BEING PATIENT: EXPLORING EXPERIENCES OF, AND RESPONSES TO, SOCIAL CONSTRUCTIONS OF PATIENT-HOOD

by

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Abstract

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The term "patient" is widely used within public and nursing domains. Arguably, the word is assumed to have common meaning across all disciplines. But is this the case? Does the word-label patient contain implicit assumptions and values? What social, political and professional constructions of patient-hood exist? How do people in the position of patient experience and respond to these images? For example, nursing research confirms that nurses actively construct patients based on such characteristics as income, age, gender and social position and that, on the basis of these and similar criteria, nurses make decisions about the worth of individuals and act, in various ways, on those judgments. While this phenomenon has been well-studied, little work has been done to explore how patients experience and respond to popular constructions of patient-hood.

In this study, I sought to shift attention away from the dominant discourse of professional perspectives and toward examination of these issues from an emic view -- that of patients. Using interpretive description, I invited seven people with varying degrees of experience within the health care system to discuss their experiences while in the position of patient. Through this analysis I offer an expanded understanding of how the role of patient is both experienced and responded to. People in the position of patient experience constant threats to self and to personal integrity. These threats included objectification, invisibility against a background of technology, and a lack of value for individuals' contributions as agents in their own health and illness experiences.
The findings of this study point to a need for nurses to cultivate a critical awareness of the impact of technology on both physical and practice environments. In addition, study findings call further attention to the need of people in the position of patient to be known and valued as individuals and as active agents.
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Chapter 1: Background to the Problem

The term "patient" is widely used within public and health care domains. Arguably, the word patient is assumed to have common meaning across all disciplines. But is this the case? Does the word-label patient contain hidden assumptions and values? What does it mean to “be” in the position of a patient? How is patient-hood constructed by nurses? For example, research confirms that nurses actively construct the role of patients based on such characteristics as income, age, gender, social habits and social position (Corley & Goren, 1998; Fagermoen, 1997; Faugier & Sargeant, 1997; Hughes & Griffiths, 1997; Juliana et al., 1997; Minick, Kee, Brokat, Cain, & Oparah-Iwobi, 1998; Pill, Rees, Stott, & Rollnick, 1999; Sherwin, 1994; Spigner, 1998; Tang & Anderson, 1999) and that, on the basis of these and similar criteria, nurses make decisions about the worth of individuals and act, in various ways, on those judgments. While this phenomenon has been well studied, less work has been done to explore how people in the position of being a patient are impacted by the values, attitudes and beliefs that underpin social constructions of the patient role.

In this research project, I elicit and interpret several individuals’ perceptions of the ways they experienced the role of patient. As well, from the perspective of participants, I consider what does it mean to “be a patient”? Specifically, I explored the ways in which people experience and respond to constructions of patient-hood. The participants in this study were patients who had experienced a broad variety of health challenges, of both an acute and chronic nature. My intent in this project was, through interpreting interviews with participants, to describe the ways in which people experienced the role of patient in the current social and political context. The
significance of this work is that the shift from examining the perspective of the patient from the nurses’ position to the patients’ position changes the focus from nursing to an examination of the experience of patient-hood from an emic perspective. Barritt (1986) describes a rationale that is consistent with my purpose in undertaking this research:

[It] is not the discovery of new elements, as in natural scientific study, but rather the heightening of awareness for experience which has been forgotten and overlooked. By heightening awareness and creating dialogue, it is hoped research can lead to better understanding of the way things appear to someone else and through that insight lead to improvements in practice. (p. 20)

This chapter introduces my research project, briefly describing the background to the research problem and purpose, the questions that were addressed in the project, and my beliefs about the significance of this study for nursing practice, education and research. Within this study, “patient” is defined as any individual who is interacting with the mainstream health-care system, and receiving nursing care.

“Patient” (in) Action

In September of 1999, I admitted a 29 year-old woman who was accompanied by an attentive and concerned partner. She related that she was being treated with chemotherapy for multiple myeloma with metastases to her brain, liver and spleen. She had been diagnosed at the end of July. I was surprised at how healthy she looked. She related that the chemotherapy, other than causing hair loss, had not affected her at all and had prevented the spread of her cancer. In the course of interviewing her for admission, I learned that she had a ten-month old baby boy -- her first child. After the admission, I went over the physician’s orders with her. The third order was "no code". She asked what that meant. I casually explained that no code meant we would not resuscitate her if she were ill enough to experience a cardiac or respiratory arrest. She was surprised and
asked that we please undertake to resuscitate her if anything happened to her during this hospital visit. I came away from the bedside stunned at what had taken place. With this project in the early stages of conceptualization, I asked myself what social and political ideas about the position of the patient had contributed to this situation? I also wondered if I could have a conversation with this woman at some future point, would her experiences in the health-care system illuminate other examples of the ways in which patient-hood is experienced? This was, for me, a concrete example of the ways in which conceptualizations of patient-hood and nursing practice interact directly and it reinforced the importance of re-visiting taken-for-granted language and underlying assumptions regarding the patient role.

This research project, including the foundational concept of patient, evolved directly from my work with Dr. Colleen Varcoe, an associate professor of nursing at the University of Victoria (Varcoe, 1997). During her doctoral dissertation, she studied how the social context of health care influenced the experiences of women who have been battered in intimate relationships. In the course of interviewing women for Varcoe’s project, it became obvious that women attending emergency department settings actively "put their best foot forward" or constructed themselves as deserving of the care and attention of health-care providers. Thus, not only are patients not passive recipients of health care, they are active participants in constructing their experiences (MacKean & Thurston, 1996; Tang & Anderson, 1999). From this research, arose my intrigue with the notion of "patient" and how the social construction of the role of the patient influences experiences of health and illness and people’s participation in their health care.
Initial reflection forced me to think about the uncritical ways in which the term "patient" is used in practice, in the nursing literature, in nursing education, within popular literature and media. I became fascinated by questions about the uncritical use of the word “patient” and the multitude of hidden meanings and codes we attach to the word. Gradually, I became curious about the specific values, assumptions and beliefs that underpin the concept of "patient". After reading, debating with colleagues and further reflection, I wondered about the ways in which those ideas are translated into action.

From this reflection, I considered the notion of position – the position of nurses and patients vis a vis each other. I asked myself, how do I see nurses positioning themselves in relation to patients? What stance do members of the health-care team take in relation to “patients” and how does this translate into practice? During these reflections, I encountered the woman described in the beginning of this section. This encounter strengthened my conviction that sometimes, the way we conceptualize “patients” operates to support actions that eliminate their person-hood and cancel their ability to actively participate in the health care they receive except as passive recipients.

In search of a word to address the notion that people are active participants in their own health-care experiences, I located the term "agency", a concept used commonly in the literature of psychology and less frequently, in the literature of nursing. Interestingly, after choosing this word, I found that agent could be considered an antonym for “patient” (Hendrickson, 1997). However, the literature confirmed that notwithstanding references to partnership and autonomy as ideals, patients continue to be viewed as passive recipients of health care - at least in the hospital setting (Hartrick, 1997; Lupton, 1993; Tang & Anderson, 1999). In this study, I sought to explore a small
portion of the genesis and perpetuation of notions about patient-hood. By exploring the origins of the word patient, seeking out coded messages about the values and assumptions society attaches to the role of patient in North American mainstream medical care, and by interacting with people about their experiences with health care and their responses to the socially prescribed role of the patient, I hoped to develop an understanding of people in the position of the patient within a larger socio-political context. My goal was to create an expanded understanding of the experience of patient-hood in the current social and political context that will support nurses in caring for people in a manner consistent with valuing individual autonomy, independence and self-determination.

Purpose of the Study

The purpose of this descriptive study was to explore, from patients' perspectives, how they experience and respond to social constructions of the patient role. In particular, through interaction with patients, this study explores (a) the experience of being a patient, (b) the ways in which dominant values and beliefs are experienced within health-care encounters, and (c) the ways in which patients respond to social constructions of patient-hood.

Research Questions

The questions I explore in this project are from the perspective of individuals in the patient role:

1. What does it mean to “be a patient”?
2. What are the social constructions of the role of the patient?
3. How are values, attitudes and beliefs about the role of the patient experienced by individuals interacting with the health care system for the purpose of receiving nursing care?

4. How do people in the position of the patient respond to these social constructions of patient-hood?

**Assumptions**

The following assumptions underlie this research and shaped my thinking throughout the research process:

1. Patients, as people, hold individual values, beliefs, and assumptions about the meaning of being a patient.

2. Patients are entitled to the acknowledgment and preservation of their personal agency.

3. There is value in exploring taken for granted relations and/or assumptions.

**Summary**

In this introduction to my research project, I outlined the background of the research problem and briefly described my beliefs about why this research is important. In addition I presented my research questions and stated the assumptions that underpin my research. In the next chapter, the literature review, I explore relevant theory and research literature to locate this project within existing knowledge and to make explicit the theoretical starting point that guided the initial phase of this research.
Chapter 2: Literature Review

In this chapter I explore relevant literature in order to locate this project within existing knowledge. While the word label “patient” is used freely in a multitude of contexts, few researchers deconstruct the concept specifically. Nor would a simple deconstruction of the concept create a new definition. Rather, as I argue in the following literature review, our ideas about patient-hood are deeply embedded and may not be easily altered by a “re-labeling”.

In this chapter, I describe my search for implicit messages, values and assumptions revealed in the common usage of the word “patient”. I have focused this discussion on the most prevalent themes or lenses through which people in the position of patient seem to be viewed within the literature. These include the social lens, the practice lens, the political lens and the professional lens. To frame my discussion, I begin by presenting a brief description of the power of language in shaping and transforming professional practice.

Language Discourse

Language is a process of labeling common situations, objects and ideas for the purpose of communication and shared understanding (Boutain, 1999). Discussing definitions and word labels, Kinsman (1994) argues that “if we can grasp where they have come from, and how they have been put in place, we can act to challenge and transform them” (p.166).

Two main views of language exist in the literature – realist and pragmatist perspectives (Boutain, 1999). The realist perspective is based in a modern view of the world. This stance holds that language is representational of reality and that words are
merely a reflection or an accurate description of the things or situations that they
describe. Boutain states that in realism, the process of labeling is rendered invisible and
words are assumed to represent rather than constitute. In contrast, a pragmatist stance
toward language analysis is based in a post-modern view of the world. A pragmatist
would argue that language not only describes but actually constitutes reality. I take the
latter view of language. In the following review of literature I seek to explore the social
conventions that underpin the concept of "patient".

The process of analyzing the language of everyday practice is of critical
importance within the nursing profession (Boutain, 1999; Brown, Crawford, Richards &
Nolan, 1999) because, as Bandura (1998) points out, "Language shapes the thought
patterns on which actions are based" (p. 199). Taking a post-modern view, no word is
completely accurate in describing what it means to represent. Rather, specific words also
encompass a host of related ideas, values and beliefs held by society. That is, the word
label begins to represent not only the situation or group, but also begins to dictate the
characteristics of that situation or group, based on the shared values of society. In this
project, I attempt to de-construct the label of "patient" to reveal the embedded values and
beliefs.

Within this process, "rules of engagement" are created (Smith, 1987). This term
describes the unspoken rules of behavior that guide particular types of social interaction –
for example, the interaction between a nurse and an individual seeking health care.
MacKean and Thurston (1996), writing about the social climate of the Canadian health-
care system, take the position that the image of "a passive and compliant patient is
integrated into the health care system" (p. 59). Those who choose to deviate from the
prescribed behavior are sanctioned formally and informally (Faugier & Sargeant, 1997). Thus, the power of a name can be not only descriptive, but also constitutive – shaping the experiences of individuals in particular ways. In this project, I explore current social, political and professional constructions of patient-hood.

**Social Lens**

**Common Usage**

I began this process by asking the questions, What do we mean when we use the word “patient”? What are the common uses of the term? What is the impact of the label “patient”?

The Random House Dictionary of the English Language (1997) defines the adverb patient as “bearing provocation, annoyance, misfortune, delay and hardships with fortitude and calm, without anger or complaint” and as “a person who is under medical care or treatment” (p. 1421). Indeed, in nursing practice these two definitions are often inseparable. Varcoe (1997), in her research on the social context of violence against women, found that practicing nurses have particular ideas about what makes a “good” patient. Qualities such as calmness, stoic behavior, and lack of complaints ranked high on the list of desirable qualities. In fact, Random House (1997) relates that “patient” is historically defined as a sufferer or victim. Synonyms for patient include invalid, uncomplaining, resigned, passive, calm and composed while antonyms include impatient and agitated. Hendrickson (1997), author of an English usage text, relates that the word “patient” is juxtaposed with the word agent. Hence the word patient can be seen as the opposite of *agent* (Hendrickson, 1997).

In the past two decades, terminology has shifted to the use of “client” and/or “consumer” in relation to health-care services. In part this has been fueled by an
increasingly commercial influence within American health-care politics. The shift to "client" also represents a commitment to a philosophy of partnership between nurses and the individuals they care for and a valuing of self-actualized, goal directed behavior for individual development (Corring & Cook, 1999). In addition, Corring and Cook posit that the term "client" also reflects a shift in power, moving from professional-centered to client-centered interactions. Interesting, the term "client" is reported to be the preferred term for mental health clients (Mueser, Glynn, Corrigan, & Baber, 1996). Thus, there are several terms in common use that identify people in the position of the patient.

Popular Fiction and the Media

I turn attention to the use of the term "patient" to a broader scale – images of patients in the media and popular fiction. Mainstream popular movies provide particular images of people who are ill. One popular tradition among Hollywood portrayals of people in the position of patient is that of dramatizing serious illness. This process includes portraying patient-hood as if it does not interfere with life – rather people fade gracefully. A recent example is the Hollywood movie Stepmom. In the movie, Susan Sarandon plays a mother who dies of breast cancer. Throughout the movie she is strong (caring for her children even though she is ill), suffers privately (sending the children to her ex-husband when she is especially ill) and continues with her daily life despite her illness. This pattern of behavior has been portrayed frequently over the past several decades. From An Affair to Remember and Terms of Endearment to more recent films such as Philadelphia and One True Thing, people in the sick role are frequently portrayed in this dramatic tradition. Possibly, these images are one source of information about "the right way" to behave in the role of patient.
The popular press also contributes to social images of patient-hood. I cultivated an awareness of the popular media's use of the word "patient" over a period of twelve weeks. Scanning articles and newspapers, watching headlines and newscasts, I found that the word "patient" appeared with relative frequency. During this period, I observed themes in the way patients are positioned vis a vis the government and the health-care system. In particular, the popular press portrays "patients" as victims of a flawed health-care system.

*Macleans*, a weekly Canadian news magazine, features a weekly column on the topic of health. On a quick review of twelve recent issues, "patients" were specifically mentioned at least every second week. In December 1999, for example, Canadian newspapers carried stories about stretcher shortages in emergency departments across the country. Six months before this, there was a flurry of editorials and articles about the unacceptability of lengthy surgical waiting lists. And, in March 1999, there were many editorials about the implications of "reduced activity days". Physicians in British Columbia reduced their service for a specific number of days, including the cancellation of non-emergency surgeries and the closure of family physician offices. Health care and therefore the welfare of patients, is a current issue. The health and welfare of our population is hotly debated by the media, the public and the government.

In January 2000, an article in *Macleans* news magazine discussed "mistreatment of patients" as a result of counseling by non-professional people (Corbett, 2000). In February 2000, *Maclean's* health monitor section featured an article on patients as victims of contaminated blood transfusions. The article discussed a dispute over the funds given by the government as a legal settlement (*MacLeans*, February 2000).
Similarly, in March 2000, the same news magazine featured an article about the plight of Canadian armed forces people who returned from service in the Gulf War to experience long term disabilities as a result of toxic exposure to vaccines and environmental hazards (Wickens, 2000). Throughout the article, Gulf War veterans were described as “survivors” of their disabilities. Similarly, *Time* magazine, in the same time period, published a story about people in the position of patient being duped by a physician submitting false insurance claims and prescribing unnecessary fertility treatments.

On this cursory review of the popular news media, people in the position of patient emerge as targets of other, organized, powerful groups. While at first glance this seems to contrast with Hollywood’s traditional portrayal of people who are in the position of being a patient, in fact, the popular media may inadvertently add to the stereotypes surrounding the patient role, enlarging the image to include victimization. How then, do these representations compare to professional images of people in the position of the patient?

**Professional Lens**

*Medical Advertising*

Lupton (1993), using social constructionism as a guiding perspective, examined themes in professional advertisements. In the context of changing social roles for physicians in Western societies, she studied representations of people who are patients in medical advertising. Lupton reviewed six months of a weekly Australian medical magazine and identified particular constructions of the patient role. Themes included the dismembered patient, the mechanical patient, the gendered patient and the active patient. She came to the conclusion that the first two stereotypes support the biomedical tradition
of "objectifying the person". She further noted a tendency of the biomedical view to place primary importance on technology and medicine while simultaneously de-valuing the affective components of patient-physician relationships. She concluded that images presented in advertising contribute to and draw inspiration from dominant professional ideas about patient-hood.

Lusk (1999), a nurse researcher studying advertising in nursing journals, confirmed that advertisements support stereotypes held by nurses and the public. Lupton (1993) and Lusk both found that nursing and medical advertisements portray patients as less than 65 years of age, more commonly female than male, and most often Caucasian. Women were frequently depicted in advertisements for psychoactive products, while men were predominantly seen in ads related to cardiovascular illness. In fact, Lusk found that women were frequently posed smiling and/or with vases of flowers, which he argued supported the belief that women were, on the whole, less critically ill. He argues that such stereotypes are translated directly into practice. For example, research confirms that women with cardiovascular disease are under-treated compared with men (Arslanian-Engoren, 2000; Thurau, 1997).

Lusk (1999) noted that medical advertising reflects a paradox in the current context of patient representations. We are in an era emphasizing personal agency in which people are encouraged to take active roles in their health and illness experiences and yet they are constructed as dismembered, mechanical, and passive. And, medical advertising is not the exception. Stone (1997) points out that texts for professional audiences speak of patients in objectified terms. He suggests that this reflects biomedical dominance of health and illness.
The representations of people in need of some form of health or medical care may contribute to unrealistic expectations on the part of the public and health-care professionals. Kalisch and Kalisch (1987) noted that the media is not neutral. Instead, the media not only reflects society’s values and beliefs, but also shapes those beliefs. Inadvertently, popular representations of people who are in the position of patient distort reality. The media portrayal of such individuals gives particular messages about what constitutes a “good patient” and reflects social stereotypes about health, age and illness. In particular, advertising is influenced by a biomedical perspective on health and illness.

**Biomedical Gaze**

As Torrence (1998) and many others point out, health care and the delivery of health care services are dominated by a strong biomedical paradigm – a paradigm that equates health with biology (Bartky, 1995; Hartrick, 1997; Liaschenko, 1994; Lock, 1998; Morgan, 1998; Sherwin, 1998; Tang & Anderson, 1999). A view of health and illness dominated by a biomedical perspective results in particular constructions of patient-hood. A comprehensive discussion of this topic is beyond the scope of this work, however, several related points require consideration.

One effect of the biomedical gaze is that the body becomes “medicalized”. Bodily functions that are a part of the developmental cycle, such as childbirth or menopause, become, under the biomedical gaze, health problems (Morgan, 1998). In the process, a biomedical view of individuals has a tendency to “reduce” those people to their component parts. On admission to a hospital for example, a man becomes a “GI bleed” (gastro-intestinal bleed) or an “appy” (appendectomy) in a particular stretcher – he is reduced to the organ system that is most obviously related to his presenting complaint.
This reductionism, rather than emphasizing relationships between parts of the whole, looks at each part in isolation, "reducing" individuals to their problems.

A biomedical lens on patient-hood also separates individuals from the context in which they live their lives. Oakley (1993) a feminist author writing about women’s health, related that with the dominant view of biology, we become less able to understand the natural evolution of health over a life span. She argued that, for women, the experience of health is "bound up with their experiences of every day life" (p. 327). In contrast, the position of the patient requires that a person be removed from the context of her daily life. In this way the social roots of stress and illness are obscured and the individual is usually assigned responsibility for the presenting illness and its solutions (Burgess, 1996; Oakley, 1993; Sachs, 1996; Wuest, 1994). Indeed, Oakley points out that a focus on individuals and their health in isolation from the social context which surrounds women and in many cases constrains their options, is an effective way to “depoliticize” the social structures and sanctions that do not support health and wellness. Rousseau (1996) points out that traditional caregivers focus on pathology and defects. As a result, patients have learned to present caregivers with symptoms as opposed to addressing the underlying causes of the problem.

The biomedical gaze has the effect of positioning the “patient” as an object and the health-care professional as the subject. Thus, nurses become experts and the knowledge of individuals in the position of the patient becomes less valuable. Tang and Anderson (1999), investigating the experience of women with chronic health challenges, relate that “with chronic illness comes the definition of self as ‘patient’ and the culture of patient-hood that situates ‘the patient’ in relation to health care providers as knowers and
experts on the patient’s body” (p. 84). In effect, this means a devaluation of the knowledge of the person experiencing the illness.

Technological Gaze

Being a patient has particular consequences for individuals experiencing illness. In addition to the effects of a biomedical gaze, people in the position of patient may experience the effect of technology and technological surveillance. For example, when someone becomes a “patient”, that which was invisible becomes visible, and more important, one is made responsible for the newly visible, and subsequently, judged for the future success or failure of treatment. Consider health screening. Cholesterol screening is one example of that which was invisible (a cholesterol level) being made visible (via a blood test) and responsibility for controlling the cholesterol level being assigned to the individual. This can contribute to what Sachs (1996) terms “The moralizing and blame of preventative discourse” (p. 636). That is, the visible becomes a moral burden to the patient. The individual then experiences judgment on an ongoing basis even in the absence of illness, if he or she does not manage to control a cholesterol level. While few would advocate not monitoring problems if individuals are asymptomatic, there are negative, unintended consequences for people in the position of patient.

Technologies such as glucose screening and lab work also make it possible to follow glucose control in the diabetic over months (i.e., by measuring glycosated hemoglobin). As a result, individuals are re-constructed from victims of an awful disease to irresponsible agents of their own poor outcomes (Anderson, cited in Pill et al., 1999). Thus, the position of patient carries with it a culpability that is present in so many other social roles (such as motherhood). The mere process of screening creates the possibility
that people can be “bad” patients if they do not follow treatment regimens (Lippman, 1998).

Not only do people in the position of the patient experience the weight of a technological gaze, they are cared for within a system that inadvertently supports such practices. Nursing practice is systematic and as such, particular structures. In relation to this discussion, some of the structures that support nursing practice also function to support the gaze of technology. Brown et al. (1999) provide one example within their research on nursing documentation. These authors point out that “nursing records have a disturbing tendency to escape reality” (p. 22). They argue that the documentation that accumulates as a person passes through the health-care system is usually taken as factual when in truth it reflects the prejudices, values and beliefs of the professional who is recording. In the end, these researchers found that documentation records reflect broader social and cultural beliefs about men and women (Brown et al., 1999).

In summary, the dominant biomedical/technological gaze constructs patient-hood in particular ways. These images of patient-hood have a major effect on people who care for those in the position of the patient. Biomedical reductionism, removing health and illness from the context within which they exist, and positioning the nurse as expert are three ways in which people in the position of the patient experience the impact of a biomedical construction of patient-hood. In contrast with a biomedical lens on health and illness, nursing theorists focus on holism and the interaction of individuals with the environment.
Historically, grand theories of nursing treat the concept of patient in particular ways ranging from individuals as having no free will or agency to conceptualizing people as entirely autonomous individuals. Nightingale (1859), arguably the first nursing theorist, focused on nursing as a science and conceptualized people as biological, psychological, social and spiritual persons. This was the starting point for nursing theory. During the following decades, nursing theorists continued to explore the notion of patient-hood and each contribution has broadened our understanding of health and illness and altered our perspective on the position of patients within the health-care system. The following discussion is a brief overview of selected major nursing theorists and their perspectives on the "patient".

Neuman’s Systems Model focuses on clients as “a dynamic composite of the inter-relationship of variables – psychological, socio-cultural, developmental and spiritual” (Reed, 1993, p. 6). However, Neuman extends Nightingale’s conceptualization of patients to describe them as being in a dynamic constant energy exchange with the environment. She conceptualizes individuals as both acting on and being acted upon by the environment (Reed, 1993). Similarly, Rogers (1970) Theory of the Unitary Human Being also conceptualizes people as being in a constant exchange within their environment in what she terms “a human-environmental mutual process” (p. 209). Rogers describes people as open systems integrated with the environment and engaged in a continuous mutual exchange. Parse’s (1998) Theory of Human Becoming also acknowledges the importance of the environment. Her theory of nursing views individuals as “becoming” – that is, in a constant state of evolution and movement toward
becoming more human. Of particular relevance to this discussion is the idea that people are in continuous interaction with their environments, a view held by both Neuman and Parse. However, Parse extends this idea to include the notion that people are continuously moving/shifting in a way that both "enables and limits becoming" (p. 23), suggesting a process rather than a simple energy exchange.

The above theorists built on Peplau’s (1952) theory of nursing, which focuses on the nurse-patient relationship as the crux of the science of nursing. Forchuck (1993) describes a major assumption underlying Peplau’s theory. Forchuk relates that all human behavior is purposeful and goal seeking in terms of feelings of satisfaction and personal security. This conceptualization of patients adds the notion of patients as autonomous individuals – acting as agents of their own destiny.

In contrast with the above approaches to conceptualizing the substance of “patient”, Liaschenko (1997) writes about people in the health-care system as case, patient and person. While Liaschenko is not, at first glance, a grand nursing theorist, she makes a major contribution to the ways in which practicing nurses conceptualize patienthood. Thus I have included her in this discussion. Liaschenko describes the ways in which nurses relate to the clients with whom they work. In the process, she describes three levels of “knowing” someone in a health-care interaction. Knowing the case means knowing the client as a biomedical entity. This includes general knowledge of disease processes, projected recovery, treatment options and so on. Knowing the patient represents a level of knowledge about a particular individual, including his or her past history, particular responses to treatment, medications and so on. In contrast, knowing the person is to know someone as a “subject who acts with his or her own desires and
intentions” (p. 26). In this conceptualization of “patient”, Liaschenko acknowledges the complexity of relationships between nurses and the people they care for. Thus, she builds on the work of other nursing theorists, acknowledging both a holistic view of individuals and the impact of environment on particular individuals.

In the process of reviewing nursing theory, some fundamental assumptions about what it is to be in the position of the patient are exposed. For example, Liaschenko’s (1995) work acknowledges the de-personalization and objectification that can be part of the experience of being a patient. Peplau (1952) acknowledges the central importance of human interaction in the progression of health and illness. And, Neuman (1995) conceptualizes the interaction between individuals and their environment as another major factor contributing to the health of individuals in the position of the patient. These nursing theorists confirm that individuals experience patient-hood based on the inter-relationships between a host of variables that are individually determined and unique to each person.

In summary, as is common among the many theorists attempting to conceptualize modern nursing practice, each author has attempted to help nurses appreciate the complexity and individuality that each person brings to the experience of patient-hood. This stands in contrast to images of patients that arise from a traditional biomedical view that dominates much of the media and health-care practice. Unfortunately, while this is consistent with viewing patients as holistic, complex, independent individuals – agents in their own lives – several nursing and health-care theorists note that these ways of conceptualizing patient-hood may not have the desired effect in a practice setting. That is, people in the position of the patient are still treated as passive recipients of health care

Political Lens

The Social Context of Western Medicine

The biomedical gaze has particular consequences for people interacting with the health-care system. The role of the patient is constructed in specific ways – ways that allow reductionism to operate at the level of the individual. However, perhaps of equal influence on the construction of patient-hood, are the values that underlie the Canadian health-care system. Wright, Cohen, and Caroselli (1997) point out that the term “patient” is attached to particular cultural views. In North America, the individual and individual interests are valued over those of the collective. This is reflected in the focus on “patient autonomy”, “patient rights”, “patient satisfaction” and “patient outcomes”. Dominant Western values about the importance of self-determination are embedded in our health-care system.

Stingl (1996) argues that two main philosophies compete within the North American health-care system – libertarianism and liberal egalitarianism. Libertarianism is a social view that attaches primary significance to the individual and individual rights and freedoms. In contrast, liberal egalitarianism, a social view that values personal liberty, attaches importance to individual rights and freedoms but is prepared to limit those freedoms for the good of others. Both views have in common the value of individual liberty.

In fact, a focus on the individual underpins many of our social institutions and much of the theory upon which we base our practice. Consider the example of health
care ethics. Sherwin (1998) the editor of the book *The Politics of Women's Health: Exploring Agency and Autonomy*, describes respect for individual autonomy in the context of health care as the recognition that people have the authority to make decisions about their own health care. She argues that the principle of autonomy is widely interpreted as supporting competent people's authority to accept or refuse medical intervention. On the surface, respect for autonomy seems to be a solution to the paternalism of medicine. However, autonomy, as discussed by Sherwin, is a concept located in the individual. As such, it ignores the context of health-care decisions and fails to question how much control people really have over the health care decisions they make. In addition, autonomy in its current popular conceptualization, is based on the stereotype of a well-educated, articulate, intelligent person who is often in a position of making decisions. In reality, the majority of people may not embody these characteristics.

Within the health-care system, the emphasis on individualism is translated into a focus on autonomy and patient rights. The negative effects of this political context of health are similar to the effects of biomedical dominance. A focus on the individual can mean a focus on individual responsibility for disease management and health maintenance (Burgess, 1996; MacKean & Thurston, 1996). As well, a focus on individual rights and freedoms may have the effect of removing individuals from the context in which they live their lives. Finally, a focus on individuals gives the impression that articulate, politically active "patients" would be valued as a reflection of our political ideas in action. In practice, however, MacKean and Thurston (1996) point out that
“willing, passive and compliant patients are integrated into the health care system” (p. 59).

Bartky (1995), using Foucault’s work on disciplinary practices, describes multiple layers of social practices that function to enforce conformity of individuals to dominant social constructions of roles. Although Bartky focuses on gender, many elements of her argument could be applied to the health-care system and social constructions of patient-hood. For example, Bartky writes about Foucault’s “disciplinary practices” – those practices that aim to increase the utility of the body. Disciplinary practices exist, according to Foucault (1980), within social institutions such as schools and hospitals. A key feature is the notion that there is a power differential that defines and enforces relationships to produce “docile” bodies – patients as objects, rather than as subjects. This is consistent with a biomedical and technological view of health and illness that allows the body to be broken into component pieces to be adjusted and fixed. As well, disciplinary practices may act to produce passive and compliant “patients”. Thus, people in the position of patient enter a medical system that, according to Foucault, may employ “the micro-physics of power” to fragment and partition the body’s time, space, and movement” (Foucault cited in Bartky, 1995, p. 240).

**Lens In Practice**

I have confined my discussion to the social, professional and political usage of the concept the “patient”. In this section of the literature review, I discuss, more specifically, some of the relational aspects of patient-hood. That is, the consequences are attached to the role of the patient and how these consequences impact individuals interacting with the
health-care system? How are social, professional and political ideas about what constitutes patient-hood translated into daily nursing and health-care practice?

A plethora of nursing researchers confirm that nurses actively conceptualize “patients” based on such characteristics as income, age, gender, social habits and social position (Corley & Goren, 1998; Fagermoen, 1997; Faugier & Sargeant, 1997; Hughes & Griffiths, 1997; Juliana et al., 1997; Minick et al., 1998; Pill et al., 1999; Sherwin, 1994; Spigner, 1998; Tang & Anderson, 1999) and that, on the basis of these and similar characteristics, they make decisions about the worth of individuals and act, in various ways, on those judgments. Throughout the literature, themes about “the right” way to be a patient are revealed. I have categorized these themes, for ease of discussion, into “good person”, “good patient”, and “good follower”.

Good Person

One major indicator of a particular person’s deservedness in society is social position (which is tied to economic status). For example, Minick et al. (1998) point out that homeless people are undesirable clients from the perspective of health-care providers. Similarly, Spigner (1998) states that those living in poverty can be divided into “deserving and undeserving” poor. Those living on welfare allowance and/or committing crime form the latter group. Such distinctions are inevitably tied to gender. In a startling example of the way in which gender and poverty combine to disadvantage someone seeking health care, consider that 14% of families in Canada live below the Statistics Canada poverty line. This group includes 56% of all households headed by single female parents (Hurtig, 1999). Similarly, new immigrants to Canada, experiencing language and cultural barriers, often have difficulty finding well paid work and so subsist
below the poverty line. Nurses form impressions about individuals in the position of the patient based on characteristics such as income and housing status. In fact, address and employment status are listed on the admission forms for hospitals. In my own practice as an emergency room nurse, I have witnessed the ways in which “street” people are treated compared to people with an address. Homeless people are fed reluctantly as staff do not wish to make the environment so comfortable that an individual may return repeatedly. Through socialization, media exposure, and our educational and political milieu, social judgments about what constitutes a “good person” become embedded in the thinking of members of society – all members of society – including nurses and other health-care professionals.

While some criteria for judging a person’s worth are more obvious, other judgments are based on less tangible criteria. For example, Spigner (1998) relates that coping, or being able to effectively manage the myriad of responsibilities that are societal expectations is a major indicator of the worth of a particular person. In my own practice, families are frequently “judged and found guilty” of shirking their responsibilities when they attempt to have an elderly relative admitted to hospital for respite care. Once again, gender and social position intersect to create a negative situation for clients and families. If a family cannot afford or do not have access to home support, they are forced to use the hospital system. Generally the social expectation of families is that family members care about, and are responsible for, each other. At times, nurses interpret caring through an ageist lens. Thus, if the same family wishes to have their child or infant admitted to hospital they are congratulated on their insight into their physical and emotional limits and they are supported in their decision to seek hospital admission.
Good Patient

Just as members of society, in general, and nurses, in particular, may hold shared values about what constitutes the deservedness of an individual, there may also be a shared view about what constitutes a “good patient” in the context of our current health care system. In the following discussion, the characteristics upon which nurses make judgments about people in the position of patient are illuminated.

Morgan (1998) describes an ideal female patient from the perspective of a medicalized point of view:

...She is reasonably (but not too) intelligent, enthusiastic about but only sufficiently informed about medical institutions, procedures, and technology to satisfy the minimum legal consent conditions, cooperative with respect to the paternalistically motivated medically directed use of medical technology, convinced that institutionalized medicine and medical technology provide the best health care in a larger macro-institutional setting where medicine enjoys pride of place, highly compliant with respect to following medical orders, and cheerfully responsible with respect to medicalized self-management. (p. 109)

In addition to these characteristics, Juliana et al. (1997), in their research with nurses on the topic “difficult patients,” add the following. The participants in their study described “good patients” as those who were not violent or abusive, did not lose their temper, did not ring the call bell, did not demand instant attention but rather waited patiently, were not restless or at risk for falling, did not attempt to manipulate the nurse with bribes for good behavior (i.e., smoking), did not call on nurses for “small items” such as tissues or water, were not scared about dying, did not lie, made nurses feel successful, did not have high maintenance families, and were not combative. Finally, individuals worth is also judged on the basis of their attitude towards the health care they receive. For example, Minick et al. (1998) point out that there is an implicit belief that people in North America
should not complain when they are receiving “free” benefits from health-care professionals.

As previously discussed, media representations of people in the position of patient are generally consistent with professional descriptions of “good patients”. While the media portrays such individuals as long suffering, compliant, and quietly valiant, professionals extends that image to include specific behavior that supports or does not support the stereotype of a “good patient”.

Good Follower

In addition to social position, race, gender, economic status, age and images of what constitutes a “good patient”, individuals are also judged according to their degree of cooperation with particular medical treatment plans. Pill et al. (1999) examined nurses’ attitudes toward individuals with diabetes and found that people are frequently judged based on their success with a particular treatment regimen. In their study, individuals whose sugars were abnormal were labeled as “difficult patients”. While the nurses in this study espoused the belief that people should control their own treatment, when poor control of sugars came up, the nurses were reluctant to allow participants to be autonomous. The authors point out that professionals seem to have some ownership of “patients’” behavior and outcomes.

Parsons (1951), sometimes referred to as the founder of medical sociology, described what our society seemed to do in relation to social role expectations of sick people. Parsons observed that the phenomenon of being ill requires a person to act according to a set of social norms defining appropriate and inappropriate behavior for persons in the “sick role.” Among those expectations is the obligation to seek out and
cooperate with medical treatment and with physicians and other health-care professionals in the process of trying to get well. His work has since been interpreted as describing the way things *ought* to be as opposed to providing a description of the direction things seemed to be heading. As a result, Parson's work is sometimes used to support arguments about compliance within health care literature. Thus compliance, for a long period of time, has been linked with role expectations for people in the patient role. Indeed, there is an extensive body of literature on the notion of compliance.

Finally, Lempert (1997) researched the issue of domestic violence, and describes what she called “definitional contingency”. This refers to the idea that help or assistance is dependent upon a “patient” accepting the helper’s definition of his or her situation. Varcoe and Turris (unpublished manuscript, 2001, in review) extended this concept to “compliance contingency” – the notion that help is contingent upon the compliance of an individual. Thus, people in the patient role are not only judged, their actions are dictated to them by health-care professionals. These images of appropriate behavior and messages about worth are part of a larger social context that dictates behavior to all members of society.

**Summary and Conclusions**

To summarize, patient-hood is not a neutral state. Rather, the position of a patient is constructed by social, professional and political forces that operate at every level from the individual to the global. At all times, interactions between nurses and individuals in the position of the patient are shaped by social constructions of the role of patient. People experience and respond to these constructions of patient-hood in particular ways.

Out of this literature review arises several questions relevant to this project.
These include: (a) how do social constructions of the role of a patient found in the literature compare with patient experiences? and (b) how do people in the position of a patient respond to these social constructions of patient-hood?

Enduring texts such as the Illiad and the Bible are politically successful books (Denby, 1996). Similarly, I argue that modern constructions of the role of the patient endure because they are politically successful and continue to serve a purpose. Boutain (1999) points out that commonly used words are so naturally used to categorize people that users “forget the social and political movements that contributed to their use in society and research inquiry” (p. 4). A critical perspective on the issue of “patient” demands an examination of whose interests are served and whose are harmed by traditional thoughts about people in the position of the patient.

Ruiz and College (1998) write about an American physician, Samuel Cartwright. Cartwright, practicing in the time before the American Civil War, pathologized the act of slave elopement, calling it drapetomania. In the process, he left the institution of slavery unexamined. Similarly, I believe that we pathologize patients when we focus on compliance, anxiety and cooperation – inadvertently ignoring the “institution of patient hood” and all of the social and historical structures that support the institution.

Sacks (1996) uses Foucault’s work on discourse and power to support her argument that the discourse of sexuality acts to punish women who have AIDS. In the process, Sacks acknowledges that, according to Foucault, “discourses play a key role in the creation and dissemination of “truths” that have a regulatory function” (p. 60). Sacks goes on to state that discourse is one of the vehicles through which existing modes of social control are created and enforced. Similarly, I argue that the discourse on patient-
hood, which I have attempted to address in this literature review, is an example of a group of socially constructed ideas that function to shape and govern the experiences of patients in a pervasive manner.

In this literature review, I have attempted to problematize patient-hood. I have argued that the social and political contexts of health and illness act in several ways to disadvantage individuals in the position of the patient. Firstly, "patients" are judged as worthy (or not) based on the values held by society in general and by nurses in particular. Values and beliefs about age, gender, social position, and compliance are embedded and translated in day to day nursing practice. Secondly, the effect of the biomedical gaze is to separate individuals cast as patients from the social context of their lives. In this way, the social roots of illness are obscured. In addition, the political context of the Canadian health-care system, when combined with the power of the biomedical gaze, acts to assign individuals personal responsibility for health and illness. Finally, being in the position of a patient often means that receiving help is conditional on accepting the helper's definition of the problem and upon the degree of cooperation with a particular treatment plan. Thus, the institution of patient-hood influences individual experiences of health and illness in particular ways. In this research project, I seek to understand the experience of patient-hood in the current social and political context. As well, I seek to explore the ways in which dominant values and beliefs are translated into action in health-care encounters. Finally, I seek to understand the ways in which people in the position of the patient respond to the impact of social constructions of the patient role.
Chapter 3: Methods

My goal in this research project was to explore the ways in which people in the position of a patient experience and respond to constructions of patient-hood. My intentions were fourfold. First, I described the substance of patient-hood as it is experienced by people in the position of patient, thus re-introducing an emic perspective to the issue of what it means to be a patient. Secondly, explored the ways in which the current health-care context shapes the experiences of people in the position of a patient. Thirdly, I sought to understand how people in the position of a patient respond to social constructions of patient-hood. And finally, I developed an understanding of the experience of patient-hood that encourages critical exploration, by nurses, of assumptions and values around what it means to be a patient.

Research Design

Morse and Field (1995) describe qualitative research methods as particularly useful when describing a phenomenon from the "emic" or native point of view. In this study, I sought to describe the construction of a "patient", as seen through the eyes of patients. By exploring the values, assumptions and beliefs that underlie the concept, I created an understanding of how these ideas or dominant ideologies are translated into action. Creswell (1998) identifies that qualitative study designs arise from questions about what or how, in contrast to quantitative methods that seek, more commonly, to explain why. Thus, qualitative methods were suited to my research questions.

Interpretive description is a research method that acknowledges "the constructed and contextual nature of the illness-health experience" (Thorne, Kirkham, & MacDonald-Emes, 1997, p. 172), while allowing for shared realities. Such a method can contribute
directly to our understanding of how people experience health and illness. In this qualitative method, what is already known serves as a foundation for new research. In the form of an "analytic framework", critical analysis of existing literature and/or clinical interpretation forms the foundation of this qualitative design. As described by Thorne et al., as inductive analysis of data proceeds, the content of the literature is challenged.

**Sample Selection**

The data for this study consisted of open-ended interviews with seven people who had experienced the role of a patient within the mainstream health-care system. Participants had varying degrees of experience with the health-care system. I recruited participants using word of mouth.

**Method of Sampling**

Interpretive description uses purposive, theoretical sampling for participant selection. This approach encourages the researcher to strive for maximal variation between participants, guided by the inductive emergence of themes from the data. Creswell (1998) defines maximum variation as focusing on diverse variations and identifying important common themes in the data. For example, my initial organizing framework told me that people experiencing chronic versus acute illness experience might respond to social constructions of patient-hood in different ways. My developing analysis, however, illustrated many commonalities of experience. Thus, I actively recruited several more participants with acute and chronic health challenges in order to faithfully represent relevant patterns. In addition, Thorne et al. (1997) suggest seeking participants who "are articulate, thoughtful and eager to share their abstractions and analysis of a situation" (p. 174). Finally, in recruiting participants, I sought people who
had experienced a shared phenomenon from different perspectives. While such sampling fails to provide an exhaustively strong description, it is useful for guiding the course of future research.

In this study, the sample was entirely female in composition. Gender might be one relevant factor upon which experience might vary. However, due to time and resource constraints associated with this project as a master's thesis, I focused recruitment on variation in illness experiences rather than on socio-demographic factors recognizing that this represents an inherent limitation in relation to generalization beyond my specific sample.

**Procedure for Approaching Participants**

I began recruitment for the project by sending a message to colleagues and friends indicating that I wished to speak with people who had had some interaction with the health-care system to receive nursing care. I did not approach anyone directly, rather I asked that friends and colleagues provide interested individuals with written information about the study (Appendix A). At that point, if the individual was willing to be interviewed, I asked that my phone number be given to that person. When contacted, I set up appointments at the convenience of each person. As my analysis progressed and I required particular types of participants, I sent out messages asking for volunteers with a certain profile. For instance, in the final stages of the project, I needed to speak with someone who had had an unexpected encounter with the health care system, so I sent out a note asking colleagues whether they knew anyone who fit this profile.
Sample Size

I interviewed seven participants for this study. The sample size was assessed as the study proceeded. Sandelowski (1995) states that sample size in a qualitative study is relative, often dependent on the quality of the interviews. The seven people I interviewed were thoughtful, articulate participants who shared experiences that were rich in data. The decision to cease recruiting was made in collaboration with my thesis advisors and based on the notion of obtaining maximal variation among the interviews.

Data Collection

Data Sources

The interviews with research participants were the primary source of data in this research project. In addition, after each interview, field notes were completed in an attempt to capture the contextual variables and my own reflections on the substance and essence of the interviews. Using a journaling format and summarizing each interview in writing, I sought to capture both descriptive and reflective ideas about the interview process and content.

The Interview Process

Interviews with participants took place at a mutually convenient time and in a neutral setting. Most frequently interviews took place in participants’ homes. Considerations included the need for a quiet environment, privacy, and the maintenance of confidentiality for the participants. All interviews were recorded and subsequently transcribed by a professional transcriptionist.

At the beginning of each interview, informed consent was obtained and demographic data such as age, gender, and employment status was collected. From this
point, the interviews were guided by open-ended questions (Appendix B) informed by the literature review in Chapter 2. Interviews ranged between one and three hours in length.

**Data Analysis**

Qualitative methods lend themselves to inductive reasoning. Interpretive description as a method is consistent with an inductive approach to data analysis. This means that the researcher's goal is to identify patterns and to analyze relationships as they emerge in the data (Morse & Field, 1995). Data emerging during this research process, created from the interaction between researcher and participant. As themes emerged, those themes formed the basis for further exploration within subsequent interviews.

In terms of data analysis, rather than focusing on clipping, copying and pasting individual pieces of data into categories, the analysis was based on exploring the underpinnings of an exchange. By asking questions of the data, such as "what is happening here?" Thorne et al. (1997) suggest that a greater sense of the whole is retained. Thus synthesizing and theorizing forms the basis of the analysis. For example, when coding a portion of an interview in which a participant described an experience of feeling patronized by a nurse, I had choices. Using a traditional qualitative approach, I could have focused on the particulars of the episode -- how was the nurse standing in relation to the patient? What words were used? In what ways was the nurse exerting professional power? Alternatively, consistent with interpretive description as a method I approached this vignette using a large lens and asked of the data "what went on in this encounter?" This led me to make a connection between the dominant medical discourse and that participant's experience.
Following each interview, the audio-tape was transcribed verbatim by a transcriptionist. Upon receiving the transcripts, I verified the accuracy of the typed version. Subsequently, each interview was read and listened to several times in an effort to develop a sense of the flow the interview in its entirety. In analyzing the data, I engaged in the following process:

1. After listening to and re-reading the interviews closely, I reviewed the field notes accompanying the particular interviews as part of my initial impressions.
2. At this point, as Sandelowski (1995) suggests, I wrote a brief abstract for each interview, including a summary impression of the salient elements.
3. Rereading the interview, I made tentative comments in the margins. Comments included my ideas as I read the data, notations about commonalities and differences between interviews, and ideas about very tentative themes.
4. As I read subsequent interviews, I compared and contrasted the data with my initial ideas about tentative themes. Once sections of the data were identified as sharing commonalities, I grouped the commonalities, seeking shades of differences as well as degrees of similarity.
5. As the categories or themes became consistent, I developed a framework describing participants' experiences of, and responses to, being in the position of the patient. Engaging in that process forced me to further question and explore the relationships between each category or theme and how each contributed to the whole.

Lather (1991) suggests that, to do a deconstructive reading, one should depend not only on transcripts but also note the intensity, pace and content of speech, noting both contradiction and emotion. Opie (1992) adds that attention to that which is paradoxical,
contradictory, or marginal within the interviews, and fore-grounding these elements, is a valuable lens through which to view the interview data. Attending, in particular, to those pieces of data supported my intention to challenge preconceptions about common patterns and themes as they arose in the data.

**Rigor**

In interpretive description, as with all research, rigor is of central importance. While acknowledging the impossibility of eliminating all bias from this research, I nevertheless sought to illuminate bias explicitly from both a nursing science and researcher's perspective. Koch and Harrington (1998) suggest that close examination of reasons for choosing a particular topic and exploration reveals beliefs, values and assumptions that support researcher bias. Similarly, Sherwin (1998) posits that location influences “both what is observed and what is known” (p. 5), thus I begin my discussion on rigor by describing my position. In undertaking this research, I position myself as a feminist, post-modern, praxis-oriented, novice, Caucasian, middle-class, female, nurse researcher. In addition, I acknowledge that I have some degree of personal experience with the role of patient, both in an acute and chronic context. Within this description, I acknowledge Opie (1992) who argues that “it is not sufficient to posit one’s ideological position. Instead, one must continually re-examine the extent to which that ideology contributes to a failure to see beyond it” (p. 3). Thus, throughout this project, I maintained a critical awareness of the effect of my “life lens” on the process of data analysis. In discussion with colleagues I attempted to dissect the ways in which my own experience might be influencing my analysis of the data. In an effort to understand the impact of researcher bias, throughout this process I kept a reflective journal. For
example, I found that my position as a nurse influenced my reaction to and analysis of the data. Early in the process I found that I was struggling with an emotional reaction to the situations described by participants. As a nurse I did not want to hear stories that illustrated less than compassionate and effective nursing care. In the first couple of interviews, I was so busy mentally trying to find “excuses” for the behavior of health care professionals that I wasn’t listening to the speaker with my full attention. Journalling about this issue, as well as speaking to colleagues, helped me maintain an awareness of my personal responses and set them aside by reminding myself that in this situation my role was that of a researcher.

In an effort to address the bias that arises as a result of a particular philosophical stance, I acknowledge the following epistemological and ontological assumptions that inform this project. I entered into this study with a philosophy that encompassed aspects of feminist, post-modern and critical social theories. A feminist perspective is informed by a focus on the impact of gender on the phenomenon being investigated. In addition, feminist researchers emphasize the need for social change based on the findings of the research (Creswell, 1998). Similarly, critical social theory acknowledges the central need for social change. In relation to this project, I believed that a more comprehensive, integrated understanding of current constructions of patient-hood is critical to assist nursing in caring for individuals in ways that preserve dignity, autonomy and agency.

Feminism, critical social theory and post-modern perspectives have in common a position that knowledge, or what can be known, is a social construction rather than a “truth”. Theorists from this perspective acknowledge that what can be known is contextual – shaped by political, social, historical and economic forces (Guba & Lincoln,
Accepting that all of the ideas generated by this project are likewise situated, I
addressed rigor by using particular procedures to ensure that the logic of the knowledge
generated was accessible to others. Specifically, the strategies I used to pursue rigor in
this project included insuring auditability, using reflexivity and attending to the
applicability of the analysis.

Auditability

Morse and Field (1995) confirm the importance of an audit trail to trace and
document the decisions made by a researcher. Lather (1991) suggests that this is a larger
question than documentation of a daily decision trail. Indeed, Lather suggests that a
researcher undertake a critical reading of his or her practices of representation - asking
the question, what social and political constructions inform the research process? To
address auditability I kept field notes including both specifics such as date and time and
generalities such as context and atmosphere of the interview. In addition, I made
notations about the emotions evoked during the conversation. I sought consistency in
each interview by giving the same explanations and using standard forms and information
letters. In addition, I attended to the ways in which one account may differed from
another by virtue of the prompts I gave and my focus during a particular interview.

Notes were kept on discussions with my supervisory committee members and some
colleagues. In this way I addressed auditability so that, as described by Guba and
Lincoln (1994), another researcher will be able to follow my decision trail. In practice I
found the concept of auditability a difficult one to address comprehensively. Much of my
thinking around the data and emerging themes took place in conversation with clients
during a shift in emergency, in the car while driving long distances, and while reading
literature on seemingly unrelated topics. As well, I found that, as a novice researcher, the higher levels of analysis took place when I actually began writing and having those ideas challenged. In returning to the data, I often made connections that earlier eluded me. All of this feedback and discussion forms part of the audit trail that might be used by another researcher to follow my analysis and the decisions I made in relation to the data.

**Reflexivity**

While there are many perspectives on what constitutes validity in qualitative research, reflexivity is acknowledged as a significant way of addressing rigor. Reflexivity is the process of cultivating critical awareness of the relationships between the researcher’s perspectives, the informants’ ideas, the researcher’s ideological perspective and the emerging data categories (Marcus, 1994). By keeping a reflective journal, engaging in discussion with my thesis committee members and maintaining a critical stance about the impact of my position on the data being gathered and interpreted I addressed reflexivity. Ideally, I would have liked to interview each participant a second time to discuss emerging themes. In practice, I found that due to time limitations I interacted with colleagues, clients and members of my thesis committee about emerging ideas. This was an effective strategy as it forced me to articulate the links between the data and my analysis.

Finally, Lather (1991) suggests that “reciprocal” reflexivity is one defense against imposition and reification on the part of the researcher. Thus, during each interview, I invited the participants to engage in a process of questioning, understanding and transforming their thoughts and ideas. Participation in this study, at times, served as a catalyst for transforming thought and action.
Applicability

Sandelowski (1986) states that applicability in qualitative research is defined as when the study results "fit" into contexts outside of the study situation and when participants and readers find those results meaningful and useful within their own life experiences. I addressed applicability by comparing data between participants reaching for commonalities of perspective, without denying or minimizing the existence of dissenting voices. In addition, I took my findings back to colleagues and other clients to confirm the credibility of my interpretations of the data. This also ensured the preservation of faithful, rich and vivid description as I provided the background to my interpretations.

Ethics

Ethical considerations in any research project are of significant concern. In qualitative research, because of the often personal nature of the research, ethics are of particular importance. All participants in this study were fully informed about the nature and purpose of the study. Other issues arose out of the philosophical stance informing this research project.

Reciprocity

As a researcher, I asked myself the question, What is the relationship between researcher and participant? I aimed for mutuality – dialectic theory building versus theoretical imposition. I believe that to have rigor, knowledge must emerge as co-created. Lather (1991) puts it succinctly when she says "Reciprocity implies a give and take, a mutual negotiation of meaning and power" (p. 57). In other words, neither the researcher nor the researched assumes a privileged position in interpretation (Koch &
Harrington, 1998). While keeping this philosophical stance in the forefront of my mind, I acknowledge that in this project I was in a "privileged" position to some extent – arising from my immersion in the data and my position as researcher and writer. I was in the position of being able to link individual experiences within a larger analysis. Thus, in this study, co-construction played a lesser role than it might in another project.

Reciprocity is often given lip service in qualitative research. I struggled with this idea and came to two conclusions. Firstly, reciprocity is as much a philosophical stance as an action taken. That is, as I interviewed, I looked for ways to "give back" to a particular participant. For example, in each interview I attempted to involve the participant in my ongoing analysis, stating "one of the things I am wrestling with is ... what are your thoughts?" Secondly, and most importantly, as described by Moules and Streitberger (1997) and Frank (1998) narrative or the telling of one's story is a powerful, positive intervention: One participant in this study described the opportunity to be interviewed as "another way to make sense of what happened to us." Specific benefits also included the idea that experiences are validated through the privileging of narratives (Moules & Streitberger, 1997). In practice I found that participants in this study, with the exception of a single person, experienced positive outcomes as a result of sharing their experiences. Following the majority of the interviews, when the tape recorder was turned off, participants spoke about the process as cathartic and/or thought provoking. Several participants spoke about this being the first time a health-care professional heard their concerns. In these ways I attempted to address the issue of reciprocity.
Human Subjects Approval

Approval for research with human subjects was granted by the University of British Columbia Research Ethics Committee.

Informed Consent

The participants in this study shared their perspectives on a voluntary basis after receiving both verbal and written explanations of the study. The only direct benefit gained from participation was reciprocity – being heard. The explanations included a description of the study's purpose, the process of being interviewed including audio-recording and transcription of the interviews, and the proposed dissemination of the results. Participants were asked to read and sign a consent form (Appendix C) indicating their willingness to participate and acknowledging their understanding of the project. Finally, participants were made aware that they were able to withdraw from the study or to ask that the audio tape be shut off at any point during the interview process.

Confidentiality

The nature of qualitative research – small samples, interviews and narratives – makes maintaining confidentiality particularly challenging. To guarantee confidentiality for the participants of this study, I undertook the following:

1. Participants were never referred to by name, but by interview number.
2. Interviews were transcribed without identifying references such as place names or proper nouns.
3. Tapes were not shared with anyone other than myself and my committee chair.
4. Tapes and transcripts were stored in separate locations.
5. When this research project was concluded, the tapes were destroyed.
Limitations to the Study

The limitations of this study are related to both my level of expertise as a researcher and to the data sources. I am a novice researcher, and I made many mistakes, learning about the research process throughout this project. For example, an early interview for this project took place via the telephone and the telephone tape recorder failed to pick up the voice of the participant with whom I was speaking. Fortunately, I was taking notes throughout the interview to prompt my own thinking and I was able to use these notes to reconstruct the interview. I also struggled with the data analysis process, reluctant to “appropriate” the voices of participants. In order to address this issue, I drew on the expertise of my committee chair, an experienced researcher, who guided my efforts, forcing me to take my analysis to a more sophisticated level.

Secondarily, limitations of this study are related to method in general and sampling in particular. I acknowledge that I primarily used a single source of data in this project – interviews. I acknowledge the changing nature of peoples’ narratives, depending on state of mind, anxiety, and personal history. Stories were retrospective and as such, those stories likely evolved since the experiences took place. Some detail was likely lost. As well, situations may have been re-interpreted in light of subsequent events. Despite these shortcomings, the stories of participants provided a rich data source. Limitations of this project in relation to sampling will be further discussed in Chapter 5.

Summary

In this chapter, I have described the project design. Interpretive description is the method used in this study. In addition, post-modern, feminist, and critical theory schools
of thought guided the decisions that I made in the course of designing this study, analyzing the data, and addressing ethical issues.
Chapter 4 – Findings

My challenge in describing the findings in this study is to capture and describe major themes while acknowledging and addressing the uniqueness of each participant’s experience and perceptions. The individuals who were interviewed in this project gave generously of their time and shared their experiences so that this study would contribute to an improved understanding of what it means to be in the position of a patient. In particular, they spoke of the challenges they faced while experiencing the patient role. The contribution of each participant in this study adds to my understanding of what it means to be in the position of a patient in the context of today’s health-care system. As well, their stories illuminate some of the ways in which people in the position of a patient respond to social constructions of patient-hood.

The purpose of this research study was to explore a) the experience of being a patient, b) the ways in which dominant values and beliefs are translated into action within health-care encounters, and c) the ways in which patients respond to the impact of social constructions of patient-hood. In the process of data analysis, I considered my research purpose and asked myself what I had come to understand about each of these questions. In the following chapter, I explore the dominant values and beliefs that shape health-care encounters as they were described to me by the study participants. In addition, I discuss the ways in which the participants coped with and responded to the challenges imposed by those values and beliefs.

I begin with a description of the participants in this study and then proceed to re-examine the social context of patient-hood as I heard it described by the people who have experienced the role. Using examples drawn from the text of the interviews I will explain
my analysis and, where possible, provide descriptions of when and where my analysis shifted.

**Description of Participants**

Seven people participated in this study. All were female, ranging in age from 35 to 60 years. All the participants were professionals; their careers included teaching, nursing, social work and private enterprise. Educational attainment ranged from a community college diploma level to a graduate degree. While more than one half of the study participants spoke solely from the perspective of a consumer, three individuals had experience with the health-care system as both a provider and a consumer.

The degrees of experience with the health-care system varied widely. In four cases, other than routine visits to a family physician for immunizations, the participants had little experience with the health-care system until a catastrophic event occurred. In one case, this was the death of a child, in another, a traumatic accident, and for the others the unanticipated event was emergency surgery. An illness of a chronic nature provided three study participants with ample opportunities to interact with the health-care system. One of the study participants experienced the role of patient as the family member of a critically ill patient. She felt strongly that she was as much a patient as her father during her family’s three month experience with the health-care system.

**Understanding Patient-hood**

I entered into the data collection and analysis process for this project with the perspective that the position of a patient is a socially constructed role in which particular values and beliefs are embedded. I suspected that these values and beliefs operate to influence the experiences of individuals who are patients in profound ways. In the
process of collecting and analyzing the data, I identified several dominant themes in relation to the assumptions, values and beliefs that underpin and shape health-care encounters. In the following chapter I describe my findings in relation to the research questions. From the participants, I identified three main themes that had a pervasive influence in shaping their health-care encounters in general and the experience of being in the patient role in particular. The themes addressed the impact of dominant values and beliefs operating within health care encounters. These themes included a value for technology, a positioning of patients as objects, and resistance to patient-hood.

**Dominant Values and Beliefs Shaping Health Care Encounters**

**Technology: Some of the Parts are Greater Than the Whole**

Hospitals are designed to provide highly skilled, technologically advanced medical and nursing care to people who are ill or injured. Our health-care system is based on providing health care or, more accurately, “illness care” services. Thus, our health-care system is focused on “fixing”. One of the ways we attempt to “fix” people is through the use of technology. This supports a strong focus on illness and pathology in general rather than on an individual in particular. The title above is meant to capture the notion that a value for technology and a focus on “fixing” patients are dominant ideas operating within health-care encounters. Participants in this study shared many examples of the impact of a high value for technology. This impact was significant and related to being disembodied during hospitalization (particularly during treatment for an acute illness or injury), being watched, and being problematized.
Being Disembodied

Several participants in this study spoke passionately about the notion that being a patient diminished their value as individuals in some way. They spoke of feeling ignored and being objectified. Embedded in each story was a high value for technology held by health care practitioners. For example, one participant described the way the environment was organized to support the use of technology – in this case surgical intervention. This organization had particular consequences for her experience as a surgical patient. She characterized her experience as frightening, relating that the operating room experience reduced her to a body without any thoughts or feelings. She described the operating room experience as “a ghouly show”:

The last holding tank before the operating room was to me a nightmare... All these gurneys rattling down the hall. Anyway they take you up and there's this huge room. At one time it had curtains between [each stretcher] but the curtains are gone and on the middle table there are numbers hanging all down the side. One, two, three, four, five, you know, whatever your number is. And they put a number on the end of your gurney and you just watch them coming and getting your number and then coming over to you and one by one taking people off to the operating room. I just found the whole procedure ghoulish.

The de-humanizing aspects of the operating room procedure provide a powerful example of the consequences of focusing on technology without concurrently focusing on attending to the human experiences of those involved. In this case, using technology to “fix” someone required that the body be visible and accessible.

In addition to influencing the physical environment, a high value for technology also appeared to influence the practice environment. In many interviews, participants discussed the notion of feeling fragmented, that is, rather than being cared for holistically, their experience was one of being cared for according to the bodily system affected by
illness or injury. In the following examples, participants describe the experience and the impact of this fragmentation.

One participant spoke about the fragmented care her father received. She used the phrase “broken puzzle”. She said that the staff treated her father like a broken puzzle they had to fix. In attempting to “fix” the puzzle, care was organized around body systems, rather than holistically. In practice, this meant a new care team every week and a different specialty for each body system. As a consequence the family members were forced to repeat all of their information every week and were obliged to acquaint themselves with new faces constantly. Another participant also spoke about the frustration that came with endless faces requesting information. She was assessed by staff from gynecology, plastic surgery, and general surgery. She related that the plastic surgeon was interested in her abdominal strength and the amount of scarring. In contrast, the general surgeon seemed to be interested primarily in wound healing, bowel function and post-op recovery, and so on. Each member of the team asked similar questions although they had different interests, yet no service seemed to have information from any previous assessments. As in the previous example, this participant stated that she “had to tell every single person that came to see [her] the same story over and over again.”

Stories shared by the participants in this study illuminate the ways in which a high value for technology influenced their experience of patient-hood. In particular, their stories described the ways in which the physical and practice environments were organized to support the use of technology. Being subjected to what one participant described as “an alien world” evoked different responses from the participants. As discussed in the “ghouly show” example, the participant, after being discharged from
hospital, offered to work with hospital staff to alter the pre-operative environment so that no one else would have an experience similar to her own. In this way, she attempted to shift the OR environment presently organized around the use of technology to attend to the human experience of surgery. In contrast, another participant described the way she channeled her fear and frustration into adopting the values of the world she found herself in. She internalized those values, stating,

Your sense of well-being is totally altered. You might normally get up and say ‘Oh good, I look great today, my eyes aren’t so dark and puffy’ and [you] feel great about it. But in the hospital, questions like: ‘Have you had a bowel movement? Have you passed wind?’ come daily, regularly, every time the nurse checks in. You know, have you passed gas yet? Let me listen to your stomach, I want to hear if there is gas in there. Oh good, and the doctor would come in the morning and I’d say yes [I’ve passed gas]. And he’d say, “congratulations!!” And you’re so psyched up for this and you are so happy that you’re doing something well, you’re getting well, your benchmarks are completely altered. You know, you have no idea what you are getting into once you get in there. It’s really strange. It’s an alien world, with different values.

This participant went on to speak about the idea that she became a mannequin with a broken part rather than a person. Technology, in the form of a focus on the mechanics of body systems, remained an issue for her during her entire hospitalization.

Technology is valued within today’s health care system as our major strategy for “fixing” bodies. Participants spoke, sometimes passionately about the ways in which they experienced the high value for technology. Physical and practice environments may be organized and are certainly influenced by this value. The use of technology may have the effect of objectifying patients and fragmenting care.

Being Watched

The supremacy of technology within the healing enterprise is an element that the participants in this found pervasive in the health-care system. The use of technology is
easiest if bodies are accessible. Accessibility is improved if tests can be used to follow progress, therefore, one manifestation of technology at work is the use of surveillance.

The behavior of people who are in the position of patient is scrutinized to monitor patient health status and to ensure compliance with treatment regimens. However, the use of technology for surveillance may have negative consequences for people in the position of patient. In particular, people get the sense that their worth as an individual is judged by the measures that are monitored. While common to all participants accounts, this theme was particularly strong in the stories of the participants who had long-standing contact with the health-care system.

For the participants in this study, being watched had specific consequences. In the following examples, individuals describe the impact of the professional judgments about personal worth. One participant spoke about the consequences of the close scrutiny on a personal level. "Once I came in and my blood sugar was high and I remember feeling like I was being blamed. I remember sort of, what's wrong? Do you want to tell me what's wrong? But my feeling was, I can't remember the words used, but the feeling was 'you are doing something wrong'". Similarly, another person spoke about being judged when her laboratory results were in a downward trend. Her hemoglobin levels were dropping despite iron supplements and transfusions. The nurses looked for reasons – they wondered if there was something the patient was not doing that she should be doing that might be contributing to the 'problem'. The participant expressed frustration at the idea that she had any control over her blood levels. Thus, people in the position of patient are well aware that their personal worth may be judged based on their test results.
The surveillance experienced by “patients” is another manifestation of a bias for technology.

**Being a Problem**

“Half of the time you're treated as the body part that doesn’t work, you’re treated as the problem.”

In a system that relies heavily on technology to treat and cure illness, people in the position of patient are subject to the technical gaze for the purpose of being “fixed”. However, if the use of technology is not effective, there are particular consequences for patients. Some of the participants in this study encountered the negative effects of not being “fixable,” which included being problematized and pathologized. One person spoke passionately about being problematized when her symptoms did not resolve over an acceptable period of time. She describes being shunned by the staff of her general practitioner’s office when her chronic pain did not improve over many visits. In the process of consulting with her GP through phone calls, office visits and laboratory tests, she formed a strong impression, based on the reception she received, that she had shifted from being a “patient” to being a “problem”. She felt undertones of animosity and resentment. As a result, this participant felt uncomfortable and guilty when she called or visited the office.

In another situation, the technological gaze had the effect of pathologizing normal life patterns of an individual when his condition was not improving as expected. In this case, a participant spoke about offering information to the hospital staff about her father’s usual routine at home – in particular, the fact that he is normally awake at night. The nursing staff were, at that time, attempting to medicate this man, so that he would sleep at night. The participant knew that her father had always been a “night owl” – yet his
inability to sleep during the night hours was interpreted in an intensive care setting to be pathological at best and to represent a lack of cooperation at worst. Thus, his normal sleep pattern was pathologized and he received medication that he putatively did not need. The nursing staff held the perception that this man needed to be asleep during the night to speed healing.

Being a problem in the context of the experiences of the study participants was related to any situation in which the use of technology to "fix" was either interfered with or unsuccessful. As described by the participants in this study, there are consequences if technology is used to "cure" and the cure does not work.

In this section, I have discussed findings related to the use of technology. Technology is used to "fix" bodies. Bodies may be more easily worked upon if they are accessible and visible. Work environments and health-care practices are shaped by a high value for technology. However, the use of technology may be a double-edged sword because technology, when used without a concurrent focus on the human aspects of an illness experience, has particular consequences for individuals in the position of a patient. These consequences may include experiencing disembodiment, receiving fragmented care, feelings of being scrutinized, and problematized. In addition, if and when the course of illness is longer than expected, or signs and symptoms fail to resolve, individuals in the position of a patient are aware that their personal worth may be judged based on the observations gleaned from the surveillance. Thus, the use of technology is sometimes experienced by people in the position of a patient as frightening, frustrating and disempowering.

Patient and Person: To Be or Not to Be, Is There a Question?
In the previous section, I have described findings in relation to the use of technology in practice. As well, I have discussed a few of the ways in which a high value for technology affected individuals in the position of a patient. The findings of this small study, against a background of a pervasive favoring of technology, "patients" are positioned in particular ways. When individuals enter the health-care system, they become a part of that system—in some ways they are assessed, quantified, measured, described, and named. In the process, a patient becomes a part of the machinery of the system, becoming less an individual and more a unit of work, a piece of information, or a variable to be addressed. In other words, patients become objects to be acted upon. The participants in this study provided many examples about their experiences of being treated as objects rather than as unique individuals. In fact, being treated as an object rather than as a subject was a major theme in the accounts of all of the participants in different ways.

The title above is meant to capture the notion that, to some extent, one "becomes" a patient in a form consistent with the views of health-care providers, whether one wishes to or not. This becoming is shaped by many interactions with health-care providers in which people become aware of the expectations associated with being a patient. In the following section I outline the implicit and explicit ways in which participants in this study gained knowledge about how to be a patient. As well, I discuss the myriad of ways in which conformity with an ideal image was encouraged.

Being Good

Without exception, participants in this study were aware of the sometimes unspoken beliefs around what constitutes a "good patient". Within the accounts of
participants, feeling pressure to be "good" was a powerful part of being a patient within
the health-care system. People in this study volunteered that, according to the health-care
system, a "good patient" is passive, grateful, compliant and unobtrusive. In fact, as one
participant pointed out, patients are expected to be all of the things any large system or
organization encourages.

To be honest, this stuff exists in education, this stuff exists, you know, in different
systems other than [health care]. You know, you're supposed to be a good student
and not really challenge things and not really question on every level of
education, so there's so much, you know that's transferable in all this... It just
feels that that's what I got into and that was there but it also feels like that's pretty
much life, I mean in a way, you're always expected to act.

In one interview, a participant spoke of the specific characteristics of a "good
patient" as she understood them.

Sure, a good patient is someone who is always appreciative of everything that you
do. A good patient deals stoically with whatever treatment is happening. A good
patient rarely shows signs of frustration and a good patient certainly never swears
(laughing). A good patient takes their medication and doesn't ask a lot of
questions about it. A good patient basically just does what they're told and brings
chocolates when they go home.

In another case, the characteristics of a good patient were made explicit by a nurse. This
participant was actually told that she was "good".

I was told when I was admitted into (a local hospital) emergency, that I was
probably one of the best patients that they'd ever had because I never really
bothered them, I never, I wasn't yelling and screaming, I wasn't, uh, I wasn't
putting up a fight, I was doing as I was told. Yeah, a nurse said that.

Another strong theme within the accounts of individuals was the idea that a good
patient does not demand much attention from health-care professionals. For example,
several participants stated that a good patient does not ring the call bell. This was a value
explicitly addressed within the account of one participant. She explained that her
critically ill family member circumvented the lack of a call bell in the intensive care unit
by shaking the bed rails at a particular pitch to get the attention of the staff. This was not a popular solution in the eyes of his nurses. When this participant’s father taught the habit of shaking the bedrails to a patient in the next bed, few staff found it amusing. Another participant, also recognizing that “good patients” do not ask for much attention, described her perspective in relation to this issue.

A good patient is an opportunist. She sees the nurse come in and before she gets out you say, ‘Excuse me, can you do this for me?’ So, being prepared for what your needs are, getting them dealt with in an efficient way, rather than a needy way. You hear her say to your neighbor, ‘Well let me just go down and I’ll see if I can get you another pillow.’ You know where she is going, and you say, ‘Excuse me, could you please bring me some cold water when you come back?’

In this example, not only did the participant acknowledge the unspoken criterion of not bothering the staff, she made the system work for her. She managed to conform with images of a “good” patient while addressing her own needs.

Constructions of “good” patients as cooperative, independent, compliant individuals had a powerful influence on the experiences of people in the patient role. Another criterion addressed by participants was that of passivity. The participants’ stories contained many examples of the ways in which nurses and other health-care professionals required that patients adhere to the rules and routines that govern practice. Even in the current health care environment that espouses “patient-centered” and “family-centered” care, rules were enforced even when families and patients stood in opposition. This was obvious in the example provided by one participant who requested the opportunity to be present during her father’s resuscitation. When the study participant asked the nurse if she could be present, the nurse stated that she “would ask.” Who was going to be asked? In this case the patient was not consulted, rather the
physician received and denied the request. The individual receiving care was not consulted although he was conscious and wanted his family member present.

As passive recipients of health care, people in the position of the patient are the object upon which rules and routines are practiced. In the following situation, a participant was expected to quietly suffer inconvenience when a solution was available.

I remember that I was dialyzing twice a week for four hours in the hospital. ...Monday and Wednesday and I had to have, I think it was a renal arteriogram ... So, they do this and you have to lie still for what is it six hours? So I said, 'Can I have it and then roll me up to dialysis because I have to lie there anyway for four hours?' They say, 'No, we can't do that.' I said, 'Why not?' 'Because you have to be in this ward.' All they do every so often, they come by, they'd make sure you're not bleeding, hook up the sand bags, [and check if] you're breathing. I think nurses basically are qualified to do that and so no, I couldn't do this, so as a result I had to come in Monday for four hours, Tuesday for six hours, and Wednesday for four hours.

In the majority of the interviews, rules and routines were adhered to even when this was against the best interests of a particular patient or family. One participant described how she was required to resist rule-driven practice in the last hours of her son's life.

So we weren't traditional. And then, the nurses always before babies die, like to bathe them and dress them. And I had said, in a harsh way, because the nurse was quite clear that that's what needed to happen. And I said, "No, he doesn't need to be bathed, he doesn't need to be dressed." It was January, I said, "But you can put him right here." And I know that about skin-to-skin cuddling, that's how you keep babies warm. But she, you know, that was clearly not the routine.

In every one of the above situations, people in the position of the patient appeared to be positioned as passive recipients of health care. As such, they were not infrequently the objects of rule-driven practice.

One aspect of passivity was maintaining a certain level of ignorance by not asking too many questions or challenging the status quo. The participants in this study had
many different experiences in the health-care system. In particular they had experiences in which they felt they were treated as ignorant. They associated these with the experience of being treated as “a patient”, recognizing that they were perceived to have no contributions to make to their own treatment. Rather, their contributions and expertise were devalued or ignored in many cases. For example, one participant said,

Most often it’s a very “we”, “they” kind of thing because you have the person whatever discipline in health care, they’re coming from the, if they’re a dietician, if they’re a doctor or a nurse, these people are the experts. You know in some ways having lived with diabetes for almost thirty years, right, in some ways it’s ridiculous that I have a twenty-something year old nurse who studied diabetes for two years, who professes to tell me what my body needs. I don't profess to know everything about diabetes but I've lived with my body longer than anybody else.

People in the position of patient have first hand insights about the consequence of not being perceived as “good”. These consequences included being labeled as difficult or demanding and failing to receive necessary support. For instance, one person spoke about how she is perceived in the acute care setting. “I developed friends on the renal unit, the nurses and technicians, so eventually stuff got back to me like how I was portrayed in rounds before I even got there. You know, being the loud mouthed bitch or whatever and you didn't want help from anybody and, you know, that kind of stuff.”

Another participant used the analogy of a flight attendant to describe the consequences of not being perceived as “good”. “You should just be polite, it’s like being a flight attendant. Be nice, otherwise you’re really going to piss them off and they’re [not] going to help you and it’s going to be a real bad flight.”

As discussed, the participants in this study were well aware of what constitutes a “good” patient from the perspective of health-care providers. However, this ideology is contradictory to what patients themselves believe to be important. Participants rejected
the definitions of health-care providers as inconsistent with being responsible partners in addressing their health care needs. For example, one participant said,

Well I've got to tell you, years ago I did a, a workshop thing and I looked up “patient” and it said one who endures without complaining, right? So to me, a good patient is an oxymoron, if you take that definition of patient... I think I'm an exceptional patient, I really do believe I'm a very good patient, but certainly there's tons of people out there who won't agree with me so a good patient is someone who lies there passively, who accepts the word of whatever professional as being the truth, the gospel, who just does what they're told, I mean I can't, I think that's dangerous.

Another participant also understood health-care professionals' definition of what constitutes a “good patient” to be counterproductive, and stated “My gut response is ‘fuck being a good patient’. That’s not why [I’m here]. I don’t need to be a good patient, I need to focus on getting well and if part of that means having a tantrum or screaming or being abrupt...”

Being a good patient was a powerful theme in the accounts of participants. Not only were patients well aware of the criteria for being considered “good”, they were also aware of the consequences for failing to conform. To some extent their conformity with the perspectives of health-care providers was enforced by an awareness of those consequences. According to participants health-care providers shared, both implicitly and explicitly, the criteria for being a successful patient within the system.

**Being Controlled**

Within this study, participants experienced the use of professional power – power arising from the individual’s position as a nurse or physician – to attempt to control individuals for whom they were caring. Several participants in this study described their experiences with professional power. These interactions ranged from controlling information access to direct attempts to control behavior. One of the participants in this
study described an incident in which she asked for her blood work results. The physician said he would have to discuss the results with another physician and she protested that she wanted to know the results. “So he walked away, I'm still tied to the machine, he [can] change anything [he] wants to. He could, you know, tell me what the potassium is or he can do anything he wants to me. It’s still a powerless position as much as you stomp your feet.” In this case, the physician felt he could legitimately deny access to information based on his position as expert and the patient's position vis a vis this expertise.

The same person went on to describe a particularly memorable incident that occurred during one of her many hospitalizations. In this case, it was her perception that a nurse was trying to control her behavior by making assistance conditional upon her cooperation. “I remember asking for... I don't know... can I have a band-aid? ‘Okay, well go back in your room and I'll give you one’ [was the reply]. You know, I won't swear on this tape, but don't tell me to go back to my room. Don't you dare tell me to go back to my room.” As discussed earlier in this chapter, one participant wanted to be at her father's bedside during his resuscitation and was refused admission to the trauma room.

In particular, health-care providers' directly and indirectly pressuring patients to conform and be passive, participants in this study experienced an obligation to conform with suggested treatment regimens. One participant spoke about her post-operative experience in which she was visited by a physician who wished to direct the course of her care.

I had a pompous ass of a, I think he would have been a fellow, having some knowledge of how the regime goes. [He] introduced himself. He was from
[another country] and very ... and he said, and now I'm in charge of your morphine, I guess he was the anesthesiologist. ‘This is Thursday, we will be removing the morphine pump.’ I said no, we will not be removing the morphine pump. [He said,] ‘it will be given by mouth.’

In short, participants in this study shared many examples of situations in which they felt health-care providers were attempting to control the behavior of individuals in their care.

**Being Sanctioned**

Another strategy for the creation of “good patients” is applying sanctions or rebuking individuals who are patients. Being sanctioned, rebuked or criticized was unfortunately a common experience described by participants in this study. Some of the participants theorized about the reasons for these sanctions and concluded that they represented a way in which the health-care professional was trying to maintain a sense of authority over another individual’s behavior.

In some cases, the sanctions seemed particularly harsh. One participant, as previously described, wanted to be with her father during his resuscitation. The nurse refused to allow this. In fact, when the participant continued to insist, the nurse said “You know, I am standing here with you instead to being in there, helping your dad.” This rebuke caused the participant to feel guilty and alarmed that she may have inadvertently affected the course of her father’s recovery. Another participant was attempting to decide about dialysis options. In order to make this decision, she informally interviewed fellow patients and asked what decision they had made and why. When the nurse discovered what was happening, the participant was told that her question about treatment modalities “was a stupid thing to ask.”
Sanctions were not always limited to verbal rebukes. Another person described the treatment she received when she was in hospital recovering from surgery. "The nurses were very short with me the first night I was there. I think they were getting quite frustrated."

Being patronized was another form of sanction described by some of the participants. In particular, patronizing behavior on the part of health-care providers seemed to serve the purpose of confirming who was the expert and who was ignorant. As well, patronizing behavior was used to remind individuals that they should not be asking too many questions.

So there's one clinic that I go to. As a matter of course, [they ask] 'what medications are you on?' They do this every month. So I refuse to be "tested". I will tell [them] when there's a change in my meds. 'Are you sure you know what kinds of meds you're on?' And, yes, some people might not know, some people might only know they're on their "blue" pills, right? But you can assess me in two minutes and figure out that I'm going to know which blue pills, what name it is and how much the dosage is and all that kind of stuff.

Similarly, another participant described the reception she received from her specialist. "But I went to her and ... I mean the woman would sit behind her desk with her legs up on her desk (laughter) and just scruffy... [And] not even pleasant at all, she's just like I'm bothering her and didn't even want to know about [my symptoms], just brushed me off."

In a similar case, a participant knew that something was very wrong during her post-operative recovery and sought to convey this information to the nurses on the surgical unit. "Every time we did question, it was like 'don't talk to us, don't ask dumb questions' or something."

As a result of feeling patronized, sanctioned, and controlled, participants in this study experienced and characterized the patient role in particular ways. They had
specific visceral responses to the role. Two participants opened their interviews using identical phrases, stating that “to be a patient means experiencing a total loss of control”. Other people experienced the role as “humbling,” “infantilizing,” “de-personalizing,” “de-moralizing,” and “dis-empowering.”

Sanctions, in the form of criticism or rude treatment, were a frequent experience among the participants. They theorized that sanctions might be motivated by a need on the part of health-care providers to control the behavior of individuals in their care. In fact, there may be a strong perception that it is easier to care for people who are controllable, conforming, passive and cooperative. Philosophically positioning patients as controllable and “good” may place them in the position of recipients of health care – objects to be acted upon, rather than subjects participating in the course of their own recovery.

Being a Case

As previously discussed, when individuals enter the health-care system, they are in some ways quantified, labeled, and defined according to their presenting illness. Within this study there was a strong acknowledgment among participants that they were cared for not as individuals, but rather as diagnoses.

Several participants spoke about their experiences as “cases.” In one interview, a woman spoke about her post-operative experience.

The thing is that the people who see you as a patient, the caregivers, they don’t know you as a person, so they have no point of reference. They just see you as a patient and what do they assess their information on? She’s just had abdominal surgery, she can’t sit up, she can’t go to the bathroom, she’s got a urine thing on and we’re watching to see if she has a bowel movement. That’s their frame of reference. A chart, some doctor’s instructions and whatever they ask me or whatever I ask of them.
Another participant described the enormous difference it made to her when on one occasion during her father’s three-month hospitalization, a nurse sat down and provided details of how her father had passed the night. The nurse included the small things, like the fact that her father had started rattling the bedrails to get the attention of the nurses because he did not have a call bell. She related that this made all the difference because to her it meant that her father was being seen as a person with a character and a mind.

One participant spoke passionately about the need for person to person connection versus nurse to case connection.

...just somehow to be able to, to just go past the patient role into the human being role, you know, and it goes both ways. I’ve always said that the biggest difference, if I’m in the hospital, [is when] someone comes through the door either as a doctor or a nurse or as a person with all these skills and expertise and... I will assume that you have this stuff and this expertise but you are a person first, you were a person before you were a nurse, I was a person before I was a patient and if we just go on that level, really it would be a whole lot nicer.

Similarly in another interview, a participant gave feedback about what she thought would have made a difference during her hospitalization. “I think in the beginning to find out a little bit about that person if they can only take five minutes. I think if they can somehow establish a rapport... [it would be better for patients].”

None of the people who participated in this study wanted to be treated as cases. While some participants found that they were often treated as a case, occasionally participants provided examples of when this did not occur, commenting they found this experience to be very satisfactory. These participants could not say enough about the positive effect of being known as an individual during their time in the hospital. Specifically, they felt safe and respected being known as people as opposed to simply as cases. These examples have helped me to understand that within the experience of being
a patient, being a case – being perceived and treated as a generic person with a generic complaint – is a major factor coloring the experiences of those in the position of patient.

Actually, that feeling of being known to them in that instance was all great. I mean, the fact that these three people came through the door and I knew their faces and I knew who they were, was good. In a bad situation, I was glad to see their faces. To be known. And because they knew who I was as a person... and they knew if I said “I need this”, that I was clear about most things.

She also identified that she was known as a person by her family doctor and spoke passionately about the difference this made in her recovery following the death of her baby.

After [my baby] died, every visit was created based on where I was. And I wasn’t always in a space of needing to talk about [the baby]. And she’d say, “How are you doing?” And if she’d see me go (crying sound) you know, [we’d talk]. She’d usually say, “Do you want to talk about [your baby]? Do you want to talk about your plans for the future? Or she’d say, “Are you here for your rash?” And I’d say, “Yeah, I’m just here for that.” And she’d be super efficient and very, probably detached in some ways.

In every interview, the participants in this study independently identified that being known as a person was important to their care and recovery. The findings in this study suggest that being known as a person is an important issue for people who are in the patient role.

People enter the health-care system for treatment of illness or injury. In the process, people may be assessed, labeled and categorized according to an illness or injury. Along the way people cease to be viewed as individuals and instead may be transformed or reduced to a unit of work or a case to be addressed. In this way, individuals who enter the health-care system are positioned as objects to be acted upon. As such they are treated in particular ways. These ways may include rewarding or
sanctioning behavior that is inconsistent with health-care providers’ perspectives about what constitutes a “good patient”.

Resisting Patient-hood

Indisputably, people who enter the health-care system encounter dominant ideas and values that shape the care they receive. In particular, a value for technology and a positioning of patients as objects to be cared for impact the experiences of these individuals. Despite environmental, social, and practice constraints that operate to shape the options of individuals, throughout the interviews there was a major thread of resistance. This resistance against the constraints of patient-hood took many forms and is in direct contrast to constructions of patients as “good,” “passive,” and “ignorant.” Those individuals who resist patient-hood describe themselves as agents within their own health-care experiences.

Resistance, as described by the participants in this study, was an active, constant process. Participants in this study provided many examples of the ways in which they acted as agents, responding to and in some cases actively resisting the challenges arising from the patient role. This resistance took many forms and no single approach was used consistently by any individual. Rather, strategies varied depending on such factors as energy level, familiarity with the health-care system, and the specific situation. In the following section I describe these strategies. Specifically these strategies included: keeping your head down, negotiating the system, active resistance and proactive planning.
Keeping Your Head Down

Two of the participants described the strategy of “keeping your head down” as one way of coping with the constraints and challenges of the patient role. Both referred to this as a way of “getting through” the acute portion of their illness. One participant acknowledged that her strategy of “not making waves” arose at least partially from her personality. “So I’m not a very vocal person. I’m not very aggressive that way so I don’t think I’d probably stood up for myself as much as I should have. I used to keep my head down, pretty anxious about the whole thing.”

Another participant related that, because she is independent by nature, she did not want to ask for help. Rather, she minimized her own needs and kept her “head down,” focusing on getting well. She provided the following example of this philosophy in action.

One time actually, [another patient] said to me, ‘how are you doing over there?’ Something was bothering me. And she said, ‘you should ask about that, get them down here.’ And I said, no, no, that’s ok I think I can do it myself or I’m going to wait another half hour. They’ll be here, don’t worry, they’re busy.

Keeping your head down was not a passive acceptance of the patient role as prescribed by health-care professionals. Rather it was a specific course of action consciously chosen.

Negotiating the System

Another strategy that arose in the interviews was that of negotiating the system. The purpose of negotiating the system was to address participants’ needs while keeping staff happy with them. Keeping the staff happy seemed to mean gaining or maintaining access to information and support on an as needed basis. One of the participants, who had a lengthy experience with the health-care system, mentioned strategies such as
buying donuts and making sure she remembered nurses’ names in order to “be in the
good books of the staff.” Another provided an example where negotiation would not be
an effective approach, stating;

I mean and this [was] an acute life-threatening illness, right, so the time frame
was all very short. So, there wasn’t… I know that I’ve read some things that
families, you know, negotiate the system. There wasn’t any of that, because I
knew that as soon as we took him off ventilator, he would probably only live three
or four hours. So, I wasn’t sort of invested in… developing, [those] sort of
relationships and creating a way past or through some of this.

Another aspect of negotiating the system described by participants was seeking
information. This served two purposes in the eyes of participants. Firstly, the
information itself provided the means to make informed decisions about treatments and
secondly, it provided a feeling of control over their situations. The information obtained
could then be used to make health-care professionals aware that their practice was being
observed by an informed individual. One participant said;

I asked thousands of questions. The first time I was so overwhelmed by first pain,
then drugs, you know Morphine and the shock of it all happening so quickly.
[This time] I wanted to know what was going on. I was totally prepared. How
long will this surgery take? How wide is the mesh? What is it made of? Is it
PVC or polystrene? I asked, I wanted to know.

This participant went on to explain that the surgeon seemed surprised that she was so
curious and attentive. She wanted the surgeon to know that she was thoughtful, reflective
and paying attentive to any dangers arising from the surgery that the surgeon may have
failed to mention. Similarly, another participant indicated;

I have to know things... you're changing potassium. Why are you changing my
bath? Why are you changing all this stuff? I need to know. After I had my blood
work yesterday, I called up [and asked] what's my creatinine? What's my
hemoglobin? You know, its not 'the doctor will call you if there's a problem'. I
want to know.
Active Resistance

I do put my foot in and I push things and if it doesn't work, if it doesn't work as a system then I go outside it and I'm fortunate and I have wonderful, wonderful people here that I can do that with and they're all willing to do that with me.

Active resistance took many forms as described by study participants. Resistance strategies were not necessarily reactive, that is, in response to a particular situation. Rather, active resistance as described by the participants was a proactive stance toward managing the challenges of the patient role.

In one case, a participant and her mother were asked to wait in the common waiting room of the emergency department. Because of the acuity of the illness being treated, they were both quite emotional and close to tears. The participant refused to be placed in the waiting room and asked if there was another, more private place available. Soon after, both were seated in a private family room. In this case, resistance involved advocating for herself and her family. Similarly, another participant described saying no in the operating room. “They wanted to put me out right away and I said, ‘Well, no. I want to see the face of the person doing the surgery. I’d just like to say hi.’” In this way, she attempted to establish herself as a person.

Two participants felt that they developed new personality characteristics to cope with the challenges of the patient role. One participant shared feedback she received from her family.

It’s never left me actually, that being a patient. My mother used to say, ‘You know, it’s been an awful experience, but it has brought out some very clear, and strong and don’t mess with me kinds of parts of your personality that have been dormant before.’
Another shared, "you start to become... a little more aggressive and wanting to know what is wrong with me. Now I'm a little more proactive, I'm a little more out there and aggressive."

**Proactive Planning**

Several participants provided examples of a level of agency that involved proactive planning and strategizing to meet their own needs. This was perhaps the most sophisticated and complex type of agency practiced by the participants of this study. Proactive planning involved working actively to address their own health care needs regardless of whether their health challenge was of an acute or chronic nature.

In one situation, a participant recognized that she would receive less than effective care from someone unfamiliar with her case, so when she needed medical attention and her specialist team was not on call, she went to the hospital and walked the floors, searching the admission units until she located the team. Then she stated her concerns and made herself available at the time and location of that person's earliest convenience. Another participant who was entering the health-care system for urgent surgery, recognized the state of the health-care system, in particular the staffing levels, and drawing on her own past experience with hospitals, recruited a friend who was a nurse and had that person act as a private nurse for the first two nights of her post-operative recovery.

Not only did participants in this study plan proactively from a "big picture" perspective, but they also engaged in "moment to moment" proactive planning. One participant described her strategy as follows:

A good patient is an opportunist. She sees the nurse come in and before she gets out you say, 'excuse me, can you do this for me?' So, being prepared for what
your needs are, getting them dealt with in an efficient way, rather than a needy way. You hear her say to your neighbor, well let me just go down and I’ll see if I can get you another pillow. You know where she is going, and you say, excuse me, could you please bring my some cold water when you come back?

In each of these situations, patients acted as active agents. Through proactive planning, each one ensured that their needs were being met.

The accounts of participants within this study illustrate that, contrary to the positioning of patients as objects within the system – bodies to be acted upon – people in the position of patient are active agents within their own illness experiences. In fact, participants in this study actively resisted patient-hood. This agency took many forms ranging from choosing the path of least resistance to proactive strategizing. The notion of patient agency and resistance, as described by these participants may be a useful concept for nurses in shaping nursing practice to meet the needs of individuals.

Summary

The findings from this study were described as addressing three main themes. These themes include: a value for technology, a positioning of patients as objects, and resistance to social constructions of patient-hood. A high value for technology was a strong theme in the accounts of individuals. Technology shapes the experiences of individuals who are patients in powerful ways through the organization of physical and practice environments. This has the effect of making bodies visible and accessible to health-care providers. This accessibility is supported by the use of professional surveillance in order to follow the course of recovery from an illness or injury. These individuals in the position of patient were aware that they are judged as worthy or unworthy based on the information gleaned from surveillance.
In addition to a strong value for technology, there is evidence that people who are patients are positioned within the system as objects to be acted upon. This positioning is not only present, but is also reinforced within health-care encounters. Individuals were encouraged through the use of rewards, sanctions and other strategies, to conform with health-care providers' definitions of what constitutes a “good patient”. Participants within this study were well aware of the criteria used by health-care providers. As well, individuals in the position of patient were conversant with the consequences of failing to conform with images of “good patients”.

Finally, constructions of “good” patients as passive, cooperative, undemanding, and uninformed operated to keep individuals positioned as objects rather than as subjects. However, contrary to this positioning, participants in this study were active agents within their own illness experiences. They not only resisted the constraints arising from practice constructions of patient-hood, but they also actively strategized to meet their own needs. This positioning of patients as agents stands in contrast to professional, social and political constructions of patient-hood.

Understanding the impact of a value for technology and the assumptions we make about the people we care for will contribute to improved nursing care because such an examination challenges the status quo and forces professionals to think about what has become, perhaps, traditional practice. Images of good patients are consistent with quantifiable, measurable, manageable, labeled system input. As a result, patients may not be treated as individuals, but rather as units of work based on diagnoses. Understanding practices that support this positioning of patients as passive and in particular, re-framing
“patients” as agents, rather than as passive recipients of health-care services may promote the nursing of individuals rather than cases.
Chapter 5 – Discussion of Findings

The main findings of this research study are related to the ways in which people in the position of the patient experience and respond to social constructions of patienthood. In particular, as highlighted by the research findings, people often experience the patient role as frustrating, dis-empowering and objectifying. Individuals in this study expressed the desire to be visible against a background of technology, to be known as individuals rather than to be treated as broken body parts, and to be acknowledged as agents within their own health and illness experiences.

In the course of gathering and analyzing data for this study, I came to understand that in many ways, nursing practice functions to reinforce the status quo. That is, nurses sometimes practice in ways that support a biomedical, mechanical view of health and illness. In the process, people in the position of the patient become or are reduced to input within the system rather than being treated as thinking, feeling, and contributing participants in their own illness experiences.

Participants in this study expressed anger, frustration and distress in relation to situations in which there was a difference between the way they believed they should have been treated and the way in which they were treated in health-care encounters. This chapter focuses on the issues embedded in this distress and incorporates the suggestions from “patients” for improving nursing practice. These include being seen as more than objects, being known as more than cases, and being acknowledged as agents of and participants in their own health and illness experiences.

In the following discussion I highlight the most significant findings from this small study. Using material from my original literature review and drawing on other
nursing and social theorists, I will discuss these findings and make suggestions regarding how these ideas might be useful for nursing practice. Before beginning the discussion, I will highlight the limitations of this study.

**Limitations of Study**

The limitations of this study were mainly related to the composition of the sample. The participants in this study were all female, all employed, and all had educational credentials beyond high school graduation. In addition, one participant spoke about patient-hood from the perspective of family member rather than from her own experiences in that role. Another, although a patient herself, spoke mainly about her experiences as the mother of a dying infant. Including the voices of men and the voices of less well-educated individuals as well as obtaining a larger sample may have changed the findings of this study significantly. It will be interesting, in future research, to discover whether the socio-demographic variations that were not examined in this study influence the experience of being a patient in major or minor ways.

**Being Visible as a Person**

The findings in this study suggest that people who are in the position of the patient often experience a sense of invisibility. At first glance this statement suggests a paradox as some people in the position of patient are made *more visible* through the use of surveillance by health-care providers. However, what is actually made visible through the use of technology such as laboratory tests is not the person. Rather what becomes more visible is the "broken part" of the body. The individual sometimes remains invisible against a background of technology. Rather than being seen as a person within the health-care system, people in the position of patient felt that they were part of the
machinery of health care – a piece of data, an object, and/or a body. To some extent, this invisibility may arise from a strong value for technology within the health-care system as a whole. This value for technology is supported by a biomedical paradigm that equates health with biology (Bartky, 1995; Hartrick, 1997; Liaschenko, 1994; Lock, 1998; Morgan, 1998; Sherwin, 1998), therefore privileging curing over caring (Fairman, 1999). Curing, in turn, requires intensive use of technology. In the course of using technology intensively, the person becomes less visible and the body system affected by illness or injury is foregrounded.

Two aspects of this culture of technology contribute to "patients" being invisible. The first aspect is a tendency toward reductionism – an individual becomes not a person, but a body part to be repaired upon entering the health-care system. A second aspect of the culture of technology is a tendency toward objectification – an individual becomes a body to be acted upon rather than maintaining person-hood (Gadow, 1994). Both of these tendencies played a role in the experiences of participants in this study. While these findings are not new, they do add to the debate around technology and the use of technology by confirming some of the ways in which our practice environments are organized to support the use of technology without a concomitant attention to the human experience of being ill and hospitalized.

Barnard and Gerber (1999) in a phenomenological study, interviewed surgical nurses about the subject of technology and nursing practice. They point out that the nurses they interviewed understood technology to be machinery and equipment and that their study participants equated the proficient use of technology with increased levels of respect from peers and from society. Barnard and Gerber found that although nurses
acknowledged that people may become less important in a technological environment, their study participants understood the use of technology to be fundamentally positive as it was equated with an increase in knowledge. Nurses within their study desired to use technology and technological means to create order in a chaotic environment.

In contrast with the findings of Barnard and Gerber (1999), Fairman and Antonio (1999) asserted that technology is a process and therefore not limited to machines and equipment. As well, Sandelowski (1999) states that often “technology is falsely viewed as nothing more than simple, unknowing, and even robotic application of science” (p. 201). Certainly the findings of this study support a view of technology that is not limited to machinery and equipment, but rather may be understood as a far-reaching issue that shapes the experiences of people in the position of patient. In particular, the culture of technology plays a role in the organization of the physical environment and in patterns of practice.

Although technology is often embraced by nurses as a source of professional power (Barnard & Gerber, 1999; Fairman & Antonio, 1999; Purkis, 1999; Sandelowski, 1999), Purkis (1999) emphasizes that technology is not neutral. Nettleton (1995) and many other authors acknowledge that technology and a value for technology is a major thread influencing the practice of health care (Barnard & Gerber, 1999; Fairman & Antonio, 1999; Gadow, 1994; Sandelowski, 1999). Within the health-care system, arguably, there exists what I shall term a “culture of technology” – a culture which health-care professionals share and from which people in the position of the patient are excluded. Based on the findings within this study, I argue that nurses may participate in and support a culture of technology in a way that is not critical and fails to acknowledge
the impact that such a culture has on nursing care and the experiences of individuals who are patients. Instead, we may practice in ways that make individuals invisible against a background of technology. Williams (2000) writing about health-care systems, points out that ideas and values are the currency of culture. For the participants in this study, ideas and values around the culture of technology were operationalized in ways that had a profound impact on their experiences of health and illness.

**Being Known**

The findings of this study bring attention to the importance of being known – of being attended to as a unique individual. Being acknowledged and treated as unique individuals may serve to ameliorate the frustration and limitations that “patients” experience when they are ill and hospitalized. Knowing a patient included the possession of knowledge about patterns of health and illness, social supports, and the meaning of a particular illness experience. Without this level of knowledge, these people in the position of patient feel that the care they received was less than optimal.

Liaschenko (1995) described three types of nursing knowledge related to individuals, commonly described as the “case”, the “patient” and the “person”. Knowing the case is knowledge addressing the biological and physiological. Similarly, knowing the patient includes the case knowledge previously described, but in application to a particular individual. In contrast, knowing the person is having knowledge related to the uniqueness of an individual – including what makes that individual a separate human being. The findings of this study confirm that being known as a person is often an important aspect of a health and illness experience. Participants in this study were passionate about the idea that they received superior care when their caregivers were able
to provide services based on this level of personal knowledge. In contrast, when care was based on “case” knowledge, participants often described a lack of trust, a feeling of being condescended to and a feeling of not being valued.

This is consistent with Liaschenko’s (1995) position that being treated as a case is a biomedical view of the person and, therefore, results in “the disappearance of the experiencing patient.” In opposition to this phenomenon Liaschenko writes about the notion that knowing someone as a person involves a deep commitment to and value of personal agency. She also argues that knowing a person encompasses more than a knowledge of employment, social support and the particulars of an individual’s life, but also includes temporal and spatial dimensions – or the social and political context of a person’s life. For the participants in this study, being known as a person was connected to feeling accepted, valued and safe.

However, according to Liaschenko (1995) there are some issues arising from a stance that advocates knowing all individuals as persons. Firstly, she relates that knowing someone as a person may not always be possible due to, for example, the acuity of an illness or injury. Secondly, she points out that gathering information to attain this level of knowledge may be viewed as intrusive. As well, it could be argued that attention to learning about a unique individual could accidentally further biomedical domination of health and illness by extending into personal areas. Fourthly, attention to an individual as a person may complicate nursing practice. While all of these arguments have merit to a varying degree, they also arise from a professional perspective. According to the findings of this study and from an emic perspective, knowing someone as a person may
serve as a counter-tension to forces that make individuals in the position of patient invisible.

This study may contribute to the debate about knowing the person by adding to the voices of others to confirm the central importance that being known has for individuals in the position of patient. In particular, the findings of this study suggest that contrary to professional perspectives, people in the position of the patient feel that being known as an individual is a predominantly positive process with positive outcomes.

Finally, the findings of this study suggest that “knowing the person” is not simply a choice to be made by individual nurses. Rather, nursing practice is constrained by social, political and environmental issues such as the biomedical model and a culture of technology. These constraints have a particular impact on the care provided by nurses. The findings of this study suggest that not only has nursing practice been shaped by these constraints, nurses have to some extent embraced these constraints and may as a result enter health-care encounters with a particular agenda.

These people in the position of patient were able to describe criteria used in judgments of personal worth made by health-care providers. They were also well aware of the strategies used by nurses to urge compliance with images of good patients. Using these strategies, albeit unconsciously, nurses may be educating individuals about the best way to be in a patient role – a way consistent with positioning patients as passive, ignorant, compliant recipients of health-care services.

**Being Acknowledged as an Agent**

Williams (2000) writes that the current emphasis on personal responsibility in health and illness is a legacy of individualism that health-care professionals have not yet
shed. Such an emphasis, of course, ignores social and political influences on health such as income, gender, race and age. However, the findings of this study suggest that while people in the position of the patient are frequently held responsible for their health status, there is seldom a concurrent acknowledgement of personal agency. Rather, the capacity for action on the part of patients is acknowledged most frequently in relation to negative health outcomes and may be ignored or unacknowledged the rest of the time.

Further, the findings in this study suggest that people in the role of patient are often positioned vis a vis health-care professionals, in particular ways. Rather than being viewed and being treated as experts on their own health and illness, people in the position of patient often experience the health-care provider as the expert. Tang and Anderson (1999) succinctly describe this phenomenon, stating that the culture of patient-hood situates “the patient” in relation to the health-care provider as expert on the patient’s body. In particular, this raises questions about positioning patients as passive, ignorant recipients of health-care services. Contrary to professional assumptions about the nature of patient-hood as passive and ignorant, the exercise of personal agency may allow individuals to seek information, to offer their expertise and knowledge and to resist social constructions of patient-hood.

**Personal Agency**

People in the position of the patient actively resist social constructions of patient-hood. One method of resistance is the exercise of personal agency. Sarbin (1997) describes agency as a foundational premise from which practice is generated: “people are agents – they make choices, construct self-guiding narratives and engage in actions that are purposeful” (p. 238), thus positing that agency is part of social relationships
whether we acknowledge this notion or not. This is consistent with the findings of this study – agency was in operation whether or not it was acknowledged or valued by healthcare professionals.

Definitions of Agency

According to the Dictionary of English Usage (1997), agent is defined as "undertaking an action for oneself". In fact, the word "agent" may be seen as the opposite of the word "patient". Liaschenko (1994) defines personal agency as "the capacity of the individual for meaningful action" (p.270), while Orem (1997) takes a slightly broader view and defines agency as the human power to deliberate about, make decisions about and deliberately engage in result-producing actions or to refrain from doing so. Similarly, Sarbin (1997) defines agency as people making choices, constructing self-guiding narratives, and engaging in actions that are purposeful. Other researchers acknowledge the centrality of agency in adaptable, resilient individuals (McCracken & Weitzman, 1997; Wang, Haertel & Walberg, 1998). Liaschenko (1995) proposes that personal agency may be a useful concept in understanding the capacity of a person to initiate purposeful action on his or her own behalf and argues that protecting and nurturing personal agency is a central feature of the practice of nursing (Liaschenko, 1996).

Anderson and Tang (1999) acknowledge the centrality of agency in the lives of women experiencing chronic illness. They juxtapose patient and agent stating that in order to resist patient-hood, the women in their study used agency as a strategy in the day-to-day management of their disease. Similarly, embedded in the accounts of the participants of this study, I found many examples of personal agency that arose in
response to social constructions of the patient role. Agency is about making choices and taking action – even if that action is the decision not to act. In fact, Bandura (1998), a social scientist, acknowledges the centrality of human agency when he argues that people always strive to shape events that affect their lives through the use of personal agency. According to the participants in this study, personal agency was used constantly to resist social constructions of patient-hood and to shape the course of their hospital experiences.

**Challenges of Agency**

Ruiz and College (1997) argue that the concept of personal agency, which has been popularized in the psychology literature, is a political concept. They argue that the concept of agency is not a useful one because it preserves an emphasis on individualism and ignores context. Ruiz and College further argue that a focus on individual action is at odds with a feminist perspective that seeks to expose external sources of power and control that act to limit the options of individuals. In contrast to the position of Ruiz and College, Messer-Davidow (1995) argues that agency is “co-produced” by the actors involved in a particular situation. He further argues that the actors do not create social systems, but rather reproduce them or transform them. “Although actors are always agents of history, they do not necessarily make a history of their choosing because they act in and through [the] structure… of a social system” (p.30).

I suggest that agency may be a useful concept for nurses as agency may foreground individuals in the position of patient and may have the effect of making individuals more visible against a background of technology. In addition, as was the case in this study, rather than making contextual, social and political locus of control less
visible, these issues may be illuminated. As summarized by MacPherson and Thorne (2000),

The notions of personal power and personal agency as expressed in the literature are highly reminiscent of forces at play in the context of the social culture within which health care is delivered. Beyond acknowledging them in a general, theoretical sense, nurses can develop the ability to recognize their specific manifestations and implications in a particular practice setting. When they turn their attention to the ways in which power and agency are enacted in daily social exchanges in the clinical context, they increase their ability to estimate the manner in which such forces shape [someone’s] expression of thoughts and feelings in that context (p. 26).

The findings of this study may contribute to the debate about the utility of the concept of agency by adding the voices of those in the position of patient. Stone (1997) points out that texts for professional audiences speak of patients in objectified terms, the notion of patient agency receiving little if any acknowledgment. He argues that we need to shift from a biomedical focus on disease to a focus on people who are patients (Stone, 1997). I believe that the concept of agency is useful for nurses caring for individuals in any setting. Acknowledging the person-hood and agency of an individual may diminish or reduce the influence of social constructions of patient-hood. In particular, a focus on supporting personal agency may shift thinking away from “patients are passive” toward “how can I best support this person during their hospital stay”? Indeed, Pollack and Slavin (1998) acknowledge that in the course of treatment, we often effectively rob patients of their agency by remaining immersed in our own agenda about what is in the patient’s best interests.

**Summary**

The findings of this study address some of the issues that face individuals in the position of patient as they move through their experiences of health and illness. In this
chapter I have highlighted three aspects of the findings and attempted to locate how these findings might relate to the ideas of others. As well, I have described how study findings might contribute to the literature on the experience of and response to social constructions of patient-hood. In this study people in the position of patient expressed the desire to be seen against an often overwhelming background of technology, to be known as individuals rather than simply as generic cases, and to be acknowledged as agents within their own health and illness experiences.
Chapter 6 – Summary, Conclusions and Implications

In this qualitative study I addressed the research question: how do people in the position of patient experience and respond to social constructions of patient-hood? In this study, I sought to shift attention away from the dominant discourse of professional perspectives and toward examination of these issues from an emic view -- that of patients. Using interpretive description, I invited seven participants to discuss their experiences while in the position of patient. The participants in this study were women who had various experiences with the health-care system, ranging from acute and chronic to urgent and emergent. In the process of data collection and interpretation, I came to understand ways in which people in the position of patient experience and respond to popular ideas about what it means to be a patient in today’s health-care system.

Seven women with experience in the role of patient participated in this study. To learn about their experiences I interviewed each person, initially focusing on the challenges and benefits they encountered in the patient role. As the study proceeded, the interviews became increasingly focused around participants’ responses to the challenges they identified.

The findings of this study illustrate that persons in the position of the patient believe that attention to the humanistic elements of care are of paramount importance in health-care relationships. However, it is evident that in practice a focus on knowing and attending to the person does not occur consistently. Rather, a focus on technology and images of “good patients” predominate. As well, the findings of this study illuminate that people in the position of the patient engage in a variety of practices intended to resist popular constructions of the patient role. These practices were sometimes in response to
an immediate situation and at other times are simply active practices meant to safeguard the person from the dominant practice discourses of biomedicine and technology.

As stated, the purpose of this study was to explore the ways in which people experience and respond to social constructions of patient-hood. In coming to this study, I was influenced by my own experiences as both a nurse and a patient and by my beliefs about patient’s rights to compassionate nursing care that safeguards their personal integrity and sense of self. Personal integrity and sense of self are important components of health that can be threatened by interaction with the health-care system. In particular, these things may be threatened by health-care relationships. I believe that understanding how individuals experience and respond to social constructions of patient-hood is important for nurses. With this knowledge, nurses may be better able to care for patients in ways that attend to the human elements of health and illness experiences.

**Study Conclusions**

The following represent what I see as the most important ideas to arise from the findings of this study.

1. Participants in this study believed that the use of technology often functioned to make them invisible. They argued that patients deserve to be treated as human beings, worthy of respect and consideration.

2. Participants in this study believed that a humanistic stance toward patient care makes important contributions to the health and welfare of the individual. Being known as a person, versus as a case or a patient, was universally identified as being vital.
3. The people who shared their stories experienced distress when the dominant practice ideologies of biomedicine and technology were operationalized within health-care relationships. These ideologies, in practice, were frequently experienced as objectification. In addition, discipline, scrutiny, judgment, and/or coercion were strategies used by health-care providers to promote compliance with images of “good patients.”

4. The participants in this study engaged in a variety of practices meant to resist popular social constructions of patient-hood. This exercise of personal agency was often unrecognized and unsupported in health-care encounters.

**Implications**

The findings of this study synthesize participants’ accounts of their experiences within the role of the patient. Discussing the threats to personal integrity and sense of self that they encountered is, perhaps, a first step in making these issues more visible. Certainly their stories contribute to a greater understanding of what it means to be a patient. As well, their sharing illuminates some of the strategies they use to resist social constructions of patient-hood. Study findings suggest specific areas for further research and exploration.

**Implications for Nursing Practice**

In particular, nurses may benefit from being critically reflective about the pervasiveness of the culture of technology and the impact that culture has on nursing care and the experiences of individuals who enter the health-care system seeking assistance. As nurses, we need to continue to critically examine the role that technology plays in shaping our practice in order to find better ways of supporting people who seek health
care. In addition, we need to uncover ways of making individuals visible against a background of technological practices.

The findings from this study also suggest that as nurses, we need to uncover the values and beliefs that drive our practice. Images of “good patients” are likely a strong factor impacting the health and illness experiences of individuals who are in the position of patient. Possibly, striving to know patients as individuals will serve as a counterweight to the forces positioning patients as “good.”

On the basis of what I have learned in the course of this study, it is my hope that a focus on personal agency may result in a re-interpretation of the behaviors of people who are in the position of patient – a more accurate and generous interpretation. It is my hope that the findings of this study will contribute to those efforts. This understanding is valuable for nurses. Without a clear understanding of the issues faced by the people we care for, it will be difficult, if not impossible to provide compassionate, sensitive nursing care to people in need. Little is written that conceptualizes “patients” as active agents of their own destiny. Rather, people in the position of patient are frequently portrayed as passive recipients of health-care services. In the face of unequal power relationships, the individuals within this study used many strategies to preserve their sense of self and their personal integrity. These strategies included (a) keeping one’s head down, (b) negotiating the system, (c) acting as a self advocate and (d) being proactive. These practices comprise the actions taken by individuals within this study in an effort of resist and/or counteract the negative sequelae that may arise from being in the role of the patient.
Should we, as nurses, stop using the term “patient?” According to the participants in this study, patient-hood and the constraints of this role arise from the context of health care and health-care practice. As such, changing the term by which we refer to those seeking care will not necessarily alter the experiences of those individuals. As Saul (1992) stated:

There is nothing particularly original about breaking down the intellectual, political, social and emotional walls behind which language has been imprisoned, freeing it, then watching while the poor thing is recaptured and locked up again… The undoubted sign of a society well under control or in decline is that language has ceased to be a means of communication and has become instead a shield for those who master it.

If we stop using the term “patient,” the concept would simply reappear under another label and the same practices may continue to exist.

According to the findings of this study, it is important that nurses develop strategies that enable them to recognize and change their own behaviors that are inconsistent with supporting the agency of patients. Nurses need support in developing the thinking frameworks needed to recognize and address the issues described by the participants in this study.

Finally, within the current health-care system there is a focus on “getting more done with less”. Within my own practice environment and those of my colleagues, there is increasing pressure to be efficient with resources. Thus, instead of focusing on clients and their needs, nurses are being asked to focus on time, equipment and the use of other tangible resources. In such an environment, it is difficult to maintain a focus on the more human components of caring for clients. As nurses, we must find ways of speaking about the importance and legitimacy of these, the less tangible aspects of nursing practice.
Implications for Nursing Education

If we are to educate nurses that have the requisite skills and knowledge to critically analyze and change nursing practice, we must consider not only how to teach students critical thinking skills, but also we must consider how to support new graduates in an often hostile new practice environment.

In addition to nursing schools, hospital educators should consider shifting the focus of inservice education days away from the technical and toward an even mix of the technical and the human. I understand that, in a new environment with ever-rising client acuity, technical expertise is valued far above critical analysis skills, however, a focus on the technical devalues the less tangible aspects of nursing care. Education days that address these aspects of caring for patient may be one strategy for helping nurses find ways to support each other in questioning practice and finding solutions to the concerns raised by the participants in this study.

Implications for Nursing Research

How people in the position of the patient experience and respond to social constructions of patient-hood was the question addressed in this study. However, there is much work that remains. We have some nursing literature addressing the question of the agency of patients. This could be strengthened by further research about the ways in which we can ally ourselves with patients to strengthen personal agency. In addition, we have little information about how to change practice so that people in the position of patient do not have experiences such as those described by the participants of this study. This is particularly problematic when one considers the enormous amount of literature that describes the philosophical underpinnings of our health-care system and the ways in
which these ideologies are played out in health-care relationships. Perhaps if we acknowledge that the issues are clearly outlined, we could shift our focus to solutions. We need to explore structural, educational and social interventions that will support changes in nursing practice.

**Conclusions**

In this study I investigated the ways in which people experience and respond to social constructions of patient-hood. The participants in this study spoke passionately about the challenges they encountered while in the patient role. The main findings of this study include a description of the participants’ experience of patient-hood and the strategies they used to resist the negative sequelae arising from social constructions of patient-hood that are present in today's health-care system.
References


Appendix B
Interview Questions

Code Name __________________________

Date of Interview ________________

Interview # ________________________

INTERVIEW QUESTIONS

Background (experience with health care, health history):

Questions:
You know that I am interested in understanding what it means to be a patient. Can you tell me, in your own words, what you think about this?

How does it feel to be a patient and what advantages do you perceive? Do you feel that people are seen differently when they are patients? Do you act differently when you are in the position of patient?

Drawing on your own experiences, do you get a sense of what it means in the health care system to be a “good patient”?

How have you developed your ideas about being a patient and what has influenced those ideas? How do your ideas compare with the ideas that you encounter from health care professionals?

Tell me about a health care situation during which you were especially surprised, happy or upset.

Would you like:
* a summary of my thesis findings
Consent to be Interviewed

Re: Being Patient

I, ____________________________, agree to be interviewed regarding my experiences as a patient. This study is being conducted by Sheila Turris, a graduate nursing student at the University of British Columbia who is working under the supervision of her committee, of which Dr. Sally Thorne is the chair.

I understand that the interview will be a discussion which will last 1 - 2 hours and that I may be asked if I would be willing to be interviewed a second time. The conversation(s) will be at a location which is convenient for me. I will discuss my experiences of being a patient and the meaning I attach to being a patient.

I further understand that the interview will be audio-taped and transcribed (without identifying names or places) to enable the researcher to collect accurate information for analysis. If I feel uncomfortable with what is on the tape, I am free to ask the interviewer to erase that part of the tape in my presence. The tapes will not be shared with anyone other than Sheila, two members of her committee, and the transcriptionist. The tapes will be destroyed at the conclusion of this project. The transcriptions may be used for secondary analysis in a future project.

I understand that my decision to participate is entirely my own. I also understand that my name will not be recorded with my interview or identified in any report that my be published.

I understand that I am free to withdraw from the study at any time and I may refuse to answer any specific question. If I withdraw from this study, there will be no negative consequences, nor will anyone other than the researcher know about my decision.

I understand that tapes of the interview will only be heard by the investigator and the transcriptionist. The transcripts will have all identifying names removed and will only be shared with my thesis supervisors for the purpose of assisting me with my analysis. Transcriptions of my interview will be kept for a further analysis, and will be destroyed by the researcher when the analysis is completed.

I agree to participate in the study described above and I acknowledge receiving a copy of this letter and consent form.

Signed ____________________________ Date____________________

Please print your name ______________________