomenologists believed that a researcher must remove all personal knowledge and biases toward the topic of inquiry to really focus on the lived experiences of those being studied; the impact of the researcher is continually assessed and neutralized. Bracketing requires the researcher to suspend their personal knowledge and preconceived ideas when collecting data and reflecting on the lived experiences of study participants (Drew, 1999).

Bracketing does not fit within interpretive phenomenology. Heidegger believed that the presuppositions of researchers, their prior knowledge and interests are what led them to recognize the need for research (Koch, 1995; LaVasseur, 2003). Hermeneutic phenomenologists believe that it is impossible to suspend all prior beliefs, knowledge and experiences and that personal knowledge can be useful in phenomenological research (Geanellos, 2000). Interpretive researchers make their preconceived ideas regarding the phenomenon explicit and describe in detail how they will be used in the inquiry.

LeVasseur (2003) attempted to bridge the issue of bracketing between descriptive and interpretive phenomenologists, stating that the act of being curious or having an interest in a phenomenon leads us to bracket our prior understanding. Being curious indicates that we do not understand the phenomenon fully, which leads to questioning of our prior knowledge of the phenomena. LaVasseur continues suggesting that bracketing, in the suspension of assumptions, align with the concept of a hermeneutic circle. In the hermeneutic circle, we work our way toward sense and meaning by continually questioning our knowledge. We are continually seeking new possibilities, as the process of reflection fosters the possibility of new understanding (LeVasseur, 2003).

The Interpretive Phenomenological Approach

Creswell (2007) outlined a five stage process for conducting an interpretive phenomenological study which loosely served as the basis for the design of this doctoral research program. The first step is to determine if the phenomenological approach is appropriate or suits the research question. Second, the researcher identifies a phenomenon pertinent to the research question. Third, the researcher collects data from people who have experienced the phenomena, typically through in-depth interviews and multiple interviews (Creswell, 2007). Other forms of data, collected through observation or reviews of participant journals and art, can be included (Creswell, 2007). During an interview, a researcher may ask very general questions, such as, “What have you experienced in terms of this phenomenon?” and “What situations have typically influenced or affected your experiences of this phenomenon?” The fourth step is the analysis of the data during which researcher moves from identifying individual participants’ significant statements to developing clusters of meaning and ultimately creating themes. These themes serve as the skeleton for the description of the experience – the essence of the phenomenon. The fifth step, consistent with van Manen’s (1990) suggestion, is to present a meaningful phenomenological description of the phenomenon under study. Each of these stages is discussed within this methods chapter.

Research Methods

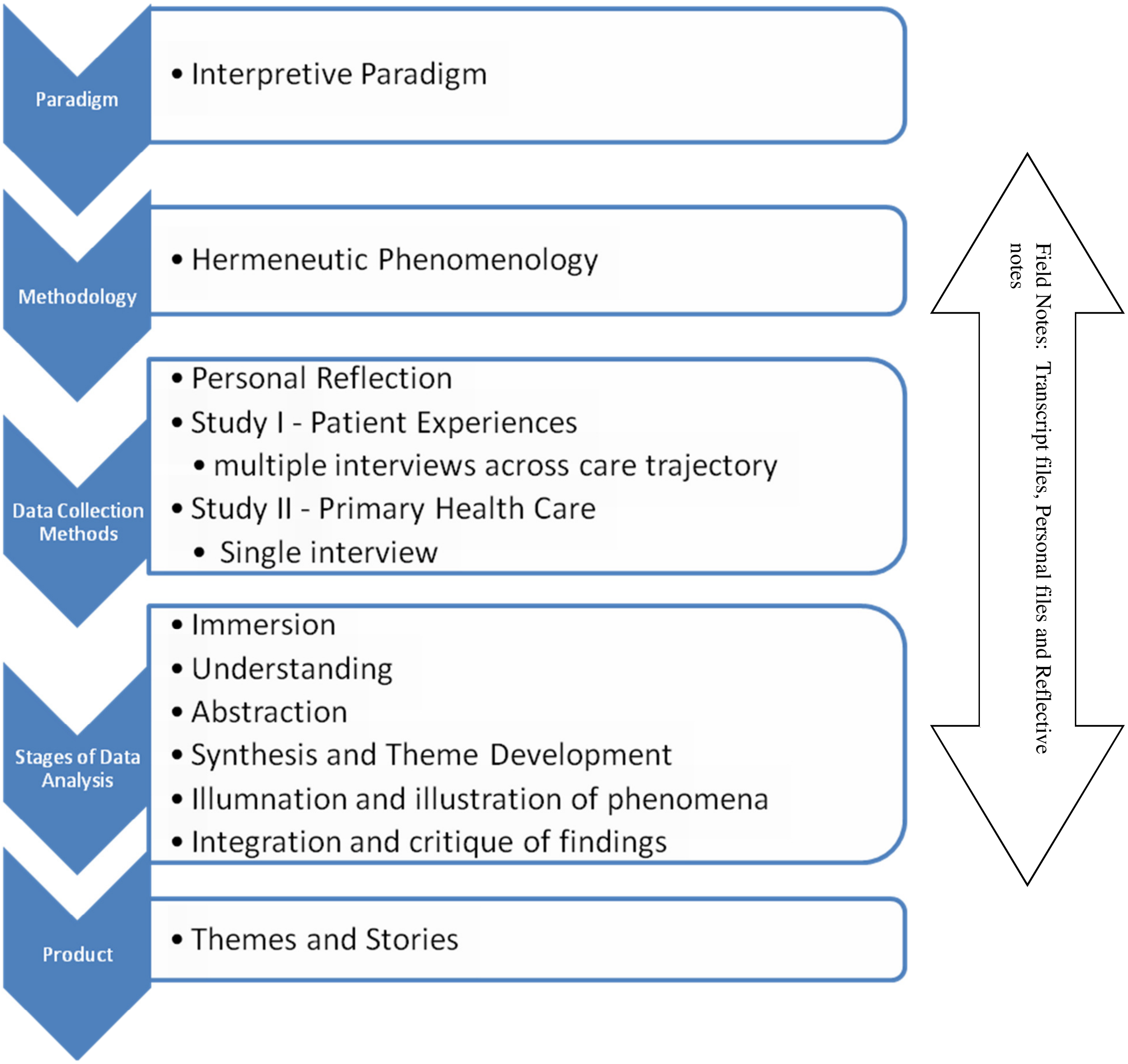
The following section provides an overview of the research methods employed during the conduct of this study with details regarding methodological activities provided to support and justification for the methods.

Overview of the Study Design

All three studies occurred in Winnipeg, Manitoba, a Canadian urban setting with a population of approximately 700 000. To address the overarching research questions, a three phase research plan was developed. Study I collected data from patients in a stroke rehabilitation program exploring patients' experiences. Study II, collected data from members of general public (primary health care patients) exploring their beliefs, attitudes and experiences with health care. Study II also assessed the degree to which contextual information influenced individuals' expectation and beliefs about health care services (through personal experiences and the use of a composite experience developed from Study I). A third and predominantly analytical activity, compared and contrasted the data collected in Study I and Study II to determine similarities and differences in patient behaviour across clinical context, personal circumstances and experiences. A schematic of the study activities and corresponding timelines are shown in Figure 2. Due to the nature of the proposed program, some study activities occurred simultaneously, rather than sequentially.

Figure 2:

Overview of the Research Approach



Overall Study Methods

Table 3 provides an overview of the research methods for both Studies I and II. Many of the methodological activities were similar between the Studies but have been reported separately for clarity. Additional information pertaining to each of the methodological activities can be found in subsequent sections of this chapter.

Table 3.

Overview of the research methods.

	Participants	**Recruitment**	**Data Collection**	**Data Analysis**	**Reporting of the Findings**
Study I	Patients admitted to and receiving stroke rehabilitation.	Purposeful recruitment strategy. Initial recruitment materials provided by clinical team member.	Up to 3 interviews with each patient using an interview guide approach.	Data analysis consistent with hermeneutic phenomenology and interpretive research paradigm	Understanding of essence of the experience (shared elements) A composite vignette of participants experience
Study II	Members of the general public in Manitoba, over the age of 18 and able to speak English.	Purposeful recruitment strategy. Posters in public locations. Snowball Sampling using email and social networking sites.	One interview using an interview guide approach.	Data analysis consistent with hermeneutic phenomenology and interpretive research paradigm	Understanding of essence of the experience (shared elements) A composite vignette of participants experience

Study I Methods

Study Participants & Recruitment

Study I participants were patients admitted to and receiving health care services on an inpatient stroke rehabilitation program. To target individuals with knowledge of the phenomena or "who have had experiences related to the phenomena to be researched" (Kruger, 1988; p. 150) I used purposeful–criterion based sampling (Patton, 1990).

At time of admission to the stroke rehabilitation program, study materials were provided to the patient by a member of the program team (usually a nurse). If the patient agreed to be contacted, their name and room number was provided to me and I contacted the patient to provide recruitment materials and answer any questions about the study. If the patient declined to participate, their contact information was disposed in a confidential manner. If they agreed to participate they signed two copies of the informed consent form; one copy was returned to me for the study files, and the other was retained by the participant for their records and information.

In qualitative research the number of participants included in a study is necessarily small, and random sampling is not required (Morse and Field, 1995). It is essential however to ensure that the recruitment of participants is consistent with the methodological approach. Hycner (1999, p. 156) notes that "the phenomenon dictates the method (not vice-versa) including even the type of participants." Experts suggest that researchers should interview between 5 and 25 individuals who have experienced the phenomenon (Morse, 1994; Polkinghorne, 1989). If new information continues to be discovered however, additional interviews should be conducted until theoretical saturation occurs – in other words, until no new information, or only minor variations emerge (Morse, 1994). For the purpose of this study “theoretical saturation” was considered met when new information added only minor variations in the themes and did not change the essence of the shared experience.

Data Collection

Interviews and participant journaling were the primary data collection activities for Study I. There are several approaches to interviewing, with varying degrees of structure imposed on to these “conversations with a purpose”; from informal conversational interviews with no predetermined questions to open-ended standardized interviews where the same questions are asked to all participants. A general interview guide approach was deemed most appropriate for this study. An interview guide is designed prior to the intervention and includes a series of questions that will be explored. The use of an interview guide provides structure to the interview while creating an environment that is relaxed and conversational, which is essential for establishing rapport (Mactavish et al, 2000). Topical questions and relevant probes are included in the interview guide; ensuring similar types of information will be gathered from all participants. This interview technique also ensures that the interview covers all the topic areas required, but allows the interviewee sufficient time and freedom to respond (Morse and Field, 1995).

The interview guides were developed from reviewed literature; copies can be found in Appendices C and D. Each question pertained to the central questions “What has your experience been like?” and “How has this experienced affected your behaviour as a patient?” using semi structured prompts to elicit further information.

Prior to data collection, the interview guides were pilot tested using a cognitive interviewing approach to ensure that the question content and format were appropriate. The cognitive interview approach (Willis, 1999) focuses on the cognitive processes individuals use to answer survey questions rather than the responses themselves. Although cognitive interviewing is usually undertaken to assess and reduce measurement errors with survey instruments, the approach was particularly useful for this study. The cognitive interview approach allowed as it allowed for an assessment of what participants thought the questions were asking (question intent) and what specific terms or phrases contained within the questions meant to participants. Specifically, each interview guide was pilot tested using the think aloud approach and the probing question approach as outlined by Willis (1999). In the 'think aloud' approach, I posed the overarching questions of the participant and explicitly asked them to think aloud as they answered, noting what they were thinking about in order to answer the question. This allowed me to identify the process participants used to answer each question and make adjustment within each question and the interview guide as a whole. A second technique utilized in the pilot testing of the interview guides was 'verbal probing', in which I asked further questions about the overarching question based on the participant's responses. The verbal probing technique was also useful throughout data collection as it allowed for fuller questioning of the patient experiences. Based on the pilot tests, some of the questions were rephrased and reordered to facilitate patient response prior to conducting additional interviews.

Revisions to the guide occurred and additional questions were added, as more interviews were conducted, to address gaps in question areas and to refine the questions based on emerging themes. Patients were encouraged to provide information beyond the scope of the question set if they felt it was relevant to their experience, and I probed for additional experiences and perspectives as necessary.

To capture the full experience of being a rehabilitation patient, I interviewed each patient on up to three separate occasions, at times and locations of convenience for the individual. Variability in the frequency and timing and duration of the interviews was due to patient activities (therapy, home visits, and visitors) and their discharge date. The first interview collected information regarding their expectations, beliefs and needs upon entry to health care system (upon admission); the second at the midpoint of their participation in the health care system (during treatment) and then finally at the patients' point of exit from the system (immediately prior to discharge). These timelines varied based on the treatment schedule of each patient.

In an effort to ensure the privacy and comfort of the participant, while decreasing possible interruptions and unwanted distractions, the location of each interview was selected by the participant. Settings included quiet public settings, private homes and for Study I participants, their private rooms within the hospital. Interviews were audio recorded with the participant's permission. After each interview, I made detailed notes about the interview, contextual factors and my general sense as to what and how things had happened. Parts of these notes have been included in the Results sections of this thesis where they provide supporting materials for themes. One patient's interviews were not audio recorded, therefore I took detailed notes during the interview, and wrote extensive notes after the meeting.

Participants were also asked to document their experiences between interviews through notes, journals, creative endeavors (poetry, art, etc.) and any other communications that they felt comfortable sharing with the researcher. I provided participants with a notebook and file folder to create or store any reflective materials, that the participant felt captured or reflected aspects of their experiences, and were formatted by the participant. Although participants accepted the journals, no participants utilized the journals to record their experiences, and as such the interviews continued as planned.

Data Analysis

Data analysis methods were designed to be consistent with the hermeneutic principles. The procedures were developed from literature of strategies to interpret phenomenological research data, but were specific to this research, as qualitative analysis is inevitably a personal process and the analysis itself is the interpretive work done by the researcher at each stage. Denzin and Lincoln (1994) view interpretive data analysis as;

> ' *..an art; it is not formulaic or mechanical. It can be learned, like any form of story telling only through doing........fieldworkers can neither make sense of nor understand what has been learned until they sit down and write interpretive text, telling the story first to themselves and then to significant others and then to the public.' (Denzin and Lincoln 1994 p 502).*

The term 'data analysis' is also used mindfully, recognizing that some researchers believe that the term 'analysis' may have connotations that do not fit with phenomenology. For instance, Hycner (1999) states that “the term usually means a breaking into parts and therefore means a loss of the whole phenomenon” (p. 161).

Data analysis process was a descriptive and iterative process consisting of eight activities which are outlined in Table 4. Each interview was analyzed separately, identifying significant statements and creating a detailed description of the participant and setting. The researcher used these themes and quotes to develop detailed descriptions of the participants groups’ experiences and how the participants’ experienced the phenomenon being studied.

Table 4

Study I Data Analysis

Activity	Description of Analysis Activity
I.	A description of the researcher’s personal experiences with the phenomenon under study.
II.	Data from Study I was organized and prepared for analysis – includes typing field notes, transcribing interviews, scanning materials and sorting data into different types depending on the sources of information immediately after the interview.
III.	Review of all data collected to obtain an overall sense of the meaning and a scope of the information collected. Development of an initial impression of the overall depth, credibility and potential usefulness of the information. The researcher also assessed whether theoretical saturation had been met or if additional interviews needed to be conducted.
IV.	The researcher creates a detailed description of each participant and setting. The researcher develops a list of significant statements (nonrepetitive, not overlapping) from each of the interviews transcriptions and field notes about the experience. These significant statements were then grouped into larger units (themes). These themes were then examined for relationships to other themes generated.
V.	A description of what the participants experienced (textural description) and how the experience happened (structural description) including verbatim quotations was generated.
VI.	The textural description and the structural description were used to develop a composite description of the phenomenon. This composite description is considered the apex of a phenomenological study and was created to reflect the “essence” of the experience.
VIII.	Relating the developed themes to existing literature and the theoretical framework. Additional questions and future research directions were identified.

The Use of a Composite Vignette

Vignettes (materials that consist of text, images or audiovisual stimuli) are often used in social sciences and have been used recently in nursing research. Vignettes are useful for studies seeking to understand people's attitudes, perceptions and belief (Gould 1996; Hughes and Huby, 2002). Vignettes can allow participants to respond to a health care experience that they themselves may not have had experience with (Liker, 1982). Vignettes also provide an impersonal situation to discuss an issue resulting in a less threatening perspective (Hughes, 1998). They can mimic or simulate some aspects of a research topic under study, but it is important to note that like any research tool, vignettes cannot replicate the reality and dynamism of people's lives (Hughes and Huby, 2002). Humans are constantly interacting with their environments, and a vignette cannot mimic this interaction and feedback that is essential in human social life (Hughes 1998). The development of the composite vignette gives precedence to some information over other as the researcher selects information they consider representative of the experience. This selection of information by the researcher allows the inclusion of information that is useful and specific to the question being studied, while limiting the amount of extraneous and/or distracting information (Hughes 1998). Vignettes should be developed using (Flaskeruk, 1979 as cited in Gould, 1996) existing literature or case histories of real patients.

Written narratives are one of the most common applications of the vignette technique (Hughes, 1998). I developed a paper based/verbal story about an individual named Sam. Sam's experience was crafted from data collected during Study I, but not reflective of any single individuals' experience. The vignette was a collection of salient comments/thoughts and experiences of the rehabilitation patient group (the essence of the experience). The vignette was originally designed to be an audio recording, however, during the pilot test, participants suggested the vignette didn't ring "true". They were distracted by attempting to discern Sam's age, assessing whether or not he sounded like he'd had a stroke, and noted that the individual didn't evoke emotion in a believable way. The use of the vignette was to assess whether or not contextual information would change individuals' perspectives on health care rather than testing the different methods of vignette delivery, therefore I told Sam's story during the Study II interviews. .The composite vignette provided to participants can be found on pages 71-75 within Study I results.

Study II Methods

Participants & Recruitment

Study II participants were members of the general public. To maximize variation in the data, demographic characteristics of the participants were not limited beyond being a resident of Manitoba, be over the age of 18, and able to communicate in English.

To target individuals "who have had experiences related to the phenomena to be researched" (Kruger, 1988; p. 150) a purposeful–criterion based sampling (Patton, 1990) strategy was implemented. To recruit a sufficient number of participants, I used a variety of recruitment activities, including traditional advertising and a more contemporary strategy using technology and social media. Traditional recruitment activities included the use of public notice boards across Winnipeg to advertise the study. (See appendix B for the recruitment poster). In addition to the traditional posters and advertisements, I implemented a technological snowball sampling strategy, advertising my research through email and ‘Facebook’. The email snowball started with an initial recruitment email (see Appendix B for the script) with inclusion/exclusion criteria and contact information to approximately 50 personal contacts asking people to forward the email to anyone they thought might be interested in participating. This approach enabled me to access to a large number of potential participants anonymously. Individuals contacted me directly if they wanted more information or wished to participate. A second technological snowball sampling strategy used ‘Facebook’, a social networking site launched in February 2004 with 750 million active users as of July 2011 (Wikipedia; August 2011). Facebook users can connect with other users as ‘friends’ and exchange information. I posted an information post on my Facebook page indicating that I was recruiting participants for a study about peoples’ experiences with health care, which my friends were able to reference. Several of my ‘Facebook friends’ included the study details on their personal pages asking anyone who was interested to contact me directly.

Data Collection

Data collection for Study II also consisted of interviews using an interview guide approach. The interview guide was also pilot tested using the cognitive interview approach described in the data collection section of Study I. Please see Appendix D for a copy of the interview guide. The interview, which typically lasted between 40 and 60 minutes, collected information from members of the general public regarding their general beliefs and attitudes about health care as well as personal experiences.

Interview settings were chosen by participants and included quiet public settings and some participants' private homes.

Participants were asked to reflect and comment on their perceptions and expectations of health care generally and specific elements related to patient centredness (shared decision making, information, communication etc). As part of the interview, I provided participants with a composite vignette developed from Study I participants' experiences. Participants were asked to reflect on their comments regarding general expectation, to determine if they experienced a change in their expectations as a result of this contextual information.

Data Analysis

As previously stated, the data analysis procedures were the same for both Study I and II. The data analysis was a descriptive and iterative process. Each interview was analyzed separately, identifying significant statements and creating a detailed description of the participant and setting. I used these themes and quotes to develop detailed descriptions of the participants' experiences. Please see Table 5.for details regarding the analysis steps.

Table 5

Data Analysis Process

Activity	Description of Analysis Activity
I.	Data was organized and prepared for analysis – includes typing field notes, transcribing interviews, scanning materials and sorting data into different types depending on the sources of information immediately after the interview.
II.	Review of all data collected to obtain an overall sense of the meaning and a scope of the information collected. Development of an initial impression of the overall depth, credibility and potential usefulness of the information. The researcher also assessed whether theoretical saturation had been met or if additional interviews needed to be conducted.
III.	The researcher creates a detailed description of each participant and setting. The researcher develops a list of significant statements (nonrepetitive, not overlapping) from each of the interviews transcriptions and field notes about the experience. These significant statements were then grouped into larger units (themes). These themes were then examined for relationships to other themes generated.
IV.	A description of what the participants experienced (textural description) and how the experience happened (structural description) including verbatim quotations was generated.
V.	The textural description and the structural description was the basis for a composite description of the phenomenon. This composite description is considered the apex of a phenomenological study and was created to reflect the "essence" of the experience.
VI.	Relating the developed themes to existing literature and the theoretical framework. Additional questions and future research directions were identified.

Additional Analysis Activity

This third analytical activity consisted of a comparison between the themes developed from Study I and Study II to determine what similarities and differences existed between the experiences of both study participant groups. The findings and my interpretations from this activity are provided in the Results Chapter.

Reporting the Study Findings

Although data collection and analysis strategies and techniques are similar across qualitative research methods, the way data is reported and presented is diverse (Lofland (1974) as cited in Creswell (2003). The results of my research are reported in rich detail, presenting the participants' perspectives and experiences, and allowing the reader to see and understand the participants' reality. For van Manen, "a good phenomenological description is collected by lived experience and recollects lived experience, is validated by lived experience and it validates lived experience" (p. 27).

The findings presented in the following chapter were developed from data collected from people accessing and receiving health care services (Study I, and Study II) and is meant to reveal their collective story. Composite vignettes, exemplars or extracts of test are used as the presentation strategy for this research. Being able to 'hear' the participant through the presented text allows the audience to visualize the person in the experience (Benner, 1994). Providing these textual sections further supports the trustworthiness of the findings (Haggman-Laitila, 1999).

Wertz et al (2011) note that although the composite vignette should draw a picture of the phenomenon emerging from the participants experiences, it is not simply a retelling of their story. Interpretation on the part of the researcher is essential; they must know the literature regarding the phenomenon of interest; and they must be continually reflecting while listening to the stories told by each participant. Readers of the composite vignette should be able to relate personally to the themes; the use of the personal pronoun "I" is essential as it indicates that the narrator of the composite is someone who typifies the experience (Todres, 2007).

Accuracy and Trustworthiness

What we know is always negotiated within social settings and relationships with other people. Validity and truth cannot be grounded in objective reality. What is considered to be true is negotiated and there are multiple valid claims to knowledge. Accuracy and trustworthiness are key elements of qualitative research, comparable to the notions of validity and generalizability in quantitative research, and aid researchers in ensuring the themes developed reflect the participants' perspectives and experiences, or deemed credible. Several strategies have been proposed to determine if the themes developed are accurate or credible and consistent with the data from which they are created. I utilized the following strategies to ensure accuracy and trustworthiness of the findings:

i. Member checking – Significant statements and interpretations were reviewed and checked for accuracy with the participants from whom the data was originally collected. All participants were offered the opportunity to provide input of this nature, however most declined. In Study I, I had the opportunity to engage in member checking as part of the data collection process by taking a few minutes at the beginning of subsequent interviews to review what we had discussed previously and my interpretations of the discussion.

ii. Identification and Selection of Participants – a purposefully selected sample (Morse & Field, 1995) was recruited to collect data from individuals with knowledge of or personal experience with the phenomena of interest. The use of snowball or chain sampling allows for the identification of participants through people who know which cases are information rich examples for the study.

iii. Audit trail – Presenting a detailed description of settings and actors, and providing details about the methods, the data analysis techniques and results allow the audience to determine if the findings could be extrapolated to the contexts, individual and settings beyond the presented research.

Research Ethics

In addition to obtaining ethics approval from the Health Ethics Review Board at the University of Manitoba, I paid particular attention to the ethical concerns of this research. As stated by Lathlean (1996), "the issues of ethics in research are often portrayed as taken for granted and the same regardless of the research approach adopted" (p.175), however the nature of ethical problems is subtly different in qualitative research compared to problems explored in quantitative approaches (Orb, Eisenhauer, &Wunaden, 2001). The additional layer of phenomenology and the emergent interpretive design required a reflection of the issues of ethical conduct and research approach. Qualitative research and in particular phenomenological studies attempt to describe participants' experiences with a phenomenon and their point of view through interviews and observations. The personal interaction between the researcher and participants is fundamental to interviews as data collection; however researchers must be aware of the possibilities of potential risks to participants as a result of the data collection methods.

The study protocol was submitted to the Health Research Ethics Board (HREB) at the University of Manitoba, and appropriate institutional review boards for review and approval prior. Please see Appendix A -D for copies of the materials provided to the ethics review committee. The following were aspects included in the ethical protocol for the presented research:

- i) A cover letter from the researcher was included in the project introductory package to all potential participants. This letter explained why the research is being performed and outlined the research activities. This letter also provided the name of the researcher, their academic advisor and the HREB office who could be contacted for questions related to the project.
- ii) Written informed consent was obtained from participants prior to participating. These signed consent forms, will be stored in a secured environment.
- iii) Only the researcher was directly involved in recruiting participants;
- iv) Only the researcher and her advisory committee saw individual participant responses and identifiers;
- v) Participants received a nominal honorarium for their participation.
- vi) Data that was stored electronically on a networked computer was stored in the investigator's specified network space that is password protected. Only the researcher had access to this information.
- vii) Data collected (hard copies, computer discs/flash drives) from participants was stored for seven years in a secure location.
- viii) After the 7 year storage period, all paper data will be shredded.

CHAPTER 4

The Experience of Being a Patient

Being a Rehabilitation Patient

The aim of Study I was to explore how beliefs, attitudes and experiences influenced people's behaviour as a patient, addressing the study questions: What is the essence of being a rehabilitation patient? What influence do beliefs, attitudes, and experience of rehabilitation have on people's behaviour as a patient? This chapter includes i) a composite description of the experience and ii) a presentation of the key themes (shared element) of the experience and iii) a discussion of patient behaviour. The findings are presented using a descriptive narrative format consistent with the interpretive approach and phenomenological methods in particular. The themes and composite description presented in this chapter reflect the persons' shared experiences, beliefs, attitudes and resulting behaviour as rehabilitation patients.

I was not involved in distributing recruitment materials to recently admitted patients, and therefore cannot report the exact number of potential patients that were approached regarding the study; I received contact information for sixteen patients, 11 of whom agreed to participate. One patient was removed from the study due to personal circumstances; I subsequently interviewed 10 patients over a five month period, for a total of 31 interviews. Patient demographics can be found in Table 6. Providing participant descriptors assist the reader to contextualize the findings. Factors such as age, marital status, employment status, type of stroke and previous interactions with the health care system were derived from the patients although they did not serve as the basis for developing cohort groups.

Table 6

Study I Participant Characteristics

Patient Pseudonym	# of Contacts/ interview	Gender	Age Range	Employment Status	Marital Status	Contact with Health Care
Gordon	3	Male	80s	Retired	Widower	High
Nora	4	Female	40s	Unemployed	Married	High
Kendra	3	Female	50s	Employed	Single	High
Walt	4	Male	60s	Retired	Married	Low
Cara	4	Female	30s	Unemployed	Single	High
Dale	2	Male	70s	Retired	Married	High
Greg	4	Male	40s	Employed	Married	High
Betty	2	Female	70s	Retired	Married	Moderate
Cole	3	Male	40s	Employed	Married	Low
Colleen	2	Female	40s	Employed	Married	High

A Description of the Rehabilitation Experience

Significant statements and emergent themes served as the basis for the textural and structural description of the patient experience, presenting what and how the phenomenon was experienced. This composite description presents the "essence" of the experience and as it is considered the apex of a phenomenological study, it is presented first.

I have become a great storyteller. I've told this story so many times I know what I should include in my "stroke story". The time of day, where I was, who else was there… what was I thinking? Did I know I was having a stroke? How long did it take the ambulance to get there? These details are the core of my story. It feels like I have told the story 27 times and it makes me wonder if they (all those doctors, nurses, therapists) ever talked to each other. Why didn't they just read the chart? I told the very first doctor and the very last nurse the exact same story. Maybe they don't realize that every time I tell the story I am reliving the stroke. I almost wanted to gather them all around my bed, say it once and be done with it!

I knew something was wrong; I didn't know what - but I knew something was wrong. I didn't feel "right" and I could tell by the reactions of people around me that it was something serious. I was rushed to the hospital where I had a bunch of tests, and then they told I had a stroke. At first I didn't believe them. I hadn't ever had anything really wrong with me – sure I smoked and drank occasionally, but I did do some exercise, so I *never really thought I was in that category – you know, a stroke victim. It was a shock to the system. I know I haven't led a pristine life, maybe if I had taken better care of myself, this might not have happened. If I didn't smoke, had a healthier diet, didn't go to parties… that it might not have happened. I used to eat fast food all the time and never really thought about it. But now I think about it so much more...*

I know it is a funny way to describe it, but I really didn't enjoy my stay at the hospital. It wasn't even that I was sick – it was the absolute lack of privacy that bothered me the most. I was in a room with three other people; and I don't think I slept through the night once. If someone was always talking, or coughing or getting up to go to the bathroom, or the nurses coming to check on you or waking you up to prep you for a procedure. I tell everyone about the night a nurse woke me up to ask me if I needed pain medication... If I needed pain medication, wouldn't I have been awake already? I realize that they are busy but I think many of the nurses forget that we are people too. It is almost like we are a number to them and I don't like being just a number, everybody's different. Overall though I would say that most of the nurses were good, although there were definitely those people that didn't want to be there.

This stroke wasn't my first experience with health care. I've had other experiences and family members have been in hospital. Overall I would have said that my opinion of healthcare is generally positive but it certainly isn't without its flaws. I was never a person that ran to my doctor all the time – I usually waited to see if whatever was bothering me would go away on its own, or I would have too many other things to do to take the time to take care of myself. I haven't had a bad experience, but being here for rehab definitely changed my opinion of health care. I think we are very fortunate as Canadians to have healthcare like we do – not like the US where you have to pay out of your pocket. There are definitely people who take advantage of the healthcare system – thinking that it is their god given right, and I don't think that is right. This experience has made me think about what I used to take for granted and maybe that I should be using healthcare more regularly.

My doctor at the hospital really felt that I should come here and receive a full course of rehab rather than relying on the outpatient services and programs. Of course I didn't really want to spend another 8 weeks in a hospital, but I wanted to recover so I agreed to be transferred here. I did receive some rehabilitation while I was in the hospital, but those therapists were so busy that I didn't really get much time with them – maybe a half hour each day. It wasn't until I got here that I started to see some significant changes and improvement. Looking back, I was just existing in the hospital but the minute I moved here, it was right.

The move to RHC was definitely a turning point in my recovery. I walked into my room (amazing – a private room, with a bathroom) and thought that it looked more like a hotel than a hospital. Real wood furniture, a comfortable place to be. It was really nice to have my own pillows and blankets since I was going to be here for a couple of months. Now that I have been through it, this place really did feel like a safe haven, a refuge. I told a nurse that I feel more at home here, and maybe safer than I even felt at *home. It’s going to be hard to leave. I definitely want to go home, but y'know it's really nice here.*

Anyway, the rehab team gave me that first day to settle in and get adjusted, but the next day they got straight to work. I was assessed by all the team members (nursing, occupational therapy, physical therapy, speech language pathology) and given my rehabilitation schedule. Three hours of therapy a day – what a difference from the rehab services I got at the hospital. The first few days were really tough; it was difficult to get into the routine of meals, therapy appointments. I was so tired all of the time. Before the stroke I wasn’t the kind of person who would lie down in the afternoon for a nap, but for those first few days I would fall asleep in the afternoon and was in bed by 8 pm. I said that coming to the rehab hospital is a bit like going to summer camp; for the first few days it’s hard to get into the swing of things, but once you meet a few people and adjust to the schedule it’s not too bad. One of the nice things about being here compared to the hospital is that everyone here had a stroke so everyone is in the same boat. You realize ‘I am not just one person... thank god – you realize that there are floors and floors of people needing therapy’. It's nice to know you're not alone. When I go down to therapy, practically the whole floor is down there. I thought my experience might have been different but it turns out not really. There is a real sense of camaraderie here. After a few days you start to talk to the others at breakfast, lunch, dinner. You go into the cafeteria and they encourage you. I have definitely met people here that I would consider friends.

The experience here was different than what I thought it would be. I had to get into a new routine, I am doing new activities and lots of what we are doing here will change my lifestyle. I think it is important for people to be active in rehab - If you have to get up and go have your lunch; you’re going to get better quicker. In the hospital, I sat there, in my bed; they would bring me my food. They would bring me my medication. They would bring me everything. Here I get up and go down to therapy and you have your eureka moments. You think, hey, I can do that! I wasn’t able to do that before, I can do it now. And I often wonder if that’s part of why this works here.

They really don’t tell me a lot of stuff... since I got here I have seen the doctor three times and that is when they did the blood work and changed my medication. I try to be aware – I know that I am not a doctor – but I will remember things and I can look things up on the internet. I don’t know why they don’t answer me; after all it is my body and I sure know what is going on with my body. I know that I might not understand the technical terms but I might be able to understand in lay terms. Don’t treat me like – I hate to put it this way – the brain injury people – I can “google” better than most and if I am concerned about something, I can go on the internet and look things up. But I feel like now it is “okay, do your therapy and go home like a good girl.” Which I am fine with to some degree... but this is my body.

When I came here I had hoped to make a full recovery. I was told that most of my function would return and that I should expect to get back to normal. After eight weeks of rehab I am realizing that back to normal may not be what I imagined. They keep

telling me that I will see improvements for the next few months and that some things may never really come back. I am certainly not back to normal – I may be going home but I am not going back to the life I had before the stroke. Sure, I know some things will have to change like my physical activity, lose some weight, quit smoking - but it is hard to make all those changes at once. Really, this place might be designed to change my behaviours, but the real test will be once I get home. You know, by the end I felt like I was taking up a space that someone else needed. Out of 13 hours, I'm doing nothing for maybe 10. The bed should be taken up by someone who needs it.
I wouldn't say that I am sick though – particularly compared to the other people here. I mean, I am sitting up – and sure I have an arm that is not connecting right now, but I can still do things with this one. I still have both of my legs. So, no, I am not sick. Hospitals are for sick people. This is a rehab - yes I'm being rehabilitated or however you want to put it. But I'm not sick. I realized how fortunate I was compared to some of the other people here – some of these people have had two strokes, or they are paralyzed – I feel lucky. And then you see everyone else here and some of them are worse off than I am – one whole side of their body is paralyzed, their speech is gone and it makes you think and you realize that you are not too bad… And I am thinking that they are way worse off than I am – maybe they will never get their speech back or their arms.

I have a large amount of gratitude for the work that these people do here: if it wasn't for these people I wouldn't be where I am. They are positive; they know exactly what things you need to do and where you need to be. But sometimes, sometimes they talk to me like I'm a baby or something and I uh…think they forget we are people and it hurts sometimes. I think they should treat patients the way they'd like to be treated. Sometimes when I am down at my therapy appointments I feel like I am one of those it makes me feel like I'm one of those attractions at like Sea World. Like every time I get it right "Good Job!". I understand they have to be up and build my confidence up. But I get tired of hearing "Good job" and getting a pat on the back.

Really, the one thing I have to complain about – well I think everyone does – is the food. It is truly terrible. Some people refuse to eat the meals or make plans to either buy something at the cafeteria or have food brought in from home. I try not to complain too much about it, but some days the food is so bad I just couldn't eat it – it really makes you wonder if anyone who works here has actually tried to live on the meals? My brother said that complaining about the food was a sure sign of improvement – a couple of weeks ago I would have just ate it. I said that I think they make the food so bad as motivation to get better in six weeks and get the heck out of here! I don't go to the cafeteria for many meals, but.... like the other night they sent me something I didn't like and I went down to the cafeteria and got myself a sandwich for later. I've lost weight while I've been here – not because I was trying but because of the diet.

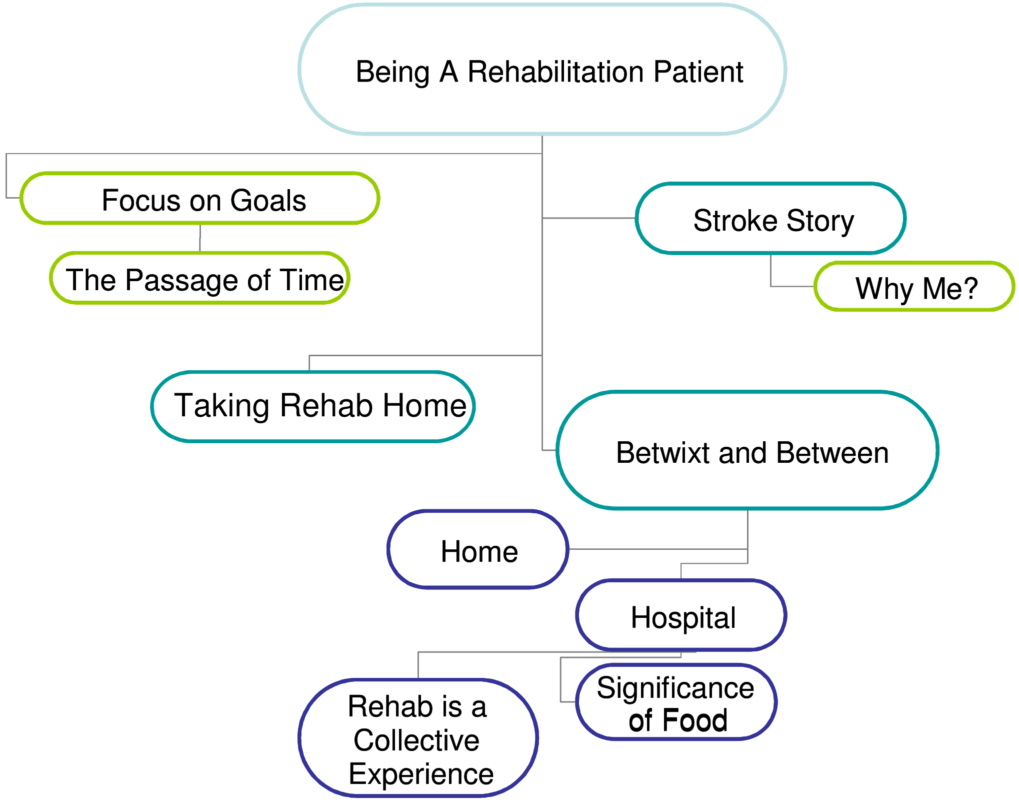
This stroke didn't only affect me though – it is really interesting to see the changes that have been happening in my family. It's funny, I was saying to one of the therapists that when you are in here – it isn't just about you… they really should have family therapy because everyone's life changes. They are quitting smoking, and have tried to start *eating better. It didn't affect my friends in the same way though; they are worried about me – but they don't think about themselves. I try to explain it to them but they keep saying "no, that won't happen to me – you might be the one in a million" but I keep saying that it happens to a lot of people and if something does happens, this conversation will come back to them. If they do end up having a stroke, I hope they are lucky enough to come here for rehab.*

The Essence of the Rehabilitation Experience

From transcriptions and field notes from the interviews, seven key elements were identified as central to the experience of "being a rehabilitation patient". These key elements captured what was identified as 'typical' or common within the patients' recounted experiences. Being a rehabilitation patient is not a process despite being situated within a clinical process (admission to discharge). The experience of being a rehabilitation patient consists of a set of realizations and reflections which are depicted in Figure 3. Some shared elements were interconnected or built upon each other, however none take precedence over another; in totality, they describe the shared experience of the participants. Each patient was focused on the goal of being discharged, which is reflected in the shared element "focus on goals", however, the experience was much more than being admitted and working to discharge. For each shared element, a detailed description of the element with transcribed materials from both the interviews and researcher field notes that help elucidate the essential elements are presented.

Figure 3

Shared Essential Elements of Being a Patient in Rehabilitation



Shared Element: "The Stroke Story"

By the time I conducted the first interview with each patient, they were well versed and rehearsed in the details to include that made up their 'stroke story'. Upon being invited to "tell me about your stroke", patients launched into a detailed recounting of their stroke.

Kendra's Stroke Story:

> Monday morning I woke up and about twenty after four having to go to the washroom and my right side didn't want to wake up with the rest of the body. And but I didn't think anything of it and went back to bed because I don't have to get up til5:30 and went to turn the alarm off at 5:30 and

> uh...the right side wasn't moving for me, but I still managed to get up and showered and dressed as if I was going to go to work...and then finally around quarter after 6, because I usually leave at 20 after 6, quarter after six I phoned into the office and told my supervisor that I wouldn't be in because I was having a problem with my right side...it wasn't working right. I waited I guess about an hour because my sister, who isn't too far from me...doesn't really have to get up until then to y'know go to her job and I just asked her, I says "Can you...get your husband to open the store" I says "And could you take me to Health Sciences, I think I've had a stroke".

Nora’s Stroke Story:

> I came downstairs and I was up, already up during the day, and I came downstairs and I grabbed the back of my head and I said to my husband, I said, I think you better call somebody. And he went, huh? I had a headache and then I said, Geez, you better, you know, it was getting worse and worse and worse. And then I just lay down on the couch and I was passed out. So my husband called the paramedics and then they came, that was when I found out really what it was, it was what they call, dissection. They figure it was that. But, also, I found out that I have, everybody has, I guess, valves and that in your heart. Well, I’ve got an extra one. It’s a wall between two of the valves that hasn’t closed. So, I’ve got this pocket there that collects blood and if I hadn’t had a dissection up here I wouldn’t have known…. Yeah, I’ve learned that as a result [of the stroke].

Colleen’s Stroke Story:

> I turn around to speak to [a friend] and all of a sudden I wasn't speaking properly. It was like I had marbles in my mouth. And he could tell I was talking funny and I was really trying to correct myself and I just looked at him and I had a really bad headache and I have to sit down. And at that moment, he called his wife who in turn called my husband and by the time Dave got up and came into the kitchen I was already sitting at the table...I had lost the left side of my face and I had lost the use of my left arm. And I had a massive headache. And basically everybody there could tell I was having a stroke. I could tell by the look on my husband's face that it was something serious. And I guess I wasn't really registering it was a stroke but I knew there was something terribly wrong.

In addition to being able to concisely tell their ‘stroke stories’, patients expressed frustration with the number of times they were required to repeat the story while in the hospital. Each patient was seen by many different physicians, nurses and other health care providers. As each new health care provider came to see them they would ask the same questions, collect the same information, making patients wonder if the health care providers were talking to each other or sharing information. It was described as incredibly frustrating and exhausting for the patient.

> That was the frustrating part. Like I said, seeing a different doctor every hour and a half or two hours and having to tell the same story over again. It is very frustrating. It got to the point where I wanted to say “You guys have

> to realize I can't keep repeating this over and over. I'm like reliving it [the stroke"]. (Nora)

Shared Element: Why Me?

People have a need to understand and share with others why this happened to them. Although I did not ask any questions about the cause of their stroke, the patients offered their perspectives, usually immediately following their 'stroke story and taking on a reflective or commentator tone (almost as an outsider to the experience).

Some patients were surprised they had a stroke. Betty, a woman in her 70's, noted that the stroke was "certainly a shock…. because I'd never had anything wrong with me". Colleen, although admitting that she engaged in behaviours associated with increased risk of strokes, was also surprised that she had a stroke:

> I'm 51 and I smoke and I have smoked for years, I am what you call a regular drinker as far as wine and that kind of stuff...but up until that point in time, I go to the gym four times a week, I eat fairly healthy, matter of fact pretty darn healthy--I'm not way over way weight or anything--could I lose 10 pounds? Yeah probably but other than that I'm not in that. I don't know what the category for stroke victims are I didn't feel like I was in that category.

Other patients felt responsibility, noting that their lifestyle had probably precipitated the stroke. Several people felt that with better behaviour the stroke may have been avoided. Gary, a self-identified obese man, knew that his weight was a contributor, "in my case, because I'm a big heavy guy I blame myself for the stroke. I think if I had taken a little better care of myself it wouldn't have happened". Several patients identified behaviours that (substance use, diet, a party lifestyle, and disregarding physician recommendations) likely played a role in their stroke. Walter noted that he didn't really exercise, and that based on the education he had received from the rehabilitation dietician, he could see how his diet had probably contributed to his stroke. Cole shared that "I know that if I didn't smoke, had a healthier diet, didn't go to parties… that it might not have happened. I used to eat fast food all the time – and never really thought about it. But now I think about it so much more". Although each patient had a different perspective on why they had a stroke, the common element was trying to understand why this had happened to them.

Shared Element: Betwixt and Between

The transition from a tertiary hospital to the rehabilitation hospital and the marked difference between the environments (regardless of which hospital patients were admitted from) served as the starting point for the idea of being betwixt and between; or 'out of the hospital', but not yet home. When patients described this transition, and what it was like to be at the rehabilitation hospital, they used terms that connoted being separate from the 'real world'. The more comfortable environment (physical and social) of rehabilitation was a nice change, but it certainly didn't mimic the individuality of home life. As Kendra pointed out "what they do in here it's not like everybody's home. It's good to know how you can do things. But if you're smart enough, you should be able to figure it out on your own."

Much of what occurs on a rehabilitation program unit is based upon a very structured schedule for meal times and menus, bath/shower schedules, and therapy appointments. Cara described it as similar to being at "summer camp", a place where it takes a couple of days to settle in, but once you get used to the routine it was a nice place to be. Others dichotomized the two health care environments, finding the rehabilitation unit to be significantly more pleasant. As both Gary and Nora shared - "this place is like a hotel. Compared to some hospitals, yup" and, "the hospital here…; I should say hotel, it's like a hotel compared to the other places!"

Cara was particularly pleased that the rehabilitation facility allowed patients to bring in personal belongings and comforting things from home to make their rooms more comfortable and homelike:

> I have two birds at home and a cat at home and they said my family can bring the birds in if I want. Because I've seen people with dogs. So they allow animals in here. And I like that. And this is my comforter from home. Yeah they allow stuff from home so that's good. And they also let you dress in your own clothes if you want to. So you don't have to wear the gown always. And I really like that. It has helped me a lot. That's what it is. To make it not seem like a hospital at all.

Over the course of five months, I had several opportunities to see the patients' rooms. Although Cara was the only patient to vocalize the value of having personal belongings, all of the patients had personalized their spaces with bedding, family photos, get well wishes, personal artifacts. I noted in a field note: "it is interesting to see over the time people spend on the unit, how personalized their rooms get. I can't help but compare to another hospital I worked at where there were 4 patients to a room and there was really no space for personal effects. I remember thinking how sad it was that peoples' get well flowers had to sit on the floor – here, everyone has enough space to display things that are special to them. Every time I interview someone I take note of how many more personal items there are – people seem to be really settling in…"

Being separate from the real world served as a source of protection or a 'buffer from the demands of real life, as patients noted upon their return from weekend passes or other special events. There was a sense of comfort and safety derived from being able to return to the unit:

> "It's funny I was getting anxious on the weekend, I guess we were out Friday, out Saturday shopping and there was a whole fiasco on Sunday we're trying to get things done we have a kitten in the house that drives me crazy and I just said to my husband at 5 o clock "take me back"….It's safe here [the rehab unit]. I don't have to worry about any of that stuff. I don't care if there are dirty dishes on the counter 'cuz it doesn't matter to me. Whereas I come back here - those dishes I'll just go put in the other room they're not my responsibility I don't have to worry about them. So yeah it's like my little safe haven coming here."
>
> (Colleen)

By the end of Cara's rehabilitation experience, she had become so comfortable with the facility and noted that she "feel more at home here. And it's going to be hard to leave...I want to leave but y'know it's really nice here.." while others noted that no matter how nice the facility, program or staff were, they would not stay willingly for any longer than they had to:

> "I can't find anything to fault them with. Some of them [staff] really go out of their way – go out of their way to make your stay welcome and a joy. Not a

> hardship or a headache, or anything like that. Not that I would be willing to stay for another couple of weeks though!"(Kendra)

Shared Element: The Passage of Time

Each conversation I had with a patient included a reference to time: the exact date of their stroke, the timeline of admission to the hospital and the move to the rehabilitation program. Once they were fully engaged in their rehabilitation program, time took on a new meaning: the passage of time as it related to their progress, the typical amount of time spent in the rehabilitation program and how they spent their "routine time" at the hospital.

In addition to being able to succinctly articulate the timeline of their stroke and hospital admission, patients were very aware of the 'typical' length of stay within the rehab program. Some of this information was communicated to them by the clinical team members regarding their treatment plan and discharge date while other information came from conversations with other patients about the typical length of stay and what happens after patients are discharged.

> Cole: I've done my six weeks already. It's usually six to eight weeks, so.
>
> Q: So everybody's counting to the six week point?
>
> Cole: Yeah. Six to eight weeks. So, there'll be a lot of people getting out tomorrow. When people leave here, usually they expect that they will be away from work for at least two more months – and then they go see their family doctor and hopefully get cleared to go to back to work

Through sharing details of their daily routines it became apparent that much of the patient experience was dependent on a continually changing schedule created and reinforced by the hospital. In addition to the ever changing therapy appointments, the regimented schedule of a hospital program dictates what time they eat their meals, when they have visitors and how they fill the remainder of the day.

> It seems that therapy appointments are not a structured scheduled appointment; rather they seem more like a moving target. On several occasions I have gone to the unit to either recruit or interview a patient and found that their therapy appointments had changed timeslots from one day to the next. Several times patients have apologized for not being in their rooms when I came to our previously arranged appointment for an interview. It appears that each morning, each patient has to check the therapy schedule board posted in the hallway to see what the format of their day will be. However, not one patient has complained about the shifting schedule as it affects them as they seem to take it in stride. (Researcher field note)

As patients approached the end of their rehabilitation patients started to feel guilty about the resources they were using and that other people needed the rehabilitation time more. Colleen reflected on the proportion of time she spent in active rehabilitation stating: “to stay here until the 17th of the month I just couldn't bear it. This bed is needed for someone else. Out of 13 hours, I'm doing nothing for maybe 10”.

Shared Element: The Importance of Goals

Interviews with each patient occurred at a minimum of two, usually three times across the duration of their stay in the rehabilitation hospital. Patients started the rehabilitation process believing that they could achieve a full recovery (“getting back to normal”) and being discharged as quickly as possible. In order to accomplish this, patients set and focused on specific goals whether it was to be able to walk without a cane, regain function in a specific limb, or more globally “get back to normal”.

By the midpoint of their rehabilitation and through to discharge patients were able to see and articulate the amount of progress they were making. Some of the feedback came from clinicians but most came from the realization or “eureka moments” they had about their own degree of functional improvement. Each patient had a personalized checklist of functional skills required for discharge, which Cara pointed out to me: “there's my sheet of what I should be doing andI've almost accomplished all the goals on the list”. Cole had memorized the scores he had received on functional assessments at admission and midpoint; relaying them as an indicator of the improvement he had made:

> “But they said for my PT, I came in at 51%, when I first came in. And now it’s up to 98%, so. I would have had 100 on one, but they said, can you walk a distance, like from my place to the mall? And I said I didn’t try it yet, so then she had to mark a cane on that one. So that’s where I lost my one point”

Verbal feedback was usually more casual with clinicians noting progress and improvement during therapy appointments. There was a concern about a disconnect between the written and verbal feedback patients were getting as demonstrated by Gary’s experience:

> “We had this family meeting, I have heard every day how well I am doing, “you are doing so well”; how much progress I am making and then for them to pull the carpet out from under me at the family meeting saying that you are not

> progressing like we hoped and we need to ship you somewhere else it really made me upset – why not just tell me the truth all along?”

Equally important were the patient’s own perceptions of improvement and progress. Each patient was aware of how much they had improved noting when they got to the point they could do activities of daily living without assistance or when things they remembered being difficult were no longer hard to do.

> “when you do the first thing, you think, my God, I’ll never be able to do that. And then, a week after, you’re doing it. A week after doing it, you’re thinking, huh – I thought this was difficult last week.” (Nora)

Shared Element: Rehabilitation is a Collective Experience

The rehabilitation experience, although an individual experience, was not a solitary one. Although the therapy schedule and treatment regimens were individualized, the rehabilitation experience as a whole was greatly dependent on and created by the interactions between the patient and the staff, other patients, and their significant others.

Shared Experience with Staff.

Patients recognized that their recovery was to a large degree due to their expertise and care of the staff, and continually stated how grateful they were “if it wasn't for these people I wouldn't be where I am. Because they really...they are positive; they know exactly what things you need to do and where you need to be” (Gordon).Receiving stroke rehabilitation services on a specialized unit was “really good, because they just deal with strokes. So they have more understanding of what you're going through” (Colleen).

The human connection, separate from the roles of patient and health care provider were very important to the patients. Patients appreciated the personal contact they had with specific team members whether it be a quick chat in the hall, a clinician talking to their family or sharing a joke. Although the patients were grateful to the staff, their interactions were not always positive. Patients commented on two things: i) the perception that some staff members did not want to be at work, and ii) that they (patients)were often not treated like adults and were excluded from discussions regarding their care.

Cara said she often felt like the staff “talk to me like I'm a baby or something and I think they forget we are people... It hurts sometimes”. During following interviews, I asked her to share any additional thoughts on this concern. Although her focus turned from a personal reflection to a more general observation, she still felt the comment was valid:

> Me: The last time we talked you had some concerns about how some of the staff talk to the patients. Could you tell me a little more about that?
>
> Cara: It still bothers me...because I know how it feels. I don't need them as much anymore but still if...they can think of how the patient is thinking or feeling. Feelings more like emotions would help.

Patients were often left wondering what the clinical team had decided regarding their care, and very rarely did they report being involved in decision making and treatment planning. Kendra shared her experience communicating with the clinicians regarding her rehabilitation which made her feel excluded from what she believed should be her business:

> “They really don’t tell me a lot of stuff... since I got here I have seen the doctor three times and that is when they did the blood work and changed my medication. But I feel like now it is… “okay, do your therapy and go home like a good girl...” Which I guess I am fine with to some degree... but this is my body”

Patients were also aware that their own behaviour could influence the relationship with the clinical team and therefore tried to be pleasant and positive and not annoy anyone. Overall patients tried to be fair and recognize that there are positive and negative people and that interaction between patients and clinicians was a reciprocal relationship.

> I am a good patient – respect the doctors, nurses, therapists, health care aides. I follow instructions. It is like they tell you things for your own good – like that sign on the wall – don’t get out of bed alone, call for help. I don’t call for help, if I need something I go and do it or get it for myself. I try to be independent. I am stubborn, but I know if I fall they will get into trouble. I try to do everything myself and respect that they are here to help me – not serve me. (Cole)

Shared Experience with other Patients

Rehabilitation is a social experience. With a large amount of free time and shared rehabilitation services, communal meals and lounge spaces, patients spent time together reading the paper and play cribbage, or visiting and watching TV. Beyond the vital social aspects of being a member of a group, these connections between patients served a greater purpose.

Being a member of the group provided patients with a reference group or a 'measuring stick' with which they could assess their progress and improvement. Other patients served as a peer support group and as a 'reality check' spurring them to count their blessing by showing them how much worse it could have been. As patients neared their discharge date, they could see the distinct difference between people who were newly admitted and those that had been there for the "full course" of rehabilitation. Often, patients toward the end of their stay would feel guilty for taking up a bed that was obviously needed by someone "worse off" than them.

"I am not the only one": Being on a unit designed specifically for stroke rehabilitation showed patients that their experience was not unique; "I heard someone else say that's what they thought as well [about recovery]. It's nice to know you're not alone" (Gary). Kendra reinforced the importance of being around others who are going through the same experience:

> "actually it has been more than I thought it would be [being in the program]. You know, the first time you hear about this hospital, and they say that they can get you into the program, you realize, I am not just one person... thank god – you realize that there are floors and floors of people needing therapy. But this is the main therapy floor – you know, when I go down to therapy, the whole 4th floor is down there practically."

Comparing self to other patients: With communal meals, shared therapy spaces and opportunities for social interaction the patients used this time to share and compare their experiences. Gordon had noted with surprise that he was easily the oldest person on the unit. Most of the other patients were quite a bit younger than he was; he thought that it would have been full of "old codgers" like himself. – (Post interview field note – Gordon).

Some of the patients compared their health status trying to determine the severity of their stroke. In comparisons with other patients many of them realized that their stroke and resulting impairments were not as bad as they could have been.

> I was fortunate...I mean I walked in here. There's people who come in here in a stretcher or a wheelchair so I've always felt since I got here that I'm a step ahead of everyone because I'm just that much further ahead than some of these people are when they get here. (Colleen)

In addition to assessing their progress, patients also tried to determine what degree of recovery they might expect. Betty was particularly aware of her progression and place within the group,

> “when you talk to people, you are just one of the group, you know. You’re just there. And either you’re worse or you’re better. And some are – I think that I’m maybe in the lower part of the learning, and that I, the others are ahead of me. But now I’m in the middle, so to speak. I will eventually get to the top too.”

Source of Information and Peer Support. Having other people who had gone through the same experience was important as patients often turned to one another to discuss what had happened in their therapy, their successes in recovery, to talk about their concerns and other aspects of being in the hospital. Communal meals often served as a time for socializing, and topics of discussion ranged from therapy to counseling newly admitted patients on the rehabilitation process or what they might expect in their recovery.

> y'know everyone that's here...had a stroke. And you can talk to them and they know what you're going through. And that really helps. Yeah. I talked to [a newly admitted patient] at lunch today and I'm like "You'll get used to the schedule. I know it's different. Your body has to get used to it" (Cara)

> “[another patient] was asking me about that – about the when does the numbness go away – I said, it is like when your hand goes to sleep, eventually it comes back. He was asking me if I had a swallowing thing and I said no – but he was worrying about getting to eat normal food again instead of the thickened stuff he is getting. (Gary)

Shared Experience with Significant Others

A stroke does not only affect the patient. Friends, family members and significant others are affected by the stroke and the rehabilitation process as well. Family members are key supporters for the patient, but often make changes in their own life as a result of the education they acquire from the process.

Family Support and Involvement. The patients were very grateful for the support of their friends and family during the rehabilitation process, for they were the ones who ‘picked up the slack’ at home, and provide essential moral support to the patients.

> ..it's not like I'm deathly ill or that I'm depending waiting for him on berated breath to keep my company, so we're fortunate that I'm in the state I'm in. And I've also got a lot of support, my two daughters come, my brother, my brother-

> in-law. So again that makes the whole thing a lot easier if you have that physical and mental support. (Colleen)

Significant Other's Changes in Behaviour. Lifestyle changes were not limited to the patients, as family members were making changes to their lifestyles as well. Families were decreasing the amount of salt and fats they consumed, were trying to incorporate physical activity into their routines and many had quit smoking. Nora identified a need for "family rehabilitation" which would give the family members the same information about healthy living:

> "But I said to one of the girls, I said, I said when they, when somebody has a stroke, or something, they almost need to have stroke rehab for the patient and stroke rehab for the family because everyone's life changes. Well, this family is not going to eat salt any more. Or we're not going to do this…"— (Nora)

The changes in behaviour did not extend to friends. Gary noted that "his friends felt bad for me, but they haven't ever had anything like this in their lives", which was echoed by Cole, and his perspectives on his friends;

> "My friends – they are worried about me – but they don't think about themselves. I try to explain it to them but they keep saying "no, that won't happen to me – you might be one in a million" but I keep saying that it happens to a lot of people and if something happens this conversation will come back to them…"

Shared Element: The Significance of Food

Hospital food is a very important part of the patient experience. No other aspect of the patient experience garnered as much time and attention in the interviews as the food and more broadly, the meal service. Although the meals provided by the hospital are designed by clinicians to help patients achieve their rehabilitation goals it became apparent that to patients the food had much more significance. The bonding between patients over the food suggested that it was significant socializing force– it served as a social bond between patients, reinforced the social distance between clinicians and patients and served as an indicator of time spent on the unit and the move toward recovery.

Patients believed that the food and meal plans were designed to meet nutritional needs and represent a 'healthy diet'; with almost patients losing weight - not by design, but rather as a result of the food being unpalatable.

> "The dietician is right – we can't do menus for everyone –but can't they make the food taste at least a little bit better? I might actually grow to like some of stuff... I have lost some weight while I've been here – not because I was trying but because of the diet. I am starting off on a pretty bland diet to begin with, and now they are cutting out stuff you like – all I asked for was a banana a couple of times a week you know, a) potassium is good for you and b)… well anyway –they did give me a banana but it was a frozen banana... I guess wherever the food comes from... I guess it got frozen in the process." (Kendra)

> Over the course of multiple interviews with patients, it is becoming apparent that even the most tolerant of patients have run out of patience with the food. Walter, Kendra, Cole, Nora, Colleen, have all over the course of their rehabilitation moved from an attitude of tolerance regarding the food to stating their frustration with how bad the food tastes. (Researcher Field Note)

The menus lacked flavor and variety and the patients resorted to bringing food from home, or they went to the cafeteria for supplements/replacements for unpalatable meals. The food in the cafeteria was really good in comparison to the meals on the unit, making patients wonder why they were not be served food made by the hospital staff.

> “I almost lost it one day last week. Both the lunch and supper that day I couldn't do it. It was like a three week cycle or whatever, and I've had those meals before and I've eaten them. Whereas now I'm not going to eat them. I'd rather not. I'll go downstairs or not eat at all. I phoned my husband and he didn't get here til about 7:30 and he said "Do you want me to bring you something?" and I said no because I don't like eating late? But the next day he brought me food from Wendy's. (Colleen)

The food served a significant social role in the rehabilitation program. Talking about the food was akin to talking about the weather. It was a common experience, and one that almost everyone had thoughts and opinions to share.

> It seems to me that the discussions about the food and the whole meal experience are part of a social ritual – it can serve as an icebreaker conversation, stimulate discussion and create bonding between the individuals who have to eat it. Today I felt like talking about the food was the hospital version of 'talking about the weather (Researcher Field Note)

When one patient was ready to be discharged, she confessed to another patient that she felt guilty that she was going home to 'good food' and they would have to stay and eat whatever was for dinner. Complaining about the food, although seen as a futile exercise, was noted as a potential signal of improvement and was suggested by Kendra to function as motivation, albeit negative, to work hard and strive for her discharge date:

> And my brother was here the next day and he said "The only positive thing about that is that you're getting better. That you can complain and say I'm not going to eat that. Because two weeks prior you would have eaten it." (Colleen)

> I mean really – it is motivation to get better in the 6 weeks so you can get the heck out of here I said, well, if the food wasn't so bad I might not mind staying for another couple of weeks... (Kendra)

Discussions about the food illuminated a disconnect between clinicians and patients, as many patients questioned whether or not anyone on staff had even tried the food or subsequently understood their experiences.

> I don’t think the dieticians have actually eaten the food in this place – and I am willing to bet that the staff, the doctors and nurses haven’t eaten it. Maybe they don’t realize, if I only had one bad meal here once a week that would be one thing, but I am eating two for sure bad meals a day. Breakfast can usually be okay because it is toast, cereal.... but because they don’t ... I don’t think they taste the food – there is no seasoning on any of the food – nothing! (Kendra)

Although each patient had a consultation with the dietician upon admission regarding their preferences and dietary requirements, they were unaware that they make some choices regarding their meals. Having the ability to exert some control over one aspect of their program was important and no one turned the opportunity down.

> I didn't know that [could choose menu items] I said to the nurse maybe because I didn't sound fussy they just gave me the standard plan. Whereas like today we had roast beef which wasn't so bad, but one of the guys wouldn't eat it so he got quiche. If I had known there was a choice I would have picked something else. [Having a choice] it's like a little prize right? It's like an added thing. It (being able to choose menu options) just gives you that feeling your making choices towards my health. (Colleen)

Unfortunately, once the highly valued opportunity was made available to them, many of them reported mistakes with their meal requests which diminished their satisfaction with the process:

> I made sure to circle the roast pork so I wouldn’t get the surprise. Some of these meals – you open the lid and look at the plate and think what the hell is that? And now with filling out your own menus – you think “that doesn’t look anything like something I would order... did someone mess with my slip or paper?” But what they could do about it I have no idea, but something needs to be done – it is like they forget that we eat this food for weeks... (Cole)

Shared Element: Taking Rehabilitation Home

As the patients got closer to their anticipated discharge date, they started talking about the changes they were going to make once they left the rehabilitation program. They had started some good habits while in rehabilitation, and they knew they were going to make changes in their home lives to keep the momentum and recovery.

> So I am going to have the same kind of plan as here, I'll get in the morning, have breakfast, I'll do my exercise for the hour and then I'll go on and start...um getting on the computer and that sort of stuff and slowly start working my way to getting back to that stuff. (Cole)

Kendra noted that making all the changes in the short time of rehabilitation was a difficult process:

> “but you can’t start shoving all these things on me starting on Monday. You can’t change that much life that quickly... you know. You gotta let me get over the smoking part too – that is a big – that was a big part of my life – the smoking. I know that I have to keep the changes going at home”.

When asked if they were prepared to go home, patients expressed apprehension about being able to keep the momentum going on their recovery, and wondered what life might really look like once they were home. They were aware that they would not be able to drive or go back to work, but they were just looking forward to finally getting home as they had been in the hospital for ten to twelve weeks at that point.

Beliefs and Attitudes about Being a Patient

Global Attitudes about Health Care

All of the patients had prior experiences with health care. When asked to describe and rate their previous experiences with health care, most of the patients gave the health care system a positive rating. Several patients gave kudos to the health care system for the care they received in both previous experiences and their current stroke although they noted there is positive and negative in everything. One patient felt quite positive about the health care system, but felt as though she shouldn't say anything too complimentary as it seemed to go against public opinion:

> : Um...I think we got it a pretty good health system. I hate saying it out loud 'cuz everyone bitches it like it's...there's something wrong with it. But I don't really think we really have it so bad. (Colleen)

Beliefs and Attitudes about Being a Rehabilitation Patient

The overall purpose of this study was to gain insight into how beliefs, attitudes and experiences influenced people's behaviour as a patient. By exploring the elements of the Theory of Planned Behaviour through the patient's experiences, I gained valuable insight into people's goals as a patient and how behaviour was viewed and constituted.

During the initial interview, I asked patients what their goals were for rehabilitation and how they intended to achieve them. All patients indicated that their goal was to recover as quickly as possible and be discharged, and that being a "good patient" was how they were going to achieve their goals. Over the course of data collection (from admission to discharge) I identified a set of actions that constituted being a good patient, working to recovery and discharge.

> I try to listen to them when they say "Oh don't do that yet" or "Go slow" so I try to go slow. Yeah I try to be... I guess a good patient because I want to get out of here" (Betty)

Having a good disposition is key to recovery. Having the right attitude/disposition plays a role in therapy progress and improvement. Patients noted that taking the experience in stride or "going for the ride" made it easier to deal with the stroke and subsequent rehabilitation. Being upset and mad won't make the situation any better, therefore it is better to be easy going and have a sense of humour.

> Like I took a shower this morning [the nurse asked] "Do you need help with anything?" No I've got it under control. I just wash one half of the body that's all. I didn't do this side; this side is squeaky clean, wash this side of my head. One of the nurses said, "You're so funny". And I said "Well gotta keep you laughing. If you can't laugh what are you going to do - cry? (Kendra)

Being Engaged: Active patients do better in their rehabilitation. Patients believed that being active and engaged in the rehabilitation process and activities facilitated a quicker recovery. If patients have to get up, get moving and do some things for themselves it fosters improvement. This was noted to be a significant difference between the acute hospital and the stroke rehabilitation program.

> If you have to get up and go have your lunch, you're going to get better quicker. And also too you'll notice things that you can do better. I often wonder if it would be better off to get people up and going better. Because, like I was saying before, in the [hospital], I sat there, in my bed. I would sit there and sit there and sit there. They would bring me my food. They would bring me my medication. They would bring me everything. Here I get up and go down and you have your little, your eureka moments, I guess. You think, hey, I can do that! I never used to do that before, I can do it now. And I often wonder if that's part of why this works here. (Nora)

Patients should strive to be independent. There are several reasons why patients should strive to be independent. First, and most importantly, having opportunities to regain independence is the point of rehabilitation and shows progress and improvement. Secondly, being independent frees up limited resources for other patients and shows respect for the health care providers on the unit – as one individual stated – the clinicians are there to help, not serve:

> I don't call for help, if I need something I go and do it or get it for myself. I try to be independent. I am stubborn, but I know if I fall they will get into trouble. I

> try to do everything myself and respect that they are here to help me – not serve me. Like at rehab –we are supposed to work hard and try our best. Like at mealtimes. Sure those little cheeses are hard to open – I think everyone has trouble. But it is important to let people try, not to come running right away and do it for us. I know one guy has figured out how to use his fork to open everything for himselfcuz his left arm isn't back to normal yet. (Cole)

Patients should trust the therapists. Patient interaction with health care providers is a key element of rehabilitation and the patients noted that by following instruction, trusting the expertise of the therapists would get them to their goal, recognizing the consequences of not recovering:

> They are the professionals. They know when I can do this, yep I'm two more percent closer to getting out of here than I was Tuesday y'know? That sort of thing. No I'm not looking to step on anyone's toes and say "I'm doing pretty good". My only thought is "You know what you're doing...I hope. Y'know? And I said that to Emily and she says "Well we're going to try this." and I says "You guys know what you're doing don't ya?" "Well we like to think so." Well. Okay. You show me. I know nothing about physiotherapy. I know nothing about occupational therapy. (Kendra)

Having determined consistency in patients' intentions and behaviour (being a good patient), it was possible to: a) identify the behavioural beliefs patients had about being a "good patient", b) determining the degree to which those beliefs were supported by friends and family and c) assess what factors helped or hindered their ability to perform the behaviour.

The combination of *Behavioural beliefs* and *Attitude* reflect an individual’s beliefs about the consequences of the behaviour and the degree to which behavioural beliefs are positively or negatively evaluated in terms of achieving the goal. Patients believed that these strategies were essential in achieving their goal and consequently they evaluated these behavioural beliefs very positively.

Patient’s behavioural beliefs and attitudes are not the only factors that influenced their behaviour. The perspectives of friends/family and the perceived expectations from broader society are equally important. Most patients noted that their friends and family were very supportive of them through their rehabilitation, but noted that there was a difference between their beliefs about health care generally and the approach to being a patient more specifically. The patients noted that perhaps due to personality differences and differing degrees of experience with health, their friends and family could not relate to their experience and therefore had different perspectives on “being a patient”.

> Like my youngest niece, she's like... But it's their job to do that for you Auntie! But I don't need that! I know it's what they get paid for. Like I said if "I don't need something..." I'm not saying don't pay them… but I don't particularly need it. And she says, but you need it too...if I felt like I needed it I would be the first one to say "Hellooooo? What about me?" (Kendra)

> “Uh they [my family members] don't really have a lot of health problems so I don't think they really understand sometimes. My husband might be totally different. Because he’s, he’s less liberal thinking. He’s not as open as I am. Like, I don’t know, I think he might be different. But like a lot of things, maybe we’re

> kind of half and half on it, but, he sees things differently than I do. Well, just from this last episode [referring to her stroke], he sees what's happening different. (Nora)

Through sharing their experiences, the patients identified factors that facilitated their ability to be a "good patient" and engage in their rehabilitation as well as factors that hindered participation. The supportive environment, tailored specifically to the rehabilitation needs of people who had a stroke, and the connections to other patients who can provide peer support and mentorship to recovery were essential factors that fostered being a good patient. Additionally, patients noted that being pushed by the therapists and nurses to try to do things for themselves encouraged them to progress; recognizing that clinicians wanted to help them regain the abilities they lost with the stroke.

Occasionally the patients felt the staff was too cautious with daily activities, hampering them in their ability to do things for themselves. Nora characterized this as systematic 'black and white thinking' where the individuality of the patient is overlooked by clinicians who want to follow the process:

> "but our health care system really sucks, as far as taking care of patients, because everything isn't black or white and sometimes the system wants it to be…But they're really cautious of it here with the policies. It is kind of hampering in a way, but I think it's too cautious also in a way because if you're used to doing something, you're used to doing it on your own or your way and they need to recognize that and work with you..."

A lack of information, or being excluded from discussions and decisions about their health care was identified as the predominant factor that hindered peoples' ability to be engaged in their own health care. Many patients noted that they were unaware of the specific details of their rehabilitation plan, including when they might be discharged and what typically happens while undergoing rehabilitation:

> "after I was, I was here for about three weeks, I was going, okay, what's happening, what's going on now? What's going to happen? I do try to be aware – I know that I am not a doctor – but I will remember things and I can look things up on the internet. But I don't know why they can't answer me... after all it is my body and I sure know what is going on with my body. I know that I might not understand the technical terms but I might be able to understand in lay terms or plain language. Don't treat me like – I hate to put it this way – the brain injury people – I can "google" better than most and if I am concerned about something, I can go on the internet and look things up. (Kendra)

Overall, patients identified a constellation of actions that were fundamental to their behaviour as a good patient. Being a 'good patient' was positively evaluated and supported by their friends and family even when they did not agree with the specific actions, which increased the likelihood the patient would engage in them (intention). This intention was moderated to some degree by the presence of factors that helped and hindered their ability to "being a good patient". From admission to discharge however, patients reiterated their intention to be a good patient and reported behaving the way they had intended.

Being a PHC Patient

The aim of Study II was to explore how beliefs, attitudes and experiences influenced people's behaviour as a primary health care (PHC) patient; addressing the study questions: What is the essence of being a primary health care patient? What influence does experience, beliefs and attitudes have on being a patient? The findings are presented using a descriptive, first person narrative approach consistent with the phenomenological methods implemented. The themes and composite description presented in this chapter reflect the patient's shared beliefs, attitudes and resultant behaviour about being a primary health care patient. The focus on primary health care is an emergent finding of the study. The original questions focused on health care in general, and through participant responses, the attention and emphasis on PHC emerged. This section contains i) a composite description of the experience, ii) a presentation of the key themes (shared elements) and iii) a discussion of patient behaviour.

A precise number of potential participants cannot be reported due to the recruitment strategies utilized. I received 33 contacts regarding my study, and subsequently interviewed 19 individuals. Patient demographics can be found in Table 7. Factors such as age range, education levels, employment status, and previous interactions with the health care system were noted, although they did not serve as a basis for developing participant cohorts. These factors are however noted in the suggestions for future work in this area.

Table 7

Study II Participant Characteristics

Participant	Gender	Age	Marital Status	Employment Status	Contact with HC
Pam	F	20s	Married	Employed FT	Low
Angie	F	40s	Common law	Works in Home	Moderate
Diane	F	30s	Single	Employed/Student	Low
Anna	F	30s	Married	Employed PT	Low
Allen	M	30s	Married	Employed FT	High
Greg	M	40s	Unknown	Self Employed	High
Glen	M	40s	Married	Employed FT	High
Jane	F	30s	Single	Employed PT	High
Jacob	M	50s	Married	Self Employed	High
Kelly	F	20s	Single	Employed FT	Moderate
Lorna	F	30s	Common law	Employed FT	Low
Mona	F	30s	Single	Employed FT	Moderate
Mike	M	40s	Married	Employed FT	Low
Molly	F	30s	Common Law	Works in Home	Low
Marta	F	30s	Single	Student	Moderate
Roger	M	30s	Common law	Employed FT	Low
Stella	F	50s	Married	Retired	High
Sally	F	40s	Married	Employed FT	High
Sarah	F	40s	Married	Employed/Student	Moderate

The Primary Health Care Patient Experience: A composite vignette

Health care isn't something that I really spend a lot of time thinking about, and I don't talk about it with my friends or family beyond 'I had to go to the doctor, I have a doctor's appointment', or how long I waited in the waiting room. We don't really talk about the big picture of health care like the issues, the politics etc... I would guess most of us have similar perspectives, but I don't know. If there were differences I would guess they might come from being different ages, men vs. women or how much we have had to use healthcare.

I think a lot of people take it for granted, because it is there. I definitely think everyone should have access to health care services. I think we as Canadians are really lucky to have the health care system that we have – I wouldn't want a system like in the USA where you have to pay out of pocket. I think it would be stressful, always worrying about whether or not you could afford some big health problem; especially when you hear horror stories about the American system. It makes you appreciate what you have here. Now I am not saying that what we have in Canada is perfect, but it is definitely better than having nothing at all. It is no secret that we don't have enough physicians, *and it seems like there are always issues with wait times for tests and procedures, but I am pretty grateful that I don't have to worry about whether I can do to the doctor or not – it is there when I need it. Although that makes me think about the people who are abusing the system; because there lots of people taking advantage of the system or using it inappropriately. If those people used the system responsibly, for example not going to the doctor for a simple cold, there might be enough to go around. Really, I think everyone has a responsibility to take care of themselves and not be a burden on the rest of the country; but I don't think everyone feels that way. If they did, we might not have so many obese people, smokers etcetera. I know I try to take care of myself, mostly to avoid having to engage with the health care system as much as I can…*

I feel like I have learned how to be a patient. When I was 22 I didn't really know anything about the system or how it worked. I followed the example set by my family about what was appropriate use of health care. But as I got more experience with the health care system, I feel like my behaviour has changed. I am definitely more actively engaged in trying to get the best possible care and avoid any possible negative experiences. I don't really trust the system – I know errors are made and I don't want my or any of my family to be the one that slips through the cracks.

You have to be really active and engaged; if you don't care about your health, who will? I have had quite a bit of experience with the system and I know that there is good, there is bad and there is downright ugly. Everything I do is to avoid the ugly and get the good… I have definitely gotten good at working the system – using my personal resources and contacts to make sure I am getting what I need. I don't really think this is circumventing the system or getting things that aren't available to everyone. I know that almost everyone is trying to negotiate and navigate the system to get the best possible care and avoid the bad. I am not so naïve to think that everyone can do what I am doing – not everyone has the abilities or resources I have: I know that my knowledge, education and even money can help… I can't imagine how frustrating it is for people who don't have those things.

Before I go to my doctors' appointments, I get prepared. Part of this is getting psyched up for the appointment itself and the other is making sure I have my list of topics to discuss ready. The worst part is the waiting room. Sometimes the wait can be short and other times I have sat there for over an hour. Once I am in the exam room, my appointments are usually pretty quick. I sometimes feel a little rushed but I have learned to be resistant, I almost feel like I am trying to slip one more concern in before they head out the door.

I have a pretty good rapport with this physician, it is professional but not chummy – I really don't want to be their friend. The relationship, it definitely is a work in progress; I chose him to be my doctor because I thought he was someone I could work with. At the beginning, I don't think he was as respectful as he is now. I think that is partly because of my approach, I've learned that if I am a little bit pushy (maybe assertive is a better word…), he pays more attention to me, but the other thing I think that has changed our relationship is him recognizing that I am not a difficult patient. I *come in with knowledge about my body, my health concerns and I am not there to waste his time. I think he respects that. He is the quarterback of my health care team but that isn't to say that I am sitting on the sidelines watching – we are working together to make sure I am as healthy as can be. I have to trust his expertise. I switched doctors to this one because I wasn't feeling comfortable with the care I was getting from the last one, but I really don't know what I am going to do if this one doesn't work out either. Everyone knows how hard it is to find a new family doctor. I also know I was lucky that I was able to get in with a new doctor – although I should thank my friend who got me in… I know lots of people who don't have a doctor and rely on walk in clinics for all their care.*

People talk about health care like it is a business, and maybe it should be run more like a business, but the idea of patients as customers is a bit tricky. I mean, sure, if people thought about themselves as consumers maybe they wouldn't be so tolerant of the bad, maybe they would speak up more and demand better service. But on the other hand, it isn't like any other business. If you have a bad experience with a physician it isn't like a bad restaurant – you can't just stop going. If you see a bad movie or have a bad meal, I mean it isn't really the same. Your doctor is your doctor. We are caught in a situation with little choice. And you see that, with the people who are resigned to sit in the waiting room for 2 hours – like the doctor is doing them a favour by seeing them 2 hours after their appointment.

I definitely don't trust the system entirely which is why I still work the system, using my contacts to double check things and get second opinions. I think it just makes sense; if I don't try to care about my health – who is? And everyone else is working the system – it is what smart, educated people do. I also appreciate that my doctor is using her connections as well to my advantage. I don't know why, but I don't seem to have to wait as long as other people report waiting for tests and procedures.

Overall though, I am pretty happy with how my appointments go; I am usually fairly satisfied with the interaction and usually leave feeling like I got what I went there for. Sometimes the appointments are more positive than others, but to be totally honest, the outcome is what is really important. I am okay with a less than positive experience as long as the outcome in positive. Really, the positive outcomes definitely outweigh a negative experience. I am not saying that I think everything is adequate – there is always room for improvement. Right now I think I am relatively satisfied, the government seems to be doing a good job but there is always room for improvement. Like I said, there is good, bad and ugly – so really it is my responsibility to work hard to get the good.

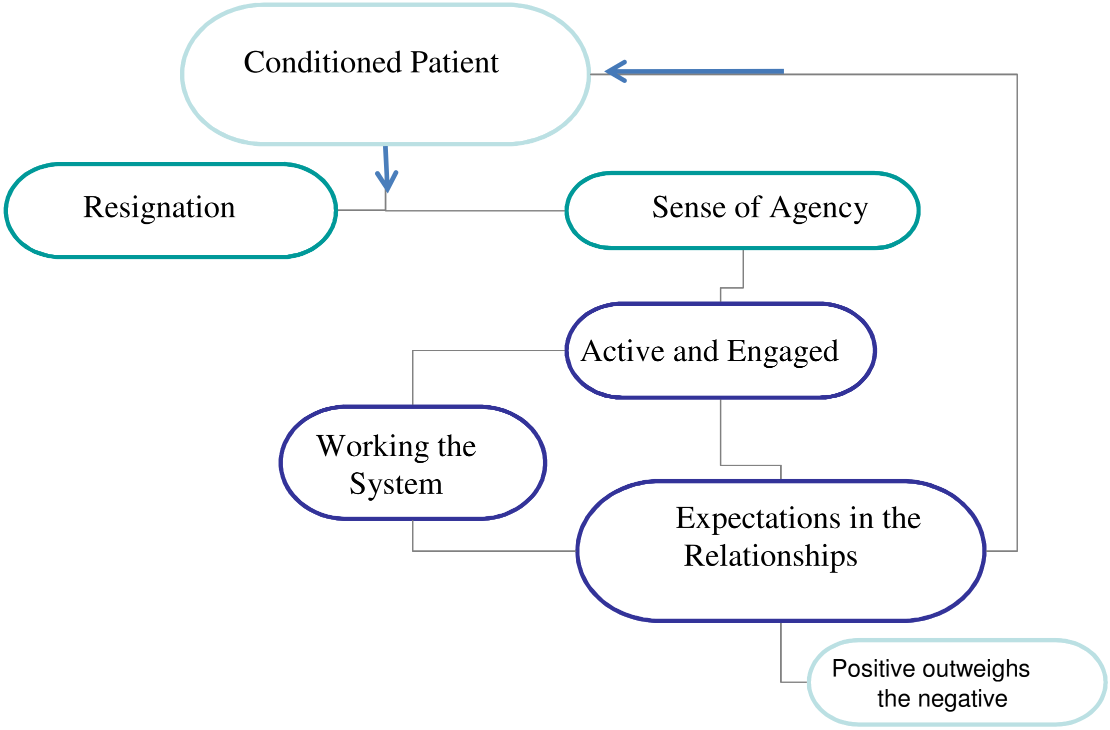
Shared Elements of the Primary Health Care Patient Experience

Seven elements were identified as composing the cyclical process of being a PHC patient, describing the 'typical' or common experience of the study participants. Figure

4 depicts the shared elements and process of being a PHC patient. Each oval contains a common element flowing from being a 'conditioned patient' to 'expectations in the relationship'. The outcome of the clinical encounter serves as the link back to the element of being conditioned starting the cycle anew.

Figure 4

Shared Essential Elements of Being a Primary Health Care Patient



Shared Element: Conditioned Patient

Due to the way PHC services are provided, patients could have several interactions with the same physician over the course of a year or several years. This ongoing relationship fosters a cyclical process whereby patients become conditioned in their behaviour. In each clinical encounter patient behaviours are 'reinforced' and/or 'punished', stimulating changes in behaviour for subsequent interactions. Previous interactions with health care providers, a fear of negative events, a perceived lack of options, and others' expectations about patient behaviour all served as the basis for patient behaviour.

Previous interactions with health care providers

Previous interactions with health care providers, and the resulting outcomes were an important conditioning force for patients. From previous interactions, patients gained experience which, "if you've been through the system you gain that knowledge, so it's not so unknown"(Jacob) making it easier to interact with health care providers on future occasions. These interactions could have been positive or negative each influencing future behaviour, with the hope of achieving the desired outcomes. If behaviour was seen as useful in acquiring desired outcomes, it was utilized again. If the behaviour was deemed ineffective or insufficient, new approaches were attempted in subsequent appointments. It is important to note that while the focus for this study was on the patients' behaviour; physicians were also seen to change their approach:

> Mona: I found that definitely I've gotten the results I'm after when I start to be pushy. I've come to the conclusion that that's the only way you're going to get action. And then it seemed like once I had the tests done; now the doctor seems to pay more attention to me. Then I felt like, now he was actually paying a little bit more attention
>
> Q: So do you think that your being assertive, pushy, to use your word, changed things?
>
> Mona: Well, now they're willing to give you your attention, right?

Fear of negative events

Although people generally had positive opinions about health care, many patients worried that there would be a breakdown in the system, and that they or their family members would suffer negative health events as a result. Patients feared they might not get the ‘best’ or ‘right’ treatment, or that they would be the one forgotten about, ‘slipping through the cracks’. Patients had faith in the system, but knew that mistakes happened. Every patient was able to reference at least one story of a person who ‘slipped through the cracks’.

There is also the fear that overburdened physicians cannot keep track of all their patients. Patients often felt that their doctor did not remember them or their health issues from one visit to another; making the question the quality of the care they were receiving:

> “But sometimes, and more recently I kind of do feel that my doctor loses track of me sometimes, forgets what medications I’m on exactly. And sure I have changed them a little bit here and there, so I can understand a bit of that - but it makes me nervous. I would think there should be a way that the accuracy on all those things should be very easily followed for physicians. It makes me wonder if I am getting the right treatments at times” (Glen)

To address some of these concerns, patients had started implementing a check and double check process regarding appointments, prescriptions, and follow up care.

Lack of options

The more patients talked more about their health care, the more they noted that they were not entirely happy with the services available to them. People felt that they lacked options limiting their ability to make choices in the pursuit of good health. There was an awareness that it is not easy to find a family physician, which made patients appreciate that they could go to the doctor at all. Being appreciative that they had physician did not stop patients from voicing their frustrations, which only exacerbated the perceived lack of options. Patients were often waiting for a new physician to become available, viewing their current physician as a better than nothing alternative:

> I don't feel I'm in a negotiable position. I feel like until I have a plan B I don't put myself in a bad situation. So plan B would be another doctor that would see me, But the fact is that I have few choices. The fact that if I went somewhere else it would be the same thing. First I don't have somewhere else to go - do I go to a walk-in clinic? Where I'm facing a similar situation there? They don't' have my file; they don't know my history. I'd have to go to many different places to get the tests done. The minute someone says to me I have a great doctor and he's seeing new patients. That's the minute I leave. (Greg)

Patients believed they were lucky to have their current level of access to health care services, “particularly compared to the United States”, but qualified their responses that what was available was good; certainly was better than nothing:

> “I do have a huge appreciation for the fact that I can go to the doctor without thinking about it. And that I do appreciate the fact that anyone in this province, anyone in Canada, if something happens to them, they are able to go to a doctor.

> I think that’s a really big deal. I do have frustration with the way that it works. But I guess my frustrations are weighed out with, well, I could have nothing… or I could have this. So, it’s not necessarily where I want to set the bar, but—“(Kelly)

Expectations regarding patient engagement

Patients’ interactions with their health care providers were influenced by messaging they received about how to be a patient, as exemplified by Greg’s statement, “well I guess it's, we're all y'know, victims of our histories and training and our experiences”. For many years, there has been a culture of deifying physicians which patients are now starting to question. Familial attitudes about accessing health and being a patient held a great amount of influence into adulthood. Roger recognized that his family’s lack of engagement with health care guided his interactions as an adult:

> “Because I was living with my parents, I guess, that could be part of it. If it had been important that we did our yearly checkup and got a physical done, I probably would have kept on doing it after moving out. But because it never really happened, and my dad really shared the same attitude toward health care, it sort of happens— My dad, he never went to the doctor. So because it was not a priority at home, it wasn’t a priority for me. (Roger)

Utilization of health care services is not static however, as spouses and significant others changed how people engaged with their health care providers; usually spurring people to start using more health services and take better care of themselves.

These four factors contribute to one of two identified patient interaction approaches: a) sense of resignation (disengaged patients) or b) sense of agency (active engaged patients).

Shared Element - Disengagement (Being Passive)

Although patients believed that being proactive and engaged was a better interaction style, a couple noted that their primary approach to being a patient was still more passive (disengaged) than active. Patients may be disengaged for several reasons. Some patients put their faith in the health care practitioners, trusting and following their recommendations. Others do not believe that they can instigate changes in the systems and become resigned to the inevitable. A third reason people may disengage from their health care service is to avoid having to deal with difficult or uncomfortable topics or diagnoses or as LK said, “sometimes ignorance is bliss”.

Even among patients who described themselves as ‘passive’ or ‘disengaged’, passivity was viewed as problematic. GY noted that “any time you’re too passive, it is a problem. So I think I should obviously be more proactive, whether that’s with my health care services, or obviously with my own personal health issues. So I have to be more proactive”. Patients who described themselves as ‘passive’ however contributed content to the other key elements, indicating that they were behaving in a more active engaged way than they described.

Shared Element: Sense of Agency

In contrast to those who felt that they lacked the ability to influence their health care, most patients described themselves as being very active and engaged. Although not naming the concept of agency, most of the discussion surrounding being an active patient focused on the idea of being able to act as an agent of change. A sense of agency bolstered patients' engagement in their health care as exemplified by the perspectives put forward by Stella and Sally.

> You can be an agent of change, you can make things happen you have to know the system, identify gaps and you can do something about it. If you just sit back and say "Oh my life isn't very good or I'm not satisfied" well nothing is going to really change! And so I see myself as an agent of change. (Stella)

> I see my role as an agent of change. And that translates completely into the healthcare system. Where you have to make things happen, you have to identify what you need. (Sally)

Shared Element: Engaged Patients

Patients agreed that being an active patient is better, describing their interaction style as 'very active', 'engaged', 'pushy' or 'attentive' – all terms that connote active participation in their health care interactions. Patients believed that they would get better care if they were willing to be involved;

> The timelines can be pretty quick if you're willing to be involved in being active yourself, and kind of push for and stay involved in it, you can get really good care really quickly. (Allen)

> See, I'm active but I don't push it too far but if I know something isn't right, then I try to find a roundabout way to get back to, well, if you look into this further, or can you check it again, or asking, are you sure? (Molly)

As patients talked about being an active and engaged patient, many of the strategies they employed contributed to the development of a shared element "working the system".

Shared Element: Working the System

'Working the system' describes a set of strategies patients used to ensure they got what they needed in a timely fashion, including: i) mobilizing personal resources, ii) having connections and contacts and iii) acquiring knowledge of the system. Patients did not describe using these strategies as circumventing the system; they were simply using the tools available to them to expedite or facilitate access to health care services.

> "I am one of many people who have contacts and who work the system. I think anyone with an education and intelligence does their research in every way they can. You know, you go online too, and you read the doctor reviews before you go see that person, right? I think if you are an educated person and it doesn't' have to be in the health care field, then you have the smarts enough to go and do a little bit of research, or to ask some other people who would have some knowledge so that you don't go in blind." (Stella)

Personal Resources. Being able to mobilize personal resources (confidence, skills, literacy, and financial resources) was key to being engaged in one's own health care.

Not all PHC patients had access to the same resources which may put people at a disadvantage.

> I think people actually worry about health care more than I do. I have a fairly comfortable living and my wife and I are in a higher percentage of the income bracket of our community, that there's many, many people who are in that situation where finances are a real problem, and they're having to sort out all kinds of issues, health care being among those. And access to services, I think it's true that people who live in poverty, or closer to poverty, have more health issues, so I think to a large degree that they are certainly more susceptible to needing health care on a regular basis, so I'm sure they're much more worried and probably much more frustrated with different things that are not working for them. (Greg)

It can be extrapolated from the comments, that having these personal resources may help individuals access and receive better health care.

Having Connections. Having connections, relationships that can be accessed to improve access to health care take two forms: i) personal connections within the health care system, and ii) the connections of your physician. Both types are very useful in accessing the best health care possible in a timely fashion.

Personal connections are those within the social circles of the individual. Many PHC patients had friends who work in health care, and used these connections to access information and services for their family:

> So we have one friend who's a doctor so if there's something going on with our kids and we feel we're not getting answers we will call him and what do you

> think? Is this something urgent or not urgent? He will never use his connections for us because that's not professional. But he will say maybe you should call your doctor again. And ask this question.(Sally)

> And the thing is, part of it was also using contacts that I had. Because when I went to a walk in, I didn't wait, because my [personal contact] worked in the clinic, and she would take me in through the back door and bump me ahead of everybody. Unethical? Maybe. Wrong? Probably. But appreciated. Then I need to find a new family doctor. We got him because a [personal contact] was his receptionist, and got me in as his patient. And he [referring to spouse] got in because I got him as a patient. My sister got in because I had him as a doctor. It's all favours you know, because he's still not taking new patients. (Molly)

Some patients hypothesized that their physician had connections or contacts in the health care system that they could use to expedite health care services. Patients reported shorter wait times for appointments with certain physicians, expedited referrals for other services, and access to top rated specialists.

Not having connections, or not realizing the benefit of using these connections could be frustrating for people. As Jane noted, not having knowledge of the system and how to "work it"; she wouldn't think of using personal connections to access health care.

> Well, it's probably common for people who know that they can do it but again, how can I possibly conceive something if I don't know how it works in the first place? And so, when we think of networking, we think of jobs, we think of

> getting places or getting resources, we don’t necessarily think of accessing medical services. (Jane)

Knowing the System. Understanding the health care system, (how each element works and then how they work together) is essential if patients are to influence aspects of their health care. Sometimes it was important to understand the condition or medical concern in order to have input into care decision and the clinical course of action. Other times, it was important to understand the process at a specific health care clinic in order to facilitate timely access. Harry shared an experience that clearly demonstrated the power of understanding how the system worked:

> I went to [a walk in clinic] and I heard it opened at 8, so I was there by 5 past 8, found the place virtually empty and thought "Wow what a good stroke of luck" - I heard horror stories of you know be there all morning. So I had already emailed the office and said I was going to be late. The reason it was empty was because people had turned up at 7, 7:30, registered and had gone back home for breakfast. By 8:30 all these people started arriving, going in ahead of me with their numbers. Hold on, then you begin to talk to people and realize that "Oh when you come here regularly you know how to work the system"(Harry)

Information and knowledge seeking. All patients sought information. The timing of the search varied depending on the concern (sometimes before, sometimes after) but the internet was the primary search tool for health information. Having access to information about their condition and the system more broadly gave patients the opportunity to prepare for their appointments, ask questions and facilitated appropriate utilization of healthcare resources. The internet searches were not used to supplant the knowledge of their physician; rather it was viewed as a mechanism to become more engaged and participatory in the clinical process. Patient often ‘Googled’ less serious queries, but when a concern was perceived as serious, they relied on the expertise of their physician.

Patients reported seeking information regarding health conditions, treatment options and strategies for engaging with the health care system at an ever increasing rate. With this increase they are starting to assess what they consider to be credible sources of information.

The Media. Although patients wanted to have information about their conditions and the health care system; they did not view the media as an impartial or credible source of information about health care services. Patients recognized that reports in the media are often sensationalized versions of the real story:

> Today there was a glaring headline of "heart surgery patients dying before they even get surgery". Well as you read through the article it's I think 6 or 8 over the course of the last 3-5 years. And then you get to the bottom and our average is actually lower than the national average. So my response to that was how irresponsible of the media to make this glaring headline with a story that has absolutely no substance. Because our numbers are actually really okay. I don't know if I trust the media a lot as far as the health care kind of commentary I think a lot of it is politically motivated and I think quite honestly the media looks to sensationalize things and if there's something they can--regardless of the topic--if it happens to be health care, if it happens to be crime stats whatever they will jump on it. (Harry)

Although recognizing that the stories in the media may be sensationalized, patients were aware that they were influenced by the stories, and how they were reported. Exposure to topics made patients reflect on how the health care system was functioning, or instigated a search for further information to either explore or corroborate what was presented in the media.

Advocacy. Through patient perspectives, two types of advocacy were identified: informal and formal. Informal advocacy was more common, with patients advocating for themselves, and advocating on behalf of others on an ad hoc basis. The concept of formal advocacy focused on the need for paid or systemically endorsed patient advocates.

Some people, as a result of their personality were natural advocates, while others were motivated to advocate for themselves and others by circumstances in their lives (developing a health condition, having children or a sick family member):

> "it's probably because of who I am that I function so well as an advocate. I will say this is the system, if it's not working - who do I have to talk to make it work. And not everyone is like that a lot of people will say I'll have to wait until 10 months until my father can have chemotherapy, so I'll wait 10 months. I wouldn't do that I would call whoever I knew who knew someone who would call someone and do my best. May not happen but I would at least try" (Sally)

The health care system (and health care providers) does not always encourage patient advocacy. Interpersonal dynamics and a perceived power differential between patients and health care providers were reported to make it difficult for patients to advocate for themselves. Once people had developed the ability however, they often volunteered or were called upon to advocate for others. Many of the skills and abilities required of active and engaged patients translated to 'working the system' to the benefit of others, and patients believed having an advocate resulted in receiving better care:

> Well, yeah, and generally if you're in a situation where you're in the hospital and stuff, you may not be thinking clearly. You're obviously not in the best of health. You probably do need a second person being involved. I think that your health care professional's probably more attentive to people they see are being cared for and somebody's there and being involved. And I think that sometimes probably makes the difference on the type of care that you get, right? (Mona)

When patients are very ill, they are not able to focus on the administrative details of their own care. This inability to advocate for themselves, even with patients who describe themselves as active and engaged, suggested the need for formal patient advocates in the system. Some patients, recognizing the need, and not having the option available in the system, had created a formal advocacy plan in another effort to 'work the system':

> I think there should be more professional advocates. I think these people who are in need, there should be a list of someone they can call that fulfills that role. Because there's the emotional involvement and then my husband doesn't have the knowledge to ask the right questions. Or demand the right treatment. So this would be my strategy. I've made a pact with a number of my classmates. Should one of us fall really ill and be in need, we will call on one of the others to be the advocate and come in and make sure nothing gets screwed up. (Stella)

Shared Element: Expectations in the Clinical Relationship

Patients are more aware, and able to communicate their expectations regarding the relationship they have with their physicians. Patients want a collegial relationship with their doctor, one where they can ask questions without fear of embarrassment, and where they get meaningful respectful responses. Patients are no longer willing to be treated as passive recipients of health care services; they are coming to their appointments mentally prepared, with lists of concerns and questions. Patients see their relationship with a physician as a team, where each individual brings expertise to the encounter:

> I still like to think that my family physician's my quarterback and I'm not necessarily calling the plays in from the sideline, but if you have to you have to. I'm the one that's going to realize that there's a problem. (Allen)

Both patients and physicians have a set of expertise; and it is important for a team oriented approach that both participants understand their role in the encounter.

> Your doctor will help you when you have a problem. That's their job. Their job is to help you with a medical issue or illness. I don't think that it's necessary to know everything that a doctor needs to knows, but I know myself and that is my job. (Marta)

Patients want a collegial relationship with the physicians, but do not necessarily need the relationship to be social. Patients want to be treated respectfully and with consideration, not as a friend. Patients no longer accept without complaint long waits in waiting rooms, brusque attention from physicians and being treated as passive recipients of health care services.

> “Because when I see a doctor, I don’t want to know their golf scores and their life story and everything else. I don’t want the chit chat. I want to know what’s wrong with me. I want to know how it can be fixed, if it can be fixed. And just be, like the bedside manner should be nice but not too personal, if that makes any sense.”(Diane)

Shared Element: Positives Outweighs the Negatives

Although patients had expectations regarding the relationship with their physician, they also indicated that they were willing to tolerate unpleasant experiences in the pursuit of the best healthcare or a positive health outcome. Although participants were able to recount negative experiences they had with health care professionals, a positive outcome made up for any discomfort. Many patients are willing to tolerate “good physicians with bad personalities” (Marta) as long as they get a positive outcome. Others feel that discomfort in health care situations is expected and should be tolerated:

> Who cares how you're treated right? Who cares over a little discomfort? I mean, it's to be expected. Who cares if he was rude? If he knows what he's doing and he's going to fix the problem - put up with it. The results are what is important ...the right outcome. (Jacob)

As the number of contacts with physicians increased, patients were aware that there was “the good, the bad, and the ugly” in health care but that the number of positive experiences will outweigh the negative ones. Negative experiences are forgotten as soon as there is a positive experience or outcome to replace it. Patients believe that most of the time the system works, noting that it is unrealistic to think there would not be any negative experiences – it is a balance. Overall however, patients recognize that accessing health care serves a purpose and as long as they get what they need, they are willing to “take it how it comes”, which for the most part is positive or as described by participants “at least tolerable” (Stella).

Based on the outcomes of the clinical encounter, patients loop back to ‘being a conditioned patient’, with these new experiences functioning as an additional conditioning force. With this new perspective, they assess the likelihood that they will get what they need, and determine how they might behave in the next interaction with their physician.

Response to the Stroke Rehabilitation Vignette – Sam’s Experience

After hearing the composite description of Sam’s experience (developed from the experiences of rehabilitation patients in Study I), patients were asked ‘what about Sam’s experience resonated with you? How did Sam’s experience match what you believe about health care? The composite vignette provided to participants can be found on pages 71-75 of the Study I results.

Patients were not surprised by Sam’s hospital experience. The crowded rooms, hospital noise and lack of privacy all resonated with people whether through personal experiences or those of friends and family. Most expressed surprise at how good Sam’s rehabilitation experience was reported to be. Some patients were familiar with the rehabilitation facility and also described it as a pleasant environment that did not seem like a hospital.

Sam’s experience did not change their perspectives about healthcare; participants reiterated that second hand stories and experiences, unless recounted by someone they knew well, did not affect their opinions. Much like media representations of health care issues, the credibility of the individual telling the story is essential. Further to this, hearing someone else share their experiences with health care was reported to have very little effect on their own intentions and behaviour.

When asked “If you were in his situation, what would have done or expected?”, participants did not feel that they could respond because “until you are there, you don’t know how you’ll be” (Angie). Others speculated that their strong advocacy approach would carry thorough to other clinical situations:

> “and as long as I have the physical ability, I imagine that I will always advocate for myself. In the situation that you gave me of Sam, I imagine that I would always advocate, including refusal of service- that kind of thing, if I ever go to that point that I was diagnosed with something that I was, like, no, I’m not taking that treatment. It’s my body, my life.” (Jane)

Beliefs and Attitudes about Being a Patient

Global Attitudes about Health Care

All the PHC patients reported having a number of prior experiences with health care, from regular check-ups, diagnostic tests, minor procedures and some serious illnesses. When asked to describe and rate their previous experiences with health care, patients positively rated their care and the system. Patients were appreciative of the health care system in Canada, but believe it could be delivered more effectively and efficiently. There is a perception that health care is a scarce resource and that government needs to re-evaluate how health care is currently being delivered and whether or not it is meeting the public’s needs.

Beliefs and Attitudes about Being a PHC Patient

The overall purpose of this study was to gain insight into how beliefs, attitudes and experience influenced people's behaviour as a patient. By exploring the elements of the Theory of Planned Behaviour thorough the patients' experiences, I gained insight into their behaviour and how it related to their goals. During the interview, I asked people to share their experiences with health care, and how they would characterize their interactions with their health care providers. From their responses, I was able to ascertain their perspectives on being a patient; how they defined or described their behaviour as well as their beliefs and attitudes about being a patient.

PHC patients are engaged in the health care system to maintain their health, which they equate with getting the best possible care (goal). Being a patient was not a single behaviour, but rather a constellation of actions or strategies targeted at that goal. Through the data collected from PHC patients, a set of actions and their corresponding beliefs were identified.

Health care is a scarce resource. Patients noted that there are many people who have difficulty accessing and utilizing health care services due to shortage of physicians. Patients were aware that wait lists for certain procedures can be long. Inappropriate use of health care resources by other patients was identified as a contributing factor in the scarcity:

> I think it's because there's a lot of people that are sick and can't get to the doctor or don't have a doctor and that's a big problem. Lots of people don't have a regular people who don't have a regular doctor. I know at least 5 people that don't have a regular doctor. If these people who don't actually need to see the

> doctor stop going there would be more time for patients who don't have a family doctor. And need to see one. (Marta)

If I don’t care, no one else will. Reinforcing the need to be an active and engaged patient was the belief that people have to look out for themselves. The onus of responsibility for health is with the patient because no one else will be watching out for your well being.

> “But I think anything that you involve in your life – whether it’s business or career or what have you—as proactive as you are, the better the situation. Really it boils down to – if you don’t care, who else will?” (Pam)

Active patients get better care. As previously identified, patients believed that being active and engaged would result in their receiving better and more timely health care.

Having determined consistency between patients’ behaviours and intentions (getting best care) it was possible to determine i) the behaviour beliefs about being an active patient, ii) the degree to which those beliefs were supported by their friends, family and the broader society and iii) assess what factors helped or hindered their ability to perform the behaviour. The combination of behavioural beliefs and attitude reflect an individual’s beliefs about the consequences of the behaviour and the degree to which the behavioural beliefs are positively or negatively evaluated in terms of achieving their goals. PHC patients clearly articulated that the previously described strategies were essential in achieving their goal of accessing and receiving the best health care possible by being an active patient. Consequently, they evaluated these beliefs very positively.

As previously noted, the behavioural beliefs and attitudes of patients are not the only factors that influence their behaviour. The perspectives of friends and family members as well as the perceived expectations of the broader community have influence. PHC patients, although noting that the beliefs and actions of their family was an important socializing force – did not recall discussing health care or the role of being a patient with friends and family. Patients speculated that their perspectives would be similar but noted that any conversations they may have had about health care were likely superficial. It was also noted that there is a social expectation that people assume responsibility for care of themselves:

> I think that the general expectation for people is that they will be proactive in their health - it's more of a "You need to take charge of your own health". (Angie)

Through sharing their experiences, the patients identified factors that facilitated their ability to be an "active patient" and engage in their rehabilitation as well as factors that hindered participation.

Having a physician that was willing to engage with their patients as partners in the care process was essential to being an engaged and active patient.

> "my doctor has worked with me so I don't have to take medication for some of my problems. Then he was fine with that, he said as long as you know what you can and cannot eat and what you can control then there is a reason yes why you have to take this medication. I don't know I guess we work well together" (Lorna)

Not being able to ‘work the system’ is a factor that hinders people’s ability to be active engaged patients. Participants identified several characteristics that enabled them to be active and engaged (resources, contacts, advocacy), therefore it can be extrapolated that not having these characteristics may constrain individuals’ pursuit of best health care.

Patients recognized that regardless of how much they ‘worked the system’, their scope of influence only extended so far. If physicians are unwilling to work collaboratively, patients lack the range of options to make a change. Several participants’ physicians had instituted a ‘two concern rule’ for each appointment which made it difficult for patients to address all of their concerns. Finally, unlike many other industries, health care is not driven or directed by patient perspective. This fundamentally hindered the patients’ ability to influence the care process:

> Society lives on word of mouth. That's just the way we are. If you tell all your friends that you had the worst dining experience ever at a restaurant they are probably not going to go there because "Well she said it wasn't very good'…can you do that with your doctor? You can't do that with your doctor. Your doctor is your doctor. You go to the ER, you don't like somebody because they got a bad review, you can't say "I'm not taking that doctor, get me the next on the cycle". Healthcare doesn't work that way. (Marta)

Overall, the patients provided insight into the set of strategies that were foundational to their behaviour as an active engaged patient. Being active was positively associated with the goal of getting best health care and was deemed essential by the broader community. Patients noted that their behaviour was generally consistent with their intentions; adjusting their behaviour to accomplish their goal.

Similarities and Differences between Patient Experiences

One of the aims of this research study was to explore the commonalities and differences between patient experiences in different clinical contexts. Participants of Studies I and II shared their experiences being a patient. Composite descriptions of the experiences were developed and served as the basis for a comparative analysis. Several similarities and differences between the experiences of rehabilitation and primary health care patients were identified.

All of the patients had prior experiences with health care and believed that Canadians are fortunate to have universal health care, particularly in comparison to the system in the United States. Participants felt it was important for all members of society to have access to health care services. This did not mean that patients were fully satisfied however, as each group identified aspects of the system that could be improved (for example: waiting list times, access to services, and the engagement of the patient). Both groups felt that health care was becoming a scarce resource, with more people needing services and less available options.

All patients believed that people have a responsibility to take care of themselves and be proactive in their own health care. Patients should be actively engaged in their own health care; identifying ‘being active’ as a key element of being a patient. Both participant groups were very *goal oriented*; but the goals themselves were very different, revealing a significant difference between the groups. PHC patients were trying to ensure they got the best health care possible, while rehabilitation patients believed they were already getting the best possible care. This distinction became evident in relation to patient behaviour. For rehabilitation patients, the goal was to recover and be discharged; and therefore all their behaviour was specific to achieving this goal. Primary health care patients were focused on making sure they got the best health care possible, avoiding adverse events, and as a result engaged in strategies that they believed would help them get best possible care.

Both patient groups noted that being '*active patients'* was essential to achieving their goals. Each group however defined 'active' differently – the rehabilitation patients talked about active as getting up and around, following the therapists' directions and working on the necessary skills on their own. Active for PHC patients meant being engaged in the system and identified a set of activities (working the system) that fostered their participation. Patient conceptualizations of 'being active' directly translated to their approach to being a patient (their behaviour).

PHC patients '*worked the system'* in an attempt to manipulate the circumstances of their encounter while people in rehabilitation, believing they were getting best possible care tried to work *within the system* to accomplish their goals. In other words, people in PHC tried to manipulate and manage the system to get what they wanted while people in rehabilitation tried to model whatever behaviour would get them out of the hospital as quickly as possible. This was apparent in their behaviour beliefs, each group positively evaluated the behaviours that would help them accomplish their goals.

For both groups, the experience of being a patient was socially constructed, or created in conjunction with others. In PHC, the primary contact was the physician, while rehabilitation patients engaged with many individuals (several types of health care providers, other patients and friends/family) who influenced their experiences. The nature of these interactions with health care providers was different between PHC and rehabilitation patients viewed the clinicians as content and process experts and enjoyed the social contact with the health care providers. PHC patients did not want to engage in a friendly or overly social way with their physicians. PHC patients desired a collegial, business like relationship with their physician and were not willing to follow blindly

All the patients, regardless of group wanted *access to information* about their conditions, treatment options and likely outcomes. Rehabilitation patients often felt that they were not kept informed whereas PHC patients were more proactive in seeking information from their physicians. When this information was not forthcoming from the physicians, the patients admitted turning to the internet for health information, which they in turn took to their next interactions with their health care providers. Rehabilitation patients also turned to the internet for health information.

Although there were commonalities between the participant groups shared experiences, it is important to note that the frame of reference and context for their reflections differed significantly. Being a rehabilitation patient in a tertiary hospital environment was very different from accessing and receiving community based care, which was reflected in the data collected. Stroke rehabilitation patients described and reflected on a current experience in their life, while PHC patients had to recall, recount and reflect previous experiences. Rehabilitation patients shared their experiences within a single context (the hospital program), while PHC patients had to select experiences out of a potentially wide array of clinical interactions to answer the questions. It is also important to note that the experience of being a rehabilitation patient occurred within a consistent network of health care providers simultaneously over a very intensive time period, while the PHC patient interacted with a very small number of individuals and most often with a single physician sporadically.

In general, for PHC patients, their beliefs, attitudes and experiences help to shape behaviour and interaction. The opposite was true for rehabilitation patients; they shaped their beliefs, attitudes and behaviour to match their goals and expectations within an experience.

CHAPTER 5

Linking to the Existing Knowledge Base

The information presented in this chapter relates the composite experiences to the existing literature, the identified conceptual grounding, and the theoretical framework; addressing the objectives of this research: (a) to understand the experience of being a patient from the perspectives of rehabilitation and primary care patients; (b) explore how beliefs, attitudes and experiences influence patient behaviour, and (c) compare the findings from each patient group to determine if patient behaviour is consistent across clinical contexts.

Although there were similarities between the shared elements of the experiences, each patient experience was contextually dependent and specific. Therefore they are discussed first separately within this chapter, and in comparison within a discussion regarding patient behaviour.

Being a Rehabilitation Patient

Being active, engaged and focused on goals is a common approach to being a rehabilitation patient (Hafsteinsdottir & Grypdonck, 1997). The patients in my study stated they felt lucky to be in the rehabilitation program and believing they were receiving the best possible care, trusted the expertise of the therapists.

Being in physical rehabilitation was a novel experience. Patients, attempting to describe the experience, used terms like ‘refuge’, safe haven’ and ‘hotel’; all terms that connote being separate from the “real world”; not ‘a hospital’, but not ‘home’ either. Becker’s (1997) work on limbo, or the anthropological concept of ‘liminality’ (the time after a disruption to one’s regular life before beginning to restore order), is a useful perspective for stroke rehabilitation. Research suggests that for individuals no longer receiving acute services, and are focused on discharge planning, the hospital unit may represent a ‘liminal space’ (Purves & Suto, 2004). Much of the patient experience, and interview content, focused on what had occurred (the stroke story) and the process of being discharged. The shared element, *focus on time*, is particularly relevant to the idea of being *betwixt and between*. Time takes on a new meaning and importance to patients (Holloway, Smith & Warren, 1998); and Giddens (1987) suggested that people become more aware of time when it becomes a problem. This was evident in the patients’ reflections; they were aware of how long they would be in the hospital, the events, special occasions, and holidays they were missing, and structured their days by the time management processes of the hospital.

Also contributing to the sense of being in limbo was the markedly different and pleasant physical environment of the rehabilitation unit and facility as a whole. There is a growing recognition that hospital environments can have a significant effect on patient outcomes (Ulrich, Zimring, Joseph &Choudhary, 2004); with the potential for patients to correlate better quality of care with more pleasant environments (Gottlieb, 2000). Rowlands & Noble (2008) noted that there is limited evidence regarding the effect of environment on quality of life; however, based on what evidence is available single bed rooms are generally preferable to shared spaces, although a number of patients prefer the social contact of multibed rooms (Lawson, 2004; Ulrich, 2004). Patients of my study were very positive about the rehabilitation unit environment, noting that the private rooms and bathrooms made for a much more enjoyable stay.

The most common complaint participants had was about the food. Food is an important aspect of being in the hospital, and the longer people stay, the less satisfied they become with the food (Stanga, Zurfluh, Sterchi, Tanner &Knecht, 2003). Naithani, Whelan, Thomas, Gulliford, & Morgan, 2008, noted that under-nutrition in hospitals is common, and patients often report having limited access to food. This is consistent with the findings of my study; patients became less satisfied with their meals over the course of their rehabilitation, despite having the discovered and acquired the ability to choose their own menus. They also expressed frustration with the lack of choices, the timing of the meals (many of them felt dinner was served too early) and reported accessing food sources off the hospital unit to supplement their diets, all of which is consistent with literature on the importance of food services in hospitals. The focus on food also served a social function –providing a way to break the ice and make connections; and was equated to the 'hospital version of talking about the weather'.

Rehabilitation is a shared experience; shared between patients, health care providers, and friends and family. Patients expressed gratitude and genuine liking of the clinical rehabilitation team members, viewing them as the experts in their recovery process. They expressed a high level of trust in the clinicians' expertise and were compliant with recommended therapies. Attachment and a strong working alliance between patients and health care providers, including trusting and liking the health care provider, is predictive of adherence to the treatment for many medical conditions (Bennet, Fuertes, Keitel & Phillips, 2011), which may help explain the reported compliance of patients. No data was collected regarding strategies implemented by therapists to promote adherence to treatment plans, and therefore further work exploring this topic from both patient and health care provider perspective would be beneficial.

The high degree of trust patient felt in the relatively short period of time contradicts the findings of Kao, Green, Davis, Koplan, & Cleary (1998) who found that a longer relationship between patient and health care providers increases a patient's level of trust. Cunningham (2007) notes that the severity of a disease influenced a patient's level of trust in their health care provider.

Researchers have suggested that rehabilitation overly focuses on physical function, and that non-physical needs are often not adequately met (Morris, Payne & Lambert (2007). Patients of this study reported contradictory relationships with the clinical team members. Patients often stated that they had very positive experiences and that the clinicians were very supportive of their emotional needs. At the same time, patients also reported feeling like they were being talked to or treated like children, or that the clinical team members were being disingenuous in their communications; particularly around motivation and validation of therapy activities and progress. Although health care providers are concerned about the professional and ethical aspects of being overly 'friendly' with their patients (Tariman, 2010), study participants craved and appreciated personal contact with them. Watson (2006) discusses how caring is a person centred, human to human relationship and only when clinicians honour the human being can authentic caring occur. Authentic caring, or when both participants come to the clinical encounter as people first, seeking connection, can lead to emotional well-being for the patient and increase the trust and comfort level with the health care provider. Consistent with Watson's theory of caring, after being involved in a "noncaring” encounter, patients reported feeling humiliated, feeling helpless and vulnerable, particularly as it related to personal activities like bathing, dressing and toileting.

Connecting with other patients was a very important aspect of rehabilitation. Holloway, Smith and Warren (1998) note that patients use social interaction as a way to pass the time while in hospital; which was one of the key functions served by other patients in my study. Patients functioned as a peer support group, a reference group and a social outlet for those unable to leave the hospital. Patients spent much of their time outside therapy playing cards, reading the paper, and watching television together. Most literature on the interactions occurring in health care has focused on the interactions between health care providers and patients. Album (1989) however, noted that even when the length of stay was short, interactions between patients was intense. He also suggested that patients talk amongst themselves to create an informal help system because the medical frame of interpretation is not sufficient. This was consistent with the finding of my study; patients talked about all aspects of their experience – their illness, hospital processes and their therapy. In addition, the presence of others going through the same experience provided a base of role models which served a very important function in helping patients form self efficacy beliefs which will be discussed within the section on self efficacy and locus of control.

In addition to providing support, family members were actively involved in the rehabilitation process. Family members’ engagement was considered so important to patients that the concept of “family rehab” was proposed. This idea is supported by research showing that patients are already engaging friends and family in their rehabilitation process and that family members are affected by the stroke as well

(Hafsteinsdottir & Grypdonck, 1997). Patients of this study involved their friends and family members in goal setting and discharge planning, which is consistent with the literature (Cott, 2004). Family engagement in goal setting (Siegert & Taylor, 2004) and discharge planning (Bull et al, 2000) can improve the well-being of patients and the family members as well as increasing compliance with rehabilitation treatment plans (Cardol, Groenwegen, Spreeuwenber, Van Dijk, Wil & De Bakker, 2006). The family's role in stroke rehabilitation and community reintegration has increased in the last few years, and families are assuming more responsibility for more domestic and care activities (Waters et al,2001). Patients' dependence on family support for care and other activities of daily life requires more focus in discharge planning; and has been noted as an important area of future research (Nelson, 2006).

The Romanow Report (2002) stated that Canadians are entitled to make informed decisions regarding their personal care, and to receive all information and medical documentation related to them, while respecting the judgment and expertise of health providers. Health care providers have a responsibility to ensure that the health care system places the highest priority on the concerns and health needs of patients and to provide information to patients on treatments, related services, and available alternatives, while taking into account the preferences of their patients. Rehabilitation patients indicated a strong desire for information about their diagnosis, treatments and discharge process; expressing frustration if information was withheld, which is a common complaint (McKain, Henderson, Kuys, Drake, Kerridge, Ahern, 2005). Maclean (2000) noted that for rehabilitation patients, having access to information about their treatment plans, goals, and decisions about discharge helped patients understand the rehabilitation process and to see they were making progress, which was apparent in this study. Patients were able to measure progression and improvement through clinician feedback and often sought additional information about their stroke, functional deficits and prescribed therapy activities online.51% of adults with chronic conditions have looked online for health information; and having a chronic condition (such as a stroke) increases the likelihood that an individual seek health information about a specific disease or medical problem (Fox and Purcell, 2010).

Being a Patient in Primary Health Care

Primary health care patients were focused on accessing and receiving the best health care possible, in an effort to avoid ‘falling through the cracks’- which is a common concern (Soroka, 2007). Despite reporting positive attitudes toward health care, feeling lucky to have universal health care and not having had any significant negative experiences, achieving their goals did not affect their perceptions about the quality of their care. Canadians, despite having had positive experiences with health care, and becoming more optimistic about the future of the system, generally have a low level of optimism about health care (Soroka, 2007).

Patients believed that people have a responsibility to take care of their health and wellbeing, not burdening the health care system unnecessarily. This perspective was evident as patients stated that people have to ‘take care of themselves’; and expressing how “appropriately” they used the health care system. Primary health care patients defined their engagement as an active approach, but based on their shared experiences, their actions may be more accurately viewed as a ‘proactive approach’; in which patients act in advance to deal with anticipated difficulties. Most of the activities that comprise the "*working the system*" element could be more aptly characterized as pre-emptive strategies to influence the outcomes of their health care, in order to access and receive the best health care possible. Common reasons for a proactive approach included: a fear of experiencing negative health events, previous encounters with health care providers, and the sense that people have to "look out for themselves because no one else will". This is consistent with the work of Glaser and Strauss (2009), who note that while the average person may not attempt to exert leverage over their physicians, individuals who have enough information, or have had previously unsuccessful encounters may realize they have some degree of control and start exerting it, shaping their encounters.

Although each participant group talked about their *relationships* with their health care providers, how the relationships were viewed and constituted were very different in each clinical setting. Primary health care was a cyclical relationship of intermittent contacts with the same physician over several years. This long standing relationship fostered patients' ability to 'work the system', creating opportunities for them to negotiate and renegotiate their relationship over time. PHC patients incorporated new strategies in their clinical encounters and evaluated the consequences. PHC patients viewed the relationship with their physician as a partnership, working as a team; the physician as the quarterback with the patient actively engaged, but not following blindly. On several occasions patients indicated that they were unsure if their physician remembered them and their health concerns from visit to visit, which made them worry, decreasing their level of trust. This was consistent with the work ofLamarche et al (2010) who noted that primary health care patients were least pleased with the quality of their relationship with their physicians (including the physicians' knowledge of them), and the quality of their communications.

An interesting finding of this study was the tolerance PHC patients expressed regarding negative experiences. Patients unequivocally stated that a positive outcome will outweigh any negatives. The tolerance of negative interactions in primary care was surprising; as it may be thought that patients would be less tolerant of negative interactions with health care providers they see regularly over a long period of time. Perhaps focusing on the goal or anticipated outcome of the clinical encounter is a coping mechanism to deal with the perceived lack of option for care? Patients expressed frustration with difficulties changing physicians and often stayed with their current doctor because they 'had nowhere else to go'. Although research has shown that women are more likely to change physicians due to dissatisfaction with care (Weisman, 2000), in my study participants of both genders expressed this concern and reported changing physicians due to concerns regarding quality of care. Additional work examining patient experiences should explore this concept of risk or negative event tolerance and the effect it has on patient behaviour and health outcomes.

Having information about conditions, prognosis, and treatment plans was very important to patients, and they often used the internet to search for health information. Iverson, Howard and Penney (2008) note that the availability of health information online fosters active engagement of patients in their health care by increasing their knowledge, competence and engagement in shared decision making. Canadians spend43.5 hours a month on the web which is twice the global average (Globe and Mail, March 8, 2011). 70% of internet users reported searching for health information online, with slightly more women searching than men. Fox & Purcell (2010) stated that “online health resources services play a supporting role in many people’s lives as they pursue better health and navigate the health care system, either as passive recipients of advice or as active partners in their care” (p.6). Patients used the information accessed online to learn about their condition, but also to help them ask better questions of their physician, and further understand the recommendations made by the physician. Consistent with the findings of my study, Iverson, Howard, and Penney (2008) also found that over half of their study participants reported changes in the way they thought about their health after accessing information online. The same patients also reported changes in their behaviour. Specifically, they reported asking more questions in their clinical appointments, following medical advice more closely, and making lifestyle changes.

For supplemental information about a health issue or to satisfy a curiosity, PHC patients used the internet. When a concern was serious however, they relied on their physicians to address the problem; which is consistent with their belief that the physician has a valuable set of knowledge, and that not all publicly available information is credible. The lack of credibility of *media* accounts of health issues was a prevalent comment from all PHC patients. Soroka (2007) found that although individuals have positive experiences with health care, Canadians as a whole have a less positive view of the system, and the “media may be partly to blame – the increasing volume of crisis-oriented media coverage of health care may lead citizens to see a failing system even as their own experiences remain positive” (p.8.)

It has been suggested that health professionals may feel threatened by patients that attend clinical visits with Internet information (Dieterich, 2007; Henwood & Wyatt;

2004; McMullan, 2006). However, patients often have more time than the health care provider to search for information regarding their conditions; and as demonstrated by the participants of this study are motivated to find information, contributing to the collaborative relationship. Iverson, Howard & Penney (2008) noted that the effect of patient information seeking in primary health care has received limited attention; my study supports the need for further work in this area.

Comparing the Patient Experiences

A connection between the study results and the literature regarding patient behaviour and engagement became apparent when the experiences were compared as significant differences in beliefs, attitudes and particularly behaviour were identified. The shared elements of being goal oriented, being active and engaged, access and use of information, and negotiating relationships were found to be relevant in each clinical context, but were characterized differently between clinical contexts.

Patients in both clinical settings indicated that they engage with health care services with a goal oriented approach, although the goals were significantly different in each clinical context. Rehabilitation patients focused on recovery and discharge, a focused contextually specific goal, while PHC patients focused on a broader goal of accessing and receiving best health care possible, hoping to avoid falling through the cracks.

Much of the experience of being a patient is focused on the concept of being active and engaged, but the application in each clinical setting relates to the idea of patient empowerment within concepts of adherence, compliance, and concordance. Patient empowerment is the extent to which the patient exerts control over aspects of their care, signaling a move away from the traditional model of health care delivery (Lau, 2002). The terms adherence, compliance and concordance reflect the relationship between patient behaviour and health care provider recommendations (Horne, 2006).

Rehabilitation patients' behaviour can be viewed most aptly as compliant; matching their behaviour to the clinical teams' recommendations and advice. The patients' described themselves as active and engaged, but active was defined as following the treatment schedules and plans of the therapists. Rehabilitation patients described very connected relationships with their health care providers due to their intimate, frequent and intensive interactions. The clinicians, and particularly the therapists, were viewed as the experts in the clinical setting, and patients were diligent about following recommendations stating that they would not go against the therapy plan. This clinician expert perspective was evident in the patients' assignment of credit for their functional recovery.

The one area where patients attempted to exert some control was in regards to meals and menu options. Patients had several conversations with the dietician regarding their dietary preferences; ultimately, if the hospital food was unpalatable, they either purchased food from the cafeteria or brought food from home.

Although recognizing that some PHC patients may disengage from health care services, participants of this study described themselves as very active and engaged. Their approach to accessing health care could be best described as pushing for concordance; or attempting to create shared perspectives with their physicians, that would translate into recommendations and treatment plans. PHC patients wanted their preferences taken into account; and were willing to 'shop around' should the relationship be unsatisfying. Patient clearly described their ideal relationship as a partnership; one where they are on the team with the physician, not simply passively receiving care. This is evident in their approach to accessing health information. Patients were proactive in searching information, bringing it to their physician's attention and demanding specific tests and treatments. Patients reported being the driver of their relationship with their physician; due to concerns about medical mistakes, previous interactions with health care providers, and social expectations regarding participation. All of these considerations served as the stimulus for being proactive; or in some cases, the effort to drive their own health care.

Self Efficacy and Locus of Control

Self-efficacy, as described by Bandura (1977; 1994) is a person's beliefs about their ability to produce an effect or achieve an outcome; affecting all aspects of peoples' lives; how they feel, think, motivate themselves and behave. Bandura (1994) identified four primary sources for the development of self-efficacy beliefs; mastery experiences, observations of others (role modeling), social persuasion and physiological feedback.

Patients from both participant groups communicated high levels of self-efficacy. Achieving success in their separate and distinct goals (mastery experiences) was a significant source of self-efficacy beliefs for both groups. This is an important finding, as mastery experiences are considered the most reliable source of self-efficacy information (Schwartzer, 1992). Patients from both clinical settings noted that they had more confidence in their ability to achieve their goals with each success they achieved. This was particularly relevant for the PHC patients, as it served the basis for the identified process of patient engagement as a *conditioned behaviour*. When proactive strategies were attempted and proved successful, patients believed they could influence the outcome, and reported re-using those effective strategies.

Role modeling, by the reference group of other patients, was a second source of self-efficacy beliefs for the rehabilitation patients. Watching others engage in rehabilitation and achieve success bolstered the patients' beliefs that they too could be successful. For this to occur however, patients had to see the other patients as similar to them; which was apparent in the patients' appreciation for being in a hospital unit dedicated solely to stroke rehabilitation and recovery. Patients often sought out opportunities to gain motivation from others by comparing experiences and asking each other about their progress. Social persuasion, the third source of self-efficacy beliefs was also evident in the rehabilitation patients' experiences. Patients received, and highly valued, verbal support and encouragement from each other, friends and family, as well as the clinical team. It is important to note that some patients felt that encouragement provided by therapists could be disingenuous, which could have lowered patients' self-efficacy beliefs. Physiological feedback, the final source of self efficacy beliefs, served an important function for patients of both participant groups. Primary health care patients reported getting "mentally prepared" for their appointments, using the emotional arousal as an energizing force to be proactive and get what they needed from their physician. Rehabilitation patients focused on the need to have a positive attitude toward their therapy and believe in themselves. These mindsets, and the energy derived from them, were considered essential in achieving their health care goals.

Patients in both participant groups exhibited a high internal health locus of control believing that they influenced what happened in their health and health care a result of their actions. As Brincks, Feaster, Burns & Mitrani (2010) indicate, ‘”an internal locus of control suggests that positive health results from one’s own doing, willpower, or sustained efforts” (p.721). When rehabilitation patients indicated that they credited the staff for their recovery and had a high level of trust in the clinicians, it suggested that the patients may be exhibiting a high ‘powerful others locus of control’ (Helmes, Bowen, & Bengel, 2002). However, additional information about their approach to being a patient (being active, seeking information, doing extra therapy exercises, and being determined) clarified that patients believed they were ultimately responsible for their own functional improvement and recovery, with the support and assistance of the clinicians. In primary health care, the proactive patient approach clearly exhibited a high internal health locus of control. Patients questioned the authority of the physician, worked the system to exert their own influence upon their care and clearly identified their actions as being a determining factor in several care decisions and encounters.

Examining the Results within a Theory of Planned Behaviour Context

During conceptualization of this study, it was anticipated that Ajzen’s Theory of Planned Behaviour (TPB) may be a useful theoretical framework, as the aim of the study was to explore the influence of lived experiences on people’s beliefs and attitudes about being a patient. Ajzen (2011) states that behaviour is “the manifest, observable response in a given situation with respect to a given target”. An individual’s actions is influenced by three factors: (a) their attitude toward the behaviour, (positive or negative evaluation of the behaviour) (b) the subjective norms regarding the behaviour (perceived social pressures to perform/not perform the behaviour) and (c) perceived behavioural control (whether people believe they have the capability to perform the behaviour). These three factors work in combination to form an intention for behaviour. Generally, the more favourable a person's attitude and subjective norms is, with a high degree of behavioural control, should lead to an intention to perform the behaviour (Ajzen, 1988).

The behaviour of interest for this study was the concept of "being a patient", and the 'given situation', was accessing/receiving health care. Ajzen (1988) noted single behavioural observations could be aggregated across contexts and times to produce a more broadly representative measure of behaviour. In this study I sought to assess the degree to which 'being a patient' could be aggregated across contexts. More specifically, I sought to understand if people's beliefs, attitudes and behaviour as a patient remained constant or changed from one clinical context to another, hence the two clinical program study design (rehabilitation and primary health care).

Through the interpretation of data, it was determined that this theory was unsuitable for exploring and understanding peoples' beliefs, attitudes and behaviour as a patient. Being a patient was not a single, observable behaviour. Based on participant's experiences, being a patient may be described more accurately as a set of actions or strategies patients enact directed at a particular goal or, 'the target'. Based on the collective descriptions of rehabilitation and primary health care patients, the target (goal) of the behaviour was different for each group. For the rehabilitation patients, the goal was recovery and discharge from the hospital and for primary health care patients, the target was accessing and receiving the best health care possible.

Patients did not approach each interaction with health care with a set of behavioural beliefs about being a patient. Rather, during the course of their participation, patients identified, developed and adopted strategies to assist in achieving the target; subsequently evaluating those strategies more positively (positive attitude). For example all patients evaluated “being active” positively, even the patients who identified themselves as being somewhat passive. These patients deemed active participation in health care as better, and conversely passivity as problematic.

Patients noted that their friends and family, as well as the broader social perspectives contributed to their perspectives about being a patient; although the strength of their influence was limited, as most patients did not report changing their approach based on family expectations. An interesting finding from the rehabilitation patient study was the change in behavioural beliefs of family members due to their contact with the stroke rehabilitation program. Further work examining the secondary effects of exposure to rehabilitation and behaviour change would be very interesting.

All patients believed that they had the personal skills and abilities to engage in the actions or strategies to achieve their goal, and were able to identify factors that fostered or hindered their ability to engage in the behaviours. All patients were very aware however, that they did not have full volitional control over the outcome or target. For example, the PHC patients, despite being proactive and re-using effective strategies, were aware that they could not change the system, which served as the basis for their perceptions of the lack of choices or options.

Ajzen (1988) noted that single behavioural observations could be aggregated across contexts and times to produce a more broadly representative measure of behaviour. By comparing data collected in Studies I and II, it was possible to determine that ‘being a patient’ was not consistent across clinical domains. Although there were similarities in terminology describing the strategies or actions taken by patients, approach to “being a patient” was construed differently between the two participant groups. By exploring participants’ experiences and comparing and contrasting the shared elements of their experiences (within and between groups) it is apparent that ‘being a patient’ is grounded in and develops from the context in which it occurs. This finding, built upon the notion that being a patient is not a behaviour, indicates that the idea of ‘being a patient’ cannot be aggregated across contexts and times.

Contributions and Limitations of the Study

This study makes some important and interesting contributions to the literature regarding patient experiences and the influence on beliefs, attitudes and behaviour, in three general areas. First this study provides insight into the experience of being a patient, which has been an understudied topic. As exemplified in the literature review, there is a paucity of research to date that describes the patient experience, with a focus on patient centred health care. My study provides a perspective on two distinct patient experiences (a) the experience of being a stroke rehabilitation patient, and (b) what primary health care patients experience when accessing health care services.

Demonstrating the paucity of information regarding the patient experience, Peoples, Satink and Steultjens (2011) conducted a systematic review of qualitative studies examining stroke survivors’ experience of rehabilitation and developed a meta summary. During their initial search of the literature, they identified 194 studies to be scanned for inclusion; 49 met the inclusion criteria of being a published qualitative study written in English between 1990 and 2008 on stroke survivors' experience of rehabilitation in a clinical setting. Of the 49 studies meeting inclusion criteria, only 18 were included in the critical appraisal phase; six of which were excluded due to quality and criteria concerns. Twelve studies were subsequently included for data extraction. Based on the paucity of studies identified and included in the meta-summary, my study contributes to the limited knowledge pool about stroke rehabilitation patients' experiences. The findings of the presented research were similar to the summary findings, but also extends the knowledge base in this area by adding new information about the rehabilitation patient experience; particularly interesting are the ideas of (a) being in limbo or liminality and how that relates to patient experience and (b) the importance of patient to patient interactions while in hospital.

Additionally, the exploration and illumination of the PHC patient experience in general is a unique contribution to the literature. As previously noted, most of the research focused on the experiences of PHC patient examine a specific treatment, clinical situation or aspect of the therapeutic relationship. This study provides insight in patients' perspectives on the system and their approach to being a patient while not necessarily receiving treatment.

A second contribution of this work is insight into how patient behaviour is developed and reinforced in relation to contextually developed goals, and how behavioural beliefs are developed or adopted in relation to the goal. Winefield et al (1996) suggested that future work should examine the factors that influence goal setting and behaviours of the participants in the clinical consultation, rather than focusing on the measurement and validity of instruments to measure engagement.

The third significant contribution of my study is the recognition that 'being a patient' is not a single behaviour that can be observed and tested, rather it is a complex socially constructed experience that cannot be distilled into a single framework of beliefs, attitudes and intentions. It is particularly important to note that being a patient (the experience and people's approach to the experience) does not necessarily translate across and between clinical settings, which is a valuable finding for policy makers, health care administrators and clinicians.

A limitation of this study relates to the data collection techniques and procedures. When engaging in participant recruitment for Study I, patients were initially approached by the clinical staff, which provided the names and contact information of interested patients. The patients who chose not to participate in the study were most often individuals experiencing significant difficulties with their speech as a result of their stroke; citing this as the reason for declining to participate. Despite reassurances that deficits in word finding and expression would not cause difficulties for me, these individuals chose not to participate. Future work in this area should design and implement alternate forms of data collection for individuals experiencing speech deficits.

A second limitation of the study was the lack of member checking. The multiple interviews process implemented with rehabilitation patients allowed for member checking from one interview to the next; however only a single interview was conducted with primary health care patients. Most of the PHC patients indicated that they would be interested in receiving study results, but were not interested in reviewing materials from their interview and offering feedback on the accuracy of the information. This opportunity would have allowed the researcher to seek additional information or clarification that would have enhanced the data collected, ensuring that data presented accurately reflected to perspectives of the participants.

A final limitation of this study is the lack of patient engagement in the conceptualization and design of the research. As Tischler, D'Silva, Cheetham, Goring &Carlton (2010) noted, the concept of patient centredness is more prevalent in health care practices however little attention has been paid to including patient centred principles in research. Future work must seek patient engagement and involvement in all aspects of the research, rather than viewing them simply as study participants.

Further Research

There is limited research available regarding patient experiences, patient and behaviour and the relationship to quality of care, patient satisfaction and health outcomes. As such, further research in this area is essential. Future research should seek to include patients in all aspects of the research; but further to that, seeking to understand the concept of patient centred health care from multiple perspectives. This suggestion has been noted in the literature with Mead and Bower (2000) identifying a need for triangulation of perspectives (health care providers, patients, and family) rather than affording priority to any single perspective.

Based on my analysis and interpretation of the data from this study, I have identified several research topics that would expand on the findings of this research:

- Rehabilitation patients had been told (and believed) that they were getting the best therapy possible. What effect do preconceived perceptions of quality have on the experience as a patient? What influence does this have on patient behaviour and satisfaction?
- Primary health care patients note that having personal resources (confidence, money, education, knowledge of the system) allowed them to actively engage in their health care; perhaps more so than other patients. What are the key resources for patients to possess in order to engage as a proactive patient? A study examining the effect of real and perceived personal resources on beliefs, attitudes and behaviour would be of value, particularly in the Canadian context where universal access is a centrally held social value.
- Patients are willing to tolerate negative experiences in the pursuit of a positive health outcome. How did people develop this perspective? To what extent are patient experiencing extremely negative interactions and tolerating them for the positive outcome? How negative is too negative – what is the threshold of tolerance? What effect does perceived scarcity of health care services have on this perspective?

Perhaps most importantly, future research efforts in this area must stop thinking about the patient experience as a clinically bound, health care focused experience. ‘Being a patient’ is only one aspect of an individual’s life; examining the concept from a social perspective and grounded in social theories relating to roles and behaviour may be more useful in truly understanding the experience.

Summary and Conclusions

Little et al (2001) emphasized that when seeking to understand patient centred health care, the best place to collect information is from the patient themselves. Unfortunately, the majority of information about patient centredness has been from the clinician perspective and does not account for differences in patients' experiences and needs.

This study contributes significantly to the limited body of knowledge regarding patient experience; providing rich descriptions and elucidating their stories. By examining patient experiences, it was determined that being a patient is (a) not a single behaviour, but rather a constellation of actions or strategies and (b) different depending on the clinical program or patients' goals. This very important finding suggests that current definitions and perspectives on 'the patient' needs to be expanded to more accurately reflect the complexity of the patient experience. Being a patient is not simply about participation preferences, compliance or adherence to treatments, or satisfaction with their health care. Each clinical encounter, in a given setting, affects a patient's beliefs, attitudes and behaviour (currently and in future interactions).

Many patients can articulate their beliefs and expectations about health care; stating that they want to be actively involved in their health care when they are able, and need reliable and appropriate supports when they are unable to engage. However, what 'active' looks like is different from situation to situation, and setting to setting.

When patients worry that 'they could fall through the cracks' or feel they might not be getting the best health care possible, they either disengage or become more proactive, developing strategies to 'work the system'. These strategies, if effective, become part of their patient approach and will be used in future clinical encounters. If health care providers truly seek to be patient centred, they must understand what each patient comes to each clinical encounter needing and able to contribute to their own care, while appreciating that patient behaviour (positive and negative) is constructed from previous experiences and resulting from their goals.

This study does not merely provide information about patient beliefs, attitudes and behaviour; it clearly points to the need for health care providers to ask more questions. Health care providers, to be truly patient centred, must ask each patient about their needs, expectations and goals; determining to what degree they want to be engaged in their own care. This study has shown that these questions must be asked of each patient prior to each treatment as beliefs, attitudes and behaviour are contextually dependent – as Angie reflected, “until you’re there, you don’t know how you’ll be”.

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APPENDIX A

Study I: Rehabilitation Patient Experience Materials

Introductory Script for Stroke Rehabilitation Team

Version 1.1 July 14, 2010

A clinical team member is asked to read this introductory information script to the newly admitted patient.

A PhD candidate – Michelle Nelson, is running a research study exploring people's experiences in the health care system; and specifically within the stroke rehabilitation program. This is not a medical or drug study; she is looking for people who are willing to share their experiences during interviews. This study will not affect any aspect of care you will receive.

She has asked me to provide you with this introductory information and ask if you would be willing to have her contact you with more study information. If you agree, I will give your name and contact information to her so that she may give you more information about the study and what it will entail. You are under no obligation to participate and no one on the clinical team will know whether you are participating or not (unless you choose to tell us). I would like to assure you that whether you participate has no impact on the care you will receive.

Can I give your name and contact information to Michelle?

Instructions for Stroke Rehabilitation Team

Exploring People`s Experiences with Health Care Services
Research Study – Riverview Health Centre – Stroke Rehabilitation Program

Thank you so much for agreeing to help me recruit participants for my doctoral research study. Your support is essential for me to complete this study and my degree – so you time and assistance is very much appreciated!

The recruitment procedures shouldn`t require much time from the clinical team and are as follows:

- Upon admission to the Stroke Rehab program (no more than 4 days post admission), please read the introductory script (as attached) to newly admitted patients.
- If they agree to speak with me about the research study, please write their NAME, ROOM NUMBER and any other contact info on the introductory script and return to the folder. Please contact me- Michelle Nelson at 782-4064 **THAT DAY** to inform me that a potential participant has been admitted.
- **Please note that there are no exclusion criteria for this study**. All patients admitted to the stroke rehabilitation program are eligible to participate in this research study, and should be provided with the introductory materials.
- Within 2 days of receiving notification of potential participants - I will come to the unit, retrieve the names of people who are interested in speaking with me about the study and arrange times to meet with them. The Stroke Rehab team will not be required to assist beyond providing names and information to me.

If you have questions about the study or recruitment procedures – please contact me at nelsonm@cc.umanitoba.ca or by phone – 782-4064,

Thanks so much!

Michelle Nelson

RESEARCH SUBJECT INFORMATION AND CONSENT FORM
Study I

Title of Study: **Exploring health care services through the beliefs, expectations and lived experiences of Manitobans.**

Investigator:

Ms. Michelle Nelson
Apotex Centre
750 McDermot Avenue
Winnipeg, MB R3E 0T5
(204) 782-4064 nelsonm@cc.umanitoba.ca

Introduction and Purpose of Study

Health care policy makers are becoming increasingly aware of the need to structure the health care system in a way that meets the public and patient's needs. In the *Health Covenant for Canadians,* Commissioner Romanow stated that our health care system must be shaped around the needs of patients, their families and the community (patient centred care) as well as being a respectful ethical system with public input essential. Commissioner Romanow also states that Canadians are entitled to make informed decisions regarding their personal care, and to receiving all information and medical documentation related to them, while respecting the expertise of health providers.

Although there is a significant amount of literature specific to patient centredness there is little information that reflects the stated interests, beliefs and needs of the patient themselves. It has been emphasized that the patient is the best place to collect this information. You are being asked to participate in a research study designed to explore people's beliefs and expectations regarding health care services. This information may help administrators develop health care services that better meet Manitobans needs.

Please take the time to review this information. You may take your time to make your decision about participating in this project, and you may discuss it with anyone you wish prior to making your decision. If at any time you have further questions about your participation please feel free to contact the designated contact of this study (Michelle Nelson 204-782-4064).

Study Procedures

The data gathering phases of this research will last from approximately August 2010 to December 2010. If you decide to participate in the research, you will be asked to perform the following activities:

i) Provide consent to the researcher, indicating your willingness to participate in the research.

ii) Participate in three interviews with the researcher. The researcher would like to interview before you start any treatments, approximately halfway through your treatments, and after you have been discharged from the clinical program. These interviews will last for approximately 30 - 45 minutes and will occur a few weeks apart. The interviews will take place at a quiet location of your choosing. In order to ensure the accuracy of the reports from the interviews, the discussions will be audio taped. These tapes will be transcribed and stored in a locked location. At the end of the study, the audio tapes will be destroyed, however transcribed materials will be stored for 7 years, and then destroyed.

iii) The researcher will send you a copy of the transcribed interview materials. If you choose to review these materials, the researcher would like to receive your feedback on the accuracy of the information and themes developed from the materials. If you choose to review the materials, it may take up to 1 hour; and the follow up conversation may occur in person or by telephone, or by other electronic methods (email or fax). This interview may take approximately 10 - 20 minutes.

iv) Record any thoughts, ideas and experiences that you had or found interesting or important between interviews. You can document these thoughts or experiences in a format that is your choice (notes, doodles, audio/video/ art, etc…) to share and discuss with the researcher. The researcher will provide you with a blank notebook and a folder to store your materials.

Risks and Discomforts

It has been determined that the risks of this study to you are considered minimal. It may be possible that some of the discussion topics or specific interview questions may make you feel uncomfortable. Please be aware that you do not have to participate in any discussions, or answer any questions that make you feel uncomfortable.

Payment for Participation

You will not receive payment for you participation. The researcher will provide reimbursement for any transportation (parking, bus tickets, etc…) expenses related to taking part in this study. You will receive a nominal honorarium ($20.00 gift card) to express the researcher's appreciation for your participation.

Confidentiality

Please note that your participation in this research study will have absolutely no impact on the care you may receive from your health care team. The clinical team will not know if you are participating in this research study unless you choose to share that information with them.

You will be providing information during an interview. The information gathered will be kept in a secure locked filing cabinet in the researcher's office. No governing bodies will receive any raw data from this research, and only aggregate findings from this study will be presented or published in public forums. Personal information such as your name, address, or telephone number will only be seen by the researcher and her academic advisor as necessary.

Your personal information may also be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time and you will not be penalized if you decide to do so. To withdraw, simply tell the researcher that you no longer wish to participate in the study. All data collected from you will be removed from the study files and disposed of in a confidential manner.

Questions

You are free to ask questions about the study and your rights as a research participant. If you have any questions during or after your participation, please contact the researcher **(Michelle Nelson at 204–782–4064)**. If you have any questions about your rights as a research participant, please contact the University of Manitoba, Health Research Ethics Board at **204–789-3255.**

Please do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers.

Statement of Consent
I have read this consent form. I have had the opportunity to discuss any questions about the consent form and/or study procedures with the researcher. I understand that I will be provided a copy of this consent form after signing it. I understand that my participation in the study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this study, and any relationship I may have with the researcher has not influenced my participation. I authorize the inspection of any of my information that is related to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in research.

Participant Signature________________________________ Date______________
Participant Printed Name____

I would like to receive a copy of the study results: Yes____ No____
email:________________________________
Street:________________________________ Postal Code:______________

APPENDIX B

Study II: Primary Health Care Patient Experience Materials

RESEARCH VOLUNTEERS NEEDED

A PhD candidate in the Faculty of Pharmacy is conducting a study examining Manitobans beliefs and expectations regarding health care services.

Individuals will be interviewed once for approximately 60 minutes, at a time and location of their convenience. Interview questions will focus on your opinions about health care. It is not necessary to have any special knowledge about the topic.

Participants must be:

- Over the age of 18
- A Manitoba resident

Participants will receive an honorarium for their participation and any parking or transportation costs will be reimbursed.

If you are interested in learning more about this study, please contact:

Michelle Nelson
nelson@cc.umanitoba.ca
204-782-4064

<<<email message to be sent for snowball sampling recruitment>>>

Subject Line: Michelle Nelson PhD Study

Michelle Nelson, a PhD candidate in the Faculty of Pharmacy at the University of Manitoba, is conducting a study entitled, '*Exploring beliefs, expectations and lived experiences in health care"* as her doctoral research. I am forwarding this message to you as I think participating in this study might be of interest to you.

This study offers the potential for unique perspectives on health care services, as it incorporates the perspectives of both the general public and people who are currently accessing acute health care services. Although there is a significant amount of literature specific to patient centredness there is little information that reflects the stated interests, beliefs and needs of the patient themselves. It has been emphasized that the patient is the best place to collect this information. You are being asked to participate in a research study designed to explore people's beliefs and expectation regarding health care services in Canada.

Your support and assistance is important and would be greatly appreciated.

If you decide to participate in this study, you will

i) Provide consent to the researcher, indicating your willingness to participate.
ii) Participate in one interview that will take approximately 60 minutes at a mutually agreed upon location. Please be assured that you participation is voluntary and you may withdraw or refuse to answer any questions at any time.
iii) Review interview materials and provide feedback on the accuracy of the information and themes developed from the materials.
iv) Review sections of the final report, providing feedback on the accuracy of the information and results presented.

If you have any questions about this research or would like to participate, please contact the researcher **Michelle Nelson (782-4064 or nelson@cc.umanitoba.ca**

Thank you for your time and anticipated interest.

Yours truly,

Michelle Nelson, PhD Candidate

RESEARCH SUBJECT INFORMATION AND CONSENT FORM
Study II

Title of Study:	**Exploring health care services through the beliefs, expectations and lived experiences of Manitobans.**

Investigator:

Michelle Nelson PhD Candidate
Apotex Centre
750 McDermot Avenue
Winnipeg, MBR3E 0T5
(204) 782-4064
nelsonm@cc.umanitoba.ca

Introduction and Purpose of Study

Health care policy makers are becoming increasingly aware of the need to structure the health care system in a way that meets the public and patient's needs. In the *Health Covenant for Canadians,* Commissioner Romanow stated that our health care system must be shaped around the needs of patients, their families and the community (patient centred care) as well as being a respectful ethical system with public input essential. Commissioner Romanow also states that Canadians are entitled to make informed decisions regarding their personal care, and to receiving all information and medical documentation related to them, while respecting the expertise of health providers.

Although there is a significant amount of literature specific to patient centredness there is little information that reflects the stated interests, beliefs and needs of the patient themselves. It has been emphasized that the patient is the best place to collect this information. You are being asked to participate in a research study designed to explore people's beliefs and expectations regarding health care services. This information may help administrators develop health care services that better meet Manitobans needs.

Please take the time to review this information. You may take your time to make your decision about participating in this project, and you may discuss it with anyone you wish prior to making your decision. If at any time you have further questions about your participation please feel free to contact the designated contact of this study (Michelle Nelson 204-782-4064).

Study Procedures

If you decide to participate in the research, you will be asked to perform the following activities:

i) Provide consent to the researcher, indicating your willingness to participate in the research. Study activities are explained in this document.

ii) Participate in one interview with the researcher. This interview will take approximately one hour and take place at a quiet location of your choosing. In order to ensure the accuracy of the reports from the interviews, the discussions will be audio taped. These tapes will be transcribed and stored in a locked location. At the end of the study, the audio tapes will be destroyed; however transcribed materials will be stored for 7 years, and then destroyed.

iii) The researcher will send you a copy of the transcribed interview materials. If you choose to review these materials, the researcher would like to receive your feedback on the accuracy of the information and themes developed from the materials. If you choose to review the materials, it may take up to 1 hour; and the follow up conversation may occur in person or by telephone, or by other electronic methods (email or fax) which may take approximately 10 - 20 minutes.

Risks and Discomforts

It has been determined that the risks of this study to you are considered minimal. It may be possible that some of the discussion topics or specific interview questions may make you feel uncomfortable. Please be aware that you do not have to participate in any discussions, or answer any questions that make you feel uncomfortable.

Payment for Participation

You will not receive payment for you participation. The researcher will provide reimbursement for any transportation (parking, bus tickets, etc…) expenses related to taking part in this study.

Confidentiality

You will be providing information during an interview. The information gathered will be kept in a secure locked filing cabinet in the researcher's office. No governing bodies will receive any raw data from this research, and only aggregate findings from this study will be presented or published in public forums. Personal information such as your name, address, or telephone number will only be seen by the researcher and her academic advisor as necessary.

Your personal information may also be disclosed if required by law. The University of Manitoba Health Research Ethics Board may review records related to the study for quality assurance purposes.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time and you will not be penalized if you decide to do so. To withdraw, simply tell the researcher that you no longer wish to participate in the study. All data collected from you will be removed from the study files and disposed of in a confidential manner.

Questions

You are free to ask questions about the study and your rights as a research participant. If you have any questions during or after your participation, please contact the researcher **(Michelle Nelson at 204–782–4064)**. If you have any questions about your rights as a research participant, please contact the University of Manitoba, Health Research Ethics Board at **204–789-3255.**

Please do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers.

Statement of Consent

I have read this consent form. I have had the opportunity to discuss any questions about the consent form and/or study procedures with the researcher. I understand that I will be provided a copy of this consent form after signing it. I understand that my participation in the study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this study. I authorize the inspection of any of my information that is related to this study by the University of Manitoba Research Ethics Board for quality assurance purposes.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in research.

Participant Signature________________________________ Date______________

Participant Printed Name____

I would like to receive a copy of the study results: Yes____ No____

Name:__________________________ email:____________________

Street:________________________________ Postal Code:______________

APPENDIX C

Study I Interview Guides

Study I: Patient Beliefs, Attitudes, Expectations and Lived Experiences

Interview I: Referral/Admission Stroke Rehabilitation Program

Thank you for taking the time to meet with me today. ***I am conducting this study trying to understand what people's perspectives about health care and how these perspectives manifest in expectations and experiences****. There are no right or wrong answers; I am simply interested in your thoughts.*
In general, I am interested in:

- *What do we know about and what can we learn about the peoples' perspectives and expectations of the health care system? What are the beliefs and expectations of people receiving health care services regarding health care? Are these expectations sustained or do they change as a person progresses through the health care system? Do current health care processes match the expectations of people?*

Today I would like to talk about your perspectives regarding health care and your expectations regarding your referral and treatment with the stroke rehabilitation program.

Background Question:
Could you tell me a little bit about yourself?

Beliefs and Attitudes about Health Care
Before you were admitted to the stroke rehabilitation program, how would you have defined or describe health care.

Now that you are here – how has your definition or perspective of health care changed?

What were your beliefs about health care?

Possible Probes:

- What should it be or shouldn't be?
- Who is health care for? Do you think health care is delivered fairly? If yes – tell my why? If no – why not and how could the system be fairer?
- What do you expect it to provide? How should this be provided?
- How do your beliefs about health care match/differ those of your friends and family?
- Do you think your beliefs about health care match those of the general public?
- Several terms have been used to describe the recipient of health care services – patient, client, service user, and consumer. What do you think of these terms? Do you prefer one term over another? Why?
- What would "ideal" health care look like?

How would you describe your attitude toward health care?

Possible Probes:

- Would you describe your attitude toward health care as positive or negative?
- If you were to evaluate health care, how would you do this?
- What score would you give heath care generally? What is this based on?
- How has your attitude toward health care changed as a result of your referral to this program?

Experiences with Health Care

Could you describe how you ended up being admitted to this program? What has happened to date?

What other experiences have you had with health care?

Possible Probes:

- How would you describe these experiences?
- Were these experiences consistent with your expectations?
- How did these experiences affect you?
- Did your experiences change how you viewed health care?

How would you characterize your participation with health care?

Possible Probes:

- Would you describe your participation as active or passive?
- What are the benefits or risks of how you participate/engage in health care?
- How do significant others in your life feel you should engage in your health care? How about more broadly – how do you think society expects you to engage?
- What factors may facilitate or impede your participation in your health care?

What do you anticipate will happen during your treatment?

Possible Probes:

- What factors may facilitate or impede your participation in your health care?
- What have you been told will happen? Told by whom?
- What have you done to prepare?
- What do you hope will happen during your treatment?

What are you going to do to achieve the goals you've shared? or How do you plan to behave (engage) during your current interaction/treatment with health care?

Interview II: Midpoint of Treatment/Rehabilitation

Thank you for taking the time to meet with me today. As we have discussed before, I am conducting this study trying to understand what people's perspectives about health care and how these perspectives manifest in expectations and experiences. There are no right or wrong answers; I am simply interested in your thoughts.
Today I would like to hear about your experience since your admission to the stroke rehabilitation program. If you have used other methods to collect your thoughts (journal, art, diary etc), I would like to take some time to discuss that with you as well.

What has happened in your treatment thus far? How would you describe how your treatment is going?
Based on the expectations you had at the beginning – how has the experience compared?
Possible Probes:

- What has surprised you?
- What has happened the way you thought it would?
- Researcher will feedback expectations that participant identified in interview I to develop probes.

How is this experience changing your perspectives about health care?
Possible Probes:

- What should it be or shouldn't be?
- Who is health care for? Do you think health care is delivered fairly? If yes – tell my why? If no – why not and how could the system be fairer?
- What do you expect it to provide? How should this be provided?
- How do your beliefs about health care match/differ those of your friends and family?
- Do you think your beliefs about health care match those of the general public?
- Several terms have been used to describe the recipient of health care services – patient, client, service user, and consumer. What do you think of these terms? Do you prefer one term over another? Why?
- What would "ideal" health care look like?

Would you say your behaviour during your treatment/rehabilitation so far has been consistent/different with how you planned to behave? How so? Why? How do you plan to behave going into the latter stages of your treatment?

Interview III: Discharge from Stroke Rehabilitation Program

Thank you for taking the time to meet with me today. As we have discussed before, I am conducting this study trying to understand what people's perspectives about health care

and how these perspectives manifest in expectations and experiences. There are no right or wrong answers; I am simply interested in your thoughts.
Today I would like to hear about your experience/treatment since we last met. If you have used other methods to collect your thoughts (journal, art, diary etc), I would like to take some time to discuss that with you as well.

What happened in your treatment since we last met?
Possible Probes:

- Researcher will review other materials created by participant at this time

How would you define/describe health care now?
Possible Probes: (Researcher will remind participant of their perspectives in interview I)

- What should it be or shouldn't be?
- Who is health care for? Do you think health care is delivered fairly? If yes – tell my why? If no – why not and how could the system be fairer?
- What do you expect it to provide? How should this be provided?
- How do your beliefs about health care match/differ those of your friends and family?
- Do you think your beliefs about health care match those of the general public?
- Several terms have been used to describe the recipient of health care services – patient, client, service user, and consumer. What do you think of these terms? Do you prefer one term over another? Why?
- What would "ideal" health care look like?

How would you evaluate how your involvement with health care went? What is your attitude toward health care?
Possible Probes:

- Would you describe your attitude toward health care as positive or negative?
- If you were to evaluate health care, how would you do this?
- What score would you give heath care generally? What is this based on?

Based on the expectations you had at the beginning – how has the experience compared?
Possible Probes:

- Researcher will feedback expectations that participant identified in interview I to develop probes.

Given all of your experience –how does this influence your perspectives about health care?

Would you say your behaviour during your treatment was consistent/different with how you planned to behave?

Possible Probes:

- How so?
- What influenced your behaviour?
- What were the benefits or risks associated with how you behaved?

Summation Question

Given all of you've shared with me, how will you approach health care from now on?

APPENDIX D

Study II Interview Guide

Study II: Primary Health Care Beliefs, Attitudes and Expectations

Version 1.0 July 14, 2010

Introduction

Thank you for taking the time to meet with me today. I am conducting this study trying to understand what people's perspectives about health care and how these perspectives manifest in expectations and experiences. There are no right or wrong answers; I am simply interested in your thoughts.

In general, I am interested in:

- *What do we know about and what can we learn about the peoples' perspectives and expectations of the health care system? What are the beliefs and expectations of people receiving health care services regarding health care? Are these expectations sustained or do they change as a person progresses through the health care system? Do current health care processes match the expectations of people?*

Section I: Background Question

Could you tell me a little bit about yourself?

Section II: Beliefs and Attitudes about Health Care

How would you define or describe health care. What does that term mean to you?

What are your beliefs about health care?

Possible Probes:

- What should it be or shouldn't be?
- Who is health care for? Do you think health care is delivered fairly? If yes – tell my why? If no – why not and how could the system be fairer?
- What do you expect it to provide? How should this be provided?
- How do your beliefs about health care match/differ those of your friends and family?
- Do you think your beliefs about health care match those of the general public?
- Several terms have been used to describe the recipient of health care services – patient, client, service user, and consumer. What do you think of these terms? Do you prefer one term over another? Why?
- What would "ideal" health care look like?

How would you describe your attitude toward health care?

Possible Probes:

- Is your attitude toward health care positive or negative?
- If you were to evaluate health care, how would you do this?
- What score would you give heath care generally? What is this based on?

Section III: Experiences with Health Care

What experience have you had with health care?

Possible Probes:

- How would you describe these experiences?
- Were these experiences consistent with your expectations?
- How did these experiences affect you?
- Did your experiences change how you viewed health care?

How would you characterize your participation with health care?

Possible Probes:

- Would you describe your participation as active or passive?
- What are the benefits of how you participate/engage in health care?
- What are some of the risks or problems that may result from how you engage with health care?
- How do significant others in your life feel you should engage in your health care? How about more broadly – how do you think society expects you to engage?
- What factors may facilitate or impede your participation in your health care?

Have you, or do you have currently see physician?

Possible Probes:

- What kind of physician?
- How often would you see them?

Could you describe a typical visit to your physician?

Possible Probes:

- Do you have to make an appointment?
- How do you prepare for your appointment?
- Do you have to wait? If so, how do you feel about having to wait?
- When you get to the doctors' office – what typically happens? How do you feel? Do you ask questions? When they ask questions how do you answer?
- How do you feel at the end of your appointment?

Would you say your actions at your medical appointments are consistent/different with how you planned to behave? How so?

Section IV: Contextual Questions

Prior to the next questions, the researcher will share the composite vignette developed from Study I data with the participants.

Now I would like to share an individual's story with you. Based on this story I would like to ask you some questions. There are no right or wrong answers; I am interested in your thoughts and opinions.

What about this person's experience resonated with you?

How did this person's experience match what you believe about health care?

- How does this person's experience change your beliefs about health care?
- How might this experience change your attitude toward health care?

If you imagine you were in this situation, what would you have done? What would you have expected?

Section V: Summation Question

Given all of you've shared with me, how will you approach health care from now on?