

THE EXPERIENCES OF CHRONICALLY ILL PATIENTS AND REGISTERED
NURSES WHEN THEY NEGOTIATE PATIENT CARE IN HOSPITAL SETTINGS

by

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Dedication

This thesis is dedicated to my special friends Dr. John Jacono and Brenda Jacono who have been the wind beneath my wings in helping me to make Canada my new home and in my journey to get my doctoral degree.

I also dedicate this thesis to the memory of my loving Mum and Dad, who always believed in me and loved me just as I am.

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ABSTRACT

Positive hospital experiences and health outcomes for chronically ill patients are dependent on effective negotiations of care that are built on partnerships and mutual goal setting. However, studies suggest that many nurse-patient relationships continue to be dominated by paternalistic models of care and lead to negative patient experiences. Nurses are often expected to change their practice with less attention given to the contribution of institutional contexts. Furthermore, little attention has been given to the role of patients in the process.

The aim of this study was to look at the experiences of chronically ill patients and registered nurses when they negotiated care in hospital. Feminist post-structuralism informed by discourse analysis was used to explore how social and institutional discourses shaped power relations and negotiation of patient care. A total of 18 indepth interviews were conducted with eight chronically ill patients and ten registered nurses. Five themes emerged from the analysis. These themes were: *getting to know each other, they are not the sickest people, the two faces of patriarchy, the challenges of looking after chronically ill patients and finding time to listen.*

Overall both nurses and patients commented favorably about their experiences. Nurses got to know patients on a personal level, power relations were shared and most negotiations were successful. However, negotiations were not always positive. Certain institutional practices were still based on a patriarchal system that gave priority to acute illness or reinforced the traditional nurse-patient relationship. Patients exercised their agency in creative ways to ensure that they were not marginalized by such discourses. Nurses also faced challenges negotiating care with some chronically ill patients and at times felt compelled to use their authoritative position to ensure positive outcomes. Other nurses listened to patients and effectively addressed their concerns. This approach was rewarding for both patients and nurses.

This study offered an innovative way of unpacking negotiation of care between chronically ill patients and registered nurses. It exposed how social and institutional discourses play a pivotal role in shaping negotiations. By shifting the blame from nurses and patients to relations of power and institutional contexts, problematic areas were identified.

LIST OF ABBREVIATIONS USED

CAEP	Canadian Association of Emergency Physicians
CAHS	Canadian Academy of Health Care Science
CASW	Canadian Association of Social Workers
CCM	Chronic Care Model
CIDA	Canadian International Development Agency
CIHI	Canadian Institution of Health Information
CIHR	Canadian Institute for Health Research
CMA	Canadian Medical Association
CNA	Canadian Nurses Association
COPD	Chronic Obstructive Pulmonary Disease
CPSI	Canadian Patient Safety Institute
CRNNS	College of registered Nurses of Nova Scotia
DALY	Disability Adjusted Life Years
GERD	Gastro-Esophageal Reflux Disease
ICCC	Innovative Care for Chronic Illness
NP	Nurse Practitioner
NSCDPS	Nova Scotia Chronic Disease Preventive Strategy
PHAC	Public Health Agency of Canada
RN	Registered Nurse
WHO	World Health Organization

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CHAPTER 1

INTRODUCTION

In 2002 the World Health Organization (WHO) published a document, *Innovative Care for Chronic Conditions: Building Blocks for Action*, to alert decision makers that chronic diseases had become an epidemic and were the leading cause of morbidity and mortality around the world. Almost a decade later, the WHO (2011a) announced that the burden of chronic disease is still on the increase and that it accounted for 63% of the 57 million deaths that occurred in 2008 worldwide. As populations age, the WHO (2011a) predicts that the mortality rate from chronic illness will continue to increase by 15% globally between 2010 and 2020. It is estimated that about 48% of these deaths will occur amongst adults aged 30-69 years in low and middle income countries, compared with 26% in high income countries. These results show that the burden of chronic illness is a concern for all countries. Premature death from chronic illness can result in devastating effects not only in terms of loss and suffering, but also in terms of economic impact on individuals, families and society. All countries are expected to incur costs in the millions of dollars as a result of the increase in the number of Disability Adjusted Life Years (DALY)¹.

In these documents the WHO publicly declared that the current health-care system is still based on an acute episodic model of care and this model is no longer adequate to sustain today's health-care demands. Based on these prevailing trends, the WHO (2002, 2005a, 2005c) contended that unless the current health-care system seeks active ways of

1

DALY is a measurement of the potential years of productive life lost due to disability or premature death

involving patients in their care and giving patients a sense of ownership, the health-care system will continue to do a disservice to the public. To this end, health-care planners and policy makers around the world have been urged to treat chronic illness as a priority and to shift the current health-care practices that place an emphasis on provider-dependent care, to one that recognizes the patient's involvement in care. It is anticipated that by delegating health care to the individual, quality of care is improved and resources within the health-care system are optimized (WHO 2002, McQueen 2002, Jordon & Osborne 2007).

In response to this challenge, a number of initiatives, frameworks and models have been proposed on a global level, to address the problem of chronic illness and to advance the idea of more patient involvement. These initiatives include amongst others, the introduction of the Chronic Care Model (CCM) developed by Wagner (1996a; 1996b) to deal with the crises of chronic illness on a national level, and recently the Innovative Care for Chronic Conditions (ICCC) developed by WHO (2002) in collaboration with the McColl Institute for Health Care Innovation to address the management of chronic illness from a more global perspective (Epping-Jordan et al., 2004). Indeed, over the past two decades there has been a substantive decline in chronic illness mortality rates in high-income countries, which WHO (2011a) claims to be the result of the implementation of such interventions.

This preoccupation about the burgeoning increase in chronic illness has become a particular concern in Canada. In Canada alone, chronic diseases account for 89% (WHO, 2011b) of all causes of death and are estimated to cost the Canadian taxpayer \$190 billion per year (Public Health Agency of Canada, 2011). In 2005, the Government of Canada

was responsible for developing and implementing several pan-Canadian strategies, policies and programs aimed at dealing with the chronic disease crisis (Betancourt, Roberts, Bennett, Driscoll, Jayaraman, & Pelletier, 2014). These strategies are included in the mandate of the Public Health Agency of Canada (PHAC), the Canadian International Development Agency (CIDA), the Canadian Institute for Health Research (CIHR) and the Canadian Academy of Health Sciences (CAHS). In the Atlantic Provinces, the Nova Scotia Chronic Disease Preventive Strategy (NSCDPS) was developed to serve as a framework to reduce the impact of chronic disease in the province's health human resources. These models and initiatives have made a significant contribution in shifting a change in perspective from a fragmented disease oriented health-care system, to one that is inherently patient-centered and that offers better coordination of service along the continuum of care from prevention to palliative care (CAHS, 2010).

Chronic Illness and Involving Patients in Negotiations of Their Care

Finding an all-encompassing definition of chronicity is complex (Lubkin & Larsen, 2013). The term chronicity been often associated with non-communicable diseases; however Unwin (2004) prefers to use the term “chronic disease” for he argues that certain chronic conditions like HIV/AIDS are communicable. The term “disease” has also been under debate and has been criticized for focusing on pathophysiological process and biomedical models and for failing to capture the psychosocial context and the life experience of those who live with disease (Dowrick, Dixon-Woods, Homan, & Weinman, 2005). Therefore, in keeping with the scope of this study, the term “chronic illness” will be used throughout as it is more representative of the subjective (social and

emotional) experience of the individual (May, 2005).

Chronic illness is defined as an irreversible physical or mental disease state or impairment which lasts for more than three months (WHO, 2012). Nolte and McKee (2008) take it a step further and offer a more comprehensive definition that captures not just the onset of chronic illness, but also its ongoing exigencies. They define chronic illness as: “Conditions that require a complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment. (p. 1)”. Implicit in this definition is the importance of supportive care and the integral role it plays in the rehabilitation process of the patient. In most countries, this supportive care is backed up by a health-care system that offers assistance to the individual and their family by encouraging independence and self-care.

While this shift from service provider to patient participation in self-care is timely, this concept is not new. The idea of patients participating in their care has its origins in the liberal idea that individuals do not need to be taken care of, for they are capable of making their own rational decisions (Nordgren & Fridlund, 2001). There is evidence to suggest that patients benefit when they become more involved in their care. Involvement in care offers patients a voice, control and choice in the management of their lives (Hooper, 2009) and it results in positive perceptions of quality of care given (Clark et al., 2008). Current evidence suggests that patients who are more involved in their care have superior health outcomes (Greenfield, Kaplan, Ware, Martin, & Frank, 1988; Jordan & Osborne, 2007), are more empowered (Callagan, 2012; Gallant et al., 2002) and tend

to make better informed choices (Malloch & Porter-O'Grady, 1999). Other studies have shown how patient involvement in negotiation of care results in enhanced self-management skills (Barlow, Tirner, & Wright, 2000), prevention of complications, and a decrease in readmission to hospital (Barlow et al., 2000; Bodenheimer, Lorig, Holman, & Grumbach, 2002). Collectively, this leads to a better quality of care, and a reduction in the use of health services and costs (Clark et al., 2008; Kinnersley, Scott, Peters, & Harvey, 2000).

Studies show that besides the advantages to patients outlined above, involving patients in their care in hospitals can impact nurses' work and the nursing workforce. For instance, nurses seem to have better work satisfaction when patients are more satisfied with their care, and as a result nurses tend to experience less burnout (Aiken, Clark, Sloane, Sochalski, & Silber, 2002; Aiken, Clark, & Sloane, 2002; O'Brien-Pallas, Tomblin Murphy, Shamian, Xiaoqiang, & Hayes, 2010). Preventing burnout in nurses can reap benefits to organizations in terms of nurse recruitment and retention and may help to provide a solution to the current problem of staff shortages (Sochalski, 2001; 2004). Indeed, there is evidence to show how costly it is to recruit new nurses; money which could well be invested to prevent nurse shortages in the first place (O'Brien-Pallas, et al., 2010).

It appears that one way to address the current global crises of chronic disease is to encourage partnerships with patients and involve them more in their care. Clearly, the degree to which patients are involved in their care is pivotal to patient, professional and economic outcomes. Despite currently accepted standards in health care that embrace a model of openness, collaboration and negotiation of care between chronically ill patients

and professionals (Cowie, 2012; Thorne, Nyhlin, & Paterson, 2000), a number of empirical studies have concluded that partnerships between health professionals and patients remain largely rhetoric (Lindsey, 1997; Paterson, 2001) and are not yet evident in many health-care settings (Aujoulat, Luminet, & Deccache 2007; Cowie, 2012; Henderson, 2003; Playne & Keeley 1998). Instead, relationships between professionals and patients are often beset by issues of control over the management of the patient's illness, many of which result in the acquiescence of patients to the professional goals of care (Breeze & Repper, 1998; Johnson & Webb, 1995a; Price 1996; Sinivaara, Suominene, Routasalo, & Hupli, 2004; Thorne et al., 2000).

Implementing effective partnerships between nurses and patients in a health-care system that has been dominated by medicine and nursing for over a century demands a comprehensive health-care system with trained professionals who are ready to change their way of thinking, behaving, and organizing patient care. Only when these nurses are equipped with such knowledge and skills can they work together with empowered patients who are able to maximize the minimal health-care resources to keep the management of chronic illness sustainable for a period of time (WHO, 2005c). In this context, the WHO (2005c) published a document aimed at preparing the health-care workforce to better meet the needs of chronically ill patients. Central to this report is the development of core competencies for health-care professionals, such as nurses, to develop greater partnership with patients (WHO, 2005c).

Defining Partnership

Yet, what is partnership in care? Understanding what partnership means and what it involves is key in order to implement it in practice. However, what the concept of

“partnership” means and the processes it involves remain somewhat unclear (Bidmead & Cowley, 2005; Gabe, Olumide, & Bury, 2004; Gallant et al., 2002; Sahlsten, Larsson, Sjostrom, & Plos, 2009). McQueen (2000) describes the various meanings that have been ascribed to nurse-patient partnership throughout the years, and how various scholars interpret it differently. She contends partnership has been used interchangeably with interpersonal skills and was seen as a non-directive style of interaction with patients with the aim of helping them make choices, and empowering them to participate in their care. While some view partnership as an egalitarian relationship between nurse and patient, where both parties aim towards a common goal (Bayntum-Lees, 1992), others disagree with both parties being equal (McQueen, 2000; Muetzel, 1988). For example, McQueen (2000) contends that the relationship between nurse and patient is not equal, because each party brings a different but complementary contribution to the relationship; the patients bring their knowledge from a life perspective, while the nurses share their knowledge from a professional point of view. Others like Taylor (2009) looked at partnerships as a “‘shared’ style where control is mutual or exchanged thus leading to a ‘negotiated’ plan” (p.151). Implicit in this definition is the notion that partnership involves collaboration between both parties, where power relationships may be equal or unequal. Taylor explains that power relationships may shift to any one side between parties; however as long as both partners agree with this power relationship, and as long as the goal is patient centered, then partnership exists. This definition captures the process of partnerships that were explicated earlier by Gallant et al., (2002) in their concept analysis of partnerships in nursing.

According to Gallant et al., (2002) partnerships gyrate around three attributes:

relationships, power sharing and negotiation. In their in-depth analysis of the concept, Gallant et al., concluded that partnership is a relationship which involves power sharing between patients and providers, and where decisions about patients' treatment, goals and outcomes are negotiated with the patient. In this instance the nurse is expected to act as an educator, facilitator and resource person, whereas the patients are expected to bring in their knowledge about how they are experiencing and managing their own condition in the hope that this knowledge will be recognized and acknowledged (Gallant et al., 2002). The aim here is to shift the power paradigm from a previously held paternalistic approach to one which is more patient-centered and democratic (Bidmead & Cowley, 2005).

Gallant et al., (2002) explored the attributes of partnership from a structural and process perspective. In terms of the structure of partnership, Gallant et al. examined the different phases of the nurse–patient relationship from the initial point of contact to the working phase until termination of the relationship. They describe the aims and goals of each stage, and delineate the associated roles and responsibilities of both nurse and patient for each stage. This structural analysis of partnership places an emphasis on the dyadic uniqueness of nurse and patient and how the two parties can work as co-equal partners to achieve mutually agreed upon goals.

According to Gallant et al., the processes by which nurse and patient can work together as partners towards this common goal involves power sharing and negotiation. Gallant et al., explain how power sharing may include “power over”, “power with” and “power to” patients depending on the type of patient, nature of illness, and context where care is delivered. Gallant et al., do not elaborate on the type of power patients exercise and in what ways they contribute to power sharing in this relationship, possibly

suggesting that they exercise no power at all. The invisibility of the patient in the relationship is a salient feature that was predominant throughout the literature search for this study (see Chapter 2), a silence which Foucault (1971/1981) asserts speaks louder than words, and which feminist post-structural theorists would describe as disempowering discourses.

Gallant et al., (2002) also discuss the second component relating to the partnership process, namely “negotiation of care”. Gallant et al., explains how negotiation is the process by which nurse and patient resort to different concessions and compromises in order to attain the process of mutual goal setting. Gallant et al., contends that the negotiation is not always positive and there is a potential for conflict between partners. However, for partnership to take place, both parties need to agree on a mutual plan that addresses the patient’s needs. In other words, partnership is only said to exist if there is a “win–win” situation between nurses and patients.

Gallant et al., concept analysis of partnership is comprehensive in that it covers the structural and process variables that are implicated in partnership. It illustrates the complexities involved in the development of partnerships. However, although Gallant et al., concept analysis offers a solid basis for analyzing partnerships, they do not elaborate much on how nurses’ and patients’ values, beliefs and practices influence the partnership process. For example, the extent to which professionals are willing to negotiate power with chronically ill patients, or conversely, the extent to which chronically ill patients desire to partake in the management of their care, is not straight forward. Health-care professionals may value and believe in partnerships with patients; however this does not mean that they can always accommodate the patients’ wishes especially if they

compromise the patient's safety. Likewise, it would be presumptuous to assume that all chronically ill patients are unhappy with nurses taking charge of their care. When it comes to encouraging patients to participate in their care, not all chronically ill patients seem to be willing to engage in their own care. Taking charge does not necessarily create dominating and disempowering situations. For instance, some patients may prefer a paternalistic approach versus a more autonomous one simply because they were socialized and feel more comfortable with the traditional model of care (Davies & Elwyn, 2008). The extent to which chronically ill patients want or are able to participate in their care may vary substantially from the time when they are first diagnosed, during their illness progression, and at the end of life stage (Arora & McHorney, 2000; Davies, Rosamond, Sevdalis, & Vincent, 2007). Some patients do not want to engage in shared decision-making when they are acutely ill. In such situations, professional use of power may be desired and seen as productive (Nordgren & Fridlund, 2001). Therefore, one could say that institutional discourses are not always disempowering, but can be productive as well.

The above examples illustrate the complexities involved in the formation of partnerships, and the rich information that can be uncovered if one were to dig deeper and explore the perceptions of nurses and patients on *how* partnerships should transpire. This was the focus of my study. For the purpose of this study I looked specifically at the process of partnership; namely, how personal values, beliefs and practices shape power relations between nurse and patient, and how they affected negotiation of patient care. In my study I contend that partnership is not merely a mutual agreement between nurse and patient, but that one needs to look beyond the individual and examine the larger social

and institutional context in which the interaction takes place. Health-care settings are not neutral places, but are highly implicated in how nurses and patients think, feel and behave. Both society and institutions promote certain kinds of ideas and social relationships that guide how nurses and patients should behave towards each other.

Some of the contextual values, beliefs and practices that contribute to the creation of power relations and negotiation of care between nurses and patients are social and institutional discourses. These discourses are often concealed and can only be revealed through discourse analysis of stories of power inequalities, as told from the parties involved. The meaning of discourse and how discourses can configure relations of power and negotiation of care between nurse and patient will be discussed next.

Defining Discourse

The terms language, conversation and discourse are often used interchangeably to describe statements that are exchanged between one party and another when communicating with each other; however, discourses are more than that. Parker (1992) gives a working definition of discourse and describes it as “a system of statements that construct an object” (p.2). Put simply, discourse is more than words that are used to convey a message between two or more individuals. Rather, it also reflects how an object is thought about and valued in a particular society.

According to Saussure, a socio-linguist who was interested in language as a system, language is made up of signs. Each sign consists of a *signifier* (the word or sound we give it) and a *signified* (how we perceive and interpret the object in our minds). Words have no meaning on their own, but we make sense of words by the way we interpret them in our minds. How we interpret them is shaped by social and institutional

values, practices and beliefs that individual is exposed to and brought up with. Similarly, in nursing, while it may be easy to conceptualize partnership between nurses and patients as a form of conversation aimed towards negotiation of care, in reality during such conversations, nurses and patients are not merely exchanging words, but are also bringing in their own personal interpretations of what nurse-patient relationships should be like. Such interpretations are contingent on the society they live in and the discourses (values, practices and beliefs) of that society at a particular historical time.

As I will explain later in my theoretical chapter, discourses may carry a tremendous amount of power. Discourses determine how society and institutions should function by determining the norm and acceptable ways of living in a particular society. As such, social discourses help to create order in society. However, since these social discourses delineate what is normal and abnormal, they may create hegemonic situations, where anyone who deviates from the norm may be viewed as aberrant and marginalized. In reality these individuals may not necessarily wrong doers, but simply individuals who have different ways of viewing the world.

In this study I am interested in exploring how social and institutional discourses shape personal values, beliefs and practices during negotiation of patient care between nurses and patients. One of the basic assumptions that guided this study is that negotiation of patient care and its outcome do not depend on the nurse's or patient's personality or individual characteristics. Rather, they depend on the social and institutional values, practices and beliefs that guide their way of thinking and behaving.

Social and Institutional Discourses

Social and Institutional discourses are dominant ways of thinking in society that determine what is normal and acceptable, and what is deviant and inappropriate behavior. These dominant discourses determine the possibilities and limitations of what nurses and patient can say or do, and what is acceptable or not during negotiation of patient care. They affect which voices are heard and which voices are silenced. One of the most frequently cited reasons why equal partnerships in care are not yet predominantly apparent between nurses and chronically ill patients is because professional expertise is still privileged in health-care settings. A number of studies suggest that while on the surface partnerships with patients may appear as a concern in professional practice, at a deeper level there is a strongly held ideology that still views professionally-based knowledge as superior to patients' expertise (Leventhal, Riegel, Carlson, & De Geest, 2005; Lindsey, 1997; Thorne, 2008).

There is a general consensus that while many times professionals' knowledge and expertise do contribute immeasurably towards the management of chronic illness, it is the person who is living with the disease who knows best how to fine tune available resources to meet with personal demands (Coulter, 2002; Smith, 2003; Falk, Wahn, & Lidell, 2006; Thorne, Nylin, & Paterson, 2000). For instance, it is well known that many chronically ill patients have lived with their disease for a long time and may have developed a sophisticated knowledge about how their bodies respond to treatment and medication. Such patients have developed their own unique ways of coping with complex regimens, often by altering ways in which the therapeutic regimen fits their lifestyle (Aujoulat, et al., 2007; Falk, et al., 2006; Polaschek, 2003). These alterations are

often achieved through experimentation and creativity rather than by strict compliance² to standardized protocols (Thorne, 2006). These forms of adaptation are fundamental for some, if not most patients, who strive to achieve some control over the conditions that have come to dominate their lives (Leventhal et al., 2005; Polaschek, 2003). Hence, it follows that if patients want to be involved in the management of their chronic condition, they need to be key participants.

The need to recognize the patient as the key player in the management of their chronic illness rather than as a subsidiary is increasingly becoming recognized and acknowledged in the treatment of chronic illness, not only for economic reasons, but also for ethical ones (Oeseburg & Abma, 2006). Care of chronically ill patients does not revolve only around fiscal ends, but fundamentally around humanitarianism. Being treated with dignity and respect and having one's autonomy valued are basic human rights that one strives for oneself, and for others. However, most of the studies that looked at power structures between professionals and patients illustrate how professionals can be controlling, and how patients are vulnerable and need to be empowered (Tew, 2006). These studies attest that such a power imbalance exists; however such conclusions provide a restrictive view of power, which tends to overemphasize the professional's role and ignore the patient's contribution to this dynamic (Thorne &

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Although the term non-adherence is currently used to describe situations when patients do not adhere to prescribed therapeutic regime, in the rest of the text I will be using the word non-compliance since it is more reflective of power relationships. Paradoxically, this is the reason why the term 'non-compliance' is no longer being used, because it was associated negatively with patients being seen as deviant and uncooperative; however in post-structuralism, it can be interpreted that the patient is in a position of power, and is resisting professional authority. Although this may sound oxymoronic, in reality, and as I will explain later, it illustrates the power of language, and the way it has multiple meanings depending how the individual in a particular place or time makes sense of them (Weedon, 1997).

Patterson, 2000; Jarrett & Payne, 1995; Kettunen, Poskiparta & Gerlander, 2002; Shattel, 2004). Indeed, there is a need to move beyond this victim blaming mentality and listen to what the patient is saying and doing. This could lead to a better understanding of why patient participation in care has not increased to a level where we might expect it to be (Macdonald, 2007). Knowledge is multiple and various truths about social reality exist. A less disempowering discourse might be taken up by someone who attends to the voice of chronically ill patients, even if this practice “dares” to disrupt the hegemonic medical discourse (Campbell, 2003). It is indeed this need to look at, and listen to, what the patient is saying that motivated me to carry out this project.

However, as mentioned earlier, one cannot examine power relations between nurse and patient on an individual level, but one needs to consider the relative position of the two within the health-care context and broader society. The configuration of nurses’ and patients’ identities and concomitant capacity for power is not a deliberate, independent, and self-governing act, but subject to social and institutional discourses; that is, institutional ideologies, culture and practices that shape who the nurse is, who the patient is, and how the two should relate to each other. In this sense, both nurse and patient are described as being subjected to institutional discourses, which enable, or disable different forms of power relations between nurse and patient. These discourses emanate not just from the settings where care is being delivered, but are also steeped in historical and cultural discourses from society at large.

A curiosity about how social and institutional discourses configure nurse-patient partnership relations with chronically ill patients piqued my interest to conduct this study. In this study, I show how institutional discourses, as well as discourses from society at

large, can act as a resource or barrier in the shaping of power relations between nurse and patient. This is an important step that has not been adequately addressed in the literature and is crucial if one wants to understand why partnerships are or are not transpiring in health-care settings. Further, using a feminist post-structural approach I demonstrate how there is no standard rule on how to best negotiate patient care. Each negotiation between nurse and patient is a unique and complex situation that is subject to the dominant social and institutional values, beliefs and practices that guide nurses' and patients' decision making process at the time.

Research Purpose

The purpose of this research is to examine the experiences of chronically ill patients during a hospital admission as well as to understand the experiences of nurses who care for chronically ill patients in hospital. Examining these experiences will reveal how those discourses can create moments of disempowerment and moments of empowerment for patients when it comes to negotiating patient care.

Research Questions

1. How do chronically ill patients experience and negotiate their care while in the hospital?
2. How do registered nurses experience and negotiate the care they provide to chronically ill patients?

I understand that the dichotomy that exists between nurse and patient is not because of internal or innate qualities, but because of the values, beliefs, and practices that both parties have been brought up with and subjected to as persons, as patients, and as professionals. In order to study this, I needed to go beyond the participants'

descriptions of their nurse-patient interaction, and pay attention to the language that the participants used when they described these experiences. Analysis of the language, such as the terminology they used, the way they spoke about themselves, and the way they compared themselves to others, helped to identify how social and institutional values, beliefs and practices shaped power relations and negotiation of patient care. This process, known as discourse analysis, was helpful in addressing the sub-questions.

Sub Questions

1. What were the experiences of registered nurses and chronically ill patients about negotiation of care in hospital settings?
2. What were the social and institutional beliefs, values, and practices of registered nurses and chronically ill patients when they were negotiating patient care in the hospital?
3. What were the power relations between registered nurses and patients in hospital settings, and how were they negotiated?
4. What discourses inform the experiences of registered nurses and chronically ill patients and how are these discourses negotiated?

Significance of the Study

Rationale for Looking at Patients' Perspectives

Clearly my views about nurse-patient power relations are not unique. Nurse - patient partnerships have been the focus of nursing attention for decades (Armstrong, 1983; Hewison, 1995; Shattell, 2004). However, despite the plethora of information that exists, there is a paucity of studies that focus on patients' experience of their involvement

in care (Thorne & Patterson 2000, Jarrett & Payne, 1995, Shattel, 2004). These studies are imperative if one wants to gain a full understanding of how negotiation of care and power relations between nurses and patients transpire. Jarrett and Payne (1995) explain how the lack of such studies may result in nurses making assumptions about what a patient needs or wants. These authors comment that nurse–patient interaction is a two-way process, and to elicit views of one party only is not a true representation of reality, since it does not epitomize the differing aims, objectives, and perspectives with which patients may present. Hence incorporating patients’ perspectives will provide a more comprehensive view of the nurses’ and patients’ experiences. This is crucial since the nurse–patient relationship cannot be broken down separately and explored individually. Rather, one needs to see the interaction of both parties within the hospital as a gestalt view, as a synergistic whole, rather than the sum of their parts.

Most of the nursing literature has also presented an asymmetric analysis of power, one in which nurses are domineering and disempowering. Frequently patients have been portrayed as helpless and powerless (Kettunen, Marita, & Gerlander 2002). Only a few studies were found that specifically investigated patient’s use of power/resistance to nursing authority. I hope that the results of this study foster hope in chronically ill patients so that patients can see that they are not helpless and are in a position to exercise power. Hopefully this will help to break stereotypes, and the production and reproduction of patients as victims and vulnerable. Cheek (2000a) contends that dichotomous relationships, that is hierarchical relationships between nurse and patient, will persist if patients continue to be portrayed as the “weaker” or the “other” of nursing. Hall (1997, p.326) explains that hegemonic relationships are “represented through

sharply, opposed, binary extremes” and that one of the ways to contest this difference in power is to reverse this stereotype. According to Hall (1997, p. 342) this does not imply that action is taken to “overturn or subvert” this stereotype, but rather by “escaping the grip of one stereotype extreme” and simply refusing to be “trapped in its stereotype 'other'” (p. 342). In other words, rather than claiming that patients are superior to nurses, one can break these stereotypes by refusing to believe that patients are victims and powerless. I hope the results of this study help to deconstruct power relations between nurses and patients, and promote the notion that patients, too, can be in a position of power. An understanding of relations of power between nurse and patient is highly pertinent to a patient's health-care outcomes, and is more likely to encourage a patient to participate more vigorously in his/her treatment.

Rationale for Looking at Nurses’ Perspectives

Unequal power relations do not exist between nurses and patients only, but also between any professional who holds an institutional role (Andrews et al., 2005; Foucault, 1975/1977; Goffman, 1968; Heritage, 2005; Liaschenko, 1996, Valentine, 2001). However, for this doctoral work I focused exclusively on registered nurses, because such research has not been done. I was also interested in nurses because most patients see more of the nurse during their hospital stay than any other professional and hence nurses were significantly involved with the patients’ hospitalization experience. According to the Canadian Nurses Association (CNA, 2005) document *Chronic Disease & Nursing*, nurses are the most consistent and probably the first point of contact for patients in hospitals and therefore they often are in the best position to understand what it means for chronically ill patients to live with their illness. Nurses have a responsibility to advocate

for patients by attending to those needs that the patient would normally do for him/herself if they had the physical capability, knowledge, and/or will (CNA, 2005). This is crucial for patients because not only are nurses key persons who help to identify patients' needs and attend to them, nurses also have knowledge about institutional resources and therefore can help to leverage resources to meet the patient's needs. Further, nurses are central to patients' illness experience because they have the potential to facilitate or hinder the extent to which patients participate in negotiation of their care by using institutional discourse to their advantage. A fine example of this is how nurses, by virtue of being "in between" dominant medical discourse and "client discourse," have a central role in mediating and facilitating the patient's own decision making in terms of negotiating their care (Polaschek, 2003).

Yet these nursing roles can only be effective if nurses are able to negotiate care with patients successfully. Understanding what works and what does not work during negotiation of patient care will help to identify achievements or failures that make negotiation of patient care effective. The results of this study could increase nurses' awareness and sensitivity towards chronically ill patients' experience, and help nurses to grow in elements such as facilitation, negotiation and shared decision making. More importantly, it is this researcher's hope that this study might provide nurses with insights about their practice, the power that they have, and how this is influenced by institutional discourse. I hope that this knowledge will provide nurses with opportunities to step back, reflect and reconsider if their delivery of care is motivated by misuse of this power or by empathy. In so doing, the findings of this study may help to underscore the need for nurses to be more aware of their moral, ethical and professional obligations.

However, nurses do not act in isolation. They are also accountable and expected to be agents of the institution that employs them. Therefore, nursing action is not a personal decision that nurses decide to take, but is informed by social and institutional experiences that configure who the nurse is, and how she/he will interact with patients. I think that it is important to move beyond the nurse as a person, and to look at how the discourses shape power relations between nurse and patient, and negotiation of patient care. Results from this study may also provide an opportunity for hospital institutions and subsequent managers and stakeholders to reconsider the ways the current institutional policies and procedures are providing a conducive environment for nurses to practice in a way that encourages positive negotiation of patient care between nurses and chronically ill patients. These findings may also provide insights and food for thought for institutional managers and stakeholders themselves. It may highlight their obligations as administrators, and how they can provide a supportive environment to enable nurses to practice effectively and to make it easier for nurses to negotiate care with patients.

Rationale for Looking at Social and Institutional Discourses

As the current health-care system moves towards a collaborative model that embraces partnership between chronically ill patients and nurses, it would be helpful to listen to stories of success and failure relating to the development of partnerships between nurses and chronically ill patients. Understanding nurses' and patients' experiences serves as constructive information that may identify future challenges and offer new directions for care. Lessons from past and present research studies will provide building blocks that pave the way to make the transition to partnership in care sustainable and smoother.

However, while understanding what factors facilitate or inhibit the development of negotiations between nurses and patients is important, it is equally essential to understand that these factors cannot be interpreted as fixed values that help or hinder the formation of partnerships between nurses and patients. Every nurse patient negotiation is a unique situation, and shaped by patients' and nurses' ways of thinking at a particular historical time. An exploration of how social and institutional discourses shape patients' and nurses' decision making process offers insight and helps to expose those finer nuances involved during the negotiation process that are hidden from view. A feminist post-structural approach facilitates identification of these discourses, and provides a better understanding of the process of the negotiation, that is, happening during the partnership process, how care is negotiated, and how power relations are set up (Stoddart & Bugge, 2012).

Chapter Summary

In this chapter I have highlighted the current crisis in health care and how chronic illness is becoming a concern for health administrators, policy makers and professionals. I have elaborated how decentralizing the current health-care system and involving patients in their care can lead to benefits for individuals, institutions and society. Involving patients in their care has been shown to improve the mortality and morbidity rate in adults and subsequently reduce the amount of years lost in DALY. Patients themselves benefit when they are involved in their care. It offers them an opportunity to voice their opinions, improve their overall health, and increase their perceptions of the care experienced during hospitalizations. These benefits create a ripple effect in terms of nursing and organizational outcomes. When patients are pleased with the care delivered,

nurses' job satisfaction increases and their risk for burnout and chances of leaving their jobs diminish. These factors were found to reduce organizational costs associated with recruiting and training new nurses and the associated costs of inadequate resources to deliver patient care.

Despite their acclaimed benefits, it appears that partnerships between nurses and patients are not always evident in practice. Many studies looked at the development of partnerships between nurses and patients; however exceedingly few have examined how contextual features of society and institutions influence partnerships between nurses and chronically ill patients. According to a number of theorists, these contextual features should not be considered as a background to nurse and patient communication, but central to the formation of power relations between the two parties. Exploring these contextual aspects of nurse-patient relationships is timely, and pivotal. In the following chapter I will discuss the literature relevant to this study.

CHAPTER 2

LITERATURE REVIEW

In this chapter I will critically analyze empirical studies that have explored power relations and negotiation of care between nurse and patient in hospital settings, and how these interactions were shaped by social and institutional discourses. The first section of this chapter analyzes studies that explored how nurses used their position of power to negotiate care with patients and how patients reacted to nurses' authority. The second half of the chapter looks at studies that describe how hospital settings and culture can give rise to empowering and disempowering moments during negotiation of patient care between nurses and patients

I conducted a computerized literature search from January 1990 until October 2014 using the following data bases: CINAHL, Medline, Embase, and Ovid Journals on line, Cochrane library, and the Internet. I followed this up by a manual search for other articles that were cited in some of the retrieved papers. The search was developed around five foci: nurse and patient partnerships, chronically ill patients, discourse and nursing, feminist post-structuralism and finally Foucault and nursing. I included Foucault in my search because his work was important to the theoretical framework that guided my study. The search terms used included: "chronic illness", "chronically ill patients and nursing", "partnerships with patients", "negotiation with patients", "nurse and patient and power", "nurse and patient and empowerment", "nurse and patient and powerlessness", " nurse and patient and resistance," "discourse(s) and discursive practice", "social and institutional discourse" , "factors that influence nurse-patient partnership", "Foucault and power", and "Foucault and feminism". Alternative terms

such as “nurse-patient relations/relationships”, “nurse-patient communication”, “patient participation”, “patient centered care”, “patient involvement”, “long term illness”, “environment” and “context” were also used in order to capture any relevant articles that may exist under alternative rubrics. No date restrictions were imposed and any research studies that were deemed relevant were included, as I wanted to trace longstanding work to ensure a comprehensive coverage of studies that explored nurse-patient relationships. In this way, a broad search helped to retrieve seminal work that might have otherwise been missed due to date confines.

The initial search resulted in an overwhelming number of articles, some of which were duplicates, and some of which were not related to nurses but to other health-care professionals. The first step was to identify those papers that were potentially relevant to this study by looking at the titles. This reduced the material retrieved and made it more manageable. I read through the abstracts of these selected articles and if they were pertinent, I read the full text. Following retrieval of this material, papers were organized in three categories. The first category focused on articles relating to chronic illness. This included literature relating to discussion papers on what is chronic illness, national and international documents that suggest strategies for dealing with the current burden of chronic illness, and models that address chronic illness management. The second category related to articles and studies that explored nurse-patient relationships in general and specific to chronic illness. Examples of such articles included studies on: nurse-patient partnerships or negotiation of care, power relations between nurses and patients; and environmental/contextual issues that shape nurse-patient relations. The last category related to theoretical foundations that underpin this study. The majority of these articles

were discussion papers that focused on Foucault and nursing; Feminist post-structuralism and nursing, and discourse. Organization of the literature under these three categories, each with different foci, was necessary as it facilitated quick retrieval of particular articles if I needed them. It also helped to organize my thoughts as I moved on with my writing. The following sections represent a synopsis of these studies, as well as a critique of the literature as a whole.

Current Discourses Relating To Partnerships With Chronically Ill Patients

Aging populations as well as advancements in medical science, technology and pharmaceuticals are resulting in a burgeoning increase in the number of chronically ill patients, that are challenging health-care systems around the world (Egnew, 2009; Jordon & Osborne, 2007; Temmink, Francke, Hutten, Zee, & Huijer, 2000; WHO, 2011a). Coupled with these changes in demographics, many social structures are becoming less hierarchical as patients are becoming more knowledgeable about their illness through the media and the Internet, and demanding more active involvement in their care (Cline, 2003; Pellise & Sell, 2009; Stacey, Henderson, MacArthur, & Dohan, 2009; Taylor, 2009). As a consequence of this, several health-care systems are undergoing dramatic changes and moving from a paternalistic model to a more democratic model which promotes power sharing and joint decision making in patient care (Infante et al., 2004; McWilliam, 2009; Brink-Muinen, Spreeuwenberg & Rijken, 2011; Chewing Bylund, Shah, Arora, Gueguen & Makoul, 2012; Staniswenska & West, 2004; Taylor, 2009; WHO, 2002, 2011a). These sociological, political and economic trends have also impacted nursing professional organizations, which have endorsed the need for more patient participation and respect for their autonomy as part of their professional and ethical codes of conduct

(Gallant et al., 2002; CNA, 2008). The Canadian Nurses Association (2012) has long acknowledged the important role that nurses play in supporting self-care management in chronically ill patients, and has published various documents to assist nurses in this role (CNA 2002, 2012).

Power Relationships between Nurses and Patients

Studies relating to nurse-patient interactions or one-to-one negotiations are not new in nursing literature and have been the focus of nursing attention for a number of years (Peplau, 1948; Moyle, 2003; Shattell, 2004). Although the importance of this relationship has been noted since Florence Nightingale's time, it was not until 1952 when Peplau wrote her book on *Interpersonal Relations in Nursing: A Conceptual Frame of Reference for Psychodynamic Nursing*, that the meaning and intricacies of nurse-patient relations were first acknowledged and celebrated in nursing literature (Peplau, 1952). Since then, empirical studies on nurse-patient relationships continue to proliferate and reiterate the importance of promoting patient participation in care.

Interestingly, although studies on nurse-patient relationships were abundant, there were only a few papers on the power relationship between nurses and chronically ill patients. This finding might possibly be related to the fact that professional use of power is a sensitive topic. The word "power" itself tends to be associated with undesirable behavior and to have negative connotations, even though as I describe later, the use of power can also be positive. Another interesting finding in the literature is that despite the current discourses on partnerships and patient participation, nurses continue to exhibit varying degrees and forms of authoritative control over patients (Michie, Miles & Weinman, 2003; Paterson, 2001). Professional control over patients has been

documented widely in many countries such as the United Kingdom (Hyde et al., 2006), Canada (Perron, Fluet, & Holmes, 2005; Thorne et al., 2000), the United States (Malone, 2003; Wheatley, 2005), Australia (Henderson, 2003), New Zealand (Crowe, 2000), Finland (Sinivaara et al., 2004), Iran (Hagbaglhery, Salsali, & Ahmadi, 2004), and in various settings such as acute care (Heartfield, 1996), psychiatry (Breeze & Reaper, 1998; Hamilton & Manias, 2006; Holmes, 2002, 2005), maternity (Fahy & Paratt, 2006), home care (Liaschenko, 1997), and palliative care (Oudshoorn, Ward-Griffin, & McWilliam, 2007).

This finding was also documented in a number of other theoretical and research papers about doctors (Barry, Bradley, Britten, Stevenson, & Barber, 2000; Boon & Stewart, 1998; Champion, Foulkes, Neighbour, & Tare, 2002; Heritage & Maynard, 2006; Infante et al., 2004; Poptik, 2007; Smith, 2003), social workers (Macdonald, 2008; Poland, et al., 2005; Tew, 2006), and physiotherapists (Mead, 2000) who work in various health-care settings and who also appear to share one thing in common with nursing: the need to develop a less paternalistic approach and to move towards more patient involvement in care.

This widespread and multidisciplinary call for all health-care professionals to change their attitudes towards patient care suggests that the need for this shift is not unique, or inherent to nursing as a profession, but that it is much broader, temporal, and historically situated. Indeed, it is widely documented that the reason for this shift from a paternalistic to a more shared relationship can be traced back to major sociopolitical, economic and historical developments such as the 1948 United Nations declaration of human rights, the rise of feminism in the 1960s, and recently the WHO's declaration

(2002, 2005a, 2005b, 2011a) about the chronic illness crisis. These historical changes and values have shaped priorities and directions in how care is delivered. This finding illustrates that institutional and social discourses are not benign, but play an active role in day-to-day interactions of nurses and patients.

Nurses' Use of Language to Assert Their Authority

It is clear from the literature review that one of the reasons why some nurses have not established effective negotiations with patients is because they seem reluctant to surrender their authoritative role. The types of power strategies that nurses have used to exercise control over patients were sometimes invisible and insidious in nature. These forms of power manifested themselves through nurses' use of knowledge, language, and a variety of practices. They ranged from subtle use of language, to directing the conversation towards the nurses goals of care, to more detrimental effects such as the use of language to depersonalize and reduce patients to objects, or to punish patients through the use of labelling. Such practices fall in line with Foucault's (1975, 1977) earlier work on power, and can be traced back to Foucault's writing in his initial publications in the *Birth of the Clinic* (1963/1975) and *Discipline & Punish* (1975/1977).

"Nurses Know Best"

One such study was conducted by Henderson (2003) who referred to Foucault's earlier work (1972/1977) to explore nurses' and patients' views about partnership in hospital care. In this qualitative study, Henderson (2003) used observation and interviews to discover how nurses and patients negotiated their care with medical and surgical patients in four Australian hospitals. In her analysis, Henderson (2003) reported that nurses maintained their position of authority by claiming to possess esoteric

knowledge and by using this resource to create an aura of professional elitism.

According to Henderson (2003), nurses sustain this power by limiting their interactions with patients, by restricting the information that they gave them, and by overtly claiming that they know best. The strength of this study is that Henderson used triangulation of samples, sites, methods, and data analysis to investigate her research question, thus adding rigor to the study. However, she did not elaborate much on the characteristics of the patients or the severity of their illness; therefore it is hard to conclude if such findings are transferable to chronically ill patients. Unfortunately, despite using interviews as one of her methods, Henderson did not explore why nurses were interacting in this manner with patients. The inclusion of contextual information may have furthered our understanding of underlying reasons that may have been pressing on nurses to act this way.

These findings are not new. Similar findings were reported earlier by Hewison (1995) who used grounded theory, observation, and interviews to explore nurses' power in interaction with patients in the U.K. In this study, Hewison (1995) looked at how nurses used language and discursive practices to claim a monopoly on truth and to get patients to conform to nurses' rules. Hewison (1995) reported that nurses exerted power over patients by ordering them to do tasks, by persuading patients to do what the nurses wanted, by enforcing "routine" and giving patients no option, and by using less than authentic terms of endearment or caring words that were often associated with "mothering" where patients were treated like a "child" with the nurse acting as a "parent" figure (p. 80). Hewison does not give much detail about her sample other than that they were all female and elderly. The difference between her study and that of Henderson

(2003) is that Hewison goes beyond the interpersonal level of the nurse and patient, and acknowledges that hospital rules and regulations may partially explain why nurses used “overt power” and why they “order patients” to do things. However, Hewison did not explore these phenomena in the study and hence this remains merely a speculation. Nonetheless, while both of these studies have limitations, since the findings yielded similar results, it suggests two things. Primarily it suggests there are some consistent patterns in how nurses use power in their practice, and secondly that some nurses are not willing to relinquish this power to patients. Further, the fact that these two studies were conducted in two separate countries and at different times, also suggest that some nursing behaviors tend to be similar across countries, and that nursing attitudes towards patients have not changed much over the years.

Labelling of Patients

While these studies reveal how nurses used esoteric knowledge to assert nurses’ authority and maintain their privileged position, other studies were found where nurses used language in the form of labelling as a form of power to dehumanize or punish patients. Labelling is a strategy whereby everyday practices are normalized through a process of classification, by comparing what is acceptable and non-acceptable behavior. Foucault (1975/1977) explains how labelling or normalization is a process that is used to “reward” individuals who abide by the norm, and “punish” others who deviate from the norm. These individuals could be either physically, socially, or behaviorally different from normal individuals. Feminist post-structuralist Cheek (2000a) agrees with Foucault; however she adds that labelling can create hierarchical relationships. Cheek (2000a) explains that when labelling is used a binary opposite is created. Binaries occur when

two extreme opposites are automatically put in juxtaposition next to each other (for example: normal/abnormal, acute/chronic, good/bad). This positioning of words in language creates a situation whereby these two terms are automatically related to one another, and subconsciously compared. This comparison creates a situation in which one term is perceived as superior/dominant to the other term. In this literature review, I will give some examples of labelling that nurses use with regard to patients, and demonstrate how such labelling of chronically ill patients resulted in categorization of good and bad patients. The subconscious classification contributed to the subordination of some chronically ill patients, marginalizing them from care.

Labelling patients by their medical condition. A typical example of medical labelling was evident in a study by Heartfield (1996) who used Foucault's (1969/1972) precepts on knowledge and power to describe how nurses in acute settings applied the binary of physical/emotional to prioritize their care. In this study, nurses maintained a vigilant watch on the patients' physical condition and paid little attention, or objectified the psychosocial and emotive domains. While the main focus of Heartfield's study was on the acutely ill, the findings are relevant to chronically ill patients, since chronically ill patients are commonly hospitalized when they develop an acute episode on their chronic illness. However, there are limitations. To begin with, this study is focused on situations when patients become acutely ill, and the main priority is dealing with physical and biological crises; therefore one cannot conclude that nurses also depersonalize chronically ill patients in the same way, when their illness is more stable. Further, the extent to which nurses in Heartfield's study were objective and reductionist towards patients is not clear. Heartfield arrived at these conclusions by relying exclusively on

discourse analysis of nurse's written reports of their nursing care, and did not observe or ask participants about their behavior.

The strength in this form of analysis is that it reveals the documentation practices of nurses and possible underlying agendas behind such practice. However, focusing exclusively on one's physical and physiological changes is not essentially bad, particularly if imminent or possibly life-threatening physiological conditions exist. In such instances, patients may want nurses to take control and be in charge. Further, just because nurses did not document the affective domain of their care, does not mean that nurses did not attend to patients' emotional needs. For instance, in a hermeneutic study on nurse-patient relationship in critical care, Vouzavali et al. (2011) reported a deep connection between patients and nurses who worked in intensive care units, even though some of the patients were not in a position to communicate with nurses. These intense relationships seem to be mediated by the nurses' contact and handling of the disfigured body of the critically ill patient. The sight of disfigurement and suffering drove the nurses to develop deep empathy for the patients. These different findings suggest that there is more than one way to interpret reality, and that knowledge garnered from any experience is never complete, but only a partial description of the situation. Further it implies that in order to understand nurses' behavior, one needs to go further and ask nurses why they act the way they do. Still, it is widely accepted that reduction and objectification of patients does exist in nursing practice, and when it exists, it may threaten the patients' respect (Walsh & Kowanko, 2002) and the degree to which patients can trust and are willing to collaborate with nurses (Barnard & Sandelowski, 2000). This is particularly problematic as building trust is fundamental to developing negotiations

with patients (Hook, 2006; McQueen, 2000; Soleimani & Seyedfatemi, 2010). In a study that looked at features of nurse–patient relationships in the community, Stoddart and Bugge (2012) reported that connectedness between nurses and patients depended on the degree to which patients perceived themselves as being treated as a person or objectified by nurses. Stoddart and Bugge report that in some instances patients felt they were “scrutinized” by nurses and that the interaction between them and the nurses was “clinical” with little personal involvement. This kind of relationship affected the way patients were willing to actively engage themselves during negotiation of care.

Labelling unpopular patients. Just as reducing patients to physiological or medical conditions can be damaging to the development of negotiations between nurse and patient, so can nurses’ use of social or behavioral labelling (Khalil, 2009; Lowbridge, & Hayes, 2013; Price, 2013; Shaw, 2007). One of the earliest studies that described the impact of labelling on nurse-patient relationships was Stockwell’s (1972) seminal study on the unpopular patient. In this study, Stockwell (1972) described how nurses used negative stereotyping to label patients who failed to conform to nurses’ expectations. This led to serious repercussions for some patients, including the marginalization of care. Stockwell reported how nurses dealt with such patients by avoiding and distancing themselves from such patients, by forgetting their requests and by using sarcasm. Conway (2000) followed up on Stockwell’s study by revisiting the characteristics or traits of patients who were considered as “difficult” by nurses and why nurses labelled them in this manner. Conway concluded that some nurses had certain expectations of how patients should behave. These expectations, which Conway coined as “Patient Rules,” included a list of nurse expectations from patients, such as: being polite to nurses,

assisting themselves in their recovery, restricting conversation with nurses to “illness business” and accepting and trusting nurses’ judgment and acknowledging that it is for their best. Although this was a small-scale study, these findings suggest there is a “norm” path along which patients were expected to behave. In his article on *countering the stereotype of the unpopular patient*, Price (2013) notes that with the advent of patient-centered care and emphasis on partnerships, nowadays patients are expected to be more proactive and share more responsibilities. Price says this may contribute to an increase in “unpopular patients” and marginalization of some populations who fail to subscribe to this active role.

An example of how such expectations can lead to rewards or punishments was demonstrated in a study by Khalil (2009), who explored nurses’ attitudes towards “difficult” and “good” patients. Khalil (2009) found that patients who were labelled as “good” patients were treated with tender loving care, whereas the needs of those patients who were labelled as “difficult” were ignored or deliberately delayed. Khalil went a step further and explored why nurses were acting this way. She found that nurses used this labelling because of staff shortage. According to Kahlil, nurses in her study used categorization as a rationale to move on with their nursing care; otherwise they would not be in a position to meet the needs of all patients on the unit. Although Khalil condemned this categorization of patients, and mentioned that nurses who mistreated patients were counselled, disciplined and/or dismissed (albeit punished for their “abnormal” behavior), she called on nurse managers and administrators to realize negative influences of staff shortage on nurse-patient interactions during negotiation of patient care. This finding once more demonstrated that some nurses behave the way they do not because of

personality traits, but because of extraneous contextual factors.

Similar findings were reported in a study by Maben, Adams, Peccei, Murrells & Robert, (2012), who explored the links between staff experience of work and older people's experience of hospital care. Findings in their study revealed that excessive work demands, poor staffing, ward leadership and poor staff relationships impacted the way nurses negotiated care with older adults. Nurses preferred to look after patients who gave them job satisfaction, and gave less attention and personalized care to those patients they perceived as difficult. These findings suggest that the work environment may have an impact on how nurses negotiate care with patients and that when the work environment is difficult, some nurses try to cope by labelling patients. Maben et al., comment that some nurses used this strategy in an attempt to avoid engaging with patients they perceive as difficult because they have more emotional demands.

Reconciling temporalities was also one of the salient features in a study that looked at how health-care settings may result in situations where patients were labelled as difficult. In this study, MacDonald (2005) used a grounded theory approach to uncover how environmental factors shape nurse-patient relationships. Findings from this study indicated that time constraints were one of the reasons why sometimes nurses labelled some patients as difficult. MacDonald blamed the organizational culture, which operates on a linear concept of time and that organizes nursing events in an orderly manner. Linear organization of nursing work resulted in a mounting of nursing tasks which needed to be completed within a short period of time. This created pressure on nurses, leaving them with little time to deal with any extraneous patient or family demands, and increasing the likelihood that nurses would perceive such patients as difficult.

Labelling patients who suffer from chronic mental illness. One of the areas where nurses' use of labelling predominates is in psychiatric units and mental-health institutions where patients suffer from chronic mental illness (Koekkoek, Van Meijel, Tiemens, Schene & Hutschemaekers, 2011). Such findings are not new; psychiatric patients are considered to be some of the most vulnerable patients that come into contact with nurses and are often subject to discrimination, domination and disempowerment (Homes & Gastaldo, 2002; Toombs, 2012; Wright & Morgan, 1990). Although for the purpose of my study I did not include patients who had mental illness, it is well known that patients suffering from chronic illness often experience depression in daily life (Becker & Maiman, 1980; Evangelista, Doering, Dracup, Westlake, Hamilton, & Furnarow, 2003; Riegel et al., 2002). Evidence of misuse of nurses' power with this patient group serves as an excellent demonstration of how nurses' insidious use of power can lead to opportunities for disempowerment of certain populations. For example, Mohr (1999) used Foucault's (1961/2006; 1975/1977; 1980) theoretical framework on knowledge, discipline and power to explore the way nurses in psychiatric units used language in a derogatory and careless manner when submitting written entries on patients. In this study, Mohr used deconstructive textual analysis of 26 psychiatric inpatient charts. Mohr reported that as many as 20% of the documents were unnecessarily pejorative, punitive, or inane in nature. There were few instances when positive comments were written about patients, with most entries being derogatory in nature. Mohr comments on the power of such entries and the way in which they can have subtle negative consequences for patients in terms of labelling, stigmatization, and social reification. Although this study was conducted a while ago, it was included here as it

illustrates the negative implications of labelling and how it may impact negotiation of care between nurses and chronically ill patients.

Such forms of behavioral labelling can have significant implications for those who are chronically ill and who have developed concomitant mental illness because of their chronic illnesses. These forms of labelling not only add to the already disease-laden condition that chronically ill patients have to cope with, but could also alienate and further intensify any marginalizing that chronically ill patients may experience when they negotiate their care with nurses. For example, a study conducted by Irving (2002) reported that nurses used behavioral labelling to justify the use of restraints by the health-care team. Irving describes a case study of one chronically ill gentleman on whom physical restraints were applied because he was labelled confused and uncooperative. Irving explained how the inability of this person to self-govern his care resulted in domination by staff, and discursive practices that marginalized him from the services that could be provided by the health-care team. This patient was unable to negotiate his care and his needs were ignored by nurses, no matter how relevant they were, because he was labelled irrational.

Labelling chronically ill patients as non-compliant. Other studies illustrate how health professionals have habitually labelled chronically ill patients as deviant, failures or difficult simply because they fail to follow through or agree with the prescribed medical regimen or lifestyle changes (Playle & Keeley, 1998; Price, 2013). Such forms of labelling put the blame on the patient without giving due consideration to two things: the social circumstances affecting the patient's willingness to abide with treatment, and/or the possibility the patient's noncompliance to treatment was a result of

the health-care professionals' failure to provide appropriate and effective interventions (Thirsk and Clark 2014). For instance, in a literature review that explored non-attendance to chronic disease clinics, Paterson, Charlton and Richard (2010) found evidence that suggests that some of the reasons why patients were not complying and missing appointments related to the organizational factors and the way health services were structured, organized and delivered. These included lack of accessibility to services for patients, clerical errors and inefficient booking systems. Paterson et al., explain that difficulty to access such services or dissatisfaction with delivery of care may affect the patients' ability and motivation to attend. Similarly, a systematic review that explored why patient referral to cardiac rehabilitation programs was low, Clark et al. (2013) identified a number of professional, system barriers besides patient factors to explain why such services were under-utilized. Professional barriers related to the fact that physicians were the main gatekeepers of services, that some professionals had poor knowledge or skepticism about the benefit of treatments, or made judgments that patients were unlikely to attend. Problems with health system funding and political barriers were some of the system barriers for low referral. Whereas certain patient factors related to poor memory, it was interesting to note that there was a substantial amount of studies which indicated that patients did not attend because they received limited or no information or encouragement from physicians and other health-care professionals about such programs.

Altogether, these findings indicate that a consideration of organizational or professional barriers is merited before labelling some patients as non-compliant and that one needs to go beyond blaming the patient for failing to comply with treatment. Labelling a patient as non-compliant can also serve as a means of professional power

and control (Murphy & Canales 2001). This observation was echoed earlier by Playle and Keeley (1998) who remarked that while on the surface, labelling the chronically ill patient as non-compliant may appear to be a concern for patients' outcomes, at a deeper level it is inherently based on an ideology that still views professional knowledge of health-care issues as superior to patients' knowledge about management of their illness.

Examples of this can be found in a study by Thorne (2000), who looked at the experiences of people suffering from chronic illness and the attitudes of professionals towards patient expertise. Thorne compared the experiences of two groups of patients who suffered from chronic illness. One group of patients had Type 1 diabetes - a "legitimized" chronic illness, which can be scientifically explained and controlled by medicine. The second group involved interviews with women who experienced severe adverse environmental reactions—a condition which is currently treated with skepticism simply because its etiology is not understood, and at the time of the study was not officially recognized as a disease by doctors. Comparison of data revealed how health-care professionals created hegemonic discourses by giving primacy to those discourses that can be explained and validated by medical discourse, and how they preferred patients who followed those discourses and were compliant with treatment. Thorne (2000) described how health professionals tended to be disease-oriented, how they perceived themselves as the expert who is in the best position to validate disease, and how they held on to the role of expert by discrediting, ridiculing and dismissing the patients' contribution. She noted that some patients who confronted nurses were dismissed, while others felt too vulnerable and feared sanctions if they took such risk. The latter retreated into submissiveness to avoid future gatekeeping from health-care providers. Conversely,

when patients reacted to this misuse of professional authority, nurses ended up labelling the patient as neurotic, obsessed, or as having delusions of grandeur about their capacity to control their illness. Other patients who resisted nurses' authority were assumed to be non-compliant, even when in reality; patients described their decision not to adhere to treatment as a logical, rational and thoughtful process.

Similarly, in a literature review on non-compliance, Russell, Daly, Hughes and Hoog (2003) reviewed nursing articles that looked at the way nurses negotiate non-compliance with "difficult" patients. The aim of the paper was to offer an alternative approach to negotiation of care with patients who do not comply with treatment. According to these authors, non-compliance is based on the premise that medical and scientific knowledge will benefit the patient, and therefore it is natural to assume that patients will follow this advice. As a result of this, when patients base their decisions on live experiences rather than scientific knowledge, they can be perceived by some nurses as being a "difficult patient". Russell et al., comment that although in recent years there have been many interventions to promote more patient involvement in negotiation of care about their treatment; these methods remain inadequate unless the power dynamics between nurse and patient change and the patient's contribution is recognized. Russell et al., emphasize the importance of a paradigm shift that "transfers some degree of power and authority to patients" (p.285). This can be achieved when nurses and other health-care professionals appreciate that patients' decision about whether or not to comply with treatment is a rational decision based on how such treatment will affect their lives. By acknowledging that the social context that enables or constrains patients from following a therapeutic regime, nurses and other health-care professions are less like to label the

patient as non-compliant and instead they will be in a better position to negotiate care with patients (Russell et al., 2003).

Along the same lines, Thirsk and Clark (2014) note how despite the use of “self” in self-management and management of chronic conditions is not individualistic, but subject to family, social and environmental constraints that may limit the choices that patients can make. Thirsk and Clark (2014) comment that monitoring of self-care tends to be focused on biomedical markers that are monitored by health-care professionals, and ignores the social and contextual factors that are influencing self-management. Thirsk and Clark (2013) explain that some patients may have other more powerful motives for not participating in self-care, such as social inclusiveness and a feeling of belonging. Price (2013) emphasizes the importance that a nurse try to understand the patient’s narrative and priorities when negotiating care with him or her. Like Thirsk and Clark (2013), Price says that while doctors and nurses use medical and scientific rationale in pursuit of wellness, patients may have other values and beliefs. He comments that some people may be willing to accommodate certain degrees of infirmity, discomfort and disease, rather than deprive themselves of a “purposeful, dignified and pleasurable” (p.32) way of living. Price concludes by saying that nurses should aim to help the patient arrive at sustainable solutions that help them to live well, with a sense of dignity and integrity.

Collectively, the above findings highlight the need to understand the patient’s actions when they do not comply with treatment, rather than blame them. This can be achieved by considering the patients’ voices and acknowledging their self-knowledge (Murphy & Canales, 2001). An understanding of the patient's values, beliefs and

practices about their therapeutic regime is essential to facilitating negotiation of patient care. However, one cannot quickly blame some nurses for failing to achieve this during negotiation of patient care. It is equally important to understand why some nurses fail to attend to the patients' needs, by taking into consideration the hospital and the contextual environment that influences and shapes nurses' practices.

Summary: Nurses' Use of Language to Assert Their Authority

The preceding studies attest to how nurses' use of power can be insidious, how it can be controlling, and how it can hinder the development of partnerships with patients (Adams, 1996; Tew, 2006). While these studies have advanced nursing knowledge, they are still based on the traditional Marxist view of power in which nurses hold power as oppressors, while patients are powerless and oppressed. According to Foucault and feminist post-structural theory, power is not a quality that one possesses or does not possess, but rather it is the result of personal, social and institutional discourse. It is these discourses that position nurses and patients in a relationship of power that might create opportunities of disempowerment and empowerment. Understanding power relations through this lens will help to shift the blame and focus from individuals to social and institutional practices. This will help to eliminate stereotypes and assumptions about chronically ill patients and nurses, which predispose them to labelling and marginalization. By shifting the focus from individuals to discourses, one can also identify moments of disempowerment, as well as opportunities of empowerment, which both nurse and patients can challenge, or take advantage of, in order to facilitate positive negotiation of patient care between the two parties.

Another limitation of these studies is their focus on the negative aspect of power.

As such, we do not know how patients felt about this assumed authority because they were not asked. In the current literature search it was not evident if an authoritarian relationship between nurse and patient was ever solicited by chronically ill patients. For example, an aspect of power that was not investigated is the possibility that despite nurses being objective and authoritarian, there may be instances when patients welcome the professional taking charge of their care. Indeed, while there are many studies that looked at the negative consequences of power, there are few studies that explored the possibility that despite being domineering and authoritarian, professional power may not necessarily be damaging, but may be desired by some patients (Millard, Hallett, & Luker, 2006; Tew, 2006). Certainly one of the reasons why patients go to hospital is because they want their health condition/concern taken care of, either because they do not have the expertise, or because they are too sick to look after themselves. Assessing if patients want to be involved in their care is a preliminary step in the negotiation process. Clark, Hall, & Rosencrance (2004) contend that maintaining professional authority is still perceived as involving patients in the negotiation of their care if patients wish to do so.

Patients' Reactions to Nurses' Authority

Some Patients Want Nurses to be Authoritarian

In situations where nurses' use of power may seem unwarranted from an outsider's vantage point, one cannot assume that it was unmerited and damaging unless the patient's perception is also sought. For instance, in some studies patients reported that they were happy to have health professionals make decisions for them, and they did not want to take an active role in the management of their care (Loft, McWilliam, Ward-Griffin, 2003; Millard, et al., 2006; Wong et al., 2000), or they found self-care too

stressful, causing them further frustrations (Gallant et al., 2002). Even in psychiatric settings, when nurses were described as insensitive, the extent to which patients found this unacceptable was unpredictable. A study by Holmes (2002) serves as a good illustrative example. This study explored the way forensic psychiatric nurses used power to exert governance on mentally ill inmates who were in penitentiary institutions. Holmes captured the comments made by one of the inmates, who stated that he was grateful when one of the nurses was controlling, because she helped him to “set the limits straight” (Holmes, 2002, p. 89). Likewise, there are theoretical observations that indicate that in some cultures, some patients have been socialized in the traditional model of care and expect the professionals to tell them what to do (Clark, Hall, & Rosencrance, 2004; Emmanuel & Emmanuel, 1992; Maben et al., 2012; Waterworth & Luker, 1990). These reports confirm that patients’ opinions about nurses’ use of authoritative power differs between individuals.

In nurse-patient relations, the nature and extent of power sharing is not predetermined or fixed, and the extent to which power can be shared between nurses and patients’ needs to be negotiated between them (Bidmead & Cowley, 2005; Gallant et al., 2002; Kiesler & Auerbach, 2006). Patient participants cannot be seen as in a state of complete liberation from professional control, but rather, as on a spectrum of control that runs along a continuum (Taylor, 2009). The degree of patients’ control varies along the continuum, from total paternalism at one end of the continuum to complete patient autonomy at the other extreme. The extent to which power is relegated to the patient is circumstantial to the patient condition and the context where care is being delivered. According to Taylor (2009), power relations along this continuum can still be perceived

as patient-centered as long as they are negotiated with the patient. There is a paucity of studies that sought patients' opinions about what they thought and how they felt about nurses' use of power, and those that did, do not give much detail about the patients they investigated, the type or stage of their disease, and whether the types of nursing power used conformed to the patients' wishes or not. In this study I explore this further, and ask chronically ill patients about their expectations when they were negotiating care with nurses. This should reveal the patient's values, beliefs and practices about nursing authority.

Patients' Are Not Docile

Consideration of the patients' wishes is imperative if negotiation between nurse and patient is to be successful. Failure to consider the patient's wishes may become problematic during clinical encounters when the patient's opinion may conflict with the recommendation of the professional (Cline, 2003; Paterson, 2001; Paterson, Charlton and Richardson, 2010; Wilson & Brooks, 2006). As mentioned earlier, health professionals may react to these challenges by ridiculing patients and discrediting their contribution, simply because it is labelled as lacking scientific backing. Sometimes punitive measures such as controlling access to health services through gate-keeping have also been exercised by health care providers (Thorne et al., 2000). However, most of the literature reviewed focused on nurses' use of power, rather than on the patients' action or reaction to such power. Not only has most of the nursing literature presented a unidirectional picture of power, it portrays patients as docile and mute. Nurse-patient interaction is a two-way process and to elicit views of only one party is not a complete representation of what occurs in reality (Thorne & Patterson, 2000; Shattell, 2004; Jarrett & Payne, 1995).

There is a paucity of studies that have investigated patients' resistance; instead examples of patients' resistance could only be found by coincidence during secondary analysis of these studies. Further, some studies did not seem to recognize that some patients were being difficult not because of their personality, but because they were resisting professional domination. For example, while much has been written about possible reasons why patients do not comply with treatment, and how this was a possible way of exercising professional control, few studies mention that non-compliance could be a covert way of patients exercising power.

One such study was conducted by Thorne et al. (1990), who explored how patients suffering from chronic illness negotiated their health care. Although Thorne did not give details about the sample and the study itself, she reported in-depth how patients resisted professional authority through non-compliance with the therapeutic regime. Thorne found that patients were fully aware of their actions, and described non-compliance as a deliberate and conscious decision not to adhere to professional advice, rather than mere forgetfulness or misunderstanding. Patients talked about the arrogance, insecurity and defensiveness of some doctors, and how they had little appreciation of their illness experience outside the realm of biomedical science. Many of these patients felt that they knew what was best for them, and they wanted to take charge of their health. For instance, one respondent commented she wanted to be the "manipulator not the manipulated" (Thorne, 1990, p. 64). As a result of this, patients in this study were often selective when taking advice from physicians, and tended to opt for those doctors who were willing to abandon their "expert role" and let the patient take the lead. Thorne concludes by stating that noncompliance has been, up to now, considered an irrational

response that complicates medical/nursing management, rather than as a form of resistance to the paternalistic approach.

Likewise in a literature review on why some chronically ill patient do not attend clinics, Paterson, Charlton and Richardson (2010) noted that one of the reasons why patients were not complying with treatment was as a reaction to poor patient-provider relationships. One of the researches they refer to was a study by Lacy (2004) who explored why some patients failed to keep scheduled clinical appointments. Lacy reported that some patients did not keep their clinical appointments because of anxiety about procedures or fear of bad news or because they did not understand the scheduling system. However as much as 44% mentioned they did not attend because of disrespect towards patients' feelings or opinions. While these findings echo what was described earlier about the need to consider contextual factors that may inhibit some patient from complying with treatment, such findings also indicate that patients are not docile and submissive to professionals, but have nuanced ways of exercising power.

Some other patients challenged medical discourses and devalued professional advice by resorting to other professionals to address their needs. In a phenomenological study, Lindsey (1997) explored the experience of eight chronically ill patients who were living with different forms of chronic illness or disability. These participants described how they coped when health-care professionals misunderstood or invalidated their subjective illness experience. Participants stated that instead of feeling victimized, they got together as a group and took charge of their illness by becoming assertive, self-defining, and self-protective, a process which Lindsey termed as “a covert way of caring”. According to this study, participants reported how they got together and formed

an alliance between them, sought information from the Internet and shared this information with each other on how best to deal with their situation. Further, they also created a network of complementary therapy healers who operated differently from the traditional health-care system, and recommended these healers to each other. The participants mentioned that the flourishing electronic communities scene was a great help to these activities.

Patients' use of power was reported as an ancillary finding in some nursing studies. In an ethnographic study whose main focus was to seek nurses' opinion about their surveillance over patients, Porter (1996) reported some of the patients' responses to the nurses' inquisitive demands. He explained how some patients resisted nurses' use of power by refusing to disclose information about themselves, thus severely constraining nurses' capacity to "control" patients in a certain way, and forcing nurses to adopt strategies of inducement, encouragement or other forms of negotiation to elicit the information they required. Although this study was conducted in the 1990s and nursing philosophies and practices have changed since then, it demonstrates that patients have often differed in their acceptance of professional authority, and that they are far from passive. Similarly, in a qualitative secondary analysis of a longitudinal study that used in-depth interviews with nurses, patients and families in home-based palliative care, Oudshoorn et al. (2007) reported how patients resisted nurses' authority during palliative care by refusing to accept any changes the nurses suggested by demanding a change of nurse and or by decreasing or canceling visits from nurses.

While the above studies show active ways how some chronically ill patients challenged professionals, other studies showed how patients resisted nursing authority by

choosing to remain silent (May 1995a, Holmes 2002). In a study that explored nurses' use of power, Holmes (2002) reported how some nurses used their position of power and tried to entice patients to disclose information of a private and personal nature by acting as a sympathetic listener. Holmes notes how nurses were able to elicit information from some patients with success; however, sometimes this approach was not effective and nurses failed to achieve their nursing goal to act as a sympathetic listener, simply because the patient refused to speak and answer their questions. Another tacit way of how some patients dealt with nurses' use of power was revealed in a literature review by Shattell (2004) who analyzed studies on nurse-patient interaction. Shattell explained how nurse-patient relationships were ruled by professional power, and how some patients tried to overcome their sense of powerlessness by actively seeking ways to solicit nursing care and by being friendly to nurses. Although at first instance the patients' reaction may appear to be submissive, the way these patients reacted to the use of professional power can be interpreted as a creative way of negotiating their care with nurses.

Most of the above studies that looked at patients' resistance to professional power were ancillary findings that surfaced from studies whose main aim was to explore something else. Only two studies were found that looked specifically at patients' use of power. These studies were conducted by Kettunen, Marita, and Gerlander (2002) and Wheatley (2005). Kettunen, Marita, and Gerlander (2002) explored how patients resisted professional authority and tried to minimize power asymmetric between them and nurses during hospital counselling. In their study, Kettunen et al. used conversational analysis to examine who was in control during the counselling session between nurses and patients. By analyzing transcripts for periods of silence during speech and between turns, onset

and termination of overlapping speech, intonation information and non-verbal communication, Kettunen et al. concluded that patients took charge during most of the conversation. Patients took control of the counselling session by asking questions, interrupting the nurse, and by offering extensive disclosures.

Wheatley (2005) conducted another study that looked specifically at patient resistance in chronically ill patients. In this participant observation study, Wheatley observed patients while assisting in the day-to-day work of nurses in two cardiac rehabilitation centers in Northern California. Wheatley used Foucault's early and late work (1961/2006; 1963/1973; 1969/1972;-1975/1977; 1980) as a conceptual framework to explore how these patients coped and negotiated their treatment with nurses during their rehabilitation program. The author reported how patients resisted the rigorous treatment regimens by complaining, making fun of the rules and regulations of the place, or simply by failing to show up for the rehabilitation program.

Summary: Patients' Reactions to Nurses' Authority

Collectively, these studies indicate that patients are not powerless and that some do resist the health professional's authority. The organizational landscape may offer constraints for one's performance; however, patients have distinctive and various ways of responding to such pressures and each individual has their own idiosyncratic way of carving a niche within such scenarios to survive such forces. Yet, while these studies are examples of patients' resistance, most of them were subsidiary to the main focus of the studies, and so, this information was retrieved by chance rather than because it was the main topic. As a result, the topic of patients' resistance to nursing authority in its entirety remains underexplored. This gap in the literature deserves further attention. Nurses need

to be aware when patients are resisting nurses' authority and imploring to be heard. This could be seen as a point of conflict, however it could also be an opportunity to deconstruct the nurse-patient binary and dispel the myth that patients are in a position of powerlessness. Moments of power and resistance during negotiation of patient care need to be unpacked, not deplored. Questioning what is going on is the first place to start. By understanding the inner workings of nurses and patients and how relations of power are being enacted, moments of patient empowerment or disempowerment may be unraveled. Identifying these moments of conflict will enable nurses to stop and then critically reflect upon the situation, and new possibilities for change might emerge. With a post-structural methodology and the method of discourse analysis, health-care providers and patients can begin to understand conflict by first questioning the practice and then listening to each other's beliefs and values about the practices of caring for chronically ill patients. Nurses and patients will then have a better understanding of the situation and ultimately be able to negotiate solutions to improve disempowering practices.

Power as Productive

It is incorrect to assume that the only power nurses use with patients is authoritative and disciplinary power. Other liberal and neoliberal³ ideals have been slowly encroaching into nursing education and practice. The introduction of the nursing process and the scores of nursing models that followed are examples of more liberal approaches to nursing care, and certainly an advent that marked this transition (Bradbury-Jones, Sambrook, & Irvine, 2008). A number of theoretical and research studies were

³ Neoliberalism refers to economic and social approaches adopted by governments in attempt to reduce public deficit. This is achieved by shifting control of economic factors from the government to the private sector. In the health-care sector it is related to reducing taxes and public welfare by delegating responsibility of health care from the state to society and the individual.

found that looked at these new bio-psychosocial approaches and how they impact patient care. Whereas some scholars criticized these models and described them as new modes of controlling patients (May, 1995a, 1995b), others lauded these holistic models for their positive and liberal approach (Porter, 1996).

For instance, in a study that explored nurses' accounts of their work and relationship with patients, May (1995a) commented about this intrusive nature of the nursing process, and how nurses are increasingly encouraged to engage in conversational practices with patients to uncover the patient's authentic character. According to May (1995a), the rites and routines of the hospital provide an opportunity for patients to cloak their private character and to give them some privacy. However, through the conversation practices of the nursing process, nurses get the privilege to unveil and expose the true character of patients, hoping to understand them better as individuals and to facilitate problem solving. May (1995a) contends that these enquiries are not only invasive into one's privacy, but are also built on the assumption that patients want to disclose such information. According to May (1995a), empirical evidence suggests that not all patients are willing to engage in such practices or to partake in collaborative relationships, and the nursing process does not respect this.

Along the same lines, but in a different study that used a grounded theory approach, May (1995b) interviewed nurses and asked them about their experience of caring for terminally ill patients. May (1995b) reported how nurses caring for terminally ill patients used the nursing process to maintain control over patients and to entice them to talk. According to May (1995b), patients who have just been diagnosed with terminal illness, and have been given this unfortunate news, are generally not expected to talk

about it unless they want to. May (1995b) mentioned how this situation created problems for nurses since they felt that they were not helping patients to cope with their situation. Like the Holmes (2002) study, nurses used “sympathetic listening” to encourage the patient to open up and to elicit information from them. In this way the nurse was able to identify the patient’s needs and problems, and fulfill his/her role as a nurse; however it did not respect the patients’ privacy.

Porter (1996) did not deny that the nursing process may be used as a tool of surveillance and control; however, he believed that the benefits of the nursing process outweighed its controlling effects. In an ethnographic study that refers to Foucault’s writings (1961-1980) Porter (1996) interviewed 28 nurses and sought their opinions about the nursing process. Porter cites examples from his study to demonstrate how this innovative way of looking at nursing could enhance nurse–patient interaction and decrease patients’ trepidation about their illness. In terms of power, Porter (1996) argued against the idea that the nursing process is a means by which nurses control patients. On the contrary, he sees the nursing process as an opportunity that situates the patient in a position of power. He asserted that today’s nurses are expected not only to explain their actions, but also to justify them. As a result of this, Porter (1996) felt that patients are better informed about their condition, and therefore in a better position to question the care they are given. Porter’s (1996) findings illustrate how nurses’ use of power is not always domineering, but can also be seen as a positive and liberal force.

Another neoliberal approach that facilitated more patient participation in the negotiation of their care is the notion of empowerment. According to Holmstrom and Roing (2010) the idea of empowerment originated from critical social theory, as a lay

reaction to professional oppression, and a need for patients to liberate themselves from domination. Piper (2010) describes how in health care empowerment has been used as a professional desire to move away from the traditional paternalistic approach to patient care, to one which embraces the need for more patient involvement in their care.

Kuokkanen & Leino-Kilpi (2000) maintain that empowerment is fundamentally a positive concept that helps to solve problems and that result in positive outcomes for nurses and patients. Similar to the nursing process, patient empowerment can be seen as another form of productive power.

In their concept analysis of empowerment in chronic illness, Dowling, Murphy, Cooney & Casey (2011) state that in order for chronically ill patients to feel empowered, both nurses and patients have a role to play. Primarily, nurses need to feel empowered themselves and realize that they can make a difference in patient care. They also need to have good communication skills and be willing to surrender their power position.

Patients, on the other hand, need to be motivated to change and to possess specific competencies such as an ability to communicate effectively, and to problem solve.

Dowling et al. conclude by saying that the clinical setting should offer a conducive environment that facilitates negotiation between nurse and patient and that allows time for it. The ultimate aim is to engage patients more actively in negotiation of their care.

However, despite the benevolent intent, empowerment has also been described as an opportunity for professionals to reinforce their authority rather than subvert it.

Aujoulat, d'Hoore & Deccache (2007) state that empowerment can result in another guise of professional dominance if the goals of patient care are pre-defined by health-care professions or restricted to disease-oriented outcomes. Powers (2003) argues that

empowerment is not a liberating approach, but another strategy whereby patients are informed of all possible choices, in an attempt to produce outcomes that the health-care professional suggests. Holmstrom and Roing (2010) contend that empowerment may translate to another form of power if the health-care profession is seen as “empowering” or “giving power” to the patient. This portrays the patient as a vulnerable individual who depends on the nurse to help them get better. This notion of “helping” rather than “empowering” has been described by Piper (2010) as disabling, exploiting and reinforcing rather than diminishing the nurse’s position of power.

There is a deluge of literature on the importance of implementing empowerment in nursing, however there are few empirical studies that explored how nurses implement or optimize patient participation in practice (Aujoulat, Luminet & Deccache, 2007; Sahlsten, Larsson, Sjöström & Plos, 2009; Mitchell & McCance, 2010). Those studies that explored empowerment in nursing found that nurses do not implement it in practice and that empowerment remains another form of professional control (Paterson 2001, Mitchell & McCance, 2010). In a small-scale study that investigated the self-care decision making process in patients suffering from diabetes, Paterson (2001) found that although practitioners embrace the language of empowerment, they still positioned themselves as the expert when they were negotiating care with patients. Patients reported that despite the compassionate demeanor of many health-care professionals, both doctors and nurses still maintained allegiance to their expert role and discounted what the patient had to say. Patients mentioned that when they voiced their concerns when they were negotiating their care; however, their views were often met with skepticism or even anger by health-care professionals. Based on these incidents, patients felt that although some practitioners

agreed and supported the notion of empowerment, they were not “walking the talk” (p.577). Similar findings were obtained in a study by Nordgren and Fridlund (2001), who sought patients’ perceptions of self-determination when they were in hospital. Overall, patients stated that they had a great sense of trust and confidence in the care provided. They mentioned that they had good relations with the staff who helped them to express their needs and who listened to them. However, when it came to the final decision about their care, patients said that they felt a sense of powerlessness because they were not involved in decision making. Patients wished that they were more involved in the management of their illness, but they were too weak to do so. This finding confirms that in order to empower patients, nurses do not simply need to listen and to understand the chronically ill patient, but they also need to actively involve them in their care.

Interestingly though, when I searched for studies relating to “patient activation” the results showed otherwise. There is a growing body of studies that suggests patient activation works, and it does improve health-care outcomes in chronically ill patients (Hibbard, Stockard, Mahoney, & Tusler, 2004; Mosen et. al, 2007; Prochaska, et. al, 2008). This was a surprising find, since empowerment and “patient activation” are deeply entwined within each other. “Patient activation” is a term that was used by Wagner et al. (1996), when he developed the Chronic Care Model (CCM). Basically, this model is built on the hypothesis that chronically ill people can become more satisfied with the health-care service and achieve a better health status, if “chronic illness care is delivered by a prepared provider team who engage with an activated informed patient” (Wagner, Davis , Schaefer , Von Korff, Austin, p. 58). This change requires a provider

team that is supported by an effective health-care system, one which offers leadership, incentives, and the appropriate resources for providers to help them execute the required patient care effectively. It also requires that the patient is adequately informed, skilled, and motivated, so that they can actively participate in their self-care.

At first glance, it seemed absurd that studies relating to patient activation contradicted studies relating to patient empowerment, because both go together. A possible explanation for this discrepancy could be related to the ontological and epistemological nature of “patient activation” and “patient empowerment”. Patient activation mainly addresses the patient's educational needs. It is still based on the traditional model that the expert has the knowledge and the expert will share it with the patient and motivate patients to adopt it. Empowerment has to do more with relational processes. The patient with chronic illness is seen to be the expert and the health-care provider aims to understand the patient and help them to achieve a state of wellness that fits the priorities of the patient. The nature of knowledge generated between health-care provider and patient is more subjective than objective. Martin & Peterson (2009) note that the notion of “activated patients” is more focused on objective and evidence-based practices rather than on social construction of illness. Likewise, Thorne (2008) contends that the CCM is built around disease management and cost-effective interventions (p.7). This observation seems to be supported by the methodological approaches that were used in studies that investigated the effectiveness of an ‘activated patient’ and those studies that explored if patient empowerment is being implemented. The former studies used quantitative approaches to measure effectiveness of interventions, where the latter used qualitative approaches to understand the patients’ experience. On the surface, it may

appear that the concept of ‘activated patient’ is superior to the concept of “empowerment”. However, I would argue that because both arise from a different world view, nurses need to apply both principles together when negotiating care with patients. Patients need education and it will work well for them, if nurses listen to what patients have to say and tailor education according to the patients’ needs.

Summary: Power as Productive

Collectively, the literature yields interesting findings. Several studies showed the multifaceted nature of power, how it can be damaging but also how it can be positive and productive. It is clear from these studies that although health-care professionals were inviting patients to express their views, and listening to what they had to say, in the end the health-care professional decided what to do. Unless health-care professionals are made cognizant of the social and institutional discourses that are situating them in a position of power, the notion of empowering or ‘patient activation’ will become yet another form of professional control over patients. These postulations highlight the need for this study. By exploring the process of negotiation of care between nurses and patients, and of unpacking the values, beliefs and practices that are shaping nurses’ and patients’ behaviors, one may create awareness of the problems and address them.

Another interesting finding from the literature reviewed is that although both nurse and patient negotiate power, the power relationship between the two remains unequal. Since these interactions do not occur in a void, but within health-care settings, this implies that institutional discourse plays a pivotal role in ensuring such asymmetry is maintained. Institutions are built around a hierarchical system, and although everybody has power, not everyone is in the same position of power. This means that nurses may be

more in a position of power than patients; however, because they are not placed higher up in the hierarchy, there are other professionals who are more in a position of power than nurses. This is crucial to consider when looking at negotiation of patient care between nurses and patients. Nurses may not be in a position to address some of the patients' needs on their own, but need to negotiate patients' needs with other professionals like physicians, nurses, managers and hospital administrators.

Institutional Discourse: Nurses as Subjectivities of Health-Care Settings

Health-care institutions and hospitals have been traditionally known for their hierarchical structures that are historically, physically and spatially structured to endorse asymmetric relationships (Halford & Leonard, 2003; Liaschenko, 1994; Valentine, 2001). Valentine (2001) elaborates on this notion and explains how institutions such as health-care settings are designed in such a way that the employees work in some form of synchrony to achieve the organizational goals and objectives, which, in this instance would be the patient's recovery and return to society, or to a peaceful death.

This synergistic effect was captured by Varcoe, Rodney, and McCormick (2003), who conducted a meta-analysis of three ethnographic studies to explore how the organizational context shapes relationships between patients, their families and nurses. Varcoe et al. (2003) juxtaposed key metaphors and terms extant from the original studies and created a matrix to illustrate the characteristic of relationships in an organization. Collectively, Varcoe et al. concluded that nurses use various forms of power over patients and over one another, in an attempt to comply with organizational discourses that meet the organizational goals and objectives. These strategies are not always helpful, and can be detrimental to the patient's and family's illness experience.

One of the researches that Varcoe et al. used was a qualitative study by McCormack (1997), who explored the impact of institutional discourses on nurse-patient and on nurse-family relationships. In her ethnographic study, McCormack (1997) used observation, interviews, and document analysis, to explore how adolescents suffering from chronic renal failure, and their families, negotiated issues of control over their nursing care. McCormack (1997) reported how nurses used “discourse of control” to deter patients from making demands that might disrupt nursing practice and impede nurses from reaching organizational goals. These discourses were multiple and included discourses of: compliance, rules, adolescents, chronic illness, cost restraints, cuts and budgets, amongst others. Altogether, nurses use these discourses to control their practice and get their work done. In other words, nurses use these discourses to impose rules, guidelines and restrictions on patients, families and other nurses, to act in a way that conforms to the nursing agenda. According to McCormack (1997), these discourses, along with other dominant discourses in the health-care system and society, help to reproduce the nursing culture and socialize nurses in their role and patients in their subjugated position.

Other studies reported that hospital life is organized for the benefit of the organization and not for the convenience of patients. In a phenomenological study informed by Heideggerian/Gadamerian philosophical hermeneutics, McCabe (2004) interviewed eight patients and asked them about their experience of how nurses communicated with them when they were inpatients. McCabe (2004) reported how the organizational culture does not uphold the importance of patient-centered care, and is more interested in task-oriented care, for it is more efficient and less time consuming.

She reports how this affected nursing practice, and how nurses could not spend time to communicate well with patients simply because they lacked organizational support and encouragement to do so. Unfortunately, there are no details on whether these people were chronically ill or not. Nonetheless, these findings suggest that the organizational structure can impact nursing care and patient outcomes.

Similar findings were reported by Oudshoorn et al. (2007) who explored nurse-patient power relations in palliative care. Oudshoorn et al. (2007) reported that nurses could not spend as much time as they wanted with palliative patients, because they were subject to the fiscal constraints of their organization. Interestingly, nurses felt less under pressure within the home-care context. It seems that in home settings, nurses had more control over their practice, an opportunity which they used to dominate or to liberate the patient. As an example, some nurses controlled patients by claiming ownership of their clients, possessively stating that they were *their* patients, and therefore they decided what care to give them. Others controlled patients by taking the lead and deciding when to visit them or shift them to another slot or nurse, without consulting them. Nonetheless, some of these nurses were able to negotiate their position of power positively, by respecting the patients as individuals, seeing them as experts in their lives, accepting their spiritual beliefs, and making decisions together. These nurses focused on what patients perceived as important, rather than basing their decisions on their own impressions.

Another example of how organization impinges on nurse-patient relationships was described in a study conducted by Hamilton and Manias (2008). This study used a Foucaudian approach (1963/1973, 1975/1977, 1980, &1994) to study how nurses used either constant or intermittent patient surveillance to monitor and control patient activity

in a psychiatric setting. Findings indicated that nurses carried out such observations to follow the institutional mandate, rather than because they wanted to control patients. Nurses challenged this custodial task by using warmth and civility when performing observations to minimize its intrusive and controlling impact. For example, one nurse tried to minimize the controlling effect of constant observation by giving one patient some privacy while bathing. This nurse was later reprimanded for failing to fulfill her role when the patient used this time to attempt suicide.

Collectively, these studies illustrate how patients are expected to behave according to institutional philosophy, values, rules and regulations, as well as how nurses are expected to follow assumptions, expectations and social behaviors that are deemed appropriate for particular institutions (Valentine 2001). In this sense, nurses are not just agencies of the institution but also subject to it. Edwards (1998) reported that upon entering the profession, nurses are subjected to a socialization process that results in a dramatic redefinition of their identity and performance in that it transforms them from social beings into professionals. This socialization process aims to legitimately confer the distant and authoritarian image of the nurse. In her study about nurses' and patients' perceptions of how nurses use physical/personal spaces and touch when communicating with patients, Edwards (1998) reported that by dictating what patients eat, how they dress and where they go, nurses created a unit culture that was governed by a set of regulations that were meant to be followed in hospital, and which were different to the rules patients follow at home. For instance, whereas nurses could roam about the unit as they pleased, hospitalized patients had a limited space as their territory, which was comprised mainly of the area within the curtains. Certain areas of the unit were out of bounds for patients,

whereas other areas they needed permission from nurses to access. These rules and regulations distanced nurses from patients. Reference was also made to how institutions equip nurses to distance themselves from patients and treat them objectively. This was illustrated through the use of touch. Nurses in this study reported how they felt threatened by patient initiated touch. Edwards (1998) explains that a possible reason for this is because nurses have been professionally trained when to use touch and when not to. As a result of this, when patients initiate touch as a social gesture, nurses become confused because they are not prepared or trained to deal with this situation. The Edwards (1998) study may have been done a long time ago, but the result of this study conveys a strong message. The findings illustrate the covert ways institutional discourses may shape nurses behaviors and affect the way nurses interact with patients when they negotiate patient care.

Along the same line, Huntington and Gilmor (2001) used feminist theory and Foucault's work (1976/1978; 1982; 1983) to illustrate how undergraduate nurse education and training is aligned with a medical condition rather than patient-centered care. Drawing on five nursing textbooks that were currently used in U.S. undergraduate studies, Huntington and Gilmor (2001) noted that information in relation to health and wellness conditions tends to follow a predictable format; it starts off with medical knowledge, followed by nursing management and patient care. The dominance of medical knowledge was evident in the way it was given preeminence within the text. It was positioned as the primary source of information, and was also dealt with in depth. The marginalization of nurses' and patients' voices was also noted. The medical knowledge was depersonalized and whole sections were written about the condition,

without any reference to the person who has the disease. Huntington and Gilmor (2001) noted that although new nursing information, such as nursing research, was included within the text, these were separated from the main body and positioned in “discrete sections that can be ignored or treated as extras” (p.905). Huntington and Gilmor (2001) give an example of how text can be rewritten so that both nurse and patient are central to the information. Giving an example of a woman’s experience of living with endometriosis, they start off with a direct quote of the woman’s experience. Attention is paid to this experience and the problems she faced. Nursing care and medical management follows from there. Huntington and Gilmour (2001) acknowledge that using one woman’s experience does not imply that this experience is common to all; however, it offers an example of how the patient’s experience should be central to the text. Another important point that this study raises is that medical discourse should not be ignored, but certainly should not be privileged. In so doing, the voice of the suppressed and marginalized can be heard.

Andrews (2006) remarked that it is not just organizational rules and regulations that impact nurse–patient power relations, but also the internal cultures between all occupants within the place. This includes anyone who inhabits the place, from nurses themselves to other occupants such as patients, families, nurses, doctors and administrators. These discourses, together with discourses from society at large, become entangled in multiple coalitions and power struggles over multiple issues. There is a large body of empirical studies that have looked at how nurses’ use of power is molded by: gender issues (Halford & Leonard, 2003; Liaschenko, 1997), nurse–doctor relationships (Heartfield, 1996; Riley & Manias, 2002), nursing culture (Riley & Manias,

2002; Rodney, 1997; Varcoe, 1997), and nurse–patient relationships (Liaschenko, 1994, 1997, 2003; Peter, 2002; Peter & Liaschenko, 2004).

Some of these studies revealed that despite nurses' claims for autonomy, nurses still feel marginalized in the health-care system and their work remains dominated by the medical model. Heartfield's (1996) study illustrates the dominance of this culture on nurses. In this study, which explored nurses' use of documentation in acute-care settings, Heartfield (1996) described how nurses tended to base the nursing process on the medical model, how they used medical terminology to express themselves and how their documentation referred only to how they carried out the doctors' orders. She commented on how nurses' work is invisible in patients' documents and blames the health-care system for failing to offer nurses opportunities to showcase their work. Heartfield (1996) identified that nurses' lack of recognition for their work and their relative invisibility from the patients' record is the epitome of how medical discourse dominates patient care, and how nursing work is viewed as insignificant. Porter (1996) also commented on other external forces that control nurses. He compared soldiers to nurses to illustrate how power is latently held by certain groups in society, contingent on the position they occupy within the social structure. While Porter (1996) did not allude to doctors per se, he cited examples to illustrate how the actions of nurses in caring for patients are enabled or constrained by social structures within the health-care system.

However, just as patients are not passive recipients of care, neither are nurses passive caregivers. In a literature review on nursing resistance in response to moral conflict with other health-care professionals, Peter, Lunardi and McFarlane (2004) reported how nurses resisted the power of physicians and defended their moral ideals by

“discussing, arguing, refusing to participate, going to ethics committees and shouting if necessary” (p.414). Interestingly though, Peter et al. (2003) noted that not all nurses defended their moral position with others, and some nurses preferred to assume a passive role by following the hospital rules and regulations. A number of studies reported that some nurses prefer to keep quiet because they fear repercussions if they challenge others (McDonald & Ahern, 2000; Vaartio & Leino-Kilpi, 2004). These repercussions do exist, and include situations where the whistleblower was isolated and rejected by peers (McDonald & Ahern, 2000) or situations where the nurse who was complaining was labelled a troublemaker and referred to a psychiatrist (McDonald & Ahern, 2000; and Lachman, 2008) or even dismissed from work (Ahern & McDonald, 2002; Attree, 2007). Waters (2008) reported that some nurses did not bother to report their peers, because from earlier experiences, when they or others reported malpractice, the nurse managers failed to fix the problem or take action. Cooke (2007) comments about the use of “instrument scapegoating” whereby administrators reprimand the whistleblower, because they threaten the manager’s position of power by questioning their ability to maintain control over incompetent nursing care.

Summary: Institutional Discourse and Nurses as Subjectivities of Health Care

Settings

The above studies illustrate how social and institutional discourses have an impact on nurses’ performance and how this may impact negotiation of care between nurses and patients. These findings underscore how nurses are subjected to institutional discourses and how some nurses resist such discourses to defend their moral stance and advocate for patients. These findings also show how some nurses prefer to play a passive role and

abide by the institutional rules and regulations, for they are aware that there will be repercussions if they do not. They will be labelled as “whistleblowers” and punished accordingly. This has implications for negotiation of patient care between nurses and patients. Unless nurses are supported to execute their duties with patients, negotiations with patients may not be optimum. Nurse and patient interactions are heavily shaped by the health-care setting where they work and the cultural ethos of the place. Pile and Thrift (1995) remark that health-care settings should not be seen as merely containing individuals, but should actively create them.

Chapter Summary

This literature review illustrated how negotiation of patient care between nurses and patients is a highly complex process. It is not just a two-way process in which nurses and patients exchange words and ideas and try to reach an agreement. Rather it is an intricate process that goes above and beyond the individual person, and is deeply embedded in social and institutional discourses that shape how nurses and patients behave towards each other.

Overall there appears to be some common trends in the literature reviewed, as well as some gaps that deserve further exploration. Most of the studies reviewed tend to explore nurse-patient interactions from a Hegelian-Marxist approach: the nurse is viewed as the oppressor or liberator, and the patient as a powerless individual who is vulnerable and needs to be empowered. Some of the studies discussed reveal how nurses use knowledge and language to assert their authority and to maintain their privileged position, while other studies were found in which nurses used language as a form of power to dehumanize or punish patients. This was mainly achieved through the use of

labelling, a strategy whereby everyday practices are normalized through a process of classification, by comparing normal and abnormal behavior. The concepts of empowerment and patient activation were discussed to illustrate how nurses do not always use their position of power in a negative way, but can use it in a productive way to emancipate patients. While in this study I do not negate that such relationships exist, I argue that this is just one way of viewing reality. Other perspectives exist which challenge this approach and provide new ways of looking at nurse-patient relationships and negotiation of patient care. As for patients, there was a paucity of studies that explored how patients reacted in such situations, if patients welcomed nurses' authoritative position or they felt victimized by it. A secondary analysis of some studies did show that some patients resisted nurses' use of power; however only two studies were found that explored patient use of power as their main focus. This gap in the literature speaks louder than words. It automatically portrays the patient as passive and a docile recipient of care.

Another feature of this literature review was that most of the studies tended to view the social and institutional environment as a backdrop that influences the trajectory of negotiations between nurses and patients, rather than one that actively produces or shapes negotiations. Only a few studies explored how discourses from institutions and society configure nurse-patient relationships. These studies described how nurses are socialized to act in an authoritarian way during their training and how rules and regulations of the organizations where nurses work may impact negotiation between nurses and patients. Other studies revealed how some nurses resisted these hegemonic discourses, by going against the rules and regulations to create situations of

empowerment for patients. Consequently, there is evidence to suggest that nurses are not always in a position of power, but are subject to disempowering discourses, too.

In this study, I was interested in unearthing social and institutional discourses that are currently informing negotiations between nurses and chronically ill patients, and opening up other possibilities for viewing this relationship. It is for this reason that I chose a feminist post-structural approach and Foucault's work to guide my study.

According to feminist post-structural approaches, power is not a personal attribute that nurses and patients possess or do not possess. Neither is it a privilege that is bestowed upon (or taken from) someone by society or institutes. Rather, feminist post-structural theorists argue that everybody is in a position of power. However, these positions of power are not equal. They are shaped by societal and institutional discourses, and the way these discourses position nurses and patients in a particular society, at a particular time in history. These discourses are not static or fixed, and they can dominate or liberate. According to Foucault and feminist post-structural theorists, it is crucial to understand how these discourses operate and how they can create hegemonic relationships. Ultimately it is just as crucial for the individual to reflect on the available discourses, and to be creative about which ones to choose, so as to deter any form of exclusion and/or marginalization within current health care. In the next chapter, I will elaborate in more detail how these theoretical underpinnings inform my research study.

CHAPTER 3

THEORETICAL UNDERPINNINGS

In this chapter I will be discussing the theoretical underpinnings of my study, the rationale for choosing feminist post-structural theory informed by Foucault, and the methods that I will be using to guide my study. I begin this chapter by highlighting the difference between traditional modern and post-structural theories of power. I will explain how feminist post-structural theories are useful for my study and how they can be used to understand the experiences of chronically ill patients and nurses. This is followed by details on Foucault's notions of power relations, resistance and subjectivity. I will explain how Foucault's work will provide ideal insights for understanding how power operates between nurses and chronically ill patients within hospital settings, and how social and institutional discourses have the potential to shape the relationship between chronically ill patients and nurses who provide care. I will be using feminist post-structuralism to show how individuals are not only subject to dominant discourses, but also subject to a system that is patriarchal in structure. Along the way I will be referring to feminist post-structural theory and explaining how this theory agrees with Foucault's precepts, or addresses areas which he ignored or missed. Throughout this discussion I will be giving examples from the literature to illustrate these complex concepts and how Foucault's work and feminist post-structural theory informs my study.

Modern and Post-Structural Approaches

Modern traditional approaches arise from the enlightenment or modern period, when science was seen as the panacea for all ailments, and absolute truths about the world and human beings were the doctrine. In the modern period, individuals were

viewed as free, autonomous and rational beings, which have an innate self beneath their public roles (Mansfield, 2000). This innate self or “essence” is described as an entity that is inside everyone, is unchanging over time, and is absolute. Each individual has a unique way of expressing themselves and can take on many identities and roles, yet the ultimate aim in human struggles is to uncover the innate self, to be true to it, and perfect it (Mansfield, 2000). In terms of world views, philosophers of the modern period believe in progress and that human beings through intellectualism can bring about progress by creating order, social understanding, and happiness (Elywn, 2004). History is perceived as evolving in a linear manner and that this progression will bring about gradual perfection in human beings, society, and the world.

Studies relating to nurse-patient power relations have been traditionally based on this modernist idea of human beings and linear progression (Huntington & Gilmour, 2001) Power is seen as an innate quality that one may or may not use depending on personal options, and if the circumstances are right. For instance, most of the studies reviewed in my literature search comment on the asymmetric relationship between nurses and patients, nurses having power over patients, or nurses giving power to patients by “empowering” them. Consequently, much of the earlier and current nursing research studies used critical social theory and advocated for emancipation and liberation of patients. It is only in recent decades that post-modern and post-structural approaches started to garner popularity in nursing (Rolfe, 2006).

Post-Structuralism, Subjectivity and Agency

Post-structuralism has been described as the death of the modern “grand narrative” or absolute truths that are based on rational, objective and fixed stories from

science. Instead, society's beliefs about the authority of science as the dominant ideology are being replaced by beliefs that the world is full of meta-narratives, conflicting and fragmented stories that are based on subjective and diverse viewpoints (Butler, 1992; Elwyn, 2004). In post-structural approaches, the notion of human beings as having a deep innate core or "essence" is questioned. Post-structural theorists reject the idea that the subject is an independent, self-contained individual being who has a deep innate core or "essence"; rather, they see the subject as a social construct (Butler, 1992). Thus instead of seeing human beings as individual subjects, i.e., as nurses who have power, or patients who are powerless, the self is viewed as a dynamic entity that is subject to larger political, institutional and cultural discourses that are dominant in society at the time. Consequently, the term post-structuralism has no standard definition or specificity, rather it is considered as a broad ontological approach and way of thinking that considers multiple voices and that privileges no one (Cheek, 2000).

A main focus of post-structural theories is the use of language in the construction of power relations. According to post-structural theory, human beings think through language, and use language to organize their thoughts and to construct reality (Ward, 2009). As a result of this, language does not lie outside of the subject, but rather it constitutes and resides in the subject (Weedon, 1997). According to Weedon (1997) and other post-structural theorists, language does not have a fixed and inherent meaning that is associated with a sign or symbol, but rather language is a reflection of personal, social and cultural discourses (values, beliefs, and practices) that shape it. Since these discourses are tied to a specific historical period and society, their meanings are not fixed, but constantly evolving (Scott, 1992). For this reason, post-structural theorists maintain

that discourses are multiple, complex and ever changing. Weedon (1997) explains that these discourses are incorporated as conscious and unconscious thoughts and emotions by individuals and used by the individual as they try to make sense of themselves, and their relationship to the world. Because these discourses are multiple, varied, and sometimes contradictory, individuals are always caught in a struggle trying to choose amongst these discourses in an attempt to make sense of the particular experience (Scott, 1992). Consequently, the individual cannot be described as having a fixed internal core that is capable of acting on its own accord. Rather, post-structuralists such as Weedon (1987) see humans as subjected to these discourses and “constantly being reconstituted in discourse each time we think or speak” (p.33). Along these lines, Weedon (1987) writes:

For post-structural theory the common factor in the analysis of social organization, social meaning, power and individual consciousness is *language* [her italics]. Language is the place where actual and possible forms of social organization and their likely social and political consequences are defined and contested. Yet, it is also the place where our sense of ourselves, our subjectivity is *constructed* [her italics] (Weedon, 1987, p. 21).

At this point, the distinction between the words “self”, “subject”, and “subjectivity” needs to be made clear. According to Mansfield (2000), the word “self” is different from “subject”. Whereas self refers to the individual being, “subject” does more than that. The word “subject” captures within it the social and cultural entanglements in which one gets caught in everyday life; a notion that is also shared by Foucault. Mansfield explains that this distinction between the “self” and the “subject” is important, because “the self is not a separate and isolated entity but one that operates in the intersection of general truths and shared principles” (p. 3) that are found within a culture or society at a particular historical period. In this sense, Mansfield explains that “one is always subject *to* or *of* something” (p.3). According to Foucault (1984/1985a;

1984/1985b: 1993), “subjectivity” refers to how the self is always linked to these external ideas and principles and constructed discursively through language and social practice (Atkins, 2005). In other words, the subject is a social construct. However, although an individual may be “subject to” or “subjective” to these exterior ideas and principles, it does not mean that the individual is held captive to them.

However, Foucault believed that the fate of each human being is not determined by these social and historical circumstances; rather, he believed that individuals are ethically responsible for taking charge of their lives. Foucault (1971/1994; 1975a; 1984/2000) writes about “the interiority of the subject” and that the subjects can use their moral and intellectual capacities to determine whether to comply with such discourses or to resist them. He uses the term “agency” to describe the process whereby individuals constantly reflect and critically think how to act in specific circumstances that surround them daily (O’Farrell, 2009). Similarly, feminist post-structuralists use the term agency to describe how each individual has the capacity to set their own goals, and to act in such a way as to avoid being oppressed or marginalized by current dominant discourse. In other words, they posit that individuals are morally responsible for their actions (Ramazanoglu & Holland, 2009).

In this thesis, I will be showing how nurses and patients use their agency to negotiate patient care in a patriarchal system. During negotiation, the individual unconsciously and sometimes consciously decides which personal, social, and institutional discourse to adopt to guide their decision making process. Each decision is based on the premise that every human has the capacity to decide which choices to make and which position to take. During a negotiation process, an individual may

unconsciously and sometimes consciously decide to stay within the norm and to be subject to, and reinforce, the current traditional dominant discourse of nurse-patient relationship. Alternatively, the individual may also choose to challenge the system, and break this stereotype by reinforcing the recently emerging ideas in health care, that the nurse is not the only one with expertise. In such instances, the individual is helping to break existing binaries and to bring other more marginalized discourses from the periphery to the center.

The Challenge of Change

The relevance of using post-structural theories and their implications for nursing research is widely debated (Aranda, 2006). Cheek (2000b) suggests that the purpose of using a particular approach in research is to guide one's way of thinking and of looking at reality, while it suppresses the other. In this sense, Cheek (2000b) contends that feminist post-structural approaches offer none of these. Instead, the very nature of post-structural approaches mitigate against the use of totalizing theories, and encourages a pluralistic way of thinking and looking at reality (Cheek, 2000b). As a result, post-structural theory can be "frustrating for those who want to know exactly what is going on" (Adams St. Pierre, 2000).

According to Aranda (2006), this uncertain and unstable way of investigating reality is considered to be "dangerous" ground, in that it disrupts the many assumptions that are taken for granted in nursing. Undoubtedly, the dichotomous position of nurse and patient is so ingrained and normalized in today's society that to question its existence challenges the status quo. Aranda (2006) explains that feminist post-structuralism can trouble the way we think because it challenges the norm and the dominant discourses that

we take for granted. Aranda contends that by raising questions about “the certainties of the human subject underpinning nursing and feminist theories, feminist post-structural theorists raise doubt about the emancipatory intent of critical theory, and they create a crisis of representation and legitimation for qualitative epistemology and ontology” (p.135). However, Aranda (2006) contends that feminist post-structural theorists do not abandon such ideals; rather they see them as just one way of looking at reality. Consequently, such approaches do not frustrate emancipatory theories; rather, they provide opportunities to include other discourses that have been silenced. On this note, Aranda (2006) contends that post-modernism and post-structuralism bring fresh ideas by offering new ways of looking at nursing practice. This observation is not new, and had been anticipated by Foucault earlier in 1976/ 2003 when he wrote:

For the last ten or fifteen years, the immense and proliferating criticizability of things, institutions, practices, and discourses; a sort of general feeling that the ground was crumbling beneath our feet, especially in places where it seemed most familiar, most solid, and closest to us, to our bodies, to our everyday gestures. But alongside this crumbling and the astonishing efficacy of discontinuous, particular, and local critiques, the facts were also revealing something, beneath this whole thematic, through it and even within it; we have seen what might be called the insurrection of subjugated knowledge (Foucault, 1976/2003, p. 6-7).

Feminist post-structural theorists have been noted for their compatibility with Foucault’s work in that they reject the notions of absolute truth and instead consider the multiplicity of voices that shape reality (Weedon, 1999). Like Foucault, they both identify the body as a site of power (Diamond & Quinby, 1988) and see its potential for resistance (Peter et al., 2004). Feminist post-structural theorists also seek to understand relationships as context dependent and shaped by discourses, rather than as interactions that are determined by free autonomous beings whose behavior is rooted in anatomy, personality or social class (Diamond & Quinby, 1988; Phela, 1990; Reinhartz, 1992).

However, these feminist post-structural theorists critique Foucault for his silence about women and gender in his writings and for his “unabashed assumption of a sexually neutral body, and by extension, sexually neutral bodies of knowledge” (Huntington & Gilmour, 2001, p. 903). As a result of this, Foucault fails to make the connection between gender, power and knowledge, a connection that can be interpreted as “a passionless approach which focuses on the way discourses create certain effects, rather than on the effects themselves” (Huntington & Gilmour, 2001, p.903). In other words, Foucault writes about how discourses create subjectivities but he leaves it at that.

Feminist post-structural theorists take this a step further. They recognize Foucault’s work on language, subjectivity and social/institutional discourses; however they integrate gender issues into the post-structural framework (Arslanian-Engoren, 2002). They seek to understand how gender contributes to hierarchical structures in society and how it creates situations of inequality and marginalization in certain populations. This assertion has implications for my study in that I am not interested just in exploring how discourses shape relationships between nurses and patients, but also on how this positioning of nurse and patient is creating situations of disempowerment or empowerment in these groups and how this can be transformed. I have used feminist post-structural principles to understand how relations of power were negotiated between different groups of people (nurses-patients, acute-chronic patients, nurses-doctors) in a hospital setting that remains embedded in a patriarchal culture and incorporates an understanding of how certain social constructs, such as gender, race, color, class and ethnicity, might inform everyday practices of nurses and patients.

Nevertheless, despite Foucault's silence about women and gender in his writings, his ideas about power, discourses and subjectivity have captured the attention of feminist post-structural theorists and have invigorated vibrant conversations about the value of Foucault's writings to feminist theory. Feminist post-structural theorists often quote Foucault to illustrate how his theory can provide opportunities to identify moments of domination, as well as provide opportunities for individuals to use creative ways that can lead to liberalization (Scott, 1992). In this sense, I hope that a feminist post-structural approach will help to illustrate how medical discourse is just one way of constructing partnerships with chronically ill patients, and how various other possibilities of constructing nurse-patient partnerships exist. By advocating for those discourses that previously have been silenced, one can help in the rewriting of negotiations of care between nurses and patients, and in breaking the cycle that is resulting in the recreation of new discourses that would reinstate these dichotomies. The similarities and tensions between post-structural feminism and Foucault, and their usefulness to my study, will be discussed below.

In the following section, I will discuss the relationship between power, knowledge and discourse and how these can create situations of subjectivity and agency in institutional settings. I will be referring in particular to hospital settings, how they are embedded in a patriarchal system and how this structure (i.e. hospital) can create moments of oppression and moments of empowerment in the development of partnerships between nurses and patients.

Power Relations And Resistance

Foucault wrote extensively about how institutions are an important structural site

for both constructing and maintaining power relations. From his early work in *The Birth of the Clinic* (1963/1973) and *Discipline and Punishment* (1975/1977), to his later works on *The History of Sexuality* (1976-1984), he describes how institutes are physically and discursively structured in such a way as to propagate hegemonic discourses. For this reason, Foucault's work is an essential resource for my study.

Traditionally, power has been associated with modernists' ideas of hierarchy and authoritative leadership, in which power is seen as a negative force exerted by one actor against the will of others. These theories emanate from Marxist, Weberian and psychosocial schools of thought and are related to "social relations of inequality, discrimination and exclusion" (Tew, 2006, p. 43). In such situations the person with power is said to possess personal capacities and privileges that advantage him/her over others and subsequently render the other person powerless or subservient.

Contrary to these beliefs, Foucault does not see power as a possession that one owns or a property that is possessed by a dominant class, state or sovereign. Instead he sees power as a process that one operates; that is, something that someone performs (Mills, 2003; Smart 2002). For this reason, Foucault (1976/1978) contends that power should be seen as a verb rather than a noun, and because he sees power as an activity, Foucault describes power as a strategic set of relations between individuals and different groups of people that change with circumstances and time (Danaher, Schirato & Webb, 2000; Foucault, 1980). Hence, in his work, he prefers to use the term "power relations" instead of the word "power". For Foucault, power is not fixed, but something that is free and alive. Neither does he see power as a force that operates in a structured and unidirectional manner, but rather as "something which circulates, or as something which

functions in the form of chain. . . through a netlike organization” (Foucault, 1980, p. 98). In other words, whereas in Marxist idea of domination, power flows down in one direction, Foucault’s notion of relations of power can be conceptualized as a system of relations spread throughout society, like a chain or net (Mills, 2006a).

This is the main rationale for choosing Foucault’s work to inform my study. In the literature search, most of the studies tended to use a Marxist view of power and how to overcome it. Few studies were found that explored the notion that neither nurses nor patients possess power, but they exercise it. Further, I was also interested in looking at how institutional and social discourses shape power relations between nurses and patients and the fluid nature of these positions, rather than seeing nurse–patient relationships as a fixed position. Looking at nurse-patient relationships through this lens opened possibilities. Patients were no longer viewed as passive recipients of care, but as actively involved in the negotiation process.

Foucault describes how power relations cannot exist unless there is resistance. This means that unless someone opposes power, there cannot be “power relations” but “a state of complete domination” (Foucault, 1975/1977). For instance, in Irving’s study (2002), when nurses used restraints to immobilize the patient, nurses can be described as using domination if they completely tied the patient to the bed and covered his eyes and mouth, for the patient would not have been capable of any activity. However, if the eyes and mouth were not covered, and the patient was still capable of responding to some degree, then a power relation is said to exist simply because he had the capacity to resist the nurses’ actions either verbally or non-verbally through gestures. Of course, such an action might have incited nurses to resort to the same or a different form of power in

response. And so the story continues, with the patient resisting and at the same time provoking nurses either to concede to the patient's wishes, or exercising some form of power to keep the patient under control. At any one point, either the nurse or the patient can have the 'upper hand'. This implies that power is not unidirectional, and does not originate from the "top", but power can also emanate from "below". Foucault (1975/1977) substantiates his argument by stating that while there may be power from above, there is always resistance from below. In this sense, Foucault does not see individuals as end points to which power can be applied, but rather as starting points where power can be resisted and enacted at the same time; thus he states that "individuals are the vehicles of power, not its point of application" (Foucault, 1980, p. 98) and that power takes "the forms of resistance against different forms of power as a starting point" (Foucault, 1982, p. 211).

Collectively, Foucault's work on power is described as being in favor of multiplicity and by so doing, it is pluralistic and indeterminate (Cheek, 2000). Indeed, Foucault (1979b) does not consider power as necessarily domineering and repressive, rather he argues for a way to understand power and its effects, as opposed to working on a way to overcome power. Unfortunately, although Foucault elaborates about the different forms of power, he does not expand on the diverse forms of resistance or other responses that are possible. Some scholars have criticized him for this shortcoming, stating that he needed to explicate the different ways people respond to power (Driver, 1994). A feminist post-structural view would add to this dimension. It will help to identify how patients negotiated the relations of power to avoid being in a disempowered position. Patients may use other positions that they have in society (for instance, being

male, being a mother, being elderly, and so forth) to negotiate power relations, as can the nurse who is also negotiating the same relation of power from her social location as an expert.

Foucault's notion of power relations is appropriate for my study in that it illustrates that while people who have an institutional role can be in a position of power, nurses' use of power should not be seen as a property that is fixed and preordained by the institution. Rather, power is mobile and something that can be exercised by everyone and that can be determined at a local level in everyday interactions by both nurse and patient. According to Foucault (1976/1978), one cannot escape power, for "power is everywhere...because it comes from everywhere"(p. 93). The type and degree of power that nurses and patients experience is neither the same nor is it equal. Nurse-patient interactions do not occur in a void, but within a physical setting. These health-care settings are not neutral places; they determine the type of power relations that exist between nurses and patients. In this sense, Liaschenko (1997) posits that nurse-patient relationships are inherently spatial in that "an interpersonal bond implies affective connection between people and therefore across space, while the work of nursing occurs in a certain physical and social space" (p.45). She explains how this relationship can be viewed "metaphorically as a kind of geography" (p.46) in that such relationships are interrelated on various levels "from the local and very intimate, to the global and structural" (p. 46). Halford and Leonard (2003) elaborate on this notion of geography and assert that nurse-patient relationships should not be limited to the level of the individual encounter, but one should also take into consideration how these relationships are shaped not just by the place, but also by the cultural ethos of the place, and the

historical/temporal events happening at the time. Feminist post-structuralism contends that individuals are not only subject to dominant discourses, but also subjective to a system that is patriarchal in structure. For this reason, feminist post-structuralists contend that the values and beliefs of an individual are not neutral, but rather that “the personal is political” (Hanish, 1970, p.1) because they have been embedded in a system of gender oppression and inequality. This theoretical positioning of post-structuralism is useful for my study in that it reflects how both the nurse and patient are sites of contested power struggles from a variety of discourses. The position that they take in their relationship with each other is subject to dominant discourses at the time and to a system that is patriarchal in nature.

Patriarchy and the Hospital System

Patriarchy refers to the way society is built around social relationships and ideas that privilege male dominance socially, economically and structurally. Johnson (2005) explains that patriarchy is not about men per se, as individual persons, but rather how a system or society operates; namely a system adopts and promotes these male privileges as its core values and the standards against which human beings are evaluated. Along these lines, Johnson (2005) explains that a society is patriarchal if it privileges a male orientated view of the world and “promotes male privilege by being *male dominated*, *male identified* and *male centered*. It is also organized around an *obsession with control* and involves as one of its key aspects the oppression of women” (p.5). According to Johnson (2005), *male dominance* relates to the way a society gives more credibility and privileges males over females by giving preference and reserving positions of authority in political, economy, legal, religion, and military for men because men are seen as

epitomes of power, strength and stability. *Male identification* refers to how women are not respected for their knowledge and individuality, but are always evaluated in relation to masculine ideals, and as a result they are viewed as less important. Johnson (2005) writes about masculine features as control, strength, toughness, logic, leadership and so forth, and how these male-identified qualities are more valued in a patriarchal society than core features that are often associated with females such as caring, vulnerability, intuition, expressiveness and so forth. Johnson (2005) refers to *male centeredness* as the way a patriarchal society mainly focuses on men and what they do; women's work is invisible or underappreciated. Finally, Johnson (2005) writes about the fourth feature of a patriarchal society, how it is obsessed with *domination and control* of others. Johnson explains that in a patriarchal society, a male oriented view can only maintain its privileged position in society by oppressing those discourses that are associated with women or anything else that threatens their position.

In this study, I will explain how the current nurse-patient relationship exists in a society which privileges and promotes patriarchal discourse through medical dominance and scientific knowledge. One feature of medical discourse is its heavy reliance on technical scientific data, and its focus on the body in its organic state rather than the individual experience. Bowling and Martin (1985) explain how the creation and certification of scientific knowledge is tied to patriarchy. They explain that scientific knowledge is the mark of patriarchy that is manifested by the association of the masculine, with features such as objectification of nature, competition and hierarchy, and the neglect of discourses that are often associated with feminine features of individuality and human experience.

I will explain below how this attention to the body has been described by Foucault as the ‘medical gaze’ and how this medical knowledge has brought power and prestige to the medical profession; a privilege which doctors do not wish to part with (Bilton, Bonnett & Jones, 2002). Bilton et al. (2002) explain how in the last two centuries scientific medicine has replaced folk and lay medicine and how “modernity is about expertise, not tradition; about critical inspection not folk beliefs; about control through scientific and technical regulation of the body; not customs and mistaken notions of healing”. Watson (1990) writes at length about patriarchy, the need to value the patients’ input and the topic of caring. She laments that the caring work of nursing is often subsumed under the important work of doctors. She questions if patriarchal dominance is the reason why caring is not a core concept that guides health-care policy and action. In this study, I explain the importance of medical and scientific discourse; however, I will also describe how valuing the individual experience is just as important as basing action on objective scientific data.

Regimes of Truth

Foucault gives various examples that can be used to demonstrate how institutions are deeply rooted in a patriarchal system. One of the ways by which these institutions claim their authoritative power is through the use of what Foucault (1975/1977) describes as “regimes of truth”. These regimes of truth are created in part by statements which are made by authorized people within a discipline, and because of the power associated with these people at a particular time in history, regimes of truth are accepted by society in general as “facts” which they perceive as true (Mills, 2006a). Experts within these disciplines will circulate this knowledge in society and proclaim it as “truth”. For

example, experts such as doctors, who operate within the discipline of medicine, will conduct research and circulate it through conferences, articles and books. Based on this knowledge, these experts create a series of statements about what is “normal” behavior and what is not. These statements are given credibility because they are endorsed by doctors and the structures within which this truth is housed. Information given by professionals has a certain amount of authority. The same information may be taken up differently if the person who is delivering the message is not seen as an authorized expert at the time. When these regimes of truth become established in a society, they become dominant discourses that govern the behavior of individuals. Individuals are given rewards or privileges if they abide by them. Conversely, if individuals choose not to abide by medical discourses, they are seen as deviants and marginalized from care. An example of how regimes of truth come into effect can be found in those studies which describe how nurses used their nursing and scientific knowledge and or labelling to control patients they perceived as being “difficult” and deviating from the traditional “good” patient. One may recall from the literature review how nurses used medical, behavioral or social forms of labelling in an attempt to prevent deviant patients from causing disruption to the status quo of the unit, and to get them to follow the nurses’ and organizational agendas (Irving, 2002; Johnson & Webb, 1995a; Mohr, 1999; Stockwell, 1972; Thorne et al., 2000).

Foucault (1979a) explains the various ways regimes of truth intersect with structures of power to form subjectivities. He describes how the scientific disciplines and institutions play a significant role in the generation of authorized discourse by prescribing and keeping in circulation only those statements which they characterize as being “in the

true” (Foucault, 1969/1972, p. 224). In particular, he explores how these regimes in turn are integral to the authorization of some individuals. For instance, within the health-care sphere, particularly in acute-care settings, it may be argued that nurses possess scientific and medical knowledge, which is perceived by many people as more real and believable than other modalities such as “old wives tales” and “folklore remedies” which lack scientific evidence. As a result of this belief, most patients will take up scientific and medical knowledge and continue to legitimize the nurses’ knowledge and practices and therefore maintain the nurse’s position of privilege. However, times are changing. In recent times, health-care discourse is claiming that patients have experience that medical treatment does not always work for them (Coulter, 2002). Consequently, in modern health care, it is suggested that chronically ill patients should be considered as the “experts” who can best handle the management of their illness (WHO, 2011a). However, change takes time, and as seen in the literature reviewed, while some nurses are willing to acknowledge patient expertise, they are not willing to surrender their authoritative position. On the other hand, if discourses from society, institutes and individuals continue to perceive the patients’ position as powerless and helpless, new discourses will be created that will continue in the making and re-making of dichotomous positions. For instance, if nursing fails to recognize that patients can exercise power, efforts will continue to be made by professionals to “empower” patients, thereby reinforcing the belief that patients are powerless and need experts to help them.

This understanding of normalization and the reproduction of stereotypes is also shared by feminist post-structuralists, who lament how throughout history, society has continued to reinforce established norms, and emphasize the use of rules and regulations

that keep certain discourses in circulation, while silencing those discourses that do not conform to these truths (Scott, 1992). As a result of this, hegemonic discourses are reinforced and marginalized and oppressed positions reinstated. Scott (1992) comments on how discursive systems shape experience and how this results in the creation of subjectivities. Scott (1992) uses the metaphor of “visibility” to describe how stereotypes are produced by exposing individuals to the same vision over and over. This vision is discursively produced through texts, such as documentation and writings. These texts continue to expose these stereotypes and reproduce these differences until they become naturalized and taken for granted. Scott (1992) comments how “writing is reproduction, transmission—the communication of knowledge gained through (visual, visceral) experience” (p.24). He remarks how “it is not individuals who have experience, but subjects who are constituted through experience” (Scott, 1992 p.26). On this note, both Foucault and feminist post-structural theorists contend that the construction of human experience is ahistorical and acultural and it is sculpted in the context where it is told (Hardin, 2003; Scott, 1992).

However, both Foucault and feminist post-structural theorists believe that individuals have the capacity to think and to choose between those discourses that reinforce their suppressed position and other discourses that are more liberating. The choice that one makes depends on whether or not one wants to subscribe to dominant discourses at the time, discourses which delineate what is normal behavior, and what is not. In other words, what Foucault would describe as “regimes of truth”.

Discourse

According to Foucault (1981), regimes of truth are established through “discourse”. According to Hall (2003), Foucault describes discourses as “a group of statements which provide a language for talking about a way of representing knowledge about a particular topic, at a particular historical moment” (p.44). According to Foucault, the word discourse goes deeper than language, for it does not simply relate a set of statements that are exchanged during social interactions; rather, these statements carry meaning (Huntington & Gilmour, 2001). Foucault (1984) asserts that knowledge is not objective, value-free and universal; rather, he maintains that discourse and discursive frameworks shape ways of thinking and speaking about reality. They reflect values, beliefs, and practices of a particular culture, at a particular place and time (Crowe, 1998; Mills, 2006b).

Foucault explains how discourses are influenced by institutional beliefs and practices, and how they can be used to convey ideas and statements that reflect the institution’s values (Danaher, et al., 2000). These discourses are not often stated directly in the language used during conversations, but are implicit in the way society and institutions resort to behaviors that are seen as appropriate in a given society at a given time. In this sense, Foucault explains how discourse determines how a topic is regulated and talked about in particular ways. In so doing, it can restrict other ways of knowing and it can govern ways of thinking about reality (Cheek, 2000a). In other words, by promoting and keeping in circulation certain ways of thinking about reality, discourse promotes one way of thinking and of looking at reality, while it suppresses other alternative ways (Cheek, 2004). What discourses dominate is an effect of the socio-

historical influences at the time (Cheek & Rudge, 1994). These dominant discourses determine “who can speak, when and with what authority, and conversely who cannot” (Cheek, 2004, p. 1142). This restriction of ideas is a central component in Foucault’s precepts on discourse. He posits that we can only think and experience things the way we do, because we are constrained to think this way (Foucault, 1969/1972b).

This view is clearly illustrated by Liaschenko (1994) who described how social practices and symbolic interactions within hospitals are responsible for the construction of identities and power relations between nurse and patients. Liaschenko (1994) contends that health-care settings are highly structured places with their own languages, codes and practices that legitimize and give authority to certain persons, while at the same time they constrain others. According to Liaschenko (1994) these discourses intersect with human agency in such a way as to constrain patients from expressing their needs. Similarly, Cheek (2000b) remarks on how the written words “nurse-patient” in themselves express an asymmetric relationship. Based on Derrida’s deconstruction method, Cheek (2000b) explains how placing two opposite terms (i.e., the words nurse and patient) next to each other results in a comparison of the two terms, and a power relation, whereby one term becomes dominant, while the other term automatically becomes weaker and subordinate. However, Cheek (2000b) contends that such views offer a partial view of reality, a restricted position of how such relationships may be viewed, one often represented by spoken/written words which come to be constituted as “truths”. An example of how discourses can create such “truths” can be seen in McCormack’s study (1997), and the way nurses organized patient care through “discourses of control”.

Discipline and Punish

Foucault writes about a range of techniques that health professionals use to maintain their authority, and through which individuals are controlled and populations regulated (Foucault, 1977; 1980). These techniques are relevant to my study in that they can serve as examples to understand how discourse shapes power structures between nurse and patient. Institutions offer a number of material, symbolic and metaphoric resources; it is only through discourse that one may analyze how these resources are operationalized and utilized to disable or enable patients. In the following section, I will be describing how health professionals use regulatory spaces and discipline to control patients on an institutional level and on an individual level. Foucault (1961/2006, 1975/1977) looked at the impact of health-care settings on patients' subjectivity and agency. He describes how upon admission to hospitals, patients undergo a "degradation ceremony", whereby they are de-robed of their personalized identity and individuality and made to conform to the collective rules and regulations. In all, this arrangement occurs in such a way that positions nurses and other health professionals in a privileged position and patients in a subjugated role. An example of how institutions mold nurses and patients in their subjugated positions is illustrated in Edward's (1998) study. Edward (1998) reported that upon entering the profession, nurses are subjected to institutional rules and regulations that transform them from an ordinary person to a professional. These discourses, which include uniforms, language and institutional hierarchies, legitimately establish the distant and authoritarian image of the nurse.

Further to this, Foucault writes about regulatory space and how professionals use different forms of practices in such a way as to discipline others. Foucault (1975/1977)

coined the term “governmentality” to describe how institutions use overt and subtle means or “micro–practices” that shape, guide and govern the conduct of others. Based on Foucault’s terms, governance is understood in terms of “conduct of conduct” (Foucault, 1982, p. 220-221) a process whereby individuals are taught how to conduct themselves in such a way so as to meet the state’s, or in this case institution’s, ends. Governmentality looks at how institutions use different forms of power to regulate others or to encourage a process of self-regulation (Holmes & Gastaldo, 2002). Such regulative technologies are not necessarily coercive or blatant, but are generally subtle and integrated into everyday institutional life without generating individual awareness. According to Foucault, this new form of power involves “acts of cunning” that “works even in sleep” (Foucault, 1975/1977, p.139). In other words, the use of power is not always visible to the naked eye, but can be subtle and silent.

There are various ways disciplinary “technologies” are put into practice in health care. In his book *Discipline & Punish*, Foucault (1975/1977) explains how certain places like prisons, schools, factories and hospitals are architecturally, functionally, and hierarchically structured so that the human body is the subject and object of the health professional’s gaze. To begin with, Foucault (1975/1977) writes about the “art of distribution” (p. 141) and how individuals are enclosed in specific places within the institution (departments, units, rooms) that are strategically set up through partitions, so that the person in authority can “supervise the conduct of each individual, to assess it, to judge it, to calculate its qualities or merits” (Foucault, 1975/1977, p.143). Foucault (1975/1977) uses the example of prisons to illustrate this principle. He explains how prisons are designed on Bentham panopticon: an architectural structure in which

prisoners are kept under constant observation from a guard who overlooks all cells from a central tower. Foucault's notion of panopticon as a disciplinary apparatus that enables strict surveillance of individual bodies can be applied to hospitals. Foucault's notion of panopticon can also be applied to nursing. The physical structure of the unit is a clear example of this, and with its central nursing station acting as a tower from which nurses are able to observe the patients. Such physical structures enable nurses to conduct the process of observing, assessing and charting about the patient from the hierarchical position of a professional. Moreover, besides exerting external control over patients, such geographical structures also serve as a means of self-regulation. The fact that patients feel that they are constantly under surveillance prompts them to internalize certain behaviors and to keep themselves in check, even when the nurses are not watching.

Control of time through timetabling is another spatial feature and a necessary accompaniment to the "cellular power" (Foucault, 1975/1977, p 149) outlined above. Again we find this feature pivotal in the organization of nursing care, so that nursing tasks are completed within a specific time. According to Foucault (1975/1977), timetabling provides a means to control the individual's minute activities, regulating them and normalizing them through a series of exercises and repetitions. This is clearly illustrated in the way hospitals set up timetables to which the patients are expected to subscribe. They are woken up at an early hour, their daily activities regulated according to preset times, visitors allowed within a certain time period and lights are turned off by a certain time. The constant "training" of bodies to abide by these practices becomes "natural" for patients and a ritual that coerces them to obey habits, rules and orders.

According to Foucault (1975/1977), this “correlation of time with body and gesture” serves to ensure optimal use of time and the highest degree of efficiency and speed through “economic use of the body” (p. 152 -154). Thus, from a nursing perspective, this regulation of human bodies helps nurses to monitor and control the patient’s activities.

This “adjustment of time” (Foucault, 1977, p.164) is also necessary for nurses to ensure coordination and order on the nursing unit. Through this adjustment of time, all patients on the unit are placed in synchronicity so that upon “signalization” (Foucault, 1975/1977, p.166), all can move in conjunction to one another to fulfill the nurses’ goals. The aim here is to ensure that practices as part of discourses are tightly scheduled, regimented in terms of physical space, and activity is minutely controlled, so that nursing care is organized without any needless hurdles. Such actions ensure a homogenous and smooth running of the unit, where patients conform to institutional norms that lead to their recovery, rehabilitation or palliative care.

On a more individual level, Foucault (1963/1973) writes about the “space of configuration” (p. 3) and how the human body provides a means through which one can transfer the flattened ontology of medicine onto a tangible three-dimensional space of the body itself. In his book on *The Birth of the Clinic*, Foucault (1963/1973) explains how patients upon hospitalization become the object and subject of the “medical gaze”, and how the patient’s body becomes subjected to a series of physical assessments and probing devoid of humanizing values. The medical professionals use their knowledge to identify a problem that produces a “saviour” or knowledge about the patient (Foucault, 1998, p 460). This knowledge is then used to classify patients against a codified system, whereby they are labelled as normal or deviant. Patients who are considered to be normal are

rewarded, whereas patients who are seen as deviants become problematic and need to be dealt with so that they become “normalized” (Foucault, 1975/1977). Examples of this can be found in the literature search, where I describe various studies of the ways in which nurses used medical, social and behavioral labels to control patients (Irving, 2002; Johnson & Webb, 1995a, 1995 b; Mohr, 1999; Thorne et al., 2000; Stockwell, 1972).

Yet other studies were also described to explain how, even in situations where nursing care is not so much based on the medical system or punishment, but rather seated in the caring domain, nurses may still use their power to categorize and to control patients. This is achieved through the nursing process in which nurses use the scientific method to identify nursing problems with patients, and consequently plan their nursing care (May, 1995a, 1995b). For instance, Bloor and McIntosh (1990) commented on how nurses use the nursing process as a new mode of patient surveillance and control, a process that they termed as “therapeutic gaze”. According to Bloor and McIntosh (1990), this type of gaze fits the same description that Foucault uses when he describes “pastoral care”, a process whereby professionals use listening to encourage patients to talk and disclose their “deepest secrets” (Foucault, 1980). In both instances, patients are “subjectified” versus “objectified”; however, they are still fragmented and subjected to confession, categorization, and intervention. Bloor and McIntosh (1990) contend that while surveillance under “clinical gaze” takes the form of physical examination and medical diagnosis, in “therapeutic gaze”, surveillance does the same thing. It cloaks itself under the pretense of talk as a means to encourage the patient to disclose information and to enable the nurse to arrive at a nursing diagnosis. The central argument is that the construction of a therapeutic role for nurses is nothing more than a

new opportunity for patient surveillance and control (Hyde et al., 2006).

Yet, one might ask: Is this type of power always negative? In what ways are these authorized discourses disempowering patients? For instance, patients tend to go to hospital on a voluntary basis because they need someone who has scientific knowledge, and when they get better, some individuals want to look after themselves if they can. Hence, do these discourses always constrain patients? And if they do find it disempowering, can patients do something about it?

Power as Productive

An important point that Foucault brings up is that power is not necessarily repressive or destructive, but can also be positive and productive. Even in its most repressive states, desirable constructive consequences may also co-exist alongside power (Holmes & Gastaldo, 2002). To begin with, nurses' disciplinary procedures of surveillance, categorization and intervention may be domineering and intrusive; however, they do ensure that patients' ailments are attended to and hopefully resolved. Likewise, nurses' use of "pastoral care" and "therapeutic gaze" as tools to access patient information, can offer patients an opportunity for catharsis (Holmes & Gastaldo, 2002). On a unit level, it may be argued that disciplinary regimes may control and limit patients' behavior on the unit; however, they also ensure that there is order and a sense of security and safety for patients on the unit, rather than an atmosphere of cacophony and chaos. Hence, the point that Foucault wanted to make is that power does not simply constrain individuals and curtail their freedom, but it can also be positive and productive (Mills, 2006c).

Another important point that emerges from this analysis is that while nursing may

appear to be domineering, the patient may not always choose to keep silent. As mentioned earlier, for Foucault, power is not fixed and preordained by the institution; rather, it is very much changeable and determined at a local level in everyday interaction through discursive practices (Mills, 2006b). This suggests that power is relational. For Foucault, at any one point power may act on an individual, who in turn may also use power on others. Thus Foucault's bottom-up approach to power portrays individuals as active subjects that can act as agents in power relations, rather than "passive dupes" (Mills 2006c, p. 34).

In this sense, Foucault's concepts stand in clear contradiction to the hegemonic notion of power, in which power is viewed as essentially negative. In his book on *The History of Sexuality*, Foucault (1976/1978) explains how power can give rise to new forms of behavior which have constructive aspects rather than repressive ones. For instance, during the era when professional elitism created asymmetry between health professionals and patients by claiming that "doctor knows best", patients were not necessarily disempowered by such discourses. Rather they invigorated some patients to create movements, and to push for legislation, such as "The Patient's Charter", that recognized the patients' rights to exercise and make decisions about their care (Henderson, 2003). This has led to changes in nursing management and the introduction of policies and standards that remind nurses to pay heed to patients' wishes and rights. Hence, rather than disempowering patients, patients took up their subjugated position and used it productively to advance their cause by creating new norms, new subjectivities, and new discourses (Mills, 2006c). In other words, instead of being situated as a victim, patients used their dominant position to raise awareness and push for their rights. This

changed the way the public and society now views and treats patients.

The point Foucault (1976/1978) tries to make is that power is not only a matter of constraint, but it can also be enabling or productive. The more constraint there is on individuals, the more likely individuals will resist, reject or deflect it. From a nursing perspective, patients should not be seen as passive recipients of care, for they may determine whether or not to comply, negotiate or set limits to the professional gaze. Indeed, a number of studies demonstrated that patients have their own particular ways of responding to health-care regimes and they can set the limits to what kind of care is given (May, 1995b; Porter, 1996; Wheatley, 2005). Such findings confirm Foucault's (1980, p. 98) assertions that power cannot be eliminated, that it is "something that circulates" and that "individuals are the vehicles of power, not its points of application". That is, people are not just points to whom power can be applied, for whenever people resist power, it triggers further or different forms of power. Foucault's work was described as being in favor of multiplicity, in that everyone at some point is in a position of power. And because everyone can have power, not just the privileged few, power is pluralistic and indeterminate (Cheek, 2000a).

The Indeterminate Nature of Power

Foucault states that one cannot escape power, and that "power is everywhere...because it comes from everywhere". In this sense, Foucault does not see individuals as free and autonomous beings that develop in the world as an expression of their own unique essence, and power as a force that presses on individuals from the outside, frustrating their dreams and restricting their abilities to express themselves (Mansfield, 2000). Rather, Foucault (1976/1978) sees the individual as a construct of

power. According to Foucault (1976/1978) power does not stand outside of a person. Instead, Foucault believes that one's individuality and its idiosyncratic nature are the effects of power (1976/1978). In other words, Foucault sees the individual as a pliable medium, in which individuality and personality are shaped and subjected to social and cultural influences at the time. However, at the same time, individuals also have the capacity and creativity to use some of these discourses to resist any form of power. To this end, Foucault refers to the terms subjectivity and agency to describe the self as the product of these external historical, social and cultural forces that shape who the person is, but which, as I explained above, can also provide opportunities for resistance. Atkins (2005) eloquently describes this complex concept in the following extract:

Foucault gives a role to the body in determining subjectivity. He regards the living body as a constellation of powerful and often conflicting urges and impulses that give rise to different forms of subjectivity according to the organism's internal organization and the "disciplinary" effects of socially regulated practices and norms (p.3).

Indeed, these actions determine what an individual becomes, and gives them their individual identity, characteristics, behavior and actions. For example, patients can be described as pleasant and cooperative; however, such personalities are not the result of some inherent qualities that they have. Rather, this person's individuality is the result of choices that the individual makes in response to professional and institutional dominance.

Foucault's theory has been described as nihilistic because the individual is seen as a product of historical and cultural discourses at the time. As a result, the individual is always subject to these discourses and is never in a position to escape power (Dreyfus & Rabinov, 1982). However the point that Foucault was trying to make is that most individuals are not always passive people, they do have an intellect and they can make choices and become self-determining agents who resist these forces. According to

Foucault (1975/1977) individuals can choose to resist the power of disciplinary and institutional discourse. While Foucault's work has been criticized for his inattention to the living body with inherent qualities of its own, and how the individual is just a product of discourse (Dreyfus & Rabinov, 1982), in his later works he does refer to the interiority of the subject and its capacity for agency. In his work on "ethics and care of the self", Foucault (1984/1985b) writes about the construction of the self, morality and identity. According to Foucault, just as historical and cultural discourses can shape who we are, individuals can use their moral and intellectual capacities to shape who they become. By analyzing the way power operates in society, individuals can focus on ways to resist the rules and regulations that are imposed on them. In this sense, Foucault (1984/1985b) writes about how individuals can apply the "techniques of self". According to Foucault, these techniques allow individuals to reflect on what's happening around them, and by using their intellect and sense of morality, they are able to change their bodies, thoughts and conduct, and fashion them in such a way to navigate and resist any form of subjectivity. Indeed, Foucault remarks that without such a critical capacity, the individual is bound to fall prey to the domineering discourses of modernity (Atkins, 2005). To this end, Foucault writes about the "arts of existence" to explain how one can craft one's life as a work of art, by learning how to navigate through fields of discourses of power and freedom (Danaher et al., 2000).

Although many feminists have rejected Foucault's work because he failed to acknowledge women's oppression and struggles (Phela, 1990), Foucault's insights on how discourses can shape subjectivity and agency have piqued the interest of feminist post-structural theorists. For instance, Butler (1990) views Foucault's ideas as a

departure point to explain situations of oppression in women and other marginalized populations. She contends that a preexisting culture has set two categories, one for men and one for women, and how after birth both genders are expected to conform to these roles. However, Butler (1990) does not see these roles as natural and essential, but she also sees an opportunity from which “a new configuration of politics would surely emerge from the ruins of the old” (p. 149). In other words, although Butler (1992) sees women and other marginalized populations as subjectivities to cultural discourses, she also sees these discourses as opportunities for individuals to actively construct their own identity and to liberate themselves from these hegemonic positions. According to Butler (1992), one’s identity is not predetermined nor fixed, but culturally construed. She contends that through a process of self-reflexivity, one can recognize the social, political, and cultural discourses that are resulting in one’s subjectivity, while at the same time, this awareness offers individuals an opportunity to challenge any form of stereotyping or subversion to oppressive discourses.

Referring to the aforementioned metaphor of experience, Scott (1992) postulates how experiences can also be used to provide opportunities for empowerment. She describes the experience of Delany, a black homosexual man, who visited a bathhouse in 1963, and how his experience of actually seeing a mass of homosexuals in public, exposed “the ‘hidden’ world of homosexuality” (p. 25) and helped to bring homosexuality into the open. Paraphrasing Delany, Scott (1992) contends how visibility of “numbers-massed bodies-constitute a movement and this, even in its subterranean, belies enforced silences about the range and diversity of human sexual experiences” (p. 23). Scott (1992) notes how bringing into the open ideas about subverted groups helps to

make them visible and to expose diversity. According to Scott (1992), by making visible what was suppressed in history, one “challenges prevailing notions, and opens new possibilities for everyone” (p.23). In other words, bringing out in the open discourses that have been silenced helps to create awareness and new knowledge that break the creation of stereotypes and normalizing discourses from which some oppressed and marginalized groups are positioned. And this is what I hope to achieve in this study: Creating awareness about the different ways the relationship between the nurse and the chronically ill patient in hospital is experienced. If nurses continue to be perceived as exerting power, and if patients continue to be viewed as vulnerable, these stereotypes will be reinforced. Breaking this cyclic pattern will herald the way for more empowering discourses.

The concepts of subjectivity and agency are also useful to my study in that they explain how institutions can create subjectivities, but at the same time offer opportunities for agency. By understanding the ways institutions use a number of material, symbolic and metaphoric resources to create subjectivities, one may uncover ways of how these resources can be immobilized by nurses and patients to resist the constraining patriarchal discourses within institutional structures that have the potential to normalize practices.

Chapter Summary

A feminist post-structural approach offers a fresh lens on how to look at negotiation of care between nurses and chronically ill patients. This approach, which was used in conjunction with Foucault's theory, shows how power is not a quality that one possesses, but it is a capacity that anyone can exercise. This view provides an opportunity to revisit the traditional view of nurse-patient relations, where the nurse is seen as the oppressor/emancipator and the patient as the oppressed/powerless individual.

Likewise, this perspective challenges the commonly held view that nurses are victims in a male-orientated medical world.

The premise that everyone is in a position of power has usefulness in invigorating nurses and patients to acknowledge the potential in them, and to challenge dominating discourses which have a tendency to subjectify and oppress individuals.

CHAPTER 4

METHODOLOGY

In this chapter, I describe my research methods, beginning with discourse analysis. This is followed by details on the sample, site and data collection process. Finally, I describe how I established trustworthiness for my study, and how I addressed ethical issues.

Foucault resisted giving a specific method for doing Foucaudian-orientated research simply because he believed that by giving a “method” one would be creating another dominant discourse, thus restricting oneself to one way of knowing and excluding other possible approaches of exposing social relationships (Cheek, 2000a). However, although Foucault left the choice of methods open to the researcher, he did show a preference for the use of text to apply his theory (Kendall & Wickham, 2004). For this reason, discourse analysis will be used for this study. It is the most commonly used method in feminist post-structural research (Frost & Elichaooff, 2014) and as I will explain, it provides a means to analyze text for the intersection between the macro worlds and microcosms (Drew & Heritage, 1992). It shows how institutional, socio-cultural, as well as historical discourses position and shape power relations between the nurse and chronically ill patient when they are in hospital.

Discourse Analysis

There are various interpretations of what discourse analysis entails, and these may range anywhere from linguistic to conversational and critical styles (Wertz et al., 2011). Each definition varies according to the discipline within which it is used, and according

to the theoretical frameworks that underpin it (Mills, 2007). Cheek (2004) contends that it is crucial to clarify which orientation one is using, as each approach explores the research field differently. For instance, discourse analysis as used in linguistics varies substantially from the way it is used in post-structural theory. The former looks at the way structural features and relationships in sentences produce meaning, whereas the latter looks at how language constructs knowledge and is a manifestation of power relationships (Huntington & Gilmour, 2001). Although there are different types of discourse analysis, I will be limiting myself to the way it is used by post-structural theorists and feminists.

Feminist post-structural theorists describe discourse analysis as a method of analyzing and exploring text and the way it creates subjectivity or agency. According to Cheek (2004), texts refer to any form of written or spoken communication that represents an aspect of reality. These can take the form of articles, interview transcripts, visual images, poems and so forth. In this study I will be using audiotaped interviews with participants that have been transcribed into written texts. Cheek (2004) contends that by analyzing text, one can identify how social identities and power relations are constructed. In this study, discourse analysis was useful to capture the dynamics of current power relations between nurses and patients, and to understand how social and personal discourses are perpetuating the current situation.

In this study, this was achieved by examining the experiences of registered nurses and chronically ill patients when they negotiated patient care, and analyzing the transcripts to find out what was being said. As part of discourse analysis, I needed to look deeper than the content of what was being said at face value in the text, and to

deconstruct the way language is used. Deconstruction involves a systematic analysis of language and searching for moments of disempowerment and moments of empowerment within these texts. The idea was to search for overt or hidden use of binaries that were creating stereotypes of nurses and patients, and to contest these claims. This process helped to understand how relations of power between nurses and patients work, how certain stereotypes are kept in circulation and how they can be challenged. Examining these experiences with the use of discourse analysis was useful to identify how relations of power between nurses and patients were constructed, how these relations may be empowering or disempowering, and how they were shaping the trajectory negotiation takes. In the following sections, I will refer to the research questions and the methods that were used to address these questions.

Research Questions

The broad research questions that guided this study were:

1. How do chronically ill patients experience and negotiate their care while in the hospital?
2. How do registered nurses experience and negotiate the care they provide to chronically ill patients?

Discourse analysis was useful to address my research sub-questions, which were:

1. What were the experiences of registered nurses and chronically ill patients about negotiation of care in hospital settings?
2. What were the social and institutional beliefs, values and practices of registered nurses and chronically ill patients when they were negotiating patient care in the

hospital?

3. What were the power relations between registered nurses and patients in hospital settings, and how were they negotiated?
4. What discourses inform the experiences of registered nurses and chronically ill patients and how are these discourses negotiated?

Selection of Sample

To address my research questions, I interviewed ten nurses and eight patients. Small sample sizes are typical in feminist post-structural studies. The aim is not to generalize or predict, but to select individuals who are deeply rooted in the situation under study and thus in a better position to yield insights and an in-depth understanding of the situation (Maxwell, 2005). Further, in feminist post-structural studies a small sample permits a better understanding of how social “processes” and “meanings” affect the individual experience (Frost & Elichaooff, 2014). In this study, the small sample size enabled me to look deeper at the language of the participants, to peruse their choice of words, and to uncover how the participants’ language was linked to the larger social and institutional discourses. A bigger sample size would not have permitted this in-depth analysis of each transcript.

LoBiondo-Wood and Haber (2005) contend that in qualitative studies like mine, when it comes to sample size, fittingness of the data (choosing participants that are experiencing the event under investigation and who can describe in-depth the experience) is more appropriate than representation (ability to generalize findings to a larger population). In this study, I was careful to select people, settings, events and processes,

which addressed my research questions. I invited chronically ill patients, and nurses who worked in hospital, to talk about their experiences when they were negotiating patient care. I explored these experiences and was able to unpack the negotiation process in depth. Although the sample size was small, the amount of data generated was extensive and relevant for the purpose of this study.

In line with feminist post-structural methodology, a convenience sample and snowballing technique were used to recruit participants for this study (Miner, Jayaratne, Pesonen, Zurbrugg, 2012). Convenience sampling is a process that involves recruiting individuals who are readily accessible (Miner et al., 2012). With the snowballing technique the researcher asks the participants for assistance to get in touch with others who fit the criteria, and who may be interested in participating in the study (LoBiondo-Wood & Haber, (2005). These forms of sampling were useful since I needed to collect data within a certain time. Such samplings are useful since they provide insights about experiences from a variety of participants when there is a short period of time; however, there is a risk that the results may deviate from the objectives of the study if the characteristics of the sample are different from the population of interest (Miner et al., 2012). For this reason selective criteria were used to define the variation in the population and to ensure that the sample is relevant to the study. For my study, I was interested in chronically ill patients, and nurses who provide care for chronically ill patients when they are in hospital. The specific selection criteria that were used in the recruitment of the sample are described below.

Patients Sample

Inclusion and Exclusion Criteria

The inclusion criteria for this sample included patients who:

1. were English speaking and over the age of 18 years
2. had been diagnosed with one or more chronic illnesses for at least two years
3. had been admitted to hospital on at least two occasions for complications related to their chronic illness
4. were not acutely ill at the time of the interview
5. were discharged from hospital
6. agreed to be tape-recorded

The sample selection criteria offered some variation of experiences in that:

1. I did not focus on one particular chronic condition, but on chronic conditions as a whole
2. I did not limit my sample by sex
3. I did not restrict my sample in terms of race, class or ethnicity

Chronically ill patients who have been previously admitted to hospital were essential for my study, as these patients would have most likely accrued a substantial amount of experience with their illness, treatment choices and institutional jargon. Further, I preferred not to focus on a specific condition as this was more reflective of reality. Many hospitalized chronically ill patients who are admitted to hospital do not have an isolated condition, but suffer from multiple chronic conditions at the same time (Lewis,

Heitkemper, Dirksen, O'Brien, Bucher, 2010). Another rationale why I opted for a full range of chronic illnesses was to capture a broad spectrum of how patients with different chronic illnesses negotiate patient care. The similarities and differences between patients helped to identify if certain situations were experienced by all chronic patients, or if they were specific to a particular group. Identification of these factors offers a wider opportunity for transferability of findings.

Timing of diagnosis was also important since such patients would likely have passed the crisis stage of being diagnosed with chronic illness and have somatically and psychosocially adjusted to their illness (Van Eijk & De Haan, 1998). According to Van Eijk and De Haan (1998), the needs of chronically ill patients vary substantially as patients progress from the crisis phase (pre-diagnostic, diagnostic and establishment phase), to the chronic stage (stabilization phase, progression phase, complication phase) to the terminal phase (pre-terminal phase, death, post-terminal phase). Van Eijk and De Haan (1998) did not provide a timeframe for each stage; however, it is reasonable to suggest that a two-year period from time of diagnosis was enough to allow for the grieving and bereavement process associated with the crisis phase. Normally, at this point the patient would have reached the early chronic stage of their illness; that is, at the stabilization phase, when patients have accepted their condition, garnered information about their illness and learned how to manage it.

To ensure a broad spectrum of perspectives, recruitment was not limited by gender. However, an examination of gender did provide an understanding of how some nurse participants experienced their position in relation to male doctors when they were advocating for patient care.

Finally, it was crucial that the patient participants were in an optimal state of health and they were well enough to be interviewed. Therefore, in terms of exclusion criteria, the following patients were excluded from the study:

1. Patients who were acutely ill,
2. Patients who were in the terminal stages of their lives,
3. Patients who lacked capacity to provide consent,
4. Patients who were cognitively impaired, children and adolescents, or non-English speaking individuals.

The first three groups have been excluded for ethical and humanitarian reasons. Children and adolescents were not asked to participate since the experience of hospitalization in children and adolescents varies substantially from that of adults (MacCormack, 1997).

Nurses' Sample

Inclusion/Exclusion Criteria for Nurses

The inclusion criteria for this sample included registered nurses who:

1. were registered with CRNNS,
2. employed as an RN for more than two years,
3. had worked in a hospital for at least a year,
4. had nursed chronically ill adult patients for at least one year.

The reason for choosing nurses who had been employed as registered nurses for more than two years was to ensure that these nurses had, up to a certain degree, been socialized

into the profession. Professional socialization has been defined as a “subconscious process, whereby persons internalize behavioral norms and standards and form a sense of identity and commitment to a professional field” (Weidman, Twale, & Stein, 2001, p.6). Whereas the amount of time required for a nurse to be socialized into nursing is indeterminate and subject to personal variables, two years appears to be the benchmark used by various studies to mark off when newly qualified nurses have acclimatized into the profession. Based on these premises, the exclusion criteria were:

1. Nurses who had been employed as RNs for less than two years.
2. Nurses who had no experience looking after chronically ill adults in hospital.

Description of Site

Participants were recruited from a regional hospital in Nova Scotia. The distinction between regional and community depends on the demand for care and complexity of services. Regional hospitals provide a wide array of services such as: acute and trauma care, emergency services, surgery, clinical and continuing care services. Community hospitals are much smaller and provide basic medical surgical services to the community. The hospital chosen for this study provides services for over 100,000 patients each year, and employs more than 1,800 health-care providers and 270 hospital and community-based physicians. There are a number of clinical services for chronically ill patients, as well as in-patient medical and surgical units. During their interviews, both patients and nurses often alluded to experiences that took place outside hospital settings. Since these experiences provided rich data on how nurses and patients negotiate care in hospital settings, this information was included in the analysis.

Sample Recruitment

After ethical approval was obtained, posters were displayed in prominent areas in the hospital to recruit participants (Appendix E & F). I met personally with the nurse managers of units caring for chronically ill patients to get their permission to recruit participants from their unit, to discuss the study and answer any questions that they may have had.

Patient Recruitment

The nurse managers were asked to identify patients who met the eligibility criteria and who were about to be discharged. However, although I went to the units a number of times, there were few discharges and/or those who were about to be discharged did not fit the criteria. In situations where the patient was accessing one of the clinics, I asked the nurse-in-charge if she could get permission from the patient to share their phone number with me. The nurse managers indicated six patients who were initially interested in participating in the study. I contacted them by phone and asked them if they were interested in participating in the study. If they were interested, I proceeded to explain briefly the nature and purpose of my study and how confidentiality would be assured. I was able to recruit four participants this way; one individual declined and said that he was no longer interested in participating, but did not explain why, and another one had passed away by the time I contacted his family. Five patients, having seen the poster, contacted me themselves. However, only two of these patients fit the inclusion criteria. Another two patients were recruited using a snowballing technique. These participants were referred to me by one of the patients, who said that they may be interested in participating in the study.

Nurse Recruitment

A variety of methods were used to recruit nurses. Initially, I asked the nurse managers of six medical units if I could hold an information session for interested nurses in the nursing conference room on the unit, as well as present at team meetings or other nurse meetings that would be appropriate for me to attend. However, the nurse managers explained that this was not possible, so I asked the nurse manager if I could approach the nurses myself and they all consented to that. All nurses that were approached were given a letter of introduction and they were invited to contact me if they were interested in participating in the study, wanted more information or had questions. Nurses were also encouraged to pass this information to other nurses they believed might be interested in the study and who fit the inclusion criteria. I disseminated 30 copies of my study to nurses; six nurses volunteered to participate in the study. Another three nurses were recruited through a snowballing technique, while one nurse contacted me after seeing the poster in hospital.

Data Collection

Data collection took four months to complete. Both nurses and patients were given the opportunity to select a place where they wanted to be interviewed. Interviews took place in a private setting within the hospital, or in a place of their choice.

Patients' Demographic Data

A total of eight patients were interviewed. The participants included three males and five females ranging in age from 26 years to 80 years. All of the patient participants had experienced the majority of their care as an in-patient/out-patient in Nova Scotia, although some of them also recounted experiences from other hospitals outside the

province but within Canada.

The participants suffered from a number of chronic illnesses. Table 1 describes basic demographic data for each patient and their self-reported chronic illnesses. Each patient has been assigned a pseudonym.

Table 1
Demographic profile of patient participants

Participant	Profile
Patricia	A female participant who had been admitted to hospital more than ten times with chronic pancreatitis.
Beth	A female participant who had been admitted to hospital 40 times with chronic pancreatitis.
Fred	A male participant who had been admitted to hospital ten times with refractory epilepsy and GERD.
Jack	A male participant who had been admitted to hospital four times with COPD/Emphysema.
Peter	A male participant who had been admitted to hospital six times with COPD/Emphysema.
Ruth	A female participant who mentioned that she had been admitted to hospital countless* times with chronic pancreatitis/Crohn's disease/osteoporosis.
Kath	A female participant who mentioned that she had been admitted to hospital countless* times with chronic pancreatitis/Crohn's disease/colitis.
Anne	A female participant who mentioned that she had been admitted to hospital countless* times with Crohn's disease/diabetes/renal failure/depression.

* These participants could not recall the number of admissions to hospital.

Seven of the patient participants wanted to be interviewed at their home, while one patient preferred to be interviewed at my house. Almost all participants were accompanied by a family member during the interview. This support from family

members was one of the factors that emerged in the data analysis and will be examined further in the results sections.

Nurses' Demographic Data

Ten nurses were interviewed. The sample consisted of nine female and one male nurse. The ratio of females to males in this sample may be disproportional, but it is aligned with the current gender mix of nurses in Canada (Canadian Institute of Health Information, 2010). The fact that the sample consisted of mainly females needs to be considered when interpreting the results. In feminist post-structural studies, it is acknowledged that gender differences can create situations of marginalization in some populations. Interestingly, whereas most gender marginalization tends to point towards females, in this study the male participant experienced a particular form of marginalization positioned as a male in a female-dominated profession. This finding will be discussed in the data analysis. The demographic details of the nurses' sample are presented in Table 2.

Table 2

Demographic profile of nurse participants

Participant	Profile
Ray	A male nurse in his forties. Has worked as an RN with chronically ill patients for nine years in critical care settings, medical/surgical units.
Lucille	A female nurse in her fifties. Has worked as an RN with chronically ill patients for 35 years in medical/renal units.
Marilyn	A female nurse in her late forties. Has worked as an RN with chronically ill patients for 12 years in medical/renal units.
Maria	A female nurse in her early thirties. Has worked as an RN with chronically ill patients for five years in geriatric and critical care settings.
Susan	A female nurse in her thirties. Has worked as an RN with chronically ill patients for seven years in emergency/critical care settings/long term/mental health units.
Tina	A female nurse in her early forties. Has worked as an RN with chronically ill patients for two and a half years in ambulatory/palliative/medical/surgical units.
Joanne	A female nurse in her thirties. Has worked as an RN with chronically ill patients for four years in critical care settings, medical/surgical units.
Lisa	A female nurse in her late forties. Has worked as an RN with chronically ill patients for 27 years in mentally challenged/critical care settings and medical/surgical/stroke units.
May	A female nurse in her thirties. Has worked as an RN with chronically ill patients for seven years in cardiac/respiratory/renal units.
Irene	A female nurse in her late forties. Has worked as an RN with chronically ill patients for 28 years in critical care settings, medical/surgical units.

The experience that nurses had looking after chronically ill patients is also noteworthy. Most of the nurses were not only seasoned in looking after chronically

patients, but they also had experience in negotiating care with them at various stages during the trajectory of their illness. Such experiences were valuable, as the needs of chronically ill patients change as they pass from one stage of their illness to another.

Five of the nurses chose to be interviewed in the hospital. These interviews were conducted in a private room of their choice. The other three nurses preferred to be interviewed at their homes. These settings provided a place where it was assumed that the participants felt comfortable and safe, and that offered the participants privacy when they shared their experiences.

Interviews

I used semi-structured interviews to elicit information from the participants (Appendix C & D). Interviews have been favored in feminist post-structural studies since they are perceived as the best way to obtain extensive information from participants about their experiences and to expose marginalized situations (DeVault & Gross, 2012). The open nature of the questions offers participants opportunities to express their opinions, and to raise issues that are important to them and to give details about situations when they felt marginalized (Schmidt & Brown, 2012). This was particularly helpful for my study since the overall aim of this research was to develop an in-depth understanding of the experiences of chronically ill patients and nurses when they negotiate patient care, and to identify these finer nuances that shaped the negotiation process in hospital. I would not have been able to elicit such information if I used structured interviews or observational studies, since such detail could only be picked up through discourse analysis of the participants narratives.

Participants were given written and oral information about the aim of the study,

data analysis and dissemination of findings. Prior to conducting the interviews, I went over the information sheet about the research study and the consent form with the participants. I also asked participants if they had any questions. The interviews were audiotaped; those with the patients lasted between 30 and 100 minutes, whereas the interviews with the nurses lasted between 30 and 60 minutes. The interviews concluded when the topic was exhausted and the participants felt that they had nothing else to add. Feminist post-structuralism focuses on the importance of language as well as personal understanding. Therefore, it was imperative that verbatim transcripts were used for analysis.

During the interviews, I asked both nurses and patients to share stories about their experiences of being a patient in hospital, or looking after patients who were chronically ill in hospital. Using these stories as a baseline, I probed further to explore nurse-patient relations and how patient care was negotiated. Hospitalization involves a number of opportunities for nurse-patient interactions; hence the participants' accounts of this period provided various opportunities to explore power relations and negotiation processes (Gibb & O'Brien, 1990; Sloan et al., 2007).

As the interviews unfolded, I asked nurses and patients more specific questions: how decisions about patient care were made, if patients wanted to be or were involved in their care, and how nurses felt about patient involvement in care. This information helped to identify the position of participant in the relationship, and if this positioning was desirable or not. Some of the participants implicitly or explicitly referred to how their positioning in the relationship was shaped by social and institutional discourses.

Finally, I asked nurse and patient participants to share with me specific stories of

negotiations between nurses and patients and how they felt about them. These questions provided examples of power relations and how they were negotiated between nurses and patients.

I used a semi-structured interview guide during the interviews; however, I did not stick rigidly with the questions. I did not ask many questions, and allowed the participants to take over the conversation. This method minimized the power relations between researcher and participant (Willig, 2013). Many times the participants were able to provide answers to my questions on my interview schedule without my having to ask them. If the interview was drifting off topic, then I would ask a question to draw the participant back into the topic. Participants were encouraged to speak openly about their personal experiences. As much as possible, I tried to make them feel at ease by making the interviews less officious and more casual and conversational in nature. I tried to control any form of power relationship with myself and the participant by focusing more on active listening (DeVault & Gross, 2012) and by validating their experiences rather than offering an interpretation of what they were trying to say (Taylor, 2003). At the end of the interview, I asked participants if they had any questions and if they wanted to add anything else. I also asked if they wanted to know the results and I took their details if they chose to be contacted.

Ethical Considerations

Ethical approval from Dalhousie University and from the local hospital was obtained before beginning recruitment. Individual consent was obtained prior to conducting the interviews. Participation in this research was voluntary. There were no risks involved for participants that were greater than their experience in everyday life.

However, since some of the discussion could possibly delve into issues that were sensitive or personal in nature, participants were told that they did not have to answer any questions on these topics in this interview if they did not wish to do so. Participants were told that they could withdraw from the study at any time during the interview and up to one month from the time the data were collected. If they decided to withdraw, their data would be removed and destroyed within a week. The reason why a timeline was given was because it would have been difficult to remove data at the last minute, and to make changes to the study if data were analyzed, conclusions drawn, or if the thesis was near its completion stage. Participants were also told that all data would be destroyed five years after the defense of the thesis.

Confidentiality was assured by informing the participants that the tapes and transcripts would be stored in a locked cabinet in my office at home. My supervisor and I, and potentially research ethics audit boards, would be the only ones who would have access to this information. They were also assured that all attempts to ensure confidentiality would be made, such as changing names and any identifying information. In terms of benefits, participants were told that although they would not benefit directly from the study, their participation might help nurses and other health-care providers/stakeholders to understand better the experiences of chronically ill people when they are in hospital.

Finally, ethical considerations were not limited to information giving and maintaining confidentiality. It would have been a disservice to the participants if the data collection process and analysis were not equally rigorous. In the following section, I will explain how I maintained rigor during my data collection and analysis.

Methodological Rigor and Positionality

Unlike quantitative studies where quality of the research is measured by the extent to which the researcher is able to distance themselves from the subjects and measure the phenomenon objectively, in qualitative research, rigor (or the quality of a study) is determined by the extent to which the researcher is able to integrate with the participants, understand their life worlds and respect the social world. Janesick (2000) explains how establishing rigor in qualitative research resembles the art of choreography in terms of fluidity and control. She explains how qualitative researchers are simultaneously able to use an open approach to natural inquiry, yet still maintain rigor. In post-structural approaches, researchers are encouraged to use this freedom, plurality and democracy to reveal reality; however, they are also expected to demonstrate an acceptable level of rigor and validate that “the findings are worth paying attention to, worth taking account of” (Lincoln & Guba, 1985, p. 290).

Lincoln and Guba’s seminal model on trustworthiness (1985) has been the traditional yardstick against which the quality of qualitative research has traditionally been measured. This model identifies four areas that can be used to measure trustworthiness in qualitative studies. These four areas are outlined in Table 3. However, with the post-modern turn, Lincoln and Guba have been questioned and criticized for their claims that that this model can accurately represent reality, particularly since the “researchers” construction of realities will inevitably be reconstructions, interpretations” (Cho & Trent, 2006, p. 323).

Table 3
Lincoln and Guba model on trustworthiness (1985)

Credibility	The extent to which the data analyzed truly reflects what the participants stated.
Auditability	The extent to which the finding would be consistent, if the study was to be replicated.
Transferability	The extent to which findings could be transferred to similar contexts of cohorts.
Confirmability	The extent to which the data collection, and analytic process is free from bias.

Further, Morrow (2005) questions how plausible it is for a qualitative researcher to remain free from bias, when in reality, the researcher is the instrument of investigation and therefore has some preconceived ideas about the topic at hand. Therefore, due to its logical inconsistencies, Morrow (2005) recommends using Lincoln's and Guba's model of trustworthiness as a basis and following more intrinsic or paradigm-specific criteria depending on the qualitative approach used. These additional criteria aim to ensure that the researcher's views are represented transparently and that the full dynamics of the research process are presented and critiqued (Marshall & Rossman, 2011). The additional criteria that Morrow (2005) suggested for postmodern/post-structural approaches are presented in Table 4.

Table 4
Criteria to establish rigor in post-modern and post-structural approaches

Verstehen	A capacity to develop a deep understanding of the participant's experience and to capture the context in which it occurs.
Authenticity	An ability to invigorate participants to elaborate on their ideas and experiences.
Fairness	Loyalty to what the participant is saying.
Consequential validity	Locating the studies within their cultural/historical situation.
Transgressive validity	An ability to extrapolate information and contribute to critical social science.

In this study, I used Lincoln and Guba's model of trustworthiness (1985) and I followed the criteria that Morrow (2005) recommended in relation to the postmodern /post-structural paradigm. The following is a detail of how I applied these criteria in this study.

Credibility was established by following the suggestions recommended by Lincoln & Guba, (1985), who recommended that the researcher use open-ended questions provide privacy during the interviews and encourage disclosure during data collection. I implemented all of the above when I conducted my interviews.

Auditability is the extent to which findings will be consistent if one were to replicate the study and interpret the findings. One way to achieve this is through providing an audit trail. Audit trail is a process whereby another researcher is given some of the transcripts and a step by step detail of how the analysis was conducted. *Auditability* is achieved if the other researcher comes to similar conclusions (Koch, 1994). Since I

followed the discourse analysis procedure as advised by my supervisor, it was convenient to do an audit trail with her. My thesis supervisor, who has a background in nursing and whose area of expertise is feminist post-structural and discourse analysis, asked to look at my first transcript and how I analyzed it. Together we deliberated on the findings, and the extent to which our conclusions were convergent or divergent. Following exchange of ideas and further analysis of two other transcripts, my supervisor was satisfied with my conclusions and believed that I was able to proceed with the rest of the data analysis on my own.

Transferability involves giving enough details about the sample so that other researchers can transfer findings to similar contexts or settings, or similar cohorts. In this instance, I have addressed transferability by making sure that my sample is well-defined in my earlier sections. However, given that social context is dynamic and ever changing, each interaction is unique and unfolding in a way that cannot be predicted or replicated and generalization cannot be assured (Taylor, 2003). Rather than claiming to generalize, I can only claim what Taylor (2003) suggested, that certain ramifications were widespread and persistent in the given population sample.

Confirmability is the extent to which the data collection and analytic process are free from bias. I have already mentioned earlier that it is not possible to approach the study without bias and preconceived ideas. However, in an attempt to control my own biases and potential influences on analysis, I constantly vigilantly adhered to what the participant said, rather than my interpretation of it. My thesis supervisor and my supervisory committee were very helpful in ensuring that my analysis remained true to the data.

Verstehen was achieved through emphatic listening. My goal was to try to get as close as possible to the participant's experience and understand it from the participant's point of view. I tried to achieve this during the interviews through active listening, by asking open questions, and by giving participants time to express their opinions during the interviews.

Authenticity involves creating an atmosphere where the participant feels safe to disclose information of a personal nature. In this study, I gave the participants the option to choose where they wanted to be interviewed. This gave participants an opportunity to choose a site where they felt comfortable talking and it facilitated disclosure. I also explained how confidentiality will be maintained, and provided the participants with information about contact persons from Dalhousie and from the ethical review committee if they needed to contact them. During the interview, I tried to get the participants to share more of their experience by listening with curiosity and asking them to tell me more when they seemed enthused about a particular experience.

Fairness was achieved by validating the participants' experience during the interviews and by summarizing what they said. The key issue here was to develop an empathetic approach by validating what participants said, rather than attempting to look for some hidden truth, or interpret what the participant was saying (DeVault & Gross, 2012; Taylor, 2003; Willig 2013). My previous training and experience in interviewing skills as a nurse and as a researcher were helpful to this end.

Consequential validity involves focusing on the historical situatedness of the research, and understanding how dominant discourses may shape the findings. This was addressed through discourse analysis. The discourse analysis process itself took into

consideration the social, institutional and historical discourses that were shaping nurse-patient negotiation of care. When I analyzed the data, I made constant reference to how these discourses contributed to the participants' experience and how these discourses contributed to creating hegemonic relationships.

Transgressive validity: The nature of feminist post-structural approaches is transgressive in itself. It aims to identify current dominant discourses and threaten their stability by contesting their claims. In this study, this was achieved through discourse analysis and deconstruction of binaries and stereotypes.

Reflexivity

Esterberg (2002) contends that qualitative researchers are not only interested in studying the subjective experience of human life, but they are also interested in the subjectivity of the researcher him/herself and how this may affect the way they conduct the research. In contrast with the quantitative tradition, the researcher in qualitative research acknowledges subjectivity. Unlike quantitative research, the role of the researcher is not to eliminate bias, but rather to view the researcher's subjectivity as something to be used actively and creatively throughout the researcher process (Eakin & Mykhalovsky, 2003).

Feminist and nursing scholars challenge the notion that a researcher can be "value free" or "value neutral" when approaching a research problem (Lather, 1986). To begin with, it is widely argued that it is virtually impossible to remain objective and free from bias, simply because the researcher always comes into the field with some preconceived ideas or hunches about the topic (Baxter & Eyles, 1997; Taylor, 2003). Furthermore, tenets of qualitative research maintain that if the researcher is objective, it is not possible

to establish rapport with the informants and thereby capture the nuances and meanings of the participant's life and worldviews (Janesick, 2000). Thus, elimination of the subjective is not only impossible, but may also be detrimental to the quality of the research (Davies & Dodd, 2002). Rather than trying to eliminate bias, Davies and Dodd (2002) advocate that the researcher admits their partiality and be responsible and account for it. According to Davies and Dodd (2002), this can be achieved through a process of reflexive self-thinking, whereby the researcher is constantly vigilant of his/her bias throughout the research process and, by being aware of it and transparent about it, hopefully he/she will not let such bias control the participant's ideas or the research process. Cho and Trent (2006, p. 324) comment that "the question of validity in itself is convergent with the way the researcher self-reflects, both explicitly and implicitly, upon the multiple dimensions in which the inquiry is conducted".

I used self-reflexivity to ensure validity of my study. During the data analysis, I was continuously aware of my bias (or reminded of it by my supervisor) and vigilant that it did not influence my findings. Reflexivity played an important role in helping me to step back and analyze the situation from a neutral stance, rather than a personal one. Ideally the best way to ensure neutrality was maintained would be to include the full transcripts within this dissertation; however, this is not practical or ethical (Gill, 2000). Instead, I have included a number of direct quotations from the participants and a description of the process I used to analyze them in the results section. The rationale is to provide transparency, and to give the readers opportunity to judge for themselves whether the interpretation of the data was in any way biased and contaminated with my ideas.

In terms of the postmodern paradigm, the need for reflexive consideration is also central to lessening power relations between the researcher and the researched. It is acknowledged that the researcher is in a position of power when conducting interviews, because he/she holds the status of academic and, supposedly, expert, and also because the researcher has more knowledge about the topic (Taylor, 2003). According to post-modern theory, the researcher is not the connoisseur of knowledge about the phenomena of interest, the participant is. Indeed, post-modern theory acknowledges that researchers are not infallible and it encourages humility (Kincheloe & McLaren, 1998). However, this does not mean to say that the researcher is to be self-deprecating or silenced; rather it means that the researcher is open to unpredictability and ready to have his/her authority challenged (Kincheloe & McLaren, 1998). Such a situation is not easy and can become quite complicated when participants express ideas that are different from or “at odds with” the researcher’s values. In such circumstances, my role was to rethink and acknowledge possible paradoxes or dissonance and use them as points of knowledge/information, rather than as aberrations that should be discarded from the study (Davies & Dodd, 2002). This approach ensured that all voices (and not just mine) were represented and that I followed “a progressive, emancipatory process leading towards social change” (Cho & Trent, 2006, p.324).

In this study, I used various strategies to minimize power imbalance between the participants and me. As mentioned earlier, giving the participant an opportunity to choose the site where they wanted to be interviewed gave them some control of the situation. Further, since I had experience in conducting interviews both as a nurse and as a researcher, I was very conscious of my communication skills during the interview and

conscious not to dominate the conversation. Instead, I focused more on attentive listening and let the participant take the lead. Taylor (2003) suggests adopting an empathetic rather than interpretive approach during the interviews to minimize the researcher's position of power. During the interviews, I made sure to focus on what the participants were saying and to validate what they said. In line with feminist post-structural methodology I refrained from making suggestions or giving my interpretations during the interview. At the end of the interview, I also asked the participants if they had anything else which they felt was important to disclose. This gave the participant an opportunity to talk about anything else which I did not ask about, but which they perceived as crucial.

Undoubtedly, reflexivity provides a path that unravels the richness, controversies and complexities of inter-subjective relationships, yet it also requires tact (Finlay, 2002). Critics of reflexivity argue that it requires that researchers have a phenomenal capacity for critical self-awareness, which, according to Seale (1999), can only be attained through intensive psychoanalysis. Furthermore, there is also the danger of "overreflection" whereby the researcher overindulges in introspection, to the point that the research loses its focus and becomes centered on the researcher, as opposed to the participant's worldview (Finlay, 2002). Thus, reflexivity has to be exercised with prudence and it demands that the researcher distinguish between purposeful reflection and defensive or self-indulgent personal analysis (Finlay, 2002). To this end, my supervisor and committee members also proved to be resourceful to point out such situations, or any bias or incongruence during my data analysis and writing.

Data Analysis

Foucault did not describe a particular way of using discourse analysis, often leaving researchers at loggerheads on how to conduct Foucaudian discourse analysis (Graham, 2005). Instead, he recommends using his ideas as a “toolbox” and applying them in any way that best suits researchers to reach their objectives. My analysis was mainly guided by the expertise of my thesis supervisor, Dr. Megan Aston, whose area of speciality is feminist post-structural studies and discourse analysis. I also borrowed ideas from the methods outlined by Carabine (2003) and Parker (1992), who provided practical suggestions on how to identify power relations and how to link them to social and institutional discourses. The following is a step-by-step breakdown of how I analyzed my data.

Transcription

I transcribed the interviews verbatim myself. This was a labor-intensive and time-consuming task, and involved listening to the recordings a number of times. However, since I had done transcription before, I was able to pick up subtle clues such as tonal changes and rhythm variations in the participants' voices and speed. Wooffitt (2003) contends that it is crucial to pick up these linguistic features and variations since they give a better orientation and interpretation of the script. I transcribed each transcript shortly after the interview and followed the above process for each individual transcript. This was very useful for it enabled me to see the emerging themes along the way, and to use these themes to inform the following interviews.

Familiarization

A preliminary step prior to starting the analytic process was to read and re-read

the transcripts a number of times so that I became familiar with them. This step was time-consuming, but crucial. Spending time getting familiar with the text helped me to get a good idea of the participants' experiences, and the salient issues that they raised. It was important to get familiar with the text, since one could easily get distracted by the minute detail of the transcript when dissecting the text, and in this process, miss the whole picture. It was also very important to stay loyal to what the participant was saying, rather than to what I was thinking the participant was saying. This means suspending personal thoughts and feelings, and reading the text for what the participant actually said, rather than looking for a hidden message underlying it (Gill, 2000). In order to read the text in this spirit, Gill (2000) suggested asking oneself questions such as: "Why am I reading this in this way? What features of the text is producing this reading? How is it organized to make it persuasive?"(p. 179).

Coding

Carabine (2003) describes the first step of discourse analysis as the "coding" stage. It involved looking closer at the text and searching for specific moments when the participant talked about negotiation of patient care. I looked for both implicit and explicit descriptions when nurses and patients reported negotiations of care, and highlighted them.

Analyzing Discourse

After the coding process, I started the discourse analysis. This involved looking closely at the language, at the terminology that participants used, the way they spoke about themselves, and how they compared themselves to others. This information was useful to unpack the negotiation process, to find out what the power relations were, and

how they were shaped by social and institutional discourses. To uncover this knowledge, I followed the following steps:

1. The first step was to find out the patient's experience about negotiation of care. I asked myself questions like: What was happening during this negotiation process? How was the trajectory of the negotiation? Did the participant say they feel good or bad about it? If it was not good, how did they negotiate their care? This step was useful in answering my first research sub-question, which was: What are the experiences of registered nurses and chronically ill patients about negotiation of care in hospital settings?
2. The second step was to look at the position of the participant in the negotiation process, and how this was informed by social and institutional discourses. When analyzing the text, I asked myself questions such as: How does each participant talk about themselves in this situation? How did they compare themselves to others? Why did they act this way? During this step I looked for binaries that were explicitly or implicitly implied by participants. This information helped to address my second research sub-question, which was: What were the social and institutional beliefs, values and practices of registered nurses and chronically ill patients when they were negotiating patient care in the hospital?
3. The third step related to power relations between nurses and patients, how these were negotiated between them and what was the outcome. I looked specifically at how power was exercised, how patient care was negotiated and if there were moments of empowerment or moments of resistance. I perused

the text and asked myself: What was the power relation between nurse and patient during negotiation of patient care? Was power shared or was it unequal? Was this power relation desired or not by the participant? How was patient care ultimately negotiated? These questions were useful in addressing my third sub-question, which was: What were the power relations between registered nurses and patients in hospital settings, and how were they negotiated?

4. The final step was to pull everything together and to identify the social and institutional discourses that informed nurses and patients during negotiation of their care. This helped to answer my last sub-question: What discourses inform the experiences of registered nurses and chronically ill patients and how are these discourses negotiated?

A crucial aspect in all of the discourse analysis stages was to look at text in its own right, not to treat the participants as units of analysis, by trying “to see through their words” (Taylor, 2003, p.19). For this reason, I made sure to refer to the participants’ exact words and not my interpretation of them. My supervisor was very helpful in keeping me on track. During the early stages of my data analysis, she would repeatedly ask: Are these the exact words that the participant uttered, or are they your interpretation? It did not take me long to realize how rigorous the data analysis process had to be and the importance of staying true to the text.

Identifying Patterns

The next action in discourse analysis is to move away from the individual transcripts and to look at all the interview transcripts as a whole. Patterns in the data

were identified by looking for consistency and divergence between and within participants' accounts. Convergent patterns helped to identify the most common discourses that shaped power relations and negotiation of care between nurses and chronically ill patients in hospital settings. Divergent discourses were equally important. They illustrated the multiple discourses that exist, and the different possibilities that exist when nurses and patients negotiate patient care.

The process of creating patterns was an arduous task. I started by making a table of all the values, practices and beliefs that were expressed by the participants, as well as all the types of power relations and ways of negotiating care that were mentioned by all participants. For each entry, I created a pseudonym to identify the participant who said it. In total 56 items were generated from the patient data, and 75 items were generated from the nurse data.

Next, I went through each patient and nurse list one by one, and color-coded each item. I used different colors for each item, but the same color if the items were similar. This color coding helped to make the data more manageable. When I completed the list, I looked for similar color codes, compiled them into groups and gave each group a title. Divergent information was also color-coded and given a title. In feminist post-structuralism, every account is given importance, even if it is uttered by a single participant. These divergent utterances show how discourses on a particular topic are not always congruent, but can be conflicting or contradictory in nature.

Creating Sub-Themes and Themes

All of the titles were put on a separate document. Titles were compared to each other and links were established. Those that could be linked together were given a sub-

theme. Those titles that did not form any links, or that deviated from the research questions, were discarded. Once the data was reduced to sub-themes, it became more manageable. I was able to look at the sub-themes all together, identifying the emerging themes from my data and to develop meaningful conclusions. In total five major themes emerged: *1. Getting to know each other. 2. They are not the sickest patients. 3. The two faces of patriarchy. 4. The challenges of looking after chronically ill patients. 5. Finding time to listen.*

A summary of these categories will be given below.

- 1. Getting to know each other.* In this category, I discuss the patients' experience of living with chronic illness and their expectations that nurses give good care. I explain how with frequent hospital visits, both patients and nurses got to know each other and developed friendly relationships with each other. As a result of these relationships, nurses showed empathy towards patients, and patients understood nurses and when to approach them. Power relations were shared or agreed upon, and negotiation of care was successful.
- 2. They are not the sickest patients.* In this category, I explain how nurse-patient interactions within the hospital settings were based on a patriarchal system that privileged acute illness over chronic illness and the voice of the expert over that of the patient. These unequal power relationships were particularly evident in situations where patients were suffering from chronic pain. Sometimes these power relationships hindered negotiations of care. I explain how nurses and patients used their creativity to avoid being marginalized and oppressed by these discourses and how to get their needs met.

3. *The two faces of patriarchy.* Despite their positive experiences, patients also had some moments of tension with nurses. These experiences tended to occur when nurses did not respect the patient's knowledge about their body or attend to their needs. In such situations, negotiation between nurses and patients were not positive and altercations arose. Institutional discourses seemed to privilege nurses who used their authoritative position to reinforce the nurse-patient binary. However, patients also availed themselves of institutional discourses of hierarchies and social discourses of family to resist nurses' use of power, and to get their needs met.
4. *The challenges of looking after chronically ill patients.* This category looks mainly at the experiences of nurses. Nurses enjoyed looking after chronically ill patients; however, sometimes they found it challenging to negotiate care with some patients. Nurses found looking after such patients “challenging”. These patients tended to be those who did not comply with treatment, who were demanding, or who were manipulative. Nurses explained that the reason some chronically ill patients were difficult is because they were depressed. Many nurses felt that they needed to assert their authority in order to help depressed patients. Other nurses used their assessment skills and tried to understand why such patients were difficult and to address the cause.
5. *Finding time to listen.* There was a general consensus between nurses and patients that finding time to listen to what the patient had to say facilitated negotiation of care. Some nurses found time to listen to patients no matter how busy they were. However, institutional discourses about routine and timetabling pushed some nurses to rush. These discourses are often reinforced by peers who have a “rush-rush mentality”.

Certain institutional practices around organization of patient care helped to prevent and break this institutional practice of “rush-rush” mentality.

CHAPTER 5

GETTING TO KNOW EACH OTHER

In this chapter I will describe some of the participants' experiences of being chronically ill, how it affected them as a person and their family and why they felt it was important that nurses understood them and were "good to them".

One of the salient features that emerged from the data was how being a frequent patient in hospital shaped negotiation of patient care. The participants mentioned that, as a result of their frequent admissions to hospital, the nurses got to know them as a person, and they developed a friendly relationship. In these instances, patients were able to negotiate care in a positive way because power relationships were shared with the nurses and patients felt comfortable talking to nurses about their concerns.

All patients felt that on the whole their experiences with nurses were positive, however, all patients mentioned there were a few occasions when the nurses did not meet their expectations or needs. In such situations, there were moments of tension between nurses and patients and negotiation of care was difficult. These patients mentioned how they negotiated care in such situations. Three patients explained how they tried to avoid such situations and negotiated their care by being a "good patient" and/or by trying not to disturb nurses when they were busy. Two other patients felt they had good relationships with nurses because they also got to know the nurses and understood their personalities. This helped patients to understand why nurses were sometimes "short" or "cranky" with them, and to take this into consideration when negotiating their care. These findings indicate that since chronically ill patients were often in hospital, they were able to understand the hospital culture and the nurses themselves. Patients used this information

to negotiate their care effectively with nurses

Interestingly, two patients mentioned that they got along well with nurses because they believed the nurses were the experts and they were willing to relinquish their care to nurses. This supports the notion that nurses' use of authority is not always oppressing, but may be desired by some patients. This finding also points to the multi-faceted nature of partnership and how it is delineated by values, practices and beliefs that both parties hold about each other (Gallant et al., 2002). I will discuss these findings under three themes: *living with chronic illness*, *getting to know each other*, and *maintaining good relationships with nurses*.

Living with Chronic Illness

All participants interviewed had been suffering from chronic illness for a long period of time. This ranged anywhere from eight to 27 years. Participants spoke in detail about how they had to cope with the signs and symptoms of illness on a regular and sometimes ongoing basis. The hardship of living with illness was evident when I asked the participants what it was like living with chronic illness. All of the participants expressed how living with chronic illness compromised their personal, family and social life to a greater or lesser degree. The following is a description of some of the participants' experiences of living with chronic illness.

Patricia, a young lady who suffered from chronic pancreatitis, explained how the disease affected her ability to function and how it disrupted her life. She explained what it was like when she got pancreatic pain:

Patricia: My quality of life is *horrible* [emphasis added] when I'm sick. I can't do anything; I don't eat, I don't drink. Like, there is no energy; like, if I get up out of bed, it's a good day. It gets really bad.

She said that once, when she was in a full pancreatitis flare-up, she “lost 50 lbs. in a matter of a couple of weeks with the pancreatitis”. Beth, a middle-aged woman who also suffered from chronic pancreatitis, described how incapacitating the pain was, how all she could do was “just lie in the bed and cry and bawl, and there is nothing you can do; like, even the pain medication, it really doesn’t do anything; it makes you feel sleepy, but it doesn’t take the pain off.” Another middle-aged woman who suffered from multiple chronic conditions including pancreatitis, talked about the hardship of living with chronic pain and how she could not “handle the pain” regardless of how many medications she took.

Physical discomforts were not the only situations that these participants were subjected to, but also social inconveniences. Ruth talked about the social discomforts as a result of Crohn’s disease and how her social life was compromised because of her constant need to use the bathroom.

Ruth: and I go to the library and more of the time I am in the bathroom than in the library reading the books [laughs]. You know, everybody, I mean socially, if we get out somewhere, I say to my husband, if they only have one bathroom here, I can’t go there!

Anne, who also suffered from multiple chronic conditions and who was on hemodialysis at the time, explained how chronic disease affected and limited her social life.

Anne: The kidney disease is completely, a complete, a 100 per cent adjustment for me. Cause [*sic*] I went from being able to travel, and go places and do things, to consider how long I’m going to be there or who am I going to be around, because I don’t have any immune system, so I have to be very careful—like public places or—all these things you have to be careful.

Many times these inconveniences affected not just the participants, but also their families. Sometimes, the adjustments the family had to make added to the participants

burden of being chronically ill. Although all participants felt grateful and fortunate for the support their family offered, Ruth and Fred did feel “bad” and “guilty” about what their family had to go through because of their chronic situation. Ruth explained that chronic illness is a disease that “affects all the family”. She was thankful for her husband who “took the brunt of it all” but she felt “bad” about what her youngest daughter had to go through while she was in hospital. Likewise, Jack kept mentioning his wife throughout the interview, clearly indicating what he meant when he said that “she has been there with me, and it’s a long time, since '95”. He explained how his wife had been a great support for him and how he felt “guilty” because he could not bear the idea of him not working and his wife having to go to work.

These comments highlight the multiple burdens the participants had to face in dealing with their chronic illness. Two of the participants mentioned that at one point they tried to take their life because they could not handle living with the burden of chronic illness and its physical and/or social consequences. Patients wanted nurses to understand their burdens, to understand that they only went to hospital because they had no choice, and to be “good to them” when they were in-patients. For example, Anne explained that she had to go to hospital, whether she liked it or not, because she “wouldn’t live more than a week” if she did not go. To this end she saw nurses as playing an important role in shaping the patients’ hospital experience. She talked about nurses and how “special” they needed to be:

Anne: They have to be special, nurses, because you see them *every* [emphasis added] week, three times a week or more. A *big* [emphasis added] part of yourself is spent in the hospital. So if you don’t want to go there because the nurse is mean to you, or don’t understand you, it’s going to make the experience horrible for you because you’ll be like “I don’t wanna [*sic*] go there! But you have to—to live!”

Anne believed that nurses affect the patients' hospital experience. Anne's choice of words that nurses "have to be special" suggests that it is a requirement of nurses to be nice to patients, because if they aren't, the hospital experience would be "horrible" for the patient. Similarly, Patricia also indicated that it is part of the nurses' job to make the patients' hospital experience a positive one.

Patricia [referring to nurses]: It's like, go in and be positive; like I know it's tough, it's tough cleaning up people, but it's part of the job. If you *don't* [emphasis added] like your job, *or* [emphasis added] like what you're doing, then get out of it. Cause [*sic*] you're in the public eye, you're dealing with people 24/7; if you're negative you're making their experience negative, and nine times out of ten, if you're in the hospital you're not having a good experience anyway.

Patricia's belief that if nurses are "negative" or if they "do not like" their jobs they should leave the profession because they are in "the public eye", suggests there is a social expectation that nurses should be "good to patients". As I will describe later, Patricia felt this way since she had some negative experiences with some nurses when she was negotiating her care. While Patricia was very vocal about the values, practices and beliefs that nurses should embrace when negotiating care with patients, she was not the only one. Similar sentiments were expressed by all other participants who mentioned at some point that it was important the nurses were there to help patients. These findings confirm how certain attributes such as caring, compassion and understanding play an important role in facilitating negotiation of care between nurses and patients (Hook, 2006).

In general, all participants were satisfied with the ongoing care and support they were receiving from their nurses and other health-care professionals. However, there were also occasions when the nurses did not meet the patients' expectations or needs, or patient care was not negotiated with success. This tended to be the exception rather than

the rule. At some point during the interview all patient participants mentioned that on the whole nurses were “good” to patients and that “it’s just a handful of them that are not”. In the following section, I will describe how just as nurses got to know patients, patients also got to know nurses and the nursing culture. I will explain how patients used their agency to avoid/deal with nurses and ensure that negotiations with nurses had a positive outcome.

Together these findings suggest how getting to know each other shaped power relations and/or facilitated negotiation of patient care. While many of these experiences were unique and different, analysis of the data revealed there were some commonalities that enable grouping of these experiences together. These commonalities have been consolidated under two sub-themes, entitled: *getting to know the patient as a person* and *getting to know the nurses and nursing culture*.

Getting to Know the Patient as a Person

The title of this sub-theme was chosen as it reflects how, as a result of the patients’ frequent admissions to the hospital, nurses got to know patients on a more personal level. When this happened, nurses moved from their authoritarian position to being on the same power level with patients. Patients often felt comfortable expressing their needs to nurses in these instances, and negotiations were successful. Although not all patient participants spoke about the ways in which being a frequent user of the hospital service affected their relationships with nurses, four of the participants did. These four patients explained that because of their repeated admissions, nurses got to know them more closely as a person. These participants used words like “they knew

me”, “got to know me, I guess, personally” or “they remembered me”, to illustrate how nurses remembered them because they had met them before from previous admissions and became familiar with them. As a result of this knowledge, the relations between the two parties tended to be close and friendly, rather than distant and objective. These friendly relationships were extremely useful when it came to negotiating patient care and developing partnerships between nurses and patients. Some patients mentioned that when nurses got to know them on a more personal level, they became more understanding and showed compassion and empathy towards patients.

For example, Fred talked about the hardship of living with intractable epilepsy and how difficult it was initially for him to adapt to living with the disease. He mentioned that when he was first diagnosed with epilepsy, he was experiencing as many as nine seizures per day. For this reason he had to spend three months in a hospital to stabilize his treatment. He explained how nurses got to know him really well and that it was a good experience for him. When I asked if he could give an example, he was quick to share one with me. Fred explained how when he was at this hospital he had a hard time accepting his diagnosis. He said one day he got upset and almost started crying. Fred explained how one nurse consoled him and made him feel better. He said this nurse, who got to know him on a personal level, “was a very empathetic nurse. She showed me a lot of empathy”. He explained how this nurse did not say “you settle down”. He later jokingly told me that this nurse “should be given an award”.

Fred: Well, like I said, my first incident was like I said before; it was when I was in Halifax, when I had encephalitis, and I was completely out of it. I shouldn’t say out of it. I had a nurse come speak to me and she said “Fred”—she got to know me, I guess personally—“you are going to suffer from these kind of seizures for the rest of your life, so just don’t worry about it. It’s no reflection on yourself, it just you

have no control over these [seizures], just relax” and she made me feel better. And I think that nurse should be awarded! [Laughs]

Attributes like empathy, respect, and trust are fundamental to the building of a therapeutic relationship between nurse and patient, and were fundamental in helping Fred to cope with his condition, and to move forward with his life. Fred later explained how with time, he learned to live with epilepsy, talk about it without fear and shame, and how he became an advocate for those individuals who suffered from epilepsy and had difficulty adjusting to it. Fred was creative and positive in dealing with his epilepsy, which was initially a daunting situation; however, he said that he was only able to do so when he accepted his situation. The fact that this nurse left such an indelible imprint on Fred seems to suggest that her empathetic response was helpful for Fred to resolve and come to terms with his qualms.

Fred emphasized the fact that the nurse called him by his first name and said “Fred”. Fred believed that the reason the nurses called him by his name was because he “got to know them” and also because the nurse “got to know me, I guess personally”. Thomas and Wareing (2003) explain that “systems of address” are culturally determined. Calling someone by their first name is a social etiquette in Canada. It is a dominant discourse in Canada to use first names only when addressing family and friends or in situations when a stranger gives them permission to use their first name (Ediplomat, 2013). Fred’s remark that the nurses called him by his first name “because she got to know me personally” suggests that this was not because he gave her permission, but because a friendly relationship developed between him and the nurse.

Thomas and Wareing (2003) also comment that the way individuals address each

other is deeper than words. They explain that the way one addresses another is a reflection of the power relationships between the two parties. Thomas and Wareing explain how addressing each other by first name is an example that illustrates how both parties are the same type or status, or belong to the same group. The purpose behind such forms of address is “to move closer to another group that they want to belong to” (p. 137). These authors explain how this relationship is different from “asymmetric relationship” where people may use honorifics like “Miss”, “Mr.”, “Dr.”, to reinforce their difference and to distance themselves from others. They explain that the way one addresses another shows the relative status of the participants, and the degree of formality and intimacy between them. Although Fred was the only participant who specifically remarked about being called by his name, this feeling of informality and being treated as an equal was also shared by other participants in this study. Three other patients in the study, Anne, Beth and Kath, gave different examples to illustrate how the friendly relationships that developed between themselves and nurses resulted in equal relations of power.

Developing Friendly Relationships and Being on the Same Level

Anne talked at length about her repeated admissions to hospital and her relationship with nurses. This participant talked about the friendly relationship that developed between her and the nurses, and how nurses were a second family to her. Anne said that in such situations, her relationship with nurses was “on the same level” and this kind of power relationship facilitated positive negotiation of care because she felt comfortable voicing her concerns with such nurses. As mentioned earlier, having a therapeutic relationship with nurses facilitated the process of negotiation of care. Anne

mentioned how “special” some of these relationships with nurses were and how she can “never forget their faces”.

Anne: You need to have people like that that are looking after you. I mean you’re out in there fifteen hours a week, I feel like they’re my second family, and they tell you that. “You’re like family to us”. They say that genuinely. “This is our second family here, you’re like family”. And when people pass away? They go to the funerals. Yeah, they go to the funerals, they send cards, they still drop in on the family afterwards, and the families always come in, so they see them all the time too. Yeah, they’re very special.

Anne’s analogy of her relationship with nurses as “family” is noteworthy.

Relationships between family members may not always be optimal. However, it is a dominant socially constructed discourse and general assumption in western society, as well as in certain disciplines like sociology, psychology and nursing, that when one uses the word “family” the relationship between family members is assumed to be one that is affectionate and nurturing (Vanier Institute of the Family, 2013). The way Anne used the word “family” suggests that her relationship with nurses leaned towards the warm and close connections that one would expect from these dominant beliefs and values of families living in Canada. Anne valued her relationship with these nurses. She believed that such nurses “cared” about her, and that her relationship with these nurses was not subjugated but “on the same level”.

Anne: I’ve had nurses come in and sit on my bed, or stand by my bed and look me in the face and ask me how I’m doing, and talk to me, talk to me, not talk down to me. But almost, you feel, on their level

Analysis of Anne’s use of words suggests she acknowledged that nurses were in a position of power, however she valued when these nurses did “not talk down to her”.

This suggests that in Anne’s mind, she still had the traditional dominant relationship of power between nurse and patient. However, her experience as a patient who felt cared

for resulted in a shift from her original belief that nurses might not care about her and would talk down to her. These power relationships were important to Anne and it affected the way she negotiated her care. Anne mentioned that she trusted these nurses. When I asked her if she would consider voicing her concerns to the nurses whom she perceived as caring about her, she cut me off mid-sentence and said “I would tell them” and she proceeded to explain situations when she actually did.

This finding suggests that developing a close and friendly relationship with nurses may be beneficial for some patients when they negotiate their care with nurses. It creates a feeling of friendliness in which one feels safe to discuss concerns or needs with ease and without fear. Anne felt more comfortable negotiating her care with and expressing her needs to such nurses who treated her on the same level than those who did not; in other words, when power relations between the nurses and her were more equally distributed, they were more desirable and therefore conducive to negotiation of care. Both Anne and the nurse had mutual control on decision-making about patient care. The importance of being on the same level with patients has been noted by Gallant et al. (2002) and Hook (2006), who argued that one of the antecedents of partnerships that led to positive negotiation of care was the nurse relinquishing her “expert” position to one that facilitates power sharing in order to facilitate patient participation. This type of relationship helps to shape the process and outcome of negotiation and ensures that planning of care is patient centered. It is interesting to note however that findings from this study suggest it is not just the nurses who have roles and responsibilities in facilitating positive negotiations of care; patients play a role, too. The following section illustrates the roles that patients play.

Getting to Know the Nurses and Nursing Culture

Just as nurses got to know patients, patients got to know nurses and their work environment. This information was helpful for patients, and they used it to maintain good relationships with nurses and to negotiate their care effectively. All patient participants spoke highly of nurses. Anne provided many examples of how she believed the nurses were “special”, “fabulous” and “wonderful”. She talked in depth to illustrate the relationship she had with some of these nurses and how “caring” they were when they got to know her. Anne said because of her chronic conditions, she had to be admitted to hospital a number of times, and she valued how kind nurses were to her. She talked about how some of these nurses would come to visit and check how she was doing whenever she was in hospital, even though she was not assigned to them as their patient. Anne talked about a particular nurse who had previously taken care of her who came in to get “caught up” with her when she heard that Anne was in hospital.

Anne: So she [nurse] said, “I thought that was you. The nurses were talking what a *sweet* [emphasis added] woman there is down there, and I knew it will be you when I saw the name”. So she came in and she just wanted to know how I was! Just wanted to get “caught up” she said, and that she always remembered me because I’ve been such a good patient! And she said, “You look really good. You’ve come a long way, and if you need anything just say my name, ask for me, and whether or not I’m on this ward, I will come”. She was—actually there was a couple who were like that, I have to say, that were—caring.

This nurse did not just come to get “caught up” but an analysis of the above quotation indicates that the nurse was also willing to go out of her way to help Anne. Interestingly, this nurse seemed to remember Anne because “she was such a good patient”. Anne believed that being a good patient and trying not to upset the nurses worked best for the nurses and for her. She felt that by “being good” to nurses, even at

times when the nurses “did not deserve it”, she would get “a lot better treatment”. Anne explained how she went “overboard with being good to them” and felt that this did help her to get “a lot further and a lot better treatment, if I was good to them!”

Anne: I never said, complained about the food, I always thanked them, and I went overboard with being good to them, even with some people whom I think didn't really deserve it, I would say “thank you” and show appreciation because I felt I'll get a lot further and a lot better treatment, if I was good to them!

Anne felt that trying to be a good patient and being extra nice to nurses was one way to get her needs met and is an example of how she negotiated care. However, she also strategically negotiated her care by trying not to be demanding and trying not to upset the nurses. She explained how she tried not to “ring the bell” even if she was in pain, and how she preferred to wait for the nurse to come. She said that she would “rock the boat” if she asked the nurse for something. Anne explained that if she was “picking up vibrations that these nurses felt tired, overworked or they don't feel paid enough” she did not want to “put them out” and add to their burden, because she feared that “they'll take it out on you”. She told me that she had seen this happen to herself and to her roommates. Anne was a very thoughtful person and she would use her intellect, by carefully observing and attending to the behavior and moods of nurses to avoid a potentially abusive interaction. Based on her assessment and knowledge of nurses and their culture, she would make a conscious decision and decide whether it was appropriate or not to consult the nurses, and identify which nurse would be best able to negotiate her care to her advantage. She believed that there were times when nurses were busy and that adding extra pressure on them during such moments was not a good decision. By being careful when to choose her moments to negotiate care with nurses, Anne was able to establish a good relationship with nurses and negotiate her care in a positive way.

Anne was not the only participant that used this tactic to negotiate her care. Beth and Kath also provide examples of how they used their intellect and agency to decide when to ring the buzzer and when not to. Beth believed that by being “not demanding” and by “not disrupting the nurses” when they were busy, she would be in a better position to get the nurses’ assistance when she needed it. She felt that she was not “powerless” and specifically stated how one nurse remarked “What Beth needs, Beth gets”.

Beth: I don’t feel powerless. I feel—I am just relating to more or less, the ... [name of hospital], because that is where I am most of the time. If I want something—like even one of the nurses said “What Beth wants, Beth gets” [laughs].

Interviewer: Why would she say that?

Beth: I don’t know, she told me that somewhere else, so I don’t know. Like, I am not demanding; I try not to be, I try not to disturb them

Interviewer: You have a way certainly, you have a good way that works [laughs]

Beth: Yes, [laughs] that works

When I asked Beth why she thought the nurse said so, Beth replied that it must be related to her “personality” and her “stubborn streak”. By this she meant that if she wanted something, she persisted until she got it. Seemingly, the nurses must have picked that up. However, Beth was also successful in getting her needs met because she was careful. She chose those moments when she thought she could insist that her needs be met and therefore not be perceived as “demanding”. Both Anne and Beth felt being nice to nurses and timing when to summon them worked. Such practices also worked with Kath, who said nurses would attend to her when she used the buzzer because they “knew” that she would only ring the buzzer when she really needed them. This suggests that getting to know a patient on a personal level plays a significant role in the development of relationships with nurses. Nurses got to know the patients’ personalities.

This was very helpful when Kath was a patient on the floor, for whenever she rang the buzzer the nurses believed that she must really need them, and so they would go to answer it.

Kath: Because I was frequent, they kinda [*sic*] knew me on a certain unit, and that's the surgical unit; that's where I kept going. So I knew the nurses, and they knew me, sooo [*sic*] they knew when I asked for something, I needed something, that I needed it, it wasn't something that waited.

Kath valued when nurses understood her. Being a frequent patient at the hospital, the nurses got to know her personality. She did not need to talk to nurses about her needs, for the nurses knew what they were. As a result, they were able to achieve a mutual agreement when to approach Kath. In this way, getting to know Kath facilitated negotiation of her care.

The above experiences seem to suggest two things. Primarily, it suggests that patients were observing nurses and got to know the nursing culture. These participants felt that they had to be very tactful in order to get their needs met. Anne, Kath and Beth knew when to disturb nurses and when not to. This implies that for successful negotiation of care, both parties need to understand each other. Just as nurses needed to understand patients, patients also needed to understand that nurses are busy and have other patients to look after. Secondly, through a feminist post-structural lens, the above experiences also illustrate how patients exercise their agency creatively when negotiating their needs with nurses; patients choose to behave in certain ways in order to negotiate care with nurses successfully. They choose to be "good" patients by being kind to nurses and not disturbing them if they were busy. In other words, the participants were obliging and inadvertently reinforcing the traditional dominant discourses of nurse-patient

binaries. This illustrates how some participants negotiated potentially abusive and oppressive situations. By respecting the fact that nurses were busy, they were able to mutually negotiate the time when it was best to discuss their concerns and when not to. This negotiation did help patients to ensure that negotiation of their care was effective and that the outcome was positive.

Understanding Nurses

Frequent admissions to hospitals not only helped patients to get to know nurses and the nursing routine, but they also got to know the nurses personalities. Patients realized that nurses have different personalities, and that some were as nice and approachable as others. Patients were able to distinguish those nurses who were “nice”, “wonderful”, “special” and “empathetic” from those they believed were “negative”, “rude”, “abrupt”, or “cranky”. This knowledge played a pivotal role when patients were negotiating their care, and they used this information to their advantage.

Anne explained how being repeatedly admitted for renal dialysis, she got to know the nurses and their different personalities and to accept them for who they were. Talking about a nurse who was “a bit short” with her, Anne explained how the nurse apologized for her behavior and how Anne was then able to build a good relationship with the nurse. She believed that those nurses who can be a bit short are “important”, for they were the ones who would tell her the truth about her condition. However, Anne only got to appreciate this quality when she got to know the nurses, and understood their personalities.

Anne: Even when one was a little short with me? She had a good reason for it, she came back and said “Don’t mind me” and I get to know those ones, the ones that at

first I was really scared of, and now I'm really good friends with them. Because, they're the ones that would tell me the truth [*sic*]. If I really wanted to know the truth, I really go to them. "Does that blood work mean I'm really bad?" They'll tell me.

Interviewer: And you value that?

Anne: I value that. Extremely valuable [*sic*]. You need to have people like that that are looking after you.

Anne learned to use the information she garnered about this particular nurse to exercise her agency. In other words, Anne used her intellectual capacity to study this particular nurse and she used this information creatively to negotiate her care. Instead of allowing herself to get upset by this particular nurse's demeanour, she realized the potential resourcefulness of this nurse, and how she could tap into this nurse's knowledge if she needed to know the truth about her situation. This was important for Anne. It is well documented since Hippocratic times how "breaking bad news" can cause despair and how it might shorten a patient's life (Rassin, et al., 2006). Based on this belief, it has become common for doctors and nurses to be custodial at times, and to refrain from disclosing the truth to patients, simply because "what patients do not know will not hurt them" (Rassin, et al., 2006). For instance, Konner (1993) wrote about the "code of silence" whereby physicians knowingly withhold information about serious illness from the patient, and instead offer to whisper it to the family. Although such practices are no longer advocated in health care (Rassin et al., 2006) and full disclosure of such information is now legally considered as a "patient's right" (Thorne, Oglov, Armstrong & Hislop, 2007, p.228), it may be that Anne believed that such practices exist, for she mentioned that it's only those nurses who are abrupt (and therefore seemingly insensitive) that will tell her the truth. Her words suggest that normally nurses are

reluctant to give news which some nurses may perceive to be upsetting for patients.

Similarly, Jack got to know nurses on a personal level. He got to know their characters and he used this information to understand why they were “cranky at times”. He explained that it was just related to “personality” issues. This belief helped him to negotiate his care, for he did not perceive negative behavior from nurses as a personal action against himself. Likewise, Peter also forgave a nurse who disrespected him, when she shouted at him and ordered him to “sit”. He said he knew what the nurse was normally like. He said she was a “good girl”, and that she “must have been in a bad mood”. Both Jack and Peter had creative and effective ways of handling potentially abrasive situations with nurses. Their way of thinking helped prevent them from building up personal grudges against these individuals, which could have escalated to moments of tension when they tried to negotiate their care. In the next chapter, I will describe some experiences when the patients did voice their concerns, and how this resulted in altercations with the nurses.

Respecting the Nurses’ Expertise

Another approach that facilitated negotiation of care for two patients was to consider nurses as the experts in the field. When I asked participants about their experience with nurses while they were in hospital, two participants, Jack and Peter, stated that they were happy to have nurses take over and look after them. Jack, a 54-year-old who also suffered from end-stage COPD and emphysema, was content to listen to doctors and nurses and to do as they suggested. He said he preferred to follow the doctor’s or nurse’s instructions, and he felt “good” when they took over his care. Jack said they were the experts and they were providing him with the help he needed. For

example, when one nurse was about to insert a naso-gastric tube, she told him, “You can do it my way, or the hard way”. He replied: “I’ll do it your way”. He appreciated that she talked him through the process and told him exactly what to do, and said that it made the insertion of the naso-gastric tube “much easier”. He said that he was willing to do everything they told him to do and he was “quite happy” about it. He said “I’m in a better condition, I keep going because I do everything that they tell me [to do]”. He believed that when health-care professionals gave him instructions, it was for his benefit, “not theirs”. He recalled one doctor who told him that if he didn’t do what he did (i.e., comply with the doctor’s suggestions), he probably would not be here now.

Interviewer: So you find it helpful to listen to what they say?

Jack: Yeah, because it’s to my benefit really. Not theirs, but mine. And Dr. [name of doctor] told me, she said, “If you didn’t do what you do, I doubt” she said “if you’ll be here,” and I probably wouldn’t, right?

Peter, an 80-year-old who also suffered from COPD and emphysema, stated that nurses and doctors were the experts and that “thanks to them” he was now better. He mentioned he could walk much farther now than he could before he was put on medication. On the whole, this patient was “quite happy” with the care he received from nurses and he had nothing but praise for them. He felt that they were “experienced people who knew what they were doing” and he “always did what he was told”. He explained: “If the nurse tells me to do something I have to do, I’ll do it! If I can do it, I’ll do it!” He said he was willing to oblige what nurses requested, even if he did not agree with it, and reaffirmed his position by saying that “nurses were there to help me, not to hurt me, you know”. This suggests that this was Peter’s preferred style of negotiating his care with nurses, whether or not he agreed with the nurse’s decision.

Peter: I always did what I was told, if they wanted me in bed or out of bed, right?

Interviewer: What if you didn't agree?

Peter: If they wanted me to come out of bed, I'm like: "Yes. Sure", right? I had no problem with that.

Jack and Peter's way of relinquishing their care to nurses was not necessarily submissive. Both participants preferred if the nurse was in charge of their care. They felt confident about the nurses' knowledge, they were there to help them not hurt them, and therefore looked up to professionals for answers. This is another reason why these participants preferred to relinquish their care to the nurse. In such situations, there was no tension, and negotiation led to agreement. Such examples illustrate that authoritative power is not necessarily always perceived as negative but can be the patient's preferred way of negotiating care and can be perceived as being productive. It is also interesting to listen to Peter's willingness to do what he was told to do, even if he did not agree with it. His willingness to relinquish his care could possibly be attributed to the dominant discourses that were prevalent and that shaped his life when he was young. As mentioned earlier, Peter was in his 80s and probably brought up at a time when the dominant discourses in medicine and society conformed to the "sick role" as described by Parsons (1951), in which patients were viewed as subordinates to physicians and health professionals. Although not all persons in this age group may subscribe to such ideas, Coulter (1999) and Jones (2003) posit that some older adults may be more comfortable with these traditional power dynamics. Foucault (1975/1977) mentions that dominant discourses are shaped by the time and place where the action takes place. Although not all individuals may choose to follow this norm, many persons may. While one may say that times change, and so do dominant discourses, still it is possible that these values,

practices and beliefs that are deeply entrenched within each individual may remain the same. Either that or the above experiences illustrate how the traditional nurse-patient relationship is not necessarily oppressive, but can be productive too.

Chapter Summary

In the above chapter I have given various examples of how being chronically ill and repeatedly admitted to hospital facilitated negotiation of care between nurses and patients. Nurses got to know patients more closely; they became friendlier and treated each other like a family. This means that the nurse-patient power relations were less formal between the two parties. As a result of these relationships, power relations were shared, patients were able to express their needs and negotiations were successful.

Patients also got to know nurses, their personalities and the nursing culture. In such situations, patients believed they had to behave in a certain way to maintain good relationships with nurses so as to ensure their needs would be attended to. They studied the nurses' personalities, their moves and their moods. Based on this information, they proceeded to identify how and when to approach nurses, negotiate their needs and have them attended to.

Another approach that facilitated negotiation of care for two patients was to accept the nurses as experts. These patients adopted the traditional nurse-patient binary to negotiate their care and reinforced the traditional discourse about hierarchies and dominance of the health-care professionals. This behavior suggests that such binaries were not oppressive for these patients, but rather helped some of the patients get what they wanted.

All of the above experiences were different from one another. However, although they were different, they shared a common theme; namely, as a result of repeated admissions, nurses got to know patients and patients got to know nurses. Each of these experiences, even if only expressed by one participant, was in line with feminist post-structural methodology. Feminist post-structural theory aims to give importance to different discourses and ways of looking at a situation. Exposing different discourses shows that there is more than one way for patients and nurses to negotiate patient care, and that successful negotiation depends on how nurses and patients work together. Exposing each one of these discourses, even if they do not represent the whole sample, is important in feminist post-structural theory. It illustrates that reality is composed of multiple ways nurses and patients negotiate patient care, and that there is no single method of negotiating care that works better than other methods..

CHAPTER 6

THEY ARE NOT THE SICKEST PATIENTS

The title of this chapter was chosen to illustrate that chronic illness is not given priority in hospital settings and that it created difficulties when patients negotiated care with nurses. This demonstrates how negotiations between nurses and patients go beyond the nurse-patient dyad, and that one has to consider the broader institutional structure in which interactions take place.

The main reason why chronic illness was not perceived as important as acute illness was because hospital settings are mostly embedded deeply in patriarchal values, beliefs and practices. The reader may recall that for the purpose of this study, patriarchy relates to the way a system operates and historically privileged the male worldview. A patriarchal society idealizes masculine culture of unity, stability and consistency over feminine qualities of plurality, vulnerability and difference (Mansfield, 2000). This is manifested in health-care settings that continue to privilege historically masculine meanings of science, power and dominance over qualities that are often associated with feminine features such as caring, compassion and emotional expression (Watson, 1990).

Although these views about patriarchy were reported more than a decade ago, results from this study indicated that the current hospital system still operates as a patriarchal structure in many ways, including perceiving the needs of chronically ill patients as less deserving of scarce resources, and dismissing the patients' needs because chronic illness "does not go anywhere". These findings confirm what is already known in the literature: that patriarchal systems make negotiation of patient care more difficult. However, this study adds another dimension to the notion of patriarchy. Patriarchal

systems may create situations of oppression, however patients are not powerless. Patients used their intellect to exercise their agency and to resist oppressing discourses when they were negotiating their care. Interesting, too, was the fact that sometimes nurses had problems advocating for patients because of gendered roles. Nurses did not feel victimized by this fact, they resisted these discourses and many times they were able to advocate for patients with success. Nurses exercised their agency by adopting similar scientific discourses as doctors, or by using different discourse and embracing the gendered characteristics of the nursing profession. This finding shows that although patriarchal discourses are privileged within hospital settings, discourses that perpetuate feminine characteristics are just as important when nurses negotiate care with chronically ill patients.

The above findings will be discussed under two main sub-themes: *Chronic illness is not a priority* and *chronic pain can wait*.

Chronic Illness is not a Priority

Under this sub-theme, I will describe how hospital services give priority to acute and life-saving situations, and give less importance to chronic ailments. This was mainly evident in emergency care, but was also experienced in intensive care settings and on the units. Chronically ill patients were marginalized when they went to the emergency department with chronic complaints, and were made to wait longer. On the units, they were also given less importance and sometimes marginalized from care. Some nurses believed that treating chronically ill patients in intensive care units was a waste of resources, and hospital managers pushed physicians to discharge chronically ill patients when their medical ailment resolved rather than when patients were ready to go home,

while some doctors dismissed the needs of chronically ill patients because they considered them as “housekeeping” issues. Many times nurses intervened and negotiated with success on behalf of the patients so that the pleas of chronically ill patients were not ignored.

Chronic Ailments are not as Important

One common occurrence and frustration for many participants was the long wait in the emergency department. Some patients believed they experienced this because in this department chronic illness was not considered by health-care professionals to be an urgent matter compared to acute illness. While these participants acknowledged that acute illness can be more serious and requires immediate intervention, they lamented that they were still suffering as a result of the process.

Ruth, a 55-year-old who suffered from multiple painful chronic conditions, said she dreaded going to the emergency department because she had to wait hours before health-care professionals attended to her needs. She did not understand why she had to go through triage and wait for hours on uncomfortable chairs when the nursing and medical staff knew that she had Crohn’s disease and what she needed was pain medication.

Ruth: And with Crohn’s, I always wait till the last minute before I go to hospital. I *dread* [emphasis added] going, because it’s the same thing all the time, you have to wait hours to get in to see somebody, and half of the time you’re waiting in the waiting room, you’re vomiting and you’re going to the bathroom with diarrhea. And I don’t think that they’re triaging people the way they should be.

Ruth only went to hospital at the last minute, when she was “drumming in pain” and unable to resolve the issue at home. Ruth tried to make her frustrations known to the nurses when she went to the emergency department. However, when she went to

the nurse's desk to complain, she was told: "You will be called when we're ready to call you. Go back out and sit down", an interaction that signifies that in health-care settings, the experts are in a position of power, they are the gatekeepers of health resources, and they decide what is most important for managing the department or system. Possibly, Ruth's needs were not seen as a priority because of the current institutional rules and regulations that govern the emergency department, whose main mission is to treat urgent and time-sensitive illness first.

Ruth's experience is not unique. People with a variety of ailments access emergency departments, ranging from acute illness to less urgent and chronic conditions. This deluge of patients has bogged down ER departments with overcrowding (Wilper et al., 2008) and has resulted in situations in which patients have experienced long wait times, decreased patient satisfaction with quality of care, and prolonged pain and suffering (CAEP, 2001). However, although the emergency department exists for acute conditions, it is indisputable that sometimes, for one reason or another, chronically ill patients still require the use of the emergency department (Lubell, 2012), because other services are not available to them elsewhere (CAEP 2001), or simply because their ailments are not treated adequately in the community (Shaw 2004).

While this study did not look at community settings and what provisions exist in these areas for chronically ill patients, Ruth said that she went to hospital because it was the only option available that could help to alleviate her suffering. Ruth described how in such situations she would sit "quietly on hard seats", "vomiting out there" and having "severe diarrhea" while she waited for her turn to be called in. In so doing, Ruth was

resigned to complying with the dominant health-care belief that the needs of chronically ill patients, or those with less visible trauma such as pain, are less of a priority compared to acute care. However, at other times Ruth would get irate and would deal with such situations by threatening to leave the emergency department, an example of how she attempted to negotiate her care. Both Ruth and her husband felt that there were better ways of dealing with the ailments of chronically ill patients in the emergency department. By their actions, we can see how they challenged and questioned the current institutional practice by refusing to abide by the rules and wait to be attended. By so doing, they were making a point that while the needs of chronically ill patients may not be life threatening compared to an acute illness, they are also significant and merit attention from health-care professionals.

Likewise, Fred, a 50-year-old who suffered from chronic respiratory disease, mentioned that he preferred to go to the hospital only “when it’s really bad”, because sometimes the nurses in the emergency department did not seem to take him “seriously” and he was made to wait for hours before he received care. However, he noted he was given immediate attention when he went to the hospital with an acute respiratory situation.

Fred: Um, like usually when I go up to Emerge [*sic*—if it’s my lungs—its bing [*sic*], bang, bing [*sic*], [claps his hands] bing [*sic*], bang, bing [*sic*—things are done pretty quick. When I go up mostly, I don’t go up unless I’m really bad, because you’re only sitting up there for ten to twelve hours. As soon as I go in, they take the pulse, check the blood pressure, and they take you in a room. I get put up on oxygen for a while, and then they start giving me intravenous antibodies.

Fred negotiated his way through the hospital system by going there only when his medical conditions got really bad. Fred felt that if he went to the emergency department in respiratory crisis, he would be attended to immediately. He was aware of how acute

illness was given priority over chronic illness and he had a creative way of dealing with waiting times; he capitalized on the fact that acute illness was given priority and went along with these institutional practices. However, it is disconcerting that he had to wait for a crisis in order to have his concerns addressed promptly.

It may be argued that the above experiences, such as being made to wait long hours in the emergency department, are not specific to people who are chronically ill. Further, while it is understandable that people with life-threatening situations should be given priority in an emergency department, this does not preclude the fact that chronically ill patients are suffering in the process; or the fact that they have to experience these situations more often, simply because they are frequent users of this service. At least five participants mentioned that they did not like going to hospital because of the long wait in emergency. They believed their needs should also be given attention.

It seems that the hospital settings in general had a system of policies and procedures designed to provide services for acute illness, but not to deal with chronic illness. However, with the use of feminist post-structural theory, we can see that each situation needs to be looked at in all its complexity in order to understand how waiting long hours has unique ramifications for those with chronic illness. It is important not to polarize “acute versus other”. Feminist post-structural theory questions “acute versus other” to understand how “other” is positioned as “less than” or seemingly “not as important” and how this is perceived, felt and experienced by those who are chronically ill and waiting. The hidden and untold stories were captured in this study through the application of feminist post-structural theory and discourse analysis. It is always the

“other” that can be better understood through a deconstruction of binary opposites and a particular understanding of relations of power. All of the participants in this study had to negotiate their care in the emergency department in different ways depending on their unique circumstances depending on their chronic illness, their beliefs about how they should be treated in the health-care system, who they had to deal with in the emergency department and the institutional rules around prioritizing care.

The Needs of Chronically Ill are “Housekeeping”

Some nurse participants also noted that chronically ill patients were treated differently compared to acutely ill clients. They gave examples of how care of chronically ill patients was affected by an institutional culture that predominantly focused on allocation of human and fiscal resources to the acutely ill. One of these nurses mentioned how some health professionals felt that treating chronically ill individuals with aggressive treatment in intensive-care settings was a waste of resources, while another nurse participant lamented how the needs of chronically ill patients were often dismissed by some doctors. Health professionals, including nurses, have been criticized for using the concept of “entitlement to treatment” to limit resources to those patients who are judged to be “more worthy of care” (Shaw, 2007, p. 36). According to Shaw, such beliefs about who is entitled to treatment or not arise from a health-care system that is struggling to come to terms with resource limitations and rationing. As a result of these discourses, some doctors and nurses have been expected to limit resources to those who deserve them most (such as the young and productive) or those who are more likely to comply with treatment (Shaw, 2007). Shaw (2007) contends such discourses may negatively influence the way professionals

respond or negotiate care with chronically ill patients.

Ray, a senior nurse who worked in various hospital settings, explained that when he worked in the intensive care unit, allocation of resources was a concern, and some doctors and nurses felt that admitting chronically ill patients into the unit was “a waste of time and resources”. He recounted an incident of an elderly gentleman who had Chronic Obstructive Pulmonary Disease [COPD] and who was in the terminal stages of his illness. Ray explained the reaction of some of the nurses when this chronically ill patient was admitted into the unit and how some nurses were “*horrified* [emphasis added] that this gentleman would still want everything done”. Ray explained that when he was looking after this patient, some nurses were reluctant to help him, because these nurses felt that this patient was a “bed blocker”. Ray explained that although the doctors and nurses did not believe this gentleman would make it through, this patient did go on to live another two years. Ray believed that everyone should be treated equally and fairly, including chronically ill patients, because they are “there for a reason”.

Ray: People do not get the attention that they deserve sometimes, because [staff] feel that people are bed blocking; and I really don't like that term, because people need to be there for a reason.

It is important to note the patient was also older and terminally ill. Ageism and terminal illness can intersect to marginalize some patients even more and create barriers to receiving optimal treatment. There has been considerable stereotyping and prejudice against older adults (Wilkinson & Ferraro, 2002; Yun-e Liu, Norman & While, 2013; Price, 2013). These stereotypes and discrimination stem from the belief that illness is to be expected and is part of the natural process of growing old (Nelson, 2005). The probability that chronically ill patients tend to be older, and that some of them may be

terminally ill, once more suggests that any participants who fall into this category are more likely to face multiple disparities when compared to other patients in hospital settings.

Another nurse, Irene, talked about the way some doctors dismissed care for chronically ill patients. Irene felt that some doctors were very busy and did not give chronically ill patients the attention they needed. They concentrated on acute situations and treated the needs of the chronically ill as “housekeeping”. She explained that she had to advocate for such patients.

Irene: And you know sometimes when chronically ill patients, doctors are “yeah, yeah, yeah”—very dismissive you know—they call them housekeeping; you know, minimal housekeeping orders. “What else”, you know [participant here suggesting that the doctors dismiss such issues], they might not seem big to them, but things often like out of the woods—you know, they may seem like little things, like creams for rash, or can you look at their legs. To them it’s like doctors are, they’re so busy, especially cardiologists, they just wanna [*sic*] know what’s the numbers; blood works and how’s his chest like, you know [participant here suggesting that doctors do not have time for what may seem minor issues]. Sometimes they are reluctant to order ... when chronically ill patients become depressed, you gotta [*sic*] look at that you know. “It’s not going anywhere”; whatever they have, it’s not getting any better, it’s a chronic disorder so...

The association Irene made between “very dismissive” and “housekeeping” suggests that she believed some doctors did not perceive some needs of chronically ill patients as being as important as the needs of patients with acute conditions. The meaning of the term “housekeeping” can be deconstructed and understood to be historically a reference to women’s work or housekeeping. It has been created through a predominantly patriarchal and hierarchical system in which women’s work has been positioned through relations of power as “less important”. Gender roles were further implicated by the way Irene talked about doctors. Irene believed that doctors, such as cardiologists, are “so busy” and they “just wanna [*sic*] know what’s the numbers [*sic*];

blood works and how's his chest like, you know". The language that Irene used suggests that certain doctors such as cardiologists are "too busy" and are more concerned with matters such as numbers and physical state, while nurses are the ones who are positioned to take care of the "little things" for the doctors who are too "busy to look at that". Science, objectivity, and treatment have historically been associated with more masculine attributes; whereas "little things," such as comfort and those that are often associated with caring, are associated with more feminine attributes. These discourses continue to perpetuate patriarchal beliefs and values about gendered roles and priorities in hospital settings. While this is changing (Amancio, 2005), it is important to understand how beliefs and values about chronically ill patients continue to be informed by social and institutional constructions of health and illness. These beliefs and values ultimately impinge on the way patients' needs are perceived by health-care professionals.

Irene also believed that doctors dismiss such concerns because "it's not getting anywhere", "it's not getting better", "it's a chronic disorder". This is also in line with a dominant biomedical model that is concerned with cure rather than care. Hall (2005) comments on how medicine has traditionally been focused more "on saving a patient's life not on a patient's quality of life" (p.191).

Although Irene believed that some chronically ill patients did not get the attention they needed because doctors dismissed their needs, she also believed that the way the hospital system "operated" also contributed to chronically ill patients receiving less than optimal care. She gave an example to illustrate this and why doctors were also reluctant to refer chronically ill patients for mental-health care when they became

depressed.

Irene: I think they should and they are reluctant to refer to mental health. And when mental health does come, they're reluctant to order anything, and they're, you know — it's a frustrating system, too, and things don't happen, like smoothly in place and you know like — there's always a delay sometimes in follow-up with another consult and stuff like that so [participant here suggesting that the hospital system is not very efficient in coordinating patient care between departments] you see that — you see the patients and that's nothing to do with what you're doing.

Irene also believed that the way the “system” operated also affected the way nurses negotiated care for chronically ill patients. She believed that the system was “frustrating” and did not “run smoothly” and for that reason there was “always a delay sometimes” in the hospital system when it came to meeting the needs of patients. While this inconvenience may exist for both acute and chronically ill patients, individuals with chronic illness may experience it more because of their repeated admissions to hospital and their multiple chronic conditions. For example, chronically ill patients may have referrals to multiple doctors, who need to communicate with each other to ensure continuation of patient care. The current health-care system does not seem to be well organized when it comes to attending to and coordinating the needs of patients suffering from chronic illness, an observation that has been noted by others and that has resulted in a number of improvement initiatives (Tomblin Murphy, Alder, MacKenzie, & Rigby, 2011). However, despite these efforts, the current system does not “run smoothly”.

Another institutional practice that hindered negotiation of patient needs was related to budgetary issues. These issues related to the hospital budget and allocation of scarce resources. Budgetary issues affect allocation of resources for both acute and chronically ill patients. Nurses in this study gave specific examples of how it affected negotiation of care with chronically ill patients.

Allocation of Scarce Resources

Both Marilyn and Lucille, two nurses, talked specifically about the allocation of scarce resources. Lucille explained how administrators pushed doctors to discharge chronically ill patients prematurely. As a result, patients were sent back to their homes before they were ready for discharge.

Lucille: Bed utilization. They hinder some days. I do not know if you are familiar with bed utilization. There are people coming around, like monitoring patients in hospital. How many days they are there or what they're there with. Mm, even the physician from the ... may call the physician and say this patient so and so should be home you know, so you'll have to answer for why they are there. The physician will have to answer for why they are there, what's going on with them—um, um—so it can be a—it's helpful to the hospital for people not being here longer than they should be right? But it can be a hindrance to nursing staff who feel there are still reasons for the patient to be there. You may need to be kind of patient advocate, in that manner.

Interviewer: Were, are you usually successful when you advocate?

Lucille: Yes! I think so. Oh yes, if the patient is not ready for discharge, but you may have to be a patient advocate.

Lucille's assertion suggests that although both nurse and patient may agree that the time is not right for the patient to be discharged, institutional practice may dictate otherwise. The above text illustrates two elements that exemplify how partnership between nurses and patients goes beyond negotiation on an individual level, and how institutional practices shape the trajectory of these partnerships.

The first element relates to financial planning and bed utilization whereby a “streamlining” process has been created for patients to be discharged. Lucille's comment that there were “people coming around, like monitoring patients in hospital. How many days they are there or what they're there with” is typically representative of a utilitarian approach that is used in health economics to justify distribution of resources in health care. The goal of this approach is to distribute resources in such a way as to

ensure the highest level of health possible for all people (Cookson & Dolan, 2000; Purilo, 1981). This funding system is driven by objective measures and targets that focus on results (Shaw, 2007). In this instance, bed management practice was to make sure to discharge patients as soon as they could be assessed by a doctor to go home, to make sure that hospital beds could be used by as many patients as possible. This system affects both patients who suffer from acute and chronic illness; however, it is based on medical and economic discourses and offers little service to chronically ill patients whose needs extend beyond this and who also require consideration of community support.

The second element that emerges from the above quotation relates to how the hospital system privileges doctors and authorizes them with the final decisions in relation to patient care. This has an impact on negotiation of care between nurses and patients since the doctor's voice is given more credit than the voice of the nurse. Although nurses are in closest contact with the patient, and possibly the ones who best understand their needs, they have no authority to discharge patients. This arrangement is typical in a patriarchal system in which those who are privileged maintain their position of power by having certain rights that are denied to others (Johnson, 2005, 2006). In this instance, it would be the exclusive right for decision making in relation to patient care. Hall (2005) explained that doctors are socialized during their training to assume an authoritarian role in health-care settings, and to take charge and leadership of patient care. As a result of this, they often struggle to share leadership with other members of the health-care team.

In the above example, we can see that the nurse spoke about needing to be a

patient “advocate” and that she was often successful in challenging doctors’ perceptions or orders to discharge patients. This highlights how nurses sometimes have to stand up for the patient and challenge the hierarchy that has historically been institutionally constructed between health professionals. It also highlights the nuances that are involved during negotiation of care between nurses and patients, and how such interactions are not simply a nurse-to-patient dialogue, but a more complex positioning of power relationships that are affected within the context in which they occur. However, despite the fact that the nurse’s voice is not as privileged in this type of hierarchical construction, there were instances throughout the interviews in which nurses managed to advocate for the patient with success. This suggests that the relationships may initially be binary and unequal, but nurses were not in a position of powerlessness. Lucille, a nurse who had more than 35 years of experience looking after chronically ill patients, explains that she had to advocate so that some patients were not discharged prematurely and many times her advocacy was successful. Lucille explained that she had to “wrangle” with doctors to get her voice heard:

Lucille: You know, you could be an advocate for a patient, you might have to actually; sometimes it’s very easy but sometimes, there are, there are issues with trying to be an advocate for a patient, but that time the doctor may be annoyed with you, and you may have to sort of wrangle to get—[takes a deep breathe in] you know, you may have to wrangle to get them to order something to the patient—or, mm, it's very much in nurses hands to look over that patient and make sure that you do that.

Lucille’s use of the word “wrangle” suggests that advocating for patients can be a power struggle with some doctors. It appears that a historical and patriarchal constructed relation between doctors and nurses continued to influence Lucille’s experience. Another nurse, Irene, had difficulty negotiating patient care with some

doctors and she believed it was because she was part of a profession that was predominantly female. Irene mentioned how some doctors were not “female friendly”

Irene: You know, not from a female friendly background, you’re trying to tell them and they don’t listen and they’re repeating “Is he on such and such medications?” “Yes, I just said that”. They don’t listen to women, and you’re trying to give a good assessment of “this is the patient that you’re presenting round” and you want a particular thing, they don’t address sometimes the issues that you bring up like, “I think he’s ... [inaudible words] he’s had a chest x-ray, you know, his blood work is good, but you won’t give him anything.

Interviewer: Would they be male doctors or female doctors?

Irene: Yes, they’re male doctors. We find it frustrating dealing with them. We had two in particular who are not female friendly, even to our female—when we do rounds—we have a pharmacist, she’s wonderful. Other cardiologists like Dr. [Name of doctor] they just love her, they would use her as a resource for medication and she would tell them “That’s not really the best medication, it has a lot of sodium, you should switch to this medication”. Well, this young cardiologist—um, um, he’s very dismissive with her, almost to the point of being rude, you know.

In the above example, Irene tried to challenge the dominant, medically-constructed relationship with this particular doctor by sharing the same scientific, objective and distant features that are often in patriarchal discourses. This exemplifies how less-privileged voices exercise their agency within a patriarchal system by negotiating care using certain scientific terms and language that are used in positivistic science, rather than narrative and experiential language that are often associated with women and qualitative research. Johnson (2006) states that when individuals opt for dominate discourses to negotiate social situations; they are following the “path of least resistance” (p.80). Johnson explains that in every decision-making situation, there are a limitless number of choices that we can make. All of these paths can lead to some social resistance from others, which may range along the gamut from mild disapproval

to torture and death. Johnson (2006) explains that the “path of least resistance is to do as they are told” (p.81). In this instance, Irene used scientific language and numbers as masculine discourses to get her voice heard. For some reason, she chose to follow the “path of least resistance” to communicate with this doctor, possibly because she believed that this particular doctor would disapprove of what she says and dismiss her on the grounds that she was female. This is an explicit example of how some doctors use the institutional hierarchy and practices to maintain their position of power and authority within the health-care system. In this instance, one might argue that the doctor was using his gender and/or his medical privileges to ensure his orders were followed. McIntosh (1998) describes this as “conferred dominance”; that is, when one group of people has power over another by virtue of belonging to a privileged group, in this instance, male gender and medicine.

Interestingly, though, Irene mentioned that not all doctors act this way, but “two in particular”. This suggests that not all males or doctors subscribe to patriarchal values. In fact, I will describe shortly how some oppose it. This is important to consider, for as alluded to earlier, patriarchy is not about individual men and women, but rather about how a system privileges certain masculine discourses over others. Further, it is a fallacy to think that some individuals who are considered to be in under-privileged positions are uniformly oppressed by such systems. If we use the lens of feminist post-structuralism, we must deconstruct the relations that exist between nurses, doctors, patients and the institution in a particular way and remember that powerlessness does not exist for individuals. On the contrary, all individuals must be seen to be active within interactions with others and are engaged with their own beliefs and values. For

example, some nurses in the study gave examples of how they resisted certain practices that had been formed by patriarchal beliefs and values, by embracing other beliefs and values and ultimately other discourses that were in conflict with hegemonic practices. Lisa provided an example of this, recounting an experience when she had an altercation with a male doctor. In her account, Lisa explained the hard time she had with one doctor who would not heed her request to send a terminally ill patient to palliative care. Lisa explained how she was able to get the doctor to consent to her request, which is an example of her use of agency.

Lisa: I said “you know”, and I said to him these exact words, “I cannot go in that room any more. My heart is broke” I said. “I cannot go in the room without crying.” I said “That man is dying in the bed, in front of his 41-year-old wife”, I said “I can’t—she can’t do this anymore, he can’t do it anymore and I can’t do it any more”. I said, “So - can we at least call palliative care or someone”. He says, “Well, yeah, OK, _____ [name of unit manager] is on call; here is her number” and he called me right back, and he said she’ll be in within the hour.

The above illustrates how emotive and expressive discourses that are often underprivileged feminine characteristics can be used creatively to advocate for patients. In the above incident, Lisa was enacting her agency by celebrating feminine features, rather than denouncing them. Feminine attributes have been discredited for being different from masculine attributes, and are often described using terms such as emotional, flighty or neurotic, all of which have negative meanings attached within this social context (Johnson, 2005; Mansfield, 2000); however, it does not mean that feminine discourses are not powerful or ineffective.

Chronic Pain Can Wait

The invisibility of chronic illness and allocation of resources were not the only aspects that seemed to marginalize and affect negotiation of care with chronically ill

patients; attitudes about pain management were one of the predominant findings in the study. At this point, it is worth mentioning that the majority of the patients (five out of eight) interviewed had chronic pancreatitis or Crohn's disease, and sometimes concurrently. One of the dominant features of both of these disorders is acute episodes of pain that are hard to relieve. It was therefore not surprising that chronic pain management was one of the salient issues that emerged from the data. All of the patients recounted episodes when they had pain and it was not given priority. Some of the factors contributing to this were institutional discourses. Other influencing factors were nursing practices and attitudes towards chronic pain.

One of the institutional practices that suggest that pain was not given priority was related to allocation of resources and how some of the participants encountered difficulties when it came to securing a bed in hospital for pain management. Two of the patient participants, Ruth and Beth, spoke about this. Ruth explained that the best way to control her pain was by infusing pain medication through a pleural catheter. This procedure involved the insertion of a catheter between the pleural membranes and the infusion of pain medications within this cavity. Ruth needed to stay in the hospital for forty-eight hours after the procedure. She felt that having a pleural catheter made a difference in her life. However, she explained how hard it was to get a bed in hospital for this procedure "because there's no bed, there's a real problem with beds". Likewise, Beth, who also suffered from pancreatitis, felt the same way. She said that by the time they got her a bed in hospital for the insertion of a pleural catheter, the pain was usually gone.

Beth: For the three days, I have to go to hospital, yes. Because like I say the pain is really bad, so when you need your, you need your, that thing

[referring to pleural catheter] done. Sometimes you have to wait months to get it done so if it's not too bad by the time they call, you have it under control. Sometimes I waited up to three months for a bed.

Ruth and Beth were not the only patients who experienced this frustration. Jack also had to wait to have his pain managed. Aside from his chronic lung condition, Jack also had pain in his feet from arthritis. Jack said that he had been on a waiting list for pain management for two years and he still had not heard anything from the hospital about his appointment. While arthritic pain was a concern in itself, it was also hindering Jack from following his pulmonary rehabilitation program for his chronic obstructive lung condition. At first glance, it may appear that there was not much these participants could do to secure a bed in the hospital. However, they chose not to be oppressed by the system but to exercise their agency. It is interesting to see the creative things participants did to get around these issues. For instance, Ruth explained that she was looking into the possibility of hiring a nurse for 48 hours to stay with her at home after the insertion of the pleural catheter. That way she would not have to wait for months to get a bed in the hospital. She got her doctor to write to her husband's insurance company so they would cover the expenses.

Patricia, who also suffered from pancreatitis but who did not have a pleural catheter, was also creative about her pain management. Having tried traditional medical treatment with little success, she resorted to seeing a naturopath, who seemed to have addressed her problem.

Patricia: I could show you my cupboard, it's sickening. What's in my cupboard for medicine, that I am supposed to be taking? All it is, is covering up symptoms, it's not actually fixing the problem. But while I am taking all this stuff, I am still sick, so why am I taking all this stuff? It's been different, after it was found to be a parasite [by the naturopath]. Nine years ago, I was out west, and I picked up the parasite out there. So hopefully, the naturopath is right and medical is wrong or something.

Patricia's way of dealing with the problem was creative. However, her words "so hopefully, the naturopath is right and medical is wrong or something" indicate that she had lost trust in medicine and that she was challenging the dominance of scientific medical discourses. In other words, she was cautiously challenging the medical discourse that medical knowledge was the absolute truth and the guiding principles that patients should follow. Interestingly too, is the reaction of some doctors about her decision to seek care outside the medical system. Whereas one of her doctors resisted and debunked such practices, his wife, who was also a doctor, supported them. Patricia stated:

Now if you ask medical doctors—I had two doctors, um, one I don't see any more because he only does emergency hours, so I see his wife, and she's completely for naturopathic. She's like: "We can't find what's wrong with you. I don't care, just get better! I don't want to see you like this, just get better". So she was very for this procedure which was effective, cause [*sic*] again it makes you feel good that like—being judged and being criticized just by doing something outside the norm. So she's been really really [*sic*] good. He, not so much! [Pause] So, I'm hoping that he's *wrong* but again, it's, it's different, it's outside your norm, it's not your medical world that you always put your trust in for years. Like it's something different.

The above demonstrates how there are multiple discourses, however, it also illustrates the pervasiveness of a patriarchal discourse and how it has infiltrated the lives of individuals. The fact that Patricia was resorting to a naturopath is an example of another discourse that exists outside orthodox medicine. Patricia may be perceived as deviating from the norm by seeking the advice of the naturopath, whether the doctor endorsed it or not. However, the fact that Patricia still consulted the doctor before contacting the naturopath, and the fact that the female doctor made Patricia "feel good" about her decision, suggests two things. First, it suggests that Patricia felt uncertain and had self-doubt about stepping outside the dominant conventional system. Secondly, the

fact that Patricia still sought their approval illustrates the impact doctors have in everyday life, and how their word is seen as more credible in a predominantly patriarchal society.

Interesting, too, is the way doctors maintain their position of authority by continuing to support medical practices and ultimately medical discourses that privilege them. The male doctor in this example certainly dismissed the participant's choice of naturopathy. The literature affirms that many medical professionals do not endorse these options because they are not "scientifically based". In their paper, *Science: a masculine discourse*, Bowling and Martin (1985) write about how patriarchy can define what is science and non-science, and create boundaries between the two. These boundaries privilege science, and laud it for its rigor, objectivity and stability. By so doing, these boundaries are valuing those characteristics that are often associated with men, and thereby helping to maintain male dominance in society. These authors explain how knowledge that is allowed into the "scientific pantheon is that which is sanctioned by professional gatekeepers" (p. 313) and how popular knowledge, such as naturopathy, is dismissed as unscientific even if it is "useful, accurate and systematized". Although this paper was published some time ago, Patricia's experience suggests that such beliefs still persist. However, things are changing and threatening the authority of patriarchal discourses in society and institutions. As the nature of science changes and embraces more qualitative studies that are associated with the social world, this androcentric concern with science and rationality is expected to change (Amancio, 2005).

For instance, the fact that Patricia was seeking assistance outside traditional medicine also confirms Foucault's (1969/1972a) precept about the instability of dominant discourses, how their dominance is determined at a local level, and how they are

constantly under threat. Foucault (1969/1972a) contends that the truth that institutions allege to have is nothing more than specific discourses and truths in their specific historical context. Foucault claims that authoritative discourse is that knowledge which emerges triumphant from this battle of competing disciplinary discourses, all of which claim to have the truth. It is imbued with contradictions, unanswered questions and cultural prejudices (Danaher et al., 2000). However, according to Foucault, these discourses are not fixed, defiant and enduring, but subject to change. For this reason, he argues that despite the fact that “regimes of truth” have certain solidity about them, they are constantly under challenge and subject to change. Consequently, some health-care professionals are continually struggling to deploy ways and means so as to ensure that their privileged position is upheld and maintained.

Interesting, too, is the fact that the female doctor was open to other discourses outside science. This suggests that not all doctors have the same values, practices and beliefs. This doctor’s practice can be interpreted as an action that is paving the way for the acceptance of non-scientific discourses such as naturopathic practice into a patriarchal world. This possibility confirms that the definition of science is changing and starting to embrace narrative and experiential studies. However, systems change over time. Demographics have changed and current studies indicate that rates of women enrolling in medical school have now increased in most countries (WHO, 2014) and in Canada (CIHI, 2012). The medical world ratio of male-to-female doctors is anticipated to flip over in the near future (Levinson and Lurie, 2004; Winyard, 2009). Female doctors are now also in command of power, and as they continue to increase in numbers they are helping to create diversity within a patriarchal system. This deluge of female doctors in a

patriarchal society may have two effects. It may perpetuate and reinforce the current patriarchal discourse, or it may create opportunities for female doctors to create diversity by bringing in other discourses that are associated with feminine characteristics such as compassion and caring. The possibility that female doctors may bring these alternative discourses into the medical arena shows promise for democratizing medicine and making it more open to popular discourses that are embraced by the community. Levinson and Lurie (2004) describe this as the “feminization of medicine”. Levinson and Lurie see this gender shift as possibility affecting the way patient care will be delivered. These authors anticipate that female doctors are more likely to actively involve patients in their care, and to embrace multidisciplinary team approaches. However, this does not preclude the possibility that female doctors may still take up and embrace medical discourses that have been put forth by men. In a study that explored practice orientation of physicians, Krupat et al.,(2000) reported that female physicians were more patient-centered, and that their practice orientation was in non-linear fashion. However, when Jovic, Wallace & Lemaire (2006) explored the perceptions of internal medical physicians on gender shift in the medical profession, there was no significant difference in the male and female physicians’ attitudes and behavior towards patient care. This finding suggests that although the introduction of female physicians may bring diversity to the medical profession, it does not preclude the possibility that female doctors may still take up and embrace medical discourses that have been put forth by men.

Nursing Practices around Pain Management

Although chronic pain was not perceived as a priority in hospital settings, this inadequacy cannot just be attributed solely to the way institutions and doctors create and

maintain a hegemonic system that is influenced by medicine and patriarchal values and beliefs. Almost all patient participants in this study complained at some point about how nurses' practices around pain management were not optimal. For instance, some participants spoke about nursing practice around pain management on the units and how these practices hindered patients from negotiating pain management effectively with nurses.

Most of the time, Beth had no problem negotiating her care with nurses. She said being physically able to attend to her "personal hygiene" was helpful. The "only time" Beth needed nurses was when she needed "medication". She said that on the whole, she always got her pain medication on time and that she never had to wait for more than "fifteen minutes and that's stretching it". She also mentioned that getting pain medication every two hours on a regular basis was "great". The only problem Beth had was during shift change. This hospital practice resulted in unnecessary distress and delays to her negotiation for pain medications. She repeatedly used the words "nothing happens during shift change" to emphasize her point. She explained how after shift change, nurses "have their popcorn" and took time to "talk to whoever has come back on the floor", rather than to "go back to the patients". She said "they don't care" what happens to the patients at "that hour" and that "you could be dying", for "nothing happens during shift change". This participant found such actions "hard" to take. She laments:

Beth: It just happens so many times, like there wasn't just one time when I needed the medication and it wasn't available; it's been many times. Like I said, he [referring to her husband] came in and I was crying and screaming, and they didn't care, they don't care. That hour, it seems to me, it's their time to relax, talk to their friends on what happened that day, and that's their time and it doesn't matter; and it happened more than once.

Beth also spoke about how she believed the nurses were aware of this situation. She explained how once her husband went to ask the nurses for pain medication for his wife, and the nurses replied that “nothing happens at shift change” and that “she has to wait like everybody else”. Beth believed that it does not take long for the nurse to “draw a needle” and give the patient their pain medication and that “something should be done” about this change of shift inconvenience. This inconvenience is an example of how institutional practices maintain control over patients. The reader may recall Foucault’s (1975/1977) notion of timetabling, and how work in a health-care system is structured to fit a timetable, rather than the needs of patients.

Another example of how institutional practices affected negotiation of care with patients could be seen in nursing practices during routine drug rounds. Drug round is a nursing task whereby one nurse is delegated the administration of medicine to all patients on the unit. It seems that this was the practice on one unit; that one nurse would do the drug round, and get around to patients when their turn came. Ruth believed that if there was more than one nurse available to do the drug round, she would not have had to wait for the nurse to make her round before she got her pain medication. Ruth explained how she rang the bell for the nurse at five o’clock in the morning for pain medications, but the nurse did not come. She rang the bell again at seven o’clock, but the nurse hollered at her and told her that she had to wait because she was not the sickest person there. Ruth felt small and unimportant.

Ruth: When I was out on the XX, I had pancreatitis. Five o’clock in the morning I woke up, and I was in bad pain. So I rang the nurse, and she didn’t come, she didn’t come, she didn’t come. At seven o’clock, I buzzed again “*I’ll get you when I’ll get you.*” [Emphasis added]. Eight or nine o’clock, she went and gave the lady next to my bed her puffer. I said, “You just gave her puffer and I have been buzzing you since five o’clock”. She said, “I’m the only one on this floor giving

meds. You're not the sickest person on this floor" and I said "Is that right? Maybe I should call the administration and ask them if they have another nurse who can give a needle". She made me feel like that big [indicates with her fingers, a very small space].

The practice on the unit was that Ruth was expected to let the nurse know when she needed pain medication. The only way she could let her know was to ring the bell and to ask the nurse for medication. This practice on the floor did not work for Ruth. The fact that she was made to wait hours before her pain was attended to, and the fact that the nurse made Ruth feel insignificant for asking for pain medications, when there were sicker patients on the floor, suggests that pain was an issue that could wait. Ruth mentioned how nurses made her feel like she was putting them out when she asked for pain medications and how after a while she would "stop to hit the buzzer and ask the nurse for a needle". In other words, she would refrain from making any efforts to negotiate her care with nurses by calling them to give her pain medication.

The above situation also shows how these participants were subject to a particular discourse that reflected a patriarchal system that predominantly positioned patients with less power and control (Johnson, 2005). The above experiences reveal how institutional discourses maintain a patriarchal culture by ensuring the experts remain in a position of power. In this instance, institutional discourses privileged nurses by placing them in a position of power when it came to medication administration and giving them control over the medication cart. However, although power relations between nurses and patients may be unequal, the patients were not powerless or silent within the institutional hierarchical structure.

In the above incident, Ruth resisted being marginalized by threatening the nurse and telling her "maybe I should call administration". Ruth was prepared to use

institutional hierarchies to enact her agency. Johnson (2005) explains although one cannot control whether or not one participates in a patriarchal system, simply because of its pervasive nature and how it has permeated social institutions and the lives of individuals, one can control 'how' they participate. By this, he means that the individual has an opportunity to choose whether to participate in some situations which perpetuate hegemonic patriarchal practices or not. However, choice is not a simple action. One may need to creatively think, talk and act along the way. This is why it is so important to hear the experiences of participants to better understand how they negotiate their care or the care of others.

Further, even though the current patriarchal institutional system may be hegemonic and ultimately oppressive for many patients and nurses, this does not mean that institutional practices cannot be changed or even that all institutional practices are oppressive. There are many institutional practices that are supportive and work well for patients and nurses and I refer to these discourses in later chapters. However, in this case Ruth believed that if the practices within the institution changed so that pain medication was given on an around-the-clock basis, her pain would be better controlled. She would not have to call the nurses, and she could always refuse the medication if she did not need it. In other words, she was asking for what Beth [above] got: pain medication on a regular basis.

Ruth's comments highlight that institutional discourses are not set in stone. Because discourses are constructed through the beliefs, values and practices of people, there is the potential for change. As Foucault (1975/1977, 1980) and feminist post-structural theorists explain, the individual may be "subject" to these discourses, but they

can enact their agency by choosing how to deal with them so that they limit the chances of being oppressed. Despite the patriarchal influences that still exist within the current institutional system, Ruth and Beth gave examples of how they believed nurses were in a position to facilitate these changes. These two participants appreciated when the nurses took initiative and called the doctor to update the medication order as needed. Therefore the above demonstrates that while nurses may be subject to institutional discourses, they can also act as agents to facilitate the patient's negotiation for better pain management. Once more this shows the complexity involved in negotiation of patient care and how it extends beyond the nurse-patient dyad.

Labelling, Stereotyping and Marginalization

Another institutional practice that impinged on negotiation of care between nurses and patients and that was related to institutional practices, was when patients were labelled, categorized and marginalized. Participants felt that some nurses had certain prejudice about people who were constantly seeking pain medication. These prejudices resulted in creating stereotypes and in labelling some chronically ill patients as "chronic complainers" or "drug seekers" and as a result they were treated differently and their needs were not attended. Foucault (1975/1977) and feminist post-structural theorists write about labelling and stereotyping, including how such labels are used to separate individuals from others, and how labels can be used to reward those who fall into mainstream categories or to punish these individuals for being different from the rest.

Certain dominant beliefs and values about substance abuse were applied to two participants in this study. Ruth mentioned that she "dreads" going to hospital. She explained that she hated having to go to emergency not only because of the long wait

time, but also because of the way nurses treated her. She said that she would see the nurses literally “roll their eyes” when they saw her coming in. She said that she was labelled as a “frequent flyer” and it bothered her when nurses gave her the impression that she was “putting them out of their way” to look after her. She also said that nurses thought she went to emergency “to get needles”. Ruth cited a number of incidences when she had altercations with the nurses in the emergency department and on the unit, because some nurses did not believe she was in pain, but rather was there to seek drugs.

Patricia also “hated” going in hospital, partly because she believed that “nobody likes to go to hospital”, but also because of the “negativity” she faced. She described various experiences when she was not able to receive pain medication even though she tried to negotiate with the nurses because the “nurses passed judgments” on her.

Patricia believed that the fact that she “was young and appeared healthy” may have led some nurses to stereotype her as an alcoholic or as a drug-seeking addict. When she was first diagnosed she explained how she was “constantly trying to convince them that I was not an alcoholic”. Other nurses did not think she was really in pain and the reason why she wanted pain medication was because she was drug seeking.

Patricia: Like, causing people to get a judgment thing, like, well, she fits the age of other people who are going and breaking in places and stealing pain meds, or buying pain meds off the street, so, mm, she falls in that category because she doesn't have broken bones, she doesn't have cancer, and she doesn't have any [long pause] debilitating [*sic*] of disease, like of, that we deal with on a regular basis. I think that thing causes the negativity and I think that does play a role in some people's mind. Again it's, “She's drug seeking”.

These beliefs and values about youth and substance abuse had negative consequences for Patricia when it came to negotiating her care. Sometimes when she asked for pain medications she would get “negative attitudes” from certain nurses. The participant said that she would get “snippy remarks, I would get dirty looks, I would get

an attitude like 'you don't need it". At one point she was lying in bed in pain and asked for her pain medications. When the nurse came she "yelled" at her and told her: "You do not need pain meds, you are fine, you do not need pain meds, you just need to lay there and relax."

Patricia cried when this happened and stated that she "felt horrible", "insignificant" and "stupid". She also started second-guessing herself as to whether or not she was "drug seeking". Patricia explained that there were times when she was made to "wait for an hour, two hours, three hours" before her pain medication was given. As a result, Patricia preferred to negotiate her care by not asking for her medications and by suffering in pain because she did not "want to deal with all that criticism and stuff". She dealt with these situations by trying not to bother the nurses and ask for medication, because she knew the outcome would be negative. She did this to protect herself from criticism and negative repercussions.

Patricia: So I found it really hard, for me, um, when I was in pain I wouldn't try to ask for my pain meds or I wouldn't ask for something to try to help me like—like relax; not relax, but like make me feel better, because I didn't want to deal with all that criticism and stuff.

The above assertions indicate the negative repercussions of being categorized, labelled and stereotyped. However, such discourses about drug seekers also need to be interpreted in the larger social and institutional discourses. The beliefs and practices about drug seekers going to the emergency department to keep up with their addictive habits are real and do exist; however, it does not mean that all patients should be seen this way. Both Ruth and Patricia had to struggle with nurses to show that they did not fit these stereotypes and that they needed opiates because they were in pain. This finding is not new. Findings in the literature indicate that chronically ill patients are

often under-medicated for their pain, and often labelled and stereotyped as drug addicts. This situation often arises when physicians develop difficulty in achieving a balance between treating chronic pain and preventing dependence, tolerance and addiction (Gouraly, Heit, & Almahrezi, 2005). As a result of this fear, doctors may under-medicate chronically ill patients for their pain, thus causing these patients to frequent various emergency departments for medication and exhibit drug-seeking behaviors (Fosnocht, Swanson, & Barton, 2005). Weissman and Haddox (1989) called this behavior pseudo-addiction. They explained that this behavior is often mistaken as addictive behavior, when in reality it reflects under-treated pain.

On this note, McCaffery et al. (2005) solicited nurses to find out what they meant when they used the label “drug seeking” for patients who frequently requested opioids/narcotics for pain relief. These authors found that nurses failed to consider other circumstances about why patients may exhibit drug-seeking behaviors, other than addiction or substance abuse. Consequently, these authors concluded that the term “drug seeking” is “ill defined, is stigmatizing and conveys no well-established criteria for concluding that the patient does or does not have addictive disease” (p.133). On this note, these authors buttress the position statement by the American Society for Pain Management (2002), and recommend that the term “drug seeking” should not be used as it results in “prejudice, bias and barriers to care” (p. 122).

Exposure to Different Discourses Helps to Break Stereotypes

It is also interesting to note that in specialist areas, where health-care professionals understand disease in more comprehensive ways, Patricia did not have such “negative experiences”. In fact, she claimed to have had the opposite. She explained that she had

“two completely different outlooks on nursing staff” between nurses in a particular general hospital and nurses in a specialized hospital.

Patricia explained that the best care she got was when she was sent to a hospital that specialized in gastro-intestinal disorders. She mentioned that she did not experience the negativity and judgments that she faced when she was a patient at the hospital, where they labelled her as a drug abuser. Patricia explained that the reason for this was “because they have seen more of it [pancreatitis] in [name of hospital], they have their hospital and chronic cases go more there”

Patricia: Because I was in a GI section, so it’s specifically just for GI patients, and I still was the youngest person there, *but* [emphasis added] they have seen other patients my age, similar to my age, within a reasonable ten years. So, they would see more there more often, versus here [general hospital] there is smaller communities, smaller population, so when I’d be in the hospital, like there would be me and the youngest person would be like in the 70s, so I found, well, I’m just kind of assuming that they would see more up there.

She said in specialized hospitals, nurses believed her when she mentioned that she was in pain and they did not make her feel “insignificant”. Patricia explained that she felt that she was treated with respect when nurses believed that what she was saying or experiencing was true, and that she was “not making this up”. This example of a positive negotiation appears to be based on respect and open communication.

Patricia: They were all over trying to help, to try to resolve it? So, um, with knowing, like with me knowing the disease, knowing, like in _____ [name of hospital], knowing my body, they, I feel they, up there, they do treat me with respect and they understand. I am taken seriously. Like they know that I have been dealing with this for nine years, but I’m not making it up kind of thing.

Patricia valued when no judgment was passed and when nurses believed her.

Negotiation of care was more positive in such instances, the nurses understood Patricia’s needs, a mutual agreement was reached and the outcome of negotiation was positive.

Patricia explained how nurses on these units were nicer to her and they were there to help

her and to make her comfortable. The nurses checked on her and made her comfortable by changing her position, and giving her pain medications as required. In such situations, there were no moments of tension. Patricia did not have to struggle to convince nurses that she needed pain medication, she simply asked for what she needed and she got it.

Patricia: I had two nurses - they were *amazing* [emphasis added]. They were in every twenty minutes, half-hour, checking to see like “How are you doing now? Can we do something to make you comfortable? Can we reposition you? Can we”, um, I guess, “Is there anything that we can do or help you get up”, or if I had to do anything. There was no negativity, they’re actually like, I actually felt that they were there to help me, they were there to support me, they were there to help me through this part.

Simply showing no negativity, being positive and asking how she was doing made it a good experience for Patricia. In such situations, she felt nurses respected her and she was treated as a “*person* [emphasis added]”.

Patricia: They respected me. They m-a-d-e [pronunciation dragged] me feel like *a person* [emphasis added]! Like they made me feel like, I knew what was going on and, mm, well, this was a completely new experience to me, so what I didn’t know they were able to help me with it and they respected me, it was great.

What Patricia noted is significant. The nurses in both hospitals may have had similar training; however, Patricia said that the reason why she got better care in these hospitals was possibly because those nurses who worked in specialized areas may have had more exposure to or specific training about chronically ill clients and their need for pain medications.

Patricia’s use of the term “person” is also significant. It implies that when nurses respected her, she felt treated like an equal, but when nurses did not respect her, she felt she was depersonalized and reduced to the level of an object or non-human being. In this sense one can say that respect plays a pivotal role in ensuring that the patient is valued as an individual and in ensuring that their relations of power are equal to the nurse when it

comes to negotiation of their care. Mallock and Porter O'Grady (1999) remark that partnership is a humanistic process in which nurses assist patients to resolve health-care problems. These authors mention that nursing qualities such as trust, respect and compassion help patients deal with their suffering and help nurses to make partnerships with patients.

Patricia also felt that the main reason why she had difficulty negotiating care with doctors and nurses was because "there is a certain narrow mindedness". From her experience, both nurses and doctors needed to be open to other possibilities outside the norm. Interestingly, exposure to chronically ill patients and experience are not the only ways that nurses can challenge stereotypes. Listening to patient expertise is also important. Listening to patients' stories is important as their beliefs, values and practices/experiences may offer alternative discourses to current dominant medical discourses. Accepting and believing patients' experiences and expertise and finding time to listen were issues which all participants talked about. These areas will be expanded on in the following chapters.

Chapter Summary

In this chapter, I discussed how negotiations between nurses and patients go beyond the individual interaction, and are heavily shaped by institutional discourses. Patients explained that overall their hospital experiences with nurses were good; however, there were times when patients felt that they were not able to negotiate their care with nurses successfully. This tended to occur as a result of certain institutional values, practices and beliefs about chronic illness. Two main areas about how institutional discourses may affect negotiation of patient care were identified. The first

relates to institutional discourses within hospital settings, where acute illnesses were privileged over chronic complaints. The second issue related to chronic pain management.

Overall, the above experiences illustrate how patriarchal discourses dominate the health-care system, and how acute care settings remain focused on addressing the needs of the acutely ill, even though most beds in hospital are now occupied by chronically ill patients. The results also demonstrate how the hospital system is informed by patriarchal beliefs and values that have permeated the institutional culture, and the work-life of health care professionals. However, this does not mean that less privileged voices, such as those of patients and nurses, were silenced. Findings from the study reveal that despite the unequal power relations, many times patients resisted professional authority. Nurses also challenged patriarchal discourses and were able to advocate successful for some patients.

CHAPTER 7

THE TWO FACES OF PATRIARCHY

In the previous chapter, I discussed how the current hospital system is based on a patriarchal system and how hospital practices shape negotiation of care between nurses and patients. These institutional discourses did not affect negotiation of patient care in a unidirectional style, but appeared to be diffuse and to affect nurse-patient negotiations in a variety of ways. They ranged from hospital rules and regulations about priorities of care and allocation of resources to more insidious and pervasive ways that shaped the health-care professionals' and nurses' ways of thinking and behaving towards chronically ill patients. These findings illustrate how negotiations between nurses and patients cannot be viewed from a positivistic ontology of cause and effect, with the nurse-patient dyad as one unit, and institutional settings as a separate entity that impinge on the nurse-patient dyad from the outside. Rather these findings illustrate how partnership is a complex relationship in which the nurse-patient dyad is not a separate entity from institutional discourses but deeply embedded and entwined with each other.

In this chapter, I go a step further to illustrate how the hospital hierarchical system is embedded in patriarchal ideology that continues to reinforce expert-patient binary. In chapter five, I mentioned how two patients felt comfortable with health-care professionals taking over their care; however the rest of the participants indicated that they did not want to take a passive role during negotiation of their care, but they wanted to voice their concerns. These situations tended to arise when patients' knowledge about their body was in conflict with the knowledge of the nurse, and the patients contested it. Nurses reacted differently when their position of expertise was challenged. Some nurses

were open to this power shift, but others guarded their position of power. When the patients' input was not acknowledged or was ignored, there was a moment of tension between nurses and patients. When altercations arose, some nurses used their professional privilege to maintain their position of power, and as a result negotiations from the patients' perspective failed and the patients suffered.

These findings fit with the characteristics of a patriarchal system in which the voice of the expert is privileged over the voice of the layperson. This results in costs to underprivileged groups such as patients simply because their voices are not acknowledged. However, although institutional discourses may appear hierarchical, they are not necessarily always oppressive. Just as institutional discourses may privilege nurses and other professionals, these discourses may privilege patients, too. In this chapter, I will discuss how some of the patients used the same institutional discourses that marginalized them from care to resist nurses' position of power and to prevent further marginalization.

A more detailed description of these results is discussed under three sub-themes: *understanding patients and acknowledging their expertise; institutional discourses that re-enforce the nurse-patient binary; institutional discourses that privilege patients.*

Understanding Patients and Acknowledging Their Expertise

I already mentioned in the first chapter how being a frequent user of the hospital helped the nurses to understand the participant as a person, and to develop more sensitivity towards their needs. However, despite the fact that all participants had positive experiences with nurses, there were also moments when some nurses maintained their authoritative position and distanced themselves from patients. In such situations,

patients felt that they were not in a position to negotiate their needs successfully with nurses because nurses did not understand them. Most of these situations arose when nurses did not believe the patients had expertise about their body. Below is an example of one situation.

Anne: So I went in [unit], and I must say the nurses once again, were very good, um, now and then you'll run into a nurse in _____ [name of unit] that really don't understand. You could tell the way that they don't understand by the way they treat you, speak to you. Because you know, maybe they'll talk down to you, or talk in front of you about your illness, not respect the fact that you are, really, hearing all this and it's not going to help you get better. If you realize that the people that are looking after you don't understand the complexity of your issues.

Anne believed that some nurses did not always understand patients. Anne mentioned that she could tell that some nurses did not understand the “complexity” of her issues by the way they spoke to her and by the way they treated her. She commented that some of them talked down to her or talked about the patients' situations without including them in the conversation or without regard to their feelings. These observations suggest power relations were not balanced and that nurses were negotiating care from an authoritative position. Ignoring the patient also suggests that nurses were negotiating care from a distant position. In this situation, one can say that negotiation of care was not optimal; these nurses could not understand Anne's needs, her contribution was not acknowledged and therefore care planning was neither patient centered nor mutual.

Anne was not the only one who felt that some nurses did not understand patients. Other participants mentioned various experiences in which they were unable to negotiate their needs successfully with nurses because nurses did not believe the patients' knowledge about their body/condition. Lack of acknowledgment of patient expertise about their body/condition was experienced by all eight participants. In all situations, the patients believed what they were experiencing was real; however, they were unable to

negotiate their care because their input was not acknowledged. Ignoring what the patient had to say left many of the participants feeling frustrated and at times resulted in conflicts between nurses and patients. Patricia commented that nurses needed to acknowledge the patient's expertise, and that nurses should not "be there to belittle them and be, like: 'I'm a nurse, I know it all!'". Although both Anne and Patricia had many positive stories to share, both participants mentioned at least one occasion when their negotiations with nurses went astray because nurses did not acknowledge the patient's input. Both Anne and Patricia said that in such situations, they preferred not to speak up if they knew that nurses or doctors were going "to ignore it".

Anne: Yeah, it's like your opinion, it's your body, but your opinion and your knowledge is really not important to them. Because they feel they know more than you because they're a doctor, or they're a nurse. And unless maybe if I were a nurse or a doctor or something, maybe they would have heard me or paid attention to me, but you would almost get to a point if you were in that situation a lot where you wouldn't even mention how you felt, if you knew they were going to ignore it.

Anne's comment that "if I were a nurse or doctor or something, maybe they would have heard me or paid attention to me" suggests that less privileged discourses such as voices from patients may be marginalized in a patriarchal system. In an attempt to prevent being silenced by patriarchal medical discourse, many of the participants chose to be well informed about their medical condition and to use the same language as health-care professionals to negotiate their care. These patients felt that by using the same language as those in the medical profession, they were in a better position to negotiate their care. One such patient was Fred, who suffered from refractory epilepsy and gastroesophageal reflux disease (GERD). Fred was extremely well informed about all his medical and surgical conditions. During the interview, I was impressed by how widely read he was, and how much he researched issues relating to his health. Fred kept himself

updated on the latest innovations in the management of his illness. Both he and his wife explained that they “do a lot of research” and “ask questions” of the doctor. He explained that he had “intractable epilepsy for twenty-six years” and jokingly said that he “knows a bit about it”.

Fred believed that one should study and be well informed about their medical condition. Although he did not explain why he thought this, Fred did say that he used his knowledge to ask for and receive the latest treatments that were available for the management of epilepsy. His wife explained that they “are always back and forth with information” to their neurologist, and how they are “always telling him the newer drugs” and asking if Fred can be put on them. She explained how the neurologist was impressed with their persistence to seek the latest information and how they “never give up”. Fred was surprised that some nurses did not have the same level of knowledge as he did, and he was even surprised that one doctor did not even know about the latest trends in the management of seizures. He explained that in such situations he used his knowledge to teach health-care professionals any information they did not know. I asked Fred what the reaction of nurses and doctors was when he was sharing this information. Fred said that for the most part nurses “were happy to learn about it” and the participant himself hoped that they had “learned a bit” from him.

Fred said that he “felt good” when nurses respected his knowledge and perhaps learned from it. Evidently, Fred was very effective in negotiating his care. Instead of feeling incapacitated when the nurses who looked after him did not have the required knowledge, he took the onus to teach nurses about issues that concerned him, so that they would be able to take good care of him. The fact that some of the health professionals

stopped to listen and take heed to what Fred had to say helped Fred to negotiate his care better. This finding shows that not all nurses embrace patriarchal discourses. Some are willing to embrace new discourses about patient expertise, and willing to surrender their position of authority to negotiate care with patients. It can also be interpreted as an astute way that nurses/doctors used to deal with the perhaps awkward moment when their expert knowledge and position of control were challenged, simply because Fred also had the privilege of medical knowledge and proved to be more updated on this medical condition. This observation is noteworthy because it challenges and in this case reverses the expert-lay binary. It demonstrates how as a result of the current profusion of medical information through the media, at times health-care professionals' position of expertise is subject to patient scrutiny. It also illustrates how professionals deal with such challenges. Instead of investing in a power struggle and asserting the existing power hierarchies, these experts chose to accommodate Fred's knowledge and acknowledge his expertise.

However, not all nurses were receptive to Fred's way of negotiating his care. I will discuss shortly an experience he recounted that demonstrated how one nurse certainly did not value his knowledge, respect his wishes, or attend to his needs. Other patient participants cited other examples. In these situations, we might conclude that some nurses used their privileged institutional position to maintain their authority.

Institutional Discourses that Re-enforce the Nurse-Patient Binary

One way to easily identify how institutional medical discourses tend to privilege health-care professionals is by examining situations in which a doctor's or nurse's expert or authoritative position was challenged. These moments included situations in which patients like Fred challenged the nurses' authority by complaining about the service, or

when patients had a different opinion about their condition compared to the health-care professionals they were dealing with.

The Nurse as a Gatekeeper of Services

Fred recounted an incident that happened when he had Nissen fundoplication, a surgical procedure to eliminate the undesirable symptoms of gastro-esophageal reflux disease (GERD). Fred explained how after surgery, he had his naso-gastric tube removed prematurely. His stomach was full of secretions, but because of the nature of the surgery, he was not able to vomit. These secretions were creating pressure on his incision and inducing pain. His ability to retch but not to vomit was causing extreme distress; however, when he rang for the nurse for assistance, the nurse insisted that he should try to vomit. Fred mentioned that the nurse said “[I’ve] been a nurse for 23 years, you *can* [emphasis added] vomit” and proceeded to get him “a container”. Fred told her “[If you] knew a little about the surgery I had, then you would understand that I cannot vomit”, to which she replied “That doesn’t matter”. Instead she told him: “You don’t know what you’re talking about! Relax”. As a result, Fred was not able to negotiate his needs, his input was not acknowledged and partnership did not develop.

Fred: It made me feel bad, because when I started to explain to the nurse that night that I was retching, she said, she said, she said like “You don’t know what you’re talking about! *Relax*” [emphasis added] and like I said, the only person that could probably have helped her that time was a doctor; a doctor knowledgeable and I am sure they would have explained the situation.

Fred did not know how to negotiate his care with the nurse at this point. He told the nurse “I don’t know what I’m going to do. Call emergency, call the doctor and get the doctor up here. He will tell you what to do”. Being a frequent user of hospitals, Fred knew that there would be “doctor on call, or the doctor in emergency” and he tried to use

his knowledge of how the system worked and asked the nurse to call the doctor. He felt that if the nurse did not respect his knowledge as a patient, she might respect the knowledge of the doctor. In so doing, he was trying to negotiate his care by using current patriarchal discourse to his advantage. However, Fred's efforts were to no avail. Fred explained that since the nurse would not call the doctor, he asked her to call his wife. The nurse preferred to call Fred's wife at 3:00 a.m. and have her come in and calm her husband rather than call the doctor in the emergency as Fred requested. Fred explained how he suffered physically and emotionally because the nurse would not listen to him. He looked visibly upset when he recalled this incident, and stated: "It was a nightmare; I can't get it out of my mind".

The above experience was disturbing to Fred and even to me as a listener. It can be interpreted as a moment of tension that escalated to a calamitous situation because the nurse chose not to relinquish her privilege of expertise. Maner and Mead (2010) wrote about leadership and power. They explain how leaders are responsible for helping groups attain their goals and are endowed with the privilege of power, which may at times be challenged by group members. Maner and Mead (2010) explain the options that leaders have when dealing with situations in which there is tension between leadership and power. They may wield their position of power to help others, or to use this position in self-serving ways to maintain their position of authority. In this instance, the nurse as a leader used her authoritative position to maintain control in the relationship. During this moment of tension, the patient used his knowledge to try to explain to the nurse, and also his institutional know-how to get her to call a doctor in the emergency department. However, despite both parties exercising power, the relationship of power between the

two of them was unequal and the patient suffered. The nurse told Fred he was “acting out of order” and proceeded to do what she believed was best for the patient in this circumstance. Although Fred’s preference was for the nurse to call the doctor, the nurse did not do so.

Analysis of the above text suggests that in this power struggle, institutional discourses privileged this nurse. It is one of the institution’s practices to endow the nurse with decision making in relation to patient care and as the gatekeeper of health-care services. In this instance, the nurse was the only one who had the institutional authority to contact the doctor and she decided whether to call him or not. As the current institutional policy stands, patients are not in a position to contact the doctor even if they want to contact him or her. The only way that they can get to do that is to ask the nurse to call the doctor. Clearly institutional discourses privilege the nurses in this regard.

The fact that the nurse is the gatekeeper to health services was not the only factor that situated this nurse in a position of power in her encounter with Fred. Another institutional discourse that privileged the nurse in this incident was the institutional discourse about documentation and who has the right to document. Nursing documentation offers a voice for nurses to state their experiences, but not for the patients. Two participants, Fred and Kate, commented about this.

Documentation as a Resource for Power

Fred was quite upset at what the nurse may have written in her documentation about him when they had their altercation, and about him not being able to vomit. He explained that after he had this incident with the nurse, a doctor visited him the next morning and told him that she heard that he had a terrible night. Based on that

information, she said that she was prescribing some sedation for him so that he could sleep. Fred was concerned about what the nurse had written on his chart and he was worried that the nurse “did not tell the right story” to the doctor.

Fred: It was like, you know, she went to my chart, who knows what she wrote on the chart. The young French doctor said: “I heard you had a real rough night” and she and you know doctors are moving fast, she didn’t, she didn’t explain what was written on the chart. Well, I’ve often wondered what that nurse had written on my chart. Did she say this man was acting erratically? And you know I had to call his wife in, which she should never have been doing?

Likewise, another patient, Kate, was also concerned about what the nurse wrote on her chart and the fact that she could do nothing about it. She related an incident when she was given a day pass and allowed to go out of the hospital for a few hours. When she came back, the nurse wrote on her chart that the participant was at a pool party. The participant was very upset by this and said that it was not true. She verbalized her concern with the nurse and the doctor, but the statement was not removed from the chart.

Interviewer: I was wondering when she wrote that, that nurse; did anything happen? You said you were upset with her.

Kate: I talked to the doctor; I told him, you know, that wasn’t true. She wrote that statement and that shouldn’t be on there, so -

Interviewer: And what happened?

Kate: After that, nothing happened.

Interviewer: So the statement [that was written about her] was still left [in her records]

Kate [cuts in]: Still there [laughs]

The above example suggests that while institutional discourses privileged the nurse to document her perspective on the incident, institutional discourse did not provide an opportunity for Kate to write her version of the event. Kate exercised her agency and talked to the nurse and doctor about it. However, in this instance, power relationships

were unbalanced and institutional discourses privileged the health professionals. Unless the nurse and the doctor did something about this documentation, Kate could not do much about the nurse's statement. She tried to deal with the situation by refusing to go to that unit again whenever she was admitted to hospital.

Kate's concern about the documentation is significant. Kate was not in a position to negotiate her needs and reach a mutual agreement with the nurse because of the current institutional practice about documentation. This event upset Kate so much that she did not want to go to the unit any more. This finding suggests that the impact that documentation had on negotiation of care was not just momentary, but could be carried over. It had the potential to impact future negotiations between Kate and the nurses. The study by Mohr (1999), discussed previously, reported how derogatory comments in nursing documentation resulted in labelling and negative consequences for patients. Based on the same supposition, anyone who reads the nurse's documentation may get a negative impression of Kate. Kate's concern was that this impression may affect the quality of care that she would be given in hospital.

This situation could have been avoided if the current institutional practice about documentation was different and offered a voice for patients. It seems that currently there are regulations to protect patients from inaccurate documentation. As it stands, the current practice about documentation reinforces the nurse-patient binary. Foucault (1975/1977) wrote about power tactics that are supported by institutional practices and are used to ensure that professionals maintain their dominant position. This is often implied through overt and covert rules and regulations that are imposed by institutions. The institutional practice of documentation may be described as one of these discourses

that hardens the health professional's position of authority within hospital settings.

Self-Regulation: Keeping Patients' Behavior in Check

Another institutional practice that emerged from the findings that was used to maintain the health professional's position of authority can be inferred using Foucault's (1975/1977) notion of self-regulation. Foucault (1975/1977) used the analogy of the panopticon to describe the way the prisons worked to shape human conduct by encouraging self-regulation. Self-regulation is a process whereby individuals internalize and practice certain behaviors that are desired by institutional constructs in order to avoid punishment. By so doing, individuals learn to control and govern themselves to act according to the institution's agenda.

Three participants spoke about how institutional practices influenced the way patients maintained compliance with the professional authorities. One of these participants referred to the security guards at the hospital, while two others explained that they kept their own behavior in check because they feared retribution from the nurses. For example, Jack talked about security service that was available in the emergency department and how this service ensured that patients did not act out of line while waiting to be seen by a doctor. Jack, like other patient participants, lamented about the long waiting time in the emergency department; however, when I asked him if he ever complained to the staff, Jack was quick to tell me that he did not want to "get too saucy" with nurses or doctors. He felt that there would be repercussions. He explained that if you "holler" at the nurses in the emergency department, they would get the security guards to escort the patient out.

Jack: I'm telling you sometimes you can get cranky. You can't say anything to them because sometimes you start talking and your voice gets up, they call security

and you're gone. You know what I mean? Well, we don't cross that line, anyways, but you get mad you know.

The above assertion suggests that Jack had to monitor his behavior. He could not raise his voice with the nurses, because institutional practices include a security system that would have guards escort him out. It is understandable that institutional security is there for a good reason; it helps to control disruptive individuals who may present a threat not only to the institution and other health professionals, but also to other patients. However, this hospital practice can also be oppressive. While this rule applies to all patients who go to the emergency department, in the case of the chronically ill participants interviewed, it forced them to keep silent even though they might have good reasons to complain.

Jack also mentioned that he tried not to get "too saucy" because he feared that health-care professionals would not show compassion for patients. Although he did not experience these repercussions himself, he recounted some experiences that his wife and sister had that he felt were good examples of how health-care professionals did not take good care of the patient. One of these experiences includes a story about how his wife was going for surgery and how the doctors gave her Gravol even though they knew she was allergic to it. I mentioned that it must have been a mistake, but Jack shook his head and said,

Jack: Um [shaking his head in disapproval] I don't know if it was a mistake or not. God, they just don't have, like some of them just don't have compassion for anybody.

Jack's interpretation of this event, that nurses still gave Gravol to his wife "even though they knew she was allergic to it", had a profound effect on him. His experience of this event shaped future negotiations and made him more careful about how to approach

nurses when negotiating his care, by not being “too saucy” with them. Clearly what happened to others seemed to shape the way he saw health-care professionals, and seemed to determine the extent to which he was willing to challenge nurses. Jack was not the only one who was mindful of his behavior; Anne worried about it too. She said that she played the good patient because she did not want to upset nurses because she was “in their care”. The reader may recall how she tried to be a “good patient” so that she did not annoy the nurses and add to their burden, because “they’ll take it out on you”.

Anne: I wanted to keep the peace, I wanted not to make trouble with the nurses, cause you’re under their care! You don’t want the RN to say “Oh my goodness, you made me feel” and neglect me, or be mean to me, or when I come back, cause I was saying nurse whatever, but it’s very rare, but unfortunately, if you’re in the hospital long enough, you gotta [*sic*] see the negative.

Similar to Jack and Anne, Beth mentioned that one had to be careful about complaining to nurses. Beth believed that nurses may retaliate towards her if she complained. She did have an experience in one hospital where nurses retaliated by making her wait for her pain medication.

Beth: I know that he [referring to her husband] complained about it, but I don’t know what he said, because [long pause], sometimes you’ve got to worry about retaliation of them, right? That also happened. It was not here, it was out west where, um, you get your, like if you cry long enough, you wait long enough, they have to give it to you, but, [Pause] they *will* [emphasis added] make you wait longer for the next one; they do retaliate. You just be careful what you say.

The reader may also recall the experiences that were shared by Patricia, Ruth, and Beth who described how they were “yelled at” and “kept waiting” for their pain medications when they kept asking for it. This suggests that everybody has power, and power relationships are unequal. Institutional discourses privileged the nurse during these moments of tension. In these situations, nurses were the ones who had control over the medication cart and administration of pain medications.

These findings illuminate the way in which institutional practices privilege the nurse as a figure of authority, and offer fewer opportunities for patients to participate in their care. These unequal relations of power between nurses and patients were not desired by these patient participants and in such situations negotiation was not successful for the patient because the nurses had the final say. Interestingly, though, although negotiations were not successful for the patient at the time, the patients still managed to find their way to ensure that similar situations did not occur again in the future. Below I discuss the ways that patients utilized the existing patriarchal discourse to ensure that delivery of care remains patient-centered and that their voices are heard.

Institutional Discourses That Privilege The Patients

Although institutional discourses did position nurses in a situation of power, it did not mean that nurses were always in control. Interestingly, just as institutional discourses privileged nurses, there were times when these same discourses privileged patients.

In the previous chapter I discussed how patriarchal discourses privileged health-care professionals and marginalized patients. However, institutions are not just governed by patriarchal discourses; other discourses such as ethical and legal discourses exist within institutions, and patients can use these discourses to prevent marginalization of care. Examples of these discourses include the code of ethics for nurses and the patients' bill of rights, both of which serve to protect patients against abuse, incompetence, and neglect. Some of the participants used these professional and legal discourses to negotiate their care when they were in disagreement with health-care professionals; other participants availed themselves of institutional hierarchies in order to ensure that any decisions about their care include their input and remained patient-centered. A detailed

description of this is presented below.

Awareness of Patients' Rights

I have already elaborated how Fred used his knowledge about his body and condition to negotiate his care and to ensure that his needs were effectively dealt with. Having knowledge about his body and condition situated Fred in a position of power at times. His frequent admissions to hospital had given Fred knowledge about certain institutional discourses on the rules and regulations of the place. He knew his rights and what institutional discourses to resort to when he needed to negotiate his care. One of these institutional discourses was the patients' charter and his right to refuse treatment. He exercised this right one night when a nurse came and gave Fred a "sleeping pill" that the doctor ordered, without telling him what the medication was. He asked the nurse what the medication was, and she said it was Ativan. He knew that Ativan was not good for him and he refused treatment.

Fred: And she said, "It's a sleeping pill." And I said, "What is it exactly? Tell me what it is" and she said "It's Ativan". Well, I said, "I don't *need* [emphasis added] Ativan". And she understood that it's the patient's right not to take the drug. And I was explained, by lots of doctors, neurologists, 'that you don't need Ativan unless you go into status epilepsy or something very serious". So I said "No, take the drug away".

It was helpful for Fred to know his rights. The nurse was able to take away the treatment without further discussion. He exercised this right to decline treatment that he did not want. Fred was not the only one who recognized his legal right to refuse treatment. Two other participants, Patricia and Jack, mentioned that they would refuse treatments that they did not wish in the future. After going through the devastating effects of Fentanyl withdrawal, Patricia decisively asserted that she would, "*never again* [emphasis added] never! let doctors put me on Fentanyl patch". Jack also stated that in

the future he would be refusing treatment that he did not want. He recounted an experience when an anesthetist performed a spinal anesthesia, even though Jack specifically mentioned that he did not want it. There was not much that Jack could do in this situation, because the anesthetist inserted the spinal needle before Jack knew it. He never saw the anesthetist after this incident, because the anesthetist did not come to the floor. However, Jack did take some form of action after the incident. He reported the incident to his family doctor, as well as to a neurologist, and both informed him of his right to refuse treatment. Jack became aware of this option after he was told by doctors of his legal right to refuse treatment. Clearly, the doctor was a resource for Jack and it helped him later enact his agency and offer a counter discourse to assert his needs.

Jack: I talked to my family doctor about it and he said, “If you refuse something like that, they’re supposed to listen to you. He said: “That’s your choice. You didn’t want the spinal tap done; he should have listened to you”. And another fella [*sic*] told me that, Dr. ___ [doctor’s name], he’s a neurologist, I had a few things there too,[he said] “if they don’t do what you want, when you go in that *or* [emphasis added], if they don’t put you out the way you want to go out, get off the table and walk out”. He said “that’s your choice, right?” So that’s what we [Fred and his wife] were told about it.

Although Jack suffered because he had not been aware of his legal rights at the time, one could look at the experience as Jack not being in a powerless situation. He did report the anesthetist to his family doctor. Likewise, when other participants went through some form of suffering, they did not remain passive about it. This is a good example of Foucault’s (1975/1977) notion of power relations. Power relations may be unequal; it is not unidirectional however, but ubiquitous. Where there is power there is the potential for resistance by any person in the relationship depending on their perception of the situation. Whether or not these moments of conflict resolve into effective moments of negotiation for both parties depends on how both nurse and patient

work together to negotiate a practice of care. The outcome of negotiation depends on how the beliefs and values that nurse and patient hold about patient care intersect. Institutional discourses about hierarchies can be used differently by nurses and by patients, and sometimes may result in a mutual agreement about the delivery of patient-centered care.

Using Doctors as a Resource

The institutional hierarchical structure of the hospital may have been a source of marginalization for some patients, but it was also a resource for these patients to enact their agency. The fact that nurses were sometimes legally and professionally bound to follow orders by doctors and their superiors was an institutional discourse that some patients tapped into when they wanted to negotiate their care. Fred found doctors to be a resource when he had his altercation with the nurse who refused to call the doctor in the emergency. One may recall how Fred suffered because the nurse did not respect this knowledge about his body and the operation. Fred used this experience to share it with me, in my role as a nurse educator and researcher to advocate for nurses' education. However, he also made use of the hospital hierarchical structure. He recalled how he accidentally ran into his doctor the next morning after his altercation with the nurse.

Fred: luckily, I ran into the surgeon that did the actual operation. And he said: "Fred, what are you doing here?" and I explained that I had a bowel blockage, and that I, I was in desperate pain, because as I said, I could not vomit, and they removed the NG tube. And he said, "You go back to your bed. I'll have it re-inserted right away". So he went right away to the desk [nursing desk], ordered for it to be re-inserted.

Fred did not "want to be negative" about the situation and to report the nurse; however, he did confide in the doctor about his ordeal and was glad that the doctor did "look after things". Fred explained how the doctor went and wrote an order for the NG

tube to be inserted. He believed that the doctor went “after the nurses” and told them “you do *this* [emphasis added]!” Although Fred kept repeatedly telling me that he did not want to “sound negative” towards this particular nurse, his choice of words/ intonations when he described the incident, as well as his non-verbal expression at the time, suggested that he was relieved that the doctor intervened for him.

Using Family as a Resource

All participants advocated for themselves when they could. However, when the patients were too sick to negotiate their care, their family intervened on their behalf. Fred’s wife stepped in for him when he was not in a position to negotiate his care. His wife, who was there during the interview, recounted a situation when her husband was not given his medication because they were not available from the pharmacy during the weekends. Upon her insistence, the nurse manager got someone to open the pharmacy and got her husband the medication he required.

Similar sentiments were expressed by all the other participants. For example, Patricia cried when she needed pain medications and the nurses did not give it to her. She repeatedly told me that she felt “powerless” and how her mother helped her when she was unable to negotiate her care. Patricia explained how her mother was “very assertive” and spoke to someone who was “higher up” and “said something” about it. As a result that nurse was no longer assigned to look after her daughter and the nurses were more responsive to her daughter’s needs. The participant felt that her mother’s intervention was effective because the nurses did not want to get into trouble and so “they had to walk on water”.

Patricia: That nurse was no longer taking care of me, she was put to other patients she wasn’t to have contact with me anymore because of how upset I had become

and how she reacted to that situation, mm, so that was a good thing, but then, the nurses after were-much better with me, but there was still kind of, a judgment based on pain meds, but kind of a judgment too; they felt that they had to walk on water now, they were scared that I was going to put a complaint in, and they didn't want to get their knuckles wrecked kind of thing; they didn't want to get into trouble. *It did make* [emphasis added] a difference, like, they weren't; I don't know how to put this in words: I wasn't yelled with [*sic*]anymore.

The above text illustrates how reporting to someone who is higher than nurses in the hospital hierarchical structure facilitated negotiation of care for Patricia.

Reporting Nurses to Doctors, Administration and Families

Patricia's mother was not the only person to report nurses. Similarly, Beth's husband got "upset" and "so frustrated" seeing his wife in pain, and the fact that nurses were not attending to her pain because "nothing happens during shift change". Beth recalled how her husband "lost his cool", spoke to someone "higher up" and got the situation "fixed".

However, not all of the patient participants' attempts to speak to administration were successful. While some hospital administrators responded positively to these actions, others were indifferent. It seems that when family members got upset and faced people in positions of authority in person, they were successful in achieving action to resolve their complaint. However, if the patient or family did not approach the authorities directly, the hospital administrators did not always take action. For instance, when one family wrote a letter to authorities complaining about the care their family member received while in hospital, their letter was not answered. Similarly, Peter's wife advocated for her husband when a nurse was abrupt with Peter and told him to "sit". On discharge, his wife and his daughter-in-law also "wrote a letter to the hospital". His wife complained about the unnecessary medications that her husband was given and the way

the nurse treated him. Although neither Peter's wife nor her daughter-in-law got any reply from anyone at the hospital, their actions demonstrate that families are not passive and that they advocate for their loved ones.

The above experiences illustrate the entanglements of relationships. Foucault (1975/1977) emphasized that power and resistance are not separate and discrete entities that directly oppose each other. Rather, according to Foucault, power relations are like a cobweb: indeterminate and ubiquitous. The incident described above is a good example. Peter was upset by this particular nurse's behavior; however, Peter did not only resist this nurse by showing his disapproval. He also reported this incident to his wife. His wife resisted the nurse's position of power by getting other family members to talk to the nurse, and also by writing a letter to the people higher in authority. The authorities, on the other hand, resisted Peter's relative's use of power by refusing to answer, and the story goes on. This shows how power and resistance were not just linear forces but branched out in all directions. Individuals can resist the use of power and exercise their agency by being aware of how the health-care system operates and by resorting to various strategies. Individuals can also resist authority by knowing how to communicate with those in power, and understanding how to negotiate their needs.

Chapter Summary

In this chapter I discussed how the current hospital system remains rooted in patriarchal discourses of power, domination and hierarchies. These discourses continue to reinforce the expert-patient binary by privileging nurses as the gatekeepers of services, by forcing patients to behave properly through self-governance and by limiting opportunities for patients to document their concerns in the patients' records. However,

although the current hospital patriarchal ideology of power and hierarchies may sometimes appear to privilege nurses, findings from this study also indicate that hospital hierarchies may also provide opportunities for patients to resist professional authority. Patients used their agency in various ways to navigate through the patriarchal system and get their needs met. This finding illustrates that although the hospital systems remains mostly dominated by patriarchal discourses and hierarchies, these structures, patients are not simply subject to these discourses. These patriarchal hierarchies and discourses may also provide opportunities for individuals to exercise their agency. The above experiences are also a good example of Foucault's (1975/1977) notion of power relations. Johnson (2005) contends that the extent to which a patriarchal system can be oppressive depends on the individual. He explained that one may be unable to eradicate a patriarchal system overnight because it has been deeply entrenched in the institutions and in the lives of individuals for centuries. However, Johnson explains how one may prevent being oppressed by such a system by learning to navigate through it, and using the system to their advantage.

CHAPTER 8

THE CHALLENGES OF LOOKING AFTER CHRONICALLY ILL PATIENTS

In the previous chapters, I focused mainly on the patient's perspectives. However, according to feminist post-structural theory, in any situation there is more than one truth, and multiple interpretations of reality. This chapter explores the experiences of nurses and what it was like for them to negotiate care with patients. Sometimes, certain nursing actions towards chronically ill patients may appear as unmerited and not conducive to positive negotiation of care; however, listening to the nurses' stories helps to provide an alternative perspective of the situation and a better understanding of their actions.

Overall, nurses enjoyed looking after chronically ill patients and they also enjoyed getting to know the patients as individuals. However, all nurses mentioned that looking after chronically ill patients was challenging, physically and mentally, at times. It involved physical work, which left nurses tired at the end of the day. They also mentioned that it could be tiring mentally because it was challenging to look after certain patients. A number of nurses capitalized on hospital's patriarchal and hierarchical system to negotiate care with such patients. Other nurses did the opposite. They embraced those discourses that are associated with nursing as a feminine profession to understand the patient, find out what is wrong, and to address the problem. Both of these nursing strategies were effective and many times negotiations with patients were successful for nurses. However, listening to the patient and letting them take control during the negotiation process yielded more positive results in the long run. Both nurse and patient were satisfied with the outcome.

The above findings will be discussed in more depth under these three sub-themes:

it can be challenging; negotiating care with “difficult” patients, turning potentially calamitous situations into rewarding ones.

It Can Be Challenging

One of the first questions that I asked nurses was: What was it like working with chronically ill patients and how were decisions about patients’ care made? I kept the questions open and let the participants talk about their experiences. Whenever they mentioned a situation that they liked or did not like about looking after chronically ill patients, I asked them to elaborate. The majority of the participants said that on the whole they enjoyed looking after chronically ill patients, even though all of them mentioned that it was challenging at times. Similar to what was found in patients’ data; they valued getting to know the patients and their families on a personal level and connecting with them. The nurses interviewed found such connections helpful to negotiate patient care in a number of ways. Seeing a patient over and over again facilitated the nurses’ work; they got to know the patient as a person and as a patient with a medical history.

Marilyn: Well, we got to know them [chronically ill patients] after a while; we got to know a lot of patients that came in quite a lot. We got to know their names and their family members well, and we got to know their [medical] history.

Marilyn indicated that as a result of repeated admissions, she did not have to start from the outset to know the person, for they had already established that foundation. This foundation was helpful when negotiating patient care. Marilyn said by knowing the patients’ medical and social history, they could anticipate what the patients’ needs were ahead of time and so it facilitated planning of care. However, it was not just the physical aspect that nurses became familiar with; nurses got to know the patient on a more

personal level. This finding confirms what the patients said in their interviews, that the relationship between nurses and chronically ill patients can become very personal.

Irene mentioned how rewarding it was for her looking after chronically ill patients and knowing “in some way that you impacted them in a good way”. She mentioned that she often saw the patients and families out in the community, and she felt good when families recognized her as their nurse. Irene said that “one cannot erase the fact” that nurses became a “part of their [patient and families] lives”. However, it seemed that getting to know the patients on a personal level also affected her emotionally and it was “sad” for her to see them deteriorate over the years. She explained that one does “not forget them” even if they pass away.

Irene’s description of her experience looking after chronically ill patients suggests that she developed an emotional connection with patients when she got to know them on a more personal level. Her choice of words also suggests that Irene could understand the patients’ misery and developed empathy towards them. This finding also aligned with what the patients said. Earlier on, patients appreciated when nurses understood them and showed empathy towards them, and how such relationships with nurses facilitated negotiation of patient care. However, although these experiences were very positive, it was also difficult for nurses. It involved emotional labor and it was one of the many “challenges” and “difficulties” that nurses mentioned when negotiating care with chronic ill patients.

Physically and Mentally Demanding

All of the nurses mentioned that looking after chronically ill patients was positive and rewarding, however all of them mentioned that it was “challenging” at times.

Marilyn, who had been a nurse for more than 12 years and spent her career working with chronically ill patients, stated that she enjoyed working with chronically ill patients, but sometimes she found it very challenging physically and mentally. Marilyn explained that as patients became “sicker and sicker” with each admission, some would lose their “mobility” and they would require more physical work. She also explained how busy the day was and listed some of the things that were required of her as a nurse.

Marilyn: It was challenging mentally, physically, um, physically as a nurse we would work twelve-hour shifts, and more and more, they [patients] would require more care. And we had several patients like this, it wasn't just one patient that we had, so several patients and we worked as a team but, um, we, we, as RNs we had to deal with a lot, with the doctors you know, and getting them, you know their blood works in their orders, and their medications again, and trying to get them, trying to get them to eat, trying to get them up and it was a lot; a very, very, busy day!!

The above assertions indicate how looking after very sick patients was physically tiring. It also illustrates what was mentioned earlier in the patients' data, that nurses do not just have one patient to look after, but there are other patients on the unit. This is important to note. All nurses mentioned at some point or other that the reason they were unable to establish positive negotiation with some patients was because of time constraints.

However, it was not just the physical care of patients that some nurses found exhausting. Marilyn also found it “mentally tiring” looking after “different personalities of patients”. Like other nurses, Marilyn stated that the more often chronically ill patients were readmitted, the more she got to know their personalities. However, she did not shy away from telling me that although some patients were a pleasure to look after, she and other nurses did not like looking after some others. Paradoxically, one can say that getting to know the patient was not always a good thing. Marilyn was not the only nurse

participant to mention this. Irene spoke about how some nurses did not like seeing some patients come back onto the unit and they would pass comments like “Oh not her again, oh my God” or “Oh God, not him again - ugh”. Maria, Joanne and Susan talked about the “difficulties” they faced looking after some patients who they perceived as “difficult” or “challenging”. These individuals tended to be patients who did not, in their opinion, comply with treatment, who kept demanding the nurses’ attention and who tried to play one nurse against the other.

When Patients do not Comply with Treatment

Joanne said that it was very frustrating looking after some chronically ill patients who “won’t do anything for themselves” to get better and would “expect you [the nurse] to fix it”. She told me that it was “fine” looking after some chronically ill patients “but there are some others; you just hate to see them come in”. She explained how some patients were “stuck in their ways and they don’t want to change”. She lamented that convincing these patients to follow nursing advice was “a chore” and “difficult” and that “they don’t want me [the nurse] to help them get better”.

Likewise, Maria explained what it’s like working with chronically ill patients. She confessed that she liked to see some faces again, but not others who did not comply with treatment. Maria mentioned various experiences when she found it difficult to look after patients who were unwilling to follow medical treatment. For instance, she recalled an experience with a lady who was admitted with high blood sugar. She explained that the health-care team could not get her sugars under control because this lady kept hiding candy bars and eating them when the nurses were not looking. Maria found it frustrating that this particular patient kept telling her that she was not eating candy bars, but in

reality did the opposite.

Maria: No, she just kept saying it. She kept telling me like, I kept reminding her, but she kept saying; Ohhhhhhhhhhhh! I could strangle her!! [Joking] She would say one thing, and I knew she was saying it because I wanted to hear it, but then she was doing what she wanted anyway, right? Just like, you are not doing me any favors, you're hurting yourself basically. I don't need to hear that. If you want to eat your candy bar, eat your candy bar; don't try to tell me that you don't want to eat it you know. I mean, I can only do so much, like you know, there is only so much insulin I can give you, like so.

The above quotation illustrates the frustration that Maria felt looking after this patient. Maria valued the patient listening to her advice, but she was frustrated by this patient's lack of cooperation. It seems that while nurses were using institutional and professional practices that were focused on cure or helping the patient to get better, patients had different ideas about what was good for them. We do not know what the woman was thinking when she hid her candy from the nurse, however, her values, beliefs and practices were clearly very different from the nurse's expectations. In the literature review chapter, Thirsk & Clark (2014) and Price (2013) remarked that while doctors and nurses may use medical and scientific rationale to guide patient management, some people prefer to settle for a degree of infirmity, and discomfort, rather than deprive themselves from things that affect their integrity and dignity.

Another possible explanation why some nurses found it difficult to look after such patients relates to the way nurses have been socialized into the profession and the fact that some nursing education programs continue to have been dominated by biomedical and managerial discourses (Crowe, 2000). Maria was one of the nurses who commented specifically on this. She told me that during her nursing training she was only taught about the "idealistic" patient and that her nursing education did not prepare her for the reality of nursing. She explained, "I think when I was in school I kinda [sic] had this

vision of what nursing is going to be, and it's not so much that!" She later continued, "I just found like, everything was a good scenario". Maria talked at length about this, and how in her training she was not taught about the reality of practice, and how to deal with demanding situations and how this knowledge was "new" to her when she qualified.

Some Chronically Ill Patients can be Demanding

Negotiating care with patients who did not "listen" or take "responsibility" to follow the advice given by the nurse were not the only situations which some nurses found challenging. Four nurse participants, Marilyn, Joanne, Maria and Susan, felt that sometimes when people were admitted over and over, they could become "demanding". All four mentioned that some patients became demanding when they kept ringing the buzzer and/or in their opinion "expect unreasonable things" from nurses. Marilyn gave an example of a chronically ill patient who was perceived as being demanding.

Marilyn: We knew him [patient] well and his family. He'd come and he'd be, he'd be demanding. He'd want certain nurses to look after him. Oh yeah, and he'd want this and he'd want that . . . he used to ring the buzzer, he'd be demanding: "4:30 p.m., where is my supper", you know, could you please take my sugar because some of the med nurses were late getting to him, or um, "I didn't get my pills at 10 o'clock in the morning" or whatever time we go around with the pills.. "Where is my pills, where is you know" or getting him settled for the night, or his a.m. care, he was very, very, vocal what he wanted. And obviously every time we'd get a call that he is coming, we'd say "Oh no! He's not coming back again!". [Laughs] We all knew him.

Marilyn found this patient was demanding not just because he did not do what she wanted him to do, but also because he kept demanding the nurses' attention. A number of nurses remarked that one of the reasons they found such patients frustrating was because "they were getting all the attention" when there were sicker patients on the floor. This finding corresponds with the results from the studies by Khalil (2009) and Mabel et al.

(2012), who reported that the reason why some nurses perceived some patients as “demanding” was because they (nurses) had other sick patients to look after. In both Khalil (2009) and Mabel et al. (2012) studies, nurses mentioned that by labelling them as “demanding” they did not have to deal with these excessive emotional demands, and they could move on with their nursing work. None of the nurses in my study mentioned that the reason why they categorized such patients as “demanding” was because of work pressure, however, many of the nurse participants mentioned that they appreciated it when patients took into consideration that nurses had other things to do and other sick patients to look after. This sentiment was captured by Marilyn, who stated:

Marilyn: Well, it was very frustrating you know for the nurses, because he was, he kept his, he was always wanting something, he was always ringing the buzzer. But we had to attend to him too, so there was the care part. Then there was the other part that you said well, you know, “Oh my goodness”. He used to be the only one getting all the attention on the floor you know.

Marilyn was torn between “needing to attend to him too” and giving attention to the other patients on the unit. Accommodating the needs of this patient would have meant that Marilyn would not be able to accommodate the needs of other patients, some of whom were more pressing. Torn between choices, Marilyn believed that the needs of this patient were not a priority, and he could wait.

Manipulative Patients

Another reason why some patients were not popular from the perspective of the nurses in this study was because they were perceived as being manipulative. Marilyn, Joanne and Maria felt that some of the patients were very good at getting what they wanted. Although these nurses did not use the word manipulative per se, these nurses used words like “play one nurse against another” or that some patients “play on you” as

examples of certain patient conducts that were suggestive of such behavior. Joanne gave an example of how some patients used language in a manipulative way.

Joanne: They kinda [*sic*] get used to the nurses and they play off each of the nurses, like “This was a good nurse because she did this and I like her, but this one didn’t do that, so”, and they’ll mention it to you too, like you know, “That nurse didn’t put cream on my legs and you did”, you know. So you’re better than her.

Joanne felt that some patients played upon the nurses’ emotions to get them to do what the patient wanted. The above example illustrates how some patients were using language to make nurses feel like a “bad” or a “good” nurse. Such strategies, often described in psychology as “splitting” (Braiker, 2004), are used by individuals to punish individuals they perceive as “bad” or to get preferential treatment from certain individuals by telling them how “good” they are. Clearly, the use of the binary good-bad, whereby the good is perceived as superior to the bad, was frustrating to some of the nurses in this study, because they did not want to come across as being “mean” to patients. Many nurses in this study spoke about how they wanted to be “appreciated” for their work by patients and others. One nurse, Lucille, mentioned how good it felt when the patients indicated that they “like” it when she looked after them. She believed that such actions “encourage any nurse” and instill a “good feeling”. Other nurse participants were not so blatant about being liked, but did give indications that they felt good when patients appreciated what the nurse did for them and thanked them. Marilyn talked about one patient who showed appreciation, how “it was always nice to look after her” and that this patient made her feel “very, very [*sic*] complete when I looked after her” because she always said “thank you”.

The above experience illustrates that by knowing how by being appreciative, some patients could get nurses to give their “best” when looking after them. This validates

what one patient, Anne, mentioned earlier on: that being a “nice patient” can be a very effective approach to negotiate care with nurses. Anne negotiated her care with nurses by being nice and good to nurses, by being appreciative and thanking them for their care even if Anne felt they “did not deserve it”. Maner and Mead (2010) comment that individuals who are in an authoritative position are more likely to have a better relationship with those in the lower hierarchical rank, if the latter show appreciation and respect towards them. In this instance, it suggests that nurses can have a better relationship with patients if patients show respect towards nurses or if patients indicate that they like nurses.

Negotiating Care with Patients who were Perceived as Difficult

Nurses found it “pleasant”, “a joy” and “a good feeling” to look after such patients, and negotiating care with them was straightforward and unproblematic. On the other hand, when nurses were negotiating care with “difficult” patients, they used a number of strategies to deal with the situation. These included using medical discourse to rationalize for the behavior, encouraging and trying to convince them to comply with treatment, coaxing them for their own good, being firm but flexible, and offering them choices. However, if negotiation was still not effective from the nurses’ perspective, nurses resorted to the hospital hierarchical system to get patients to cooperate.

Using Medical Discourse

The majority of nurses said that some chronically ill patients did not comply with treatment because the patients were “sick” and possibly depressed. In this instance, nurses were using their medical knowledge to rationalize why some patients were acting that way. While it is true that research has found a relationship between chronic illness

and depression, it is also possible that nurses were medicalizing the patients' emotions and failing to see that the patients were reacting this way because they were upset, angered or frustrated. This result once more illustrates the pervasiveness of a medical discourse and how it has permeated hospitals, and how it is partially to blame for the metamorphic transformation of an individual from a social being into a patient with a diseased body.

However, at the same time, the use of medical knowledge also helped to justify and excuse patients from behaviors that may be considered as socially undesirable, and to use this knowledge as a starting point from where to proceed with negotiation of care. For instance, Irene said:

Irene: And it does, you know, even though some people are not the nicest, you know, if they have a touch of dementia, you know, they're cursing at you or something, you know that's not who they are either because when a person is sick that's not a reflection of who they are, you know. That could be a symptom of depression, or something else you know.

Cursing at someone is socially frowned upon; however, in this instance, Irene used her medical knowledge of chronic disease to understand and justify this behavior. She understood that patients who are chronically ill often develop depression as a concomitant condition that may lead to behavior that some may consider being inappropriate or socially uncomfortable. All participants mentioned that chronically ill patients can become depressed, anxious or scared; and nurses tried to understand patients. As explained earlier, a number of nurse participants felt empathy for chronically ill patients and the multiple psychosocial problems they faced, besides their morbidity. Marilyn was frustrated by the demanding approach of one patient; however she used her knowledge of chronic disease to understand him. She felt that the reason why he was demanding was because he was "struggling to breathe" and so became "very scared".

Marilyn: But as time went on he got sicker and sicker. He was in ICU. It was very challenging, especially if you saw a person who was struggling to breathe; very challenging you know, and most of the time it was for him and I think it was, he was very scared. I think that is why he was so demanding.

In both the above quotations, as well as in other instances, nurses made use of what Potter and Wetherell (2006) call *accounting*. *Accounting* is a term that is used in linguistics when people explain/justify/excuse certain undesirable behaviors. According to Potter and Wetherell (2006), one of its functions is to create a “no-blame” situation for the person being talked about, in that it explains/justifies/excuses the person’s behavior. In the following sections I explain how nurses used medical discourse to account for why some patients were, in their opinion, being difficult and how this rationalization facilitated negotiation of care not only for patients, but also for nurses. Patients benefited because they were excused from certain behaviors. Nurses also benefited because by labelling patients as depressed, nurses were able to justify some of their actions, such as being “firm” without coming across as being “mean” to patients.

Nurses tried to negotiate care with depressed patients by getting them do as much as they could. However, as Marilyn and others pointed out, when patients became depressed they were not always able to take initiative to get better. In these instances, nurses resorted to various techniques to negotiate care with patients. For example, they tried to convince patients to arrive at a mutual agreement on patient care by telling them of the benefits of getting better, by reminding them of their families or by coaxing them into cooperating. Nurses tried to use creative ways to assert their authority without coming across as obtrusive. This fits with Foucault’s (1975/1977) teaching that power relations are not always coercive, but can be subtle and silent.

Encouraging and Convincing Patients about the Benefits of Treatment

All nurses believed that it was in the patient's best interest that they encourage them to involve themselves in their care by complying with treatment. Encouragement is a way of giving courage, hope, confidence and support. Lisa tried to encourage her patients by explaining to them the benefits they would gain if they complied with treatment and how this would help them to reach their goal and get better.

Lisa: You just have to encourage them, and tell them the benefits of it, you know. "You're breathing, and even if we have to go just a little bit at a time, if you're OK, we'll get you up for half an hour, and I'll put you back to bed" you know, "and then tomorrow we may be able to do a little longer" you know. "It's good for your lungs, it's good for your breathing and everything" and a lot of the times, we can convince them, but you have to keep your promise, that you're going to put them back you know. After an hour, or half an hour, or whatever, or the next day, they won't trust you enough. But, so, um, encouragement, you have to encourage, I think you have to have a rapport with the patient, you kinda [*sic*] have to set that.

Lisa was empathetic. She believed that patients needed to be encouraged to care for themselves. By so doing, she was able to negotiate care with the patients and help them to get better. Lisa used her assessment skills and took into consideration what self-care the patient could or could not do, and encouraged him or her to do it gradually. As Lisa mentioned, building "a rapport with the patient," and keeping promises, helped to build trust and it facilitated the negotiation process and enabled the building of partnerships.

Coaxing Them 'For Their Own Good'

Lucille also had empathy towards her patients. She wanted them to go home and to be able to look after themselves when they were discharged. Lucille said that she tried to coax some patients to get to do things for themselves "for their own good".

Lucille: You may have to coax them: “OK, we’ll just get you up for a few minutes, and we will be right here, we’re gonna [*sic*] make your bed, we’re not going anywhere, we’ll not get far” or something. Or trying to get them up for a meal, or even try to encourage them to do things for themselves, which they need to do to go home and maybe they are not going to have family, so you need to you know, to encourage them to even feed themselves, do a little bit of their own patient care, to get them up and do it sometimes it’s, it takes a little bit of coaxing (smiles) to do things for their own good!

Lucille’s way of “coaxing” patients demonstrates her creativity in trying to negotiate care with patients who are refusing treatment without being too controlling. An analysis of the text reveals Lucille negotiated care by bargaining with the patient. This was affirmed in a later statement when she explained how she negotiated care with other patients who refused treatment.

Lucille: Yes, or did not want to do something for themselves, even just to try to, actually say, “Well, I’ll wash this hand, you wash that hand”, usually you have to fiddle with, or get them up and sitting, and say, “No, I’ll wash you but you’ve gotta [*sic*] have to sit up in the bathroom”. Trying to get them to get up and use the commode instead of getting incontinent, but you help them: “We’re right here, we’ll stay with you right here”. And another thing is trying to encourage patients to report if they have something going on, sometimes they try to keep it to themselves, so to encourage them that it’s really important for them to tell you that. Chest pain or if they’re having shortness of breath, not to try and hide it and, and that you wanna [*sic*] catch something before it gets worse.

The above illustrates the ways Lucille negotiated care with patients, how patient she was, and how much she cared that the patients got better so that they could go back home. Lucille was not the only participant to demonstrate empathy and concern for patients; all the nurses interviewed did. However, this was not always easy; some nurses believed that they needed to be firm to help patients get better, particularly if they were depressed and refused everything.

Being Firm but Flexible

Irene felt that she had to be firm with some patients in order to help them get better.

Irene believed that being firm was not necessarily a bad thing, and that everyone needed “a kick” sometimes to improve.

Irene: They do; all of us would do that. I think all of us in our lives maybe need to be pushed, not at work but sometimes you appreciated that somebody gives you a kick or pushes you to do something that you appreciate later on, then you realize.

Irene was not the only one to say that there were times when they needed to be firm. All of the other nurse participants mentioned how they accomplished this by using language in an authoritative manner, but also offering choices. In such instances, when a patient’s situation was out of control, nurses took the lead, and gave the patient direction and structure.

Irene: You know, if they don’t want to get washed up, they don’t have to. If they wanna [*sic*]... not everything is done in that order and you do have to “You can get washed up in the evening if you want”, you know. I always say, “What would you want to do?” “Right now, I’ve got my schedule, but it’s about how you’re feeling”, and you gauge it by that, you know. But there’s [*sic*] a few patients that have been there on long term, you know, that are difficult to give care to, and all you can do is work around that. If they’re never wanting to get washed up, some of the days you gotta [*sic*] be insistent and say: “I know you don’t like doing this, I know you don’t like having this care done, but at a point it becomes a necessity” and “You know, this is going to take five minutes and then I’m gone, and I want to be able to do that” and you have to be firm and you know.

Irene was an experienced nurse. Like all the other nurse participants in the study, she believed that sometimes patients who were depressed needed direction and structure to get them going. She explained how many times patients were “tired or sore or don’t wanna [*sic*] get out of bed.” Irene explained that in such situations, if nurses want patients to get better, nurses should not say “Oh OK” and do nothing about it. She believed that in such situations nurses needed to be firm.

Irene: Because if you didn’t, that’s not what is best for the patient, you know. Your lung expansion, you don’t want to sit and you know, the more you, the more it’s going to be easier to breathe, and you have to really, you don’t say “Oh OK”. No!

She gave several examples to illustrate what she meant by being firm. In each of

these examples she used authoritative language and told the patient directly “you have to”. Irene explained how she would usually inform the patient of what the situation would be if they did not try to help themselves to get better. She explained that she did not use “fancy dancy [*sic*] language”. She explained that in such situations “you just say it, just the way it is” but at the same time using a “pleasant voice”. Irene’s use of the word “pleasant voice” is noteworthy. Like Marilyn, Irene was very cognizant of how to use language and voice. She believed that she needed to be firm by using direct language, yet in a way that was respectful towards the patient.

Made to Wait

Nurses also mentioned that they needed to be firm in situations where patients were demanding. However, the examples given by nurses in this study show that they practiced being firm in different ways. When patients were being demanding, many of the nurses tried to negotiate their care with them by standing their ground and explaining to these patients that they could not attend immediately to their needs because they had other patients to look after. For example, Susan described how she dealt with situations when patients become demanding or are asking for unreasonable things

Susan: You are trying to get one thing done, and they’re trying to get you to do thirty other things? Yeah. I was going to one room not that long ago, you’re trying to get say get to this patient, get them ready, and they’re saying, you know, “I want my remote control for my TV, I need the oxygen in my *nose*. *I need* [emphasis added] a bedpan and I want you to call my wife and tell her I’m here”. Yeah, and it’s just directions that they make you know. “I understand that you need all these things, we just have to get this thing done first and we will do all the other things later.” You have to be kind of firm, but *polite* [emphasis added]!

Susan tried to deal with the situation by explaining to the patient that there were other patients that she needed to look after, and that while she would attend to their

needs, they had to wait. Once more, this is another example that highlights the nurses' concerns about having other patients to look after; the pressure this creates on them and the partial reason why some nurses were not attending to certain patients' needs. Susan emphasized that whenever she needed to be firm with patients; she was "firm and polite". Like Marilyn and Irene, Susan was being respectful to the patient by being polite, and possibly also careful about the way she presented herself to the patient. I asked Susan how she felt about being firm and polite.

Susan: I don't know, sometimes I feel like I am being mean to them? But, hhh [takes a deep breath in]; you have to realize too that there's more than just them in the unit. We have other patients that we all have to look after, and I think it's OK, but I think some of them have been sick for so long, in and out of the hospital so often, they just want everything done all at once, and be done with, you know? They forget too, so you just have to explain to them: "This is how we're going to do it, I will get you everything you need, but you just have to give me a chance". *Most* [emphasis added] of them are very good; that's just the few

It is interesting to note that Susan felt she was being "mean" when she was firm with such patients. It may have been in the best interest of other sick persons to be firm with this patient, but it may not have been in the best interest of this particular individual. Yet, Susan's rationale for being firm with this patient and her use of language helped to account for her actions. Similar sentiments were expressed by Joanne who stated that she "hates to sound mean" when being firm with patients.

It appears that each of the nurses equated firmness with being mean. This could probably be traced back to patriarchal and historical discourses. Johnson (2005, 2006) contends that in a patriarchal culture there is a social expectation that women are nice, caring and gentle. Women are expected to conform to these norms (Butler, 1990; Irigaray 1980) and failure to do so is often regarded as aberrant behavior because such behavior is more characteristically considered a male trait in our society (Johnson, 2005, 2006).

Another possible explanation why nurses felt uncomfortable being firm with patients could be explained with historical images of nursing and how the ideal nurse was expected to display the vocational traits of being unselfish, giving and forgiving. Hence, it is possible that these women interpreted “being firm” as out of line with women’s character and the virtuous script of nursing. While this study did not explore why nurses think this way, this result tells us that the nurses think about their interactions with patients very carefully. It also illustrates that negotiation of patient care, on the part of the nurse, is a complex process.

Nurses need to purposefully orchestrate their negotiation with patients while taking into consideration other factors such as time, family, patient feelings and other patients’ needs. Susan and Joanne were not the only ones who were careful how to use their language when describing or dealing with situations where they had to be firm. It has already been highlighted earlier how Marilyn was firm but careful how she spoke to relatives when they were being demanding, and how Irene used language that was firm but pleasant when trying to negotiate care with patients who were refusing treatment. All of these participants were aware of the impact of language on relationships. As explained above, it is possible that these nurses were aware that being firm with patients may not be socially, professionally, or morally desirable even though, in such circumstances, these nurses felt it was necessary, either because the patients benefited, or because it was necessary for the safety of other patients.

Giving Patients Choices and Control

The above situations also illustrate how nurses paid attention to the interactions they had with clients. Irene was aware of the potential struggles when negotiating care and believed that patients wanted to be in control of their care. She capitalized on this knowledge to negotiate care with patients who were starting to get upset with her. Irene explained how she tried to deal with these potential moments of tension, by assessing carefully the situation, offering patients choices, and letting them be in control of their care. Giving patients control over their care has been described as one of the antecedents that facilitate positive negotiations with patients (Hook, 2006; Krupat et al., 2000).

Irene: Well, if there is something I would prefer if they decided on the line of management, I think first of all you gotta [*sic*] have information, you gotta [*sic*] gather good information, you have to know a good history, and when you present it to the patient, you present in a way as a choice - and “you can either do that, or that. It’s your decision and that’s your choice.” But you know, and I say you know, you could do these things, make it easier and enjoy the positive benefits, whereas if you, you know, if you give the patient a choice and paint the scenario of either or, that is what people want. They wanna [*sic*] be in control and be able to have um, be the person in charge in making their own decisions, of their own care. But I tell them, it’s, you know, it’s not the doctor or the nurses that’s going, it’s it’s [*sic*], you’re the one that’s in control of your own health care, and a lot of times you have factors that you have a high risk and you have to manage and fix. You have to manage it a lot at home and prevent the re-admission over and over and over. You know if you do the right things, you know, giving them a choice, and know what you’re saying; you gotta [*sic*] be able to back it up. And I’ve seen this, and sometimes you gotta [*sic*] scare them: “If you don’t change, you’re gonna [*sic*] be back, and it’s not gonna [*sic*] be pretty the next time. Did you ever try breathing through a straw? Well, that’s what it’s gonna [*sic*] be if things don’t, you know”.

Irene planned ahead how she would negotiate care with patients she perceived would be difficult. She made sure that she had all the information that she needed about the patient before she proceeded to speak with them. She believed that it helped to tell patients about the benefits and the consequences of complying/not complying with treatment and even to ‘scare’ them if necessary. She ultimately left the choice in their

hands, for she knew that patients wanted to be in control of their care. This is an example of how Irene used her authoritative power through sharing knowledge, giving advice and ultimately trying to get patients to do things for themselves. Irene also tried to shift power to her patients and ultimately felt that if they had the final say or choice in their care, this was placing them in a position of power. These experiences that Irene shared during the interview show the nuances involved during negotiation of care with patients and how power relationships are constantly changing. There is back and forth, working through, and critical thought that goes into the negotiation of care from many of the nurses' perspectives.

Resorting to Institutional Hierarchies

Although nurses used the above techniques to negotiate care with patients they found challenging, negotiations were not always successful in their opinion and sometimes there were moments of tension and altercation. Faced with situations where such strategies did not work, some nurses felt the need to report the patient to the nurse manager hoping the patients would listen to the manager. Joanne described how she dealt with a patient she described as being demanding. She explained to him that she was busy and she tried to negotiate care with him by offering the following compromise: she would set up things for him, he would take his bed bath, and then she would check on him later. However, this negotiation did not “fly at all” with this particular patient:

Joanne: I'm really busy, I'll set you up, and you do a little bit yourself, and I'll come back and give you a little help. Well, that doesn't fly at all! [Laughs]

Interviewer: That doesn't fly at all?

Joanne: No, that doesn't happen. Well you know what, you kind of have to stick to your grounds and all right, you have to let them know that you're really busy with

another thing. You don't let them feel like, you know... they're not important or whatever, because sometimes there's other sick people there, and if there is a bed bath, a bath that you can do, that's not priority right? Yeah, no, um, he'll get this particular, and I think they're all the same - they kinda [*sic*] get, they get angry. Yeah.

The above example shows how despite Joanne's initial efforts to negotiate care with this particular patient by explaining the situation to him, negotiation was not being effective from her perspective, and the patient became angry because she did not accommodate his request. Ray, Lucille, Marilyn, Susan, Irene, Joanne and Maria had similar experiences. They explained how sometimes patients got upset when nurses insisted on following a therapeutic regimen and how sometimes patients did not listen to them and at times got "irate" with nurses. In such situations nurses resorted to the doctor or to the nurse manager.

Joanne explained how she found herself "stuck between a rock and a hard place" in trying to negotiate care with some patients who were refusing treatment, which she knew from her nursing knowledge would help to fix the problem or help to get the patient better.

Joanne: I beg people: "Just please, keep your mask on" or especially in night shift when there is no one around, "If you don't want it, then in the morning you can talk to the doctor and he will fix up something". But kinda [*sic*] right now, you're kinda [*sic*] between a rock and a hard place, right? And you know, it's probably then that they realize, if they take it off: "Oh my God, I can't breathe".

The above situation illustrates how Joanne had to plead with some patients and "beg people: 'just please, keep your mask on'". She was caught between being firm and doing what she believed was best for the patient as opposed to respecting the patient's wishes and allowing him or her to refuse treatment that was potentially life-saving. In this situation, the nurse experienced a role conflict between professional discourse and

what she believed was best for the patient by respecting the patient's wishes. Joanne tried to negotiate care with the patient by using institutional discourses of hierarchies and including doctors to support her position.

Similarly, Maria recalled an altercation with a patient who would not put the bi-pap mask on. She explained how this patient got irate with her because she kept insisting that he put the mask on, even though it was uncomfortable. She said that she kept telling him to do so, because she knew that his situation was transient and that he would improve.

Maria: But myself, I could see that he, he was chronically ill, but if we could get him something, he would get past that and I just, I didn't want to give up on him. Like I knew once he got past that uncomfortable, this is a horrible moment, but things would improve.

Faced with such a difficult situation, Maria tried to negotiate care by scaring him and telling him of the negative consequences. She also asked him to discuss alternatives with his doctor. She tried to convince him by telling him about the complications that he would face if he did not do so. She also tried to make him think of his family and to do it for them. The gentleman got upset with her, but kept it on. At one point he got so "irate" with her, and told her to leave him alone and just let him die. She told him that if he really did not want such interventions he should discuss them with the doctor the next day, and his wishes would be respected, but as of that moment, he needed to keep it on. Maria tried to negotiate care with this patient by attempting to discuss the situation and sharing her perspective about his condition. When she felt that she was not getting anywhere with the patient, she decided to bring in more authority by suggesting the patient speak with the doctor about appropriate care. Similar experiences were shared by Marilyn, who said that some of the chronically ill patients can be "sly as a fox" when negotiating their care. They tell the nurse one thing, but when the nurse reports them to

the doctor or manager, they say another thing.

Marilyn: Well, you try to talk to them, sort of you try to explain to them this is just best for you and you are going to start feeling better to get up, and that is not just to mobilize them, but eating, to doing your general ADL like brushing your teeth and everything and all that. But a lot of them were giving up, they'd give up. Now if they really out-rightly refuse, then there isn't much that you can do. Like I said talking to them, sometimes the doctor might help, some of them idolize the doctors [laughs]. So you know the doctor, the nurse would tell the doctor, and the doctor would say: "The nurse said you're not getting up today, you refuse to get up". "Oh no, no, I'll get up" [laughs]. So you know, they tell the nurse one thing and the doctor another thing

The above examples are interesting because they demonstrate how patients may either have a different interpretation of the interaction or they may choose to interact differently with someone who has more authority. It is difficult to say exactly what they are thinking, but it is important to note how Marilyn and other nurses in the study were aware of the way some patients interacted differently with doctors and managers. More specifically, Marilyn's use of the words "idolize doctors" is an example of the way she saw power differentials between her position as a nurse and the doctor's position from the perspective of the patient. The patriarchal and hierarchical system within the hospital was evident in this example. The fact that some doctors would tell the patient that "the nurse said that you are not getting up today" also is reflective of gendered roles and patriarchal discourses of families. In traditional Western family roles, the man is stereotypically seen to be the leader of the house, who may give the ultimate reprimand to the child if the child fails to obey the mother. Similarly, the association of nurses with gendered roles that are often associated with females was evident when interviewing Maria. Maria explained how some patients did not respect her knowledge as a nurse, and she believed that they looked at her as a "glorified waitress"; an expression that suggests some patients' views of nurses is also gendered.

Maria: Some people look at you as an educated person and that you are there to help them. Some people you're just a glorified waitress; they're just: "Get me some water", I don't want your opinion basically or anything.

The above example illustrates how the doctor's voice was seen as superior and more important than the voice of the nurse. Superiority includes an assumption of having more power. However it is interesting to note how nurses used their agency to capitalize on these discourses. Both nurses laughed about it and mentioned that when this happened, they asked the doctor to speak to the patient. Evidently, these nurses capitalized on the fact that some patients respected the doctors' opinions more than their own, and they used this knowledge creatively to get patients to follow through with suggested care. By getting the patient to cooperate, the ultimate goal from the nurse's perspective was reached.

Being a Male Nurse

Interestingly, not only do some patients appear to privilege doctors over nurses, some patients also seem to still have gendered ideas about doctors being male and nurses being female. Ray explained that he enjoyed looking after chronically ill patients; however, some of his challenging moments took place when he was looking after older female patients. He explained that mainly "it's the female population that I look after here now, they are set in their ways, they are not used to male nurses". He gave me an example of a lady who was 97 years old and who "absolutely refuses to have males provide care". It seems that some older adults still have stereotypes about nurses being female.

Ray: oh I think traditionally nursing has been female and they're just used to it right? Like I said doctors come in and there's no issue, but if female nurse can come in and it's not [an issue] - *it's what they come to expect* [emphasis added]. So, I've seen on the other hand too, me go into a room and there will be an elderly lady who is quite confused, and she'll think I'm a doctor, and she'll let me do [care] and

“no I’m the nurse” and it changes immediately [snaps fingers]!

The above shows how gendered roles create subject positions which may affect negotiation of care. Ray explained how he tried to negotiate patient care in such situations, by trying to get a female nurse to attend to her needs. Although this was the only time that Ray brought up the issue of gender, and how it affected him as a nurse, it is a good example to illustrate how a patriarchal system does not oppress only women, but can oppress men too. Ray mentioned that the older generation seems more prone to gender issues, but he believed this gender bias can affect any age group. He explained that mainly “you can’t really pin it down; everybody’s values are different and stuff right?” Ray raised an important point that issues about gender may be more prevalent in the older generation, but as he explained, it does not mean that all older adults have the same views. Indeed, it depends on the individual’s personal values on the sex and or gender of the patient and personal values and preferences.

Turning Potential Calamitous Situations into Rewarding Ones

In the above section I described how some nurses dealt with situations when negotiation of care resulted in moments of tension between nurses and the patients. When altercations arose or when the patients still refused to listen to what the nurses were saying, nurses used institutional discourses of hierarchy to convince patients to arrive at a mutual agreement or to cooperate. In this instance, nurses were reinforcing the current patriarchal discourses of hierarchies, which included the belief that a doctor’s voice is superior to that of the nurse. However, not all nurses used this method. Some nurses tried to deal with moments of tension by stepping back, listening and assessing the situation. In this instance, nurses were resorting to discourses that were often associated with female characteristics of listening, attending, equity and compassion to negotiate

care with patients. Tina explained that she was always assessing the situation and trying to find out why some patients or family members were difficult by listening to what patients/families had to say. She found that by addressing the patients' and families' concerns, they would no longer be demanding. She recalled an experience when she looked after a patient who some nurses perceived to be difficult. He was physically demanding because he had a dressing that was frequently getting soiled with stool, and also psychologically demanding because he used to "swear" and was also "cranky and ornery" towards nurses. Tina used her intellect to step back, assess the situation and proceed. She used her knowledge about the patient to decide what would be the best way to negotiate care with this particular patient and reach a positive agreement with him. By so doing, she was able to turn a potentially calamitous and frustrating situation into a positive and productive one.

Tina: I went into the room first thing. He also has an ostomy in place. I had never met him before at all, so when I went into the room, the dressing at the front was in place. That was fine at the time, but the ostomy had lifted and there was large amounts of stool there and instantly I wanted to start: "Well, I'm going to get that cleaned up!" [Laughs] and he was lying there, he was awake, mind you, he just had a blue pad over it. So I put on my gloves. I had my gloves on and everything, and I was going to, and he said "No, no, no, that's fine". And I said, "Do you want to change that? I can help you". He said: "No, no, no, my wife is coming in with the supplies. No, it's fine, it's fine". And I was a little bit taken aback at first, I was "Oh well, now what should I do? Should I, it's kinda [*sic*] messy you know, but it wasn't messy everywhere, but" but I thought, "Well OK, and I instantly got an impression from him, that he was pretty comfortable with his own care, *he knew what he wanted* [emphasis added], so I said, um, "Can I do anything?" "No, I'm good, I'm fine, that's OK" and I said "OK" and I looked at the other dressing and I said "Yeah, OK". So I did what I had to do in the room, gave his medications, took the vital signs and all those things and I said "OK I'm going to check back soon", told him to "ring if anything changes, let me know OK?" A little while later I came back in and the other dressing, he was changing the other dressing as well, doing *it all* [emphasis added]! I mean, and again I thought, I should come in and help him and he was completely fine with it. I brought him supplies; I stood there, observed you know, offered to help. "No, I'm fine, I'm OK". So and I had heard from the other nurses that they were really frustrated with him and going into the room

because they were changing the dressings so often and they were getting in and out of that room, and it was getting, and I thought to myself, he wanted to do it, he was doing it. I brought him the supplies and made him comfortable; there wasn't anything that he really needed from me. So I was a little confused about why, (laughs), because you know, and again later on in the day, I kept checking back, and he was doing it again a little later on and *it was fine!* So, I thought: how much do I step in? Obviously he's independent, he can do it, he just needs the supplies and he can ring if he needs help, so I stepped back. It seems that that is what he wanted. And it was fine and people were saying too, really frustrated with him because I guess he swears and stuff like that. He can be cranky or ornery, um, and I was talking with him when I was in, and he was fine, he never, you know, he was pleasant, he was appropriate. We just talked about; I would ask him questions about "How long have you had this? What happened"? He's frustrated with his own care, you know with the situation having this wound that is not going to heal, and frustrated with the health-care system, with the, well that's why he feels he has it, a surgery that has gone wrong, *but* [emphasis added] he is frustrated and I just let him talk about that and we got along fine. He was pleasant. I had no problems with him at all that day you know

Tina valued the time that she spent with this patient, finding out what the problem was and trying to solve it. By stepping back and assessing the situation, she was able to recognize that she could delegate the change of dressing to the patient. This was no easy task for Tina, for her initial instinct was to take the lead and change the dressing herself. However, based on her assessment, she realized that the patient was capable of changing his own dressing. This example demonstrates that despite the current move towards patient-centered care and self-management, there is still an internal compulsion in some health-care professionals to take over or maintain control of patient care. Tina acknowledged that the minute she saw the "messy" wound she "instantly" wanted to start to clean it up, however, she stopped to think before she acted. Tina used reflective practice and her critical thinking skills to choose between opting for patriarchal discourses and taking charge of the situation, or considering the patient's knowledge and expertise. Tina's decision to opt for the latter helped her to build rapport with this particular patient, and it also saved her time by not having to change the dressing herself.

Negotiation of care in this instance was positive and successful.

Chapter Summary

In this chapter I discussed nurses' experiences of looking after chronically ill patients. On the whole, nurses felt it was a positive and rewarding experience because they got to know the patients, their medical and social histories, and their families. This knowledge facilitated negotiation of care, and it also helped nurses to develop empathy towards patients. However, despite these positive experiences, nurses found looking after and negotiating care with some chronically ill patients challenging and difficult at times.

When patients were difficult or challenging, nurses resorted to various strategies in an attempt to get the patient to cooperate and to comply with treatment. Some nurses used authoritative medical discourses to understand patients and to facilitate negotiation with them or resorted to hospital hierarchies to get patients to conform to what nurses believed was best for patients. In both instances nurses were reinforcing the traditional patriarchal discourse that includes the belief that "the expert knows best". However, some other nurses used discourses that are often associated with feminine qualities such as listening, attending and showing empathy to negotiate care with difficult patients and to diffuse potential calamitous situations.

CHAPTER 9

FINDING TIME TO LISTEN

In this chapter I continue to illustrate how feminine discourses of listening and attending to patients may not be given prominence in a patriarchal system, but they can be just as effective, if not more so, as the current dominant patriarchal ideas. I will be describing how both patients and nurses believed that finding time to listen to what the patient had to say was vital when negotiating care with patients. Some nurses found time to listen to patients no matter how busy they were. However, some nurses commented that certain institutional practices that were focused on routine and timetabling created pressure on nurses and prevented them from spending time with patients and families. These institutional discourses were often reinforced by peers who put pressure on each other to get things done in a timely manner. Still, some nurses explained how they were able to manoeuvre through such situations so that they were not subjected to these discourses. For this purpose, this chapter will be divided into four themes: *the importance of listening; rush-rush mentality; making it happen; and unit culture.*

The Importance of Listening

The importance of listening to patients and acknowledging their expertise about their body has been briefly discussed in earlier chapters. I described how nurses were able to negotiate care in difficult situations by listening to what the patient had to say, finding why they were upset and trying to address their needs. Earlier on it was mentioned that patients valued when nurses listened to them. Some patients mentioned that in practice some nurses still found time to sit down and listen to them no matter how busy they were. Such situations facilitated negotiation of care for the patients because

they were more comfortable to vocalize their needs. The reader may recall that when nurses listened to what patients had to say, patients felt significant and acknowledged.

The patient Anne acknowledged that the hospital was a “very very [*sic*] busy place” but she appreciated when nurses “took the time” to see how she was doing and to listen to her concerns. Anne felt it was important that nurses and all other health-care professionals listened to what she had to say. She explained that when she had a near-death experience, the doctors were not interested in finding out how she felt about it or if she had any questions to ask about it. Instead, they focused on discussing her medical crises among themselves. Anne believed that if some health-care professionals had listened to her, it would have helped her psychologically, and it may in part have prevented her physical and mental health complications that followed afterwards. She valued when one nurse came over later, sat down beside her and took the time to listen to her.

Anne: she came in and said: “I heard you had a hard time. I’m so sorry you had to go through all that” and she sat down, and she took the time! She too was very busy, it’s a very *very* [emphasis added] busy place, but she still took the time [to listen].

Likewise, Beth explained that one of the salient things that made a difference during her hospitalization was when nurses took time to listen to what she had to say. Beth noticed that when nurses took time to talk to her, they would ask her if “they can do anything” to help her. For Beth, this was an open opportunity to express her needs and to negotiate her care.

Beth: I found some nursing staff very *very* [emphasis added] friendly and professional, like that yes. And I find that they always take a minute to talk to you, see if they can do anything for you. I find them good like that here. As the nurses in _____, they don’t take that extra time with you, like they are more busy [*sic*]:

here they take the time to, you know, chat with you for a few minutes.

Both Anne and Beth valued when nurses took time to listen. Both participants remarked that some nurses were just as busy and as stressed as other nurses, however, they still found time to “take a minute” to talk to or to listen to the patient.

Many of the nurses interviewed enjoyed spending time to get to know the patient; however, finding time to listen to patients appeared to be an issue. It has already been mentioned earlier how busy the nurses’ day was, how by the end of the day they felt “spent”, and how little time they had to spare during the day. This finding may make one wonder how, despite their hectic day, some nurses still found time to listen to what the patients had to say. However, it was not just the nature of the work that created time constraints but also institutional practices and discourses.

“Rush-Rush Mentality”

Almost all nurse participants mentioned that one of the reasons that they did not seem to find time to talk to patients was because they believed some peers created pressure on them to perform their work quickly and to spend less time with patients. Eight of the 10 participating nurses in this study felt that they were subject to peer pressure to adhere to routines and finish work by a certain time.

Tina mentioned how pressure from her peers to finish work by a certain time affected her disposability to spend time with some patients. Ultimately, this affected the way she was able to negotiate care. Tina believed that in order to involve patients in their care, one needed time to listen to what they had to say and give them time to do things for themselves. Tina valued the time that she spent with patients and family, finding out what the problem was and trying to solve it. It was mentioned earlier how good Tina felt,

and how successful negotiation of patient care was, when she listened to a patient who was labelled as being “difficult” and she let him do the dressing himself. By so doing, Tina was able to develop a rapport with a patient whom other nurses had labelled difficult to work with. However, although Tina found it rewarding looking after chronically ill patients, the unit practice to rush and perform things by a certain time line was hindering Tina from doing what she enjoyed doing: taking time to listen and talk to patients.

Tina: Sometimes it’s so incredibly [*sic*] rewarding, it really is. I mean, you do have days when you cry, you know, cry tears of joy from helping someone, or being in a moment with someone that is very, *very* [emphasis added] important for them, and other times you cry tears of frustration, because you want to do something for someone or you see the problem, and you feel just like, mm, there is nothing you can do, at the time. Whether it’s being able to sit with someone, or give them a cup of tea, it makes you feel better, just to do something small you know, you’re so busy that you can’t. And then there’s pressure from the people that you work with to get things done [snaps fingers], just get things done.

Tina later elaborated on the above statement and explained how she was “frowned upon” by peers if she did not complete certain tasks on schedule. She explained how as a result of that, some of the “most important things” like talking to patients and their family “got cut off”. She explained what happens when she does not stick to the ward routine and timetable:

Tina: ... if you don’t “oh this person hasn’t been bathed yet” “but I’ve been on the phone for an hour and a half with the doctor, you know” “well, have they been washed yet?” “oh no, no. I’ve been taking care of other stuff,” you know what I mean? If that stuff isn’t done you get a lot of pressure from your peers.

Tina’s use of the word “yet” suggests that there is an expectation that patients are bathed by a certain time. Tina perceived this as “pressure” from her peers, rather than as the most important task to get done. Tina believed that work should be organized around “priorities” as opposed to “getting your tasks done”. For Tina, talking to families was just as important, if not more so, than getting tasks done. However, peer pressure and

routine where restricting her from meeting her ideal.

Analysis of the above text suggests that it's not just the physical aspect of the nurses' work that puts time constraints on nurses, but also certain unit practices about routines. Such notions resonate with Foucault's notion about the "arts of distribution" and control of individual through timetabling. According to Foucault (1975/1977), timetabling is an organizational strategy that is used to regulate individual behaviors and to ensure that organizational work runs homogeneously and smoothly. Hospital practices appear to run along this principle. Nursing tasks are organized around a schedule, and nurses are expected to abide by it. These institutional discourses are being reinforced by nurses who put pressure on each other to rush and to get the work done in a certain timely fashion. Tina found it difficult to spend time with patients and negotiate care with them, because whenever she disrupted the unit's timetable she would get frowned upon by peers. This suggests that peers pressure is in reality the force that kept the timetable running on schedule.

A good number of the nurse participants described how they were able to exercise their agency so that they did not become subject to institutional practices, such as pressures from peers. They achieved this by being flexible with routine and timetables, by making their own priorities and by multitasking.

Making it Happen

Being Flexible with Routine and Timetables

Lucille, who qualified as a nurse more than 35 years ago, said that she enjoyed

looking after chronically ill patients; she liked getting to know them and spending time with them. She said: “I enjoy patients, I like talking to them, getting to know them and I think, with, chronically ill patients you get to know them more, get to know their families more, and, I, [*sic*] always enjoy that”. However she found that the main obstacle to negotiation of care with patients was the hospital routine to get work done within a certain time frame and a feeling of pressure to “rush-rush” was reinforced by her peers. Lucille talked at length about certain nurses who rushed to do morning care so that they could get their charting done on time. Lucille believed that there was no need to rush. One could still get the work done and spend time with patients.

According to Lucille, it’s not the task itself that was hindering her availability to listen to the patient, but this “rush-rush mentality” and the institutional practice nurses need to “rush along and get all these baths and get all these beds done by a certain time”. Lucille was able to challenge these dominant hospital practices by being flexible and by not letting the hospital timetables and routines dictate and control the way she negotiated care with patients. She managed to perform the daily physical tasks that needed to be done, but she was not fixated on completing certain tasks according to a timetable.

Making Priorities

Lisa, who had been looking after chronically ill patients for a number of years, explained how she managed to find time to talk to patients. Like Lucille and Tina, Lisa enjoyed looking after chronically ill patients and their families. Lisa believed that finding time to talk to patients was as important as other tasks. She found time to do so, no matter how busy the floor was. She explained that hospital routines put undue pressure on her, and like Lucille, she believed that certain tasks could wait. Lisa believed

that priorities should be done first, and listening to patients and interacting with them may be a priority in some instances.

Lisa: Yes, absolutely. Like they gotta [*sic*] get things done, and I understand that, part of it, but I don't think it matters if you get a bath by eleven o'clock in the morning. Like, if you have stuff to do and other important things to the patient, like yesterday for example, I sat in with the patient who was going in for a biopsy. She's only forty-four years old, and she has lymphoma, and there's spots kinda [*sic*] everywhere, so Dr. ___ came in and told her, he'll take her in today if possible. So she wanted to talk to me, you know, she had questions, but she had things that he had said to her, that she wanted me to talk to her, so I sat in the room and talked to her, and everything gets done eventually, right?

Lisa resisted institutional practices about giving priority to physical tasks and timetabling. She used her assessment and critical thinking skills to set up priorities and proceeded accordingly. She saw tasks such as communicating with patients to be just as important as physical tasks and she allowed time for it. This nurse's statement resonates with the current focus on patient-centered care and fostering self-management. It speaks to the need for health-care professionals to stop and listen to the patient's expertise, and their way of managing their chronic condition.

Multitasking

Another way that some nurses created time for patients was by multitasking. Irene, Marilyn and May, who had been looking after chronically ill patients for more than five years, explained how they learned to find time to listen to patients by multitasking. Irene mentioned that time was a factor that hindered her from giving the care she wanted to give to patients; however she used multitasking to organize her work and create time to talk to patients.

Irene: Well, when you are looking after chronically ill patients there is so much that you can do, and so much that you can't. You do not have one patient. It's a time factor. You are trying to get all your work done and giving that individual care that they need, and so you learn over the years that what I have to say, you take

opportunity when you are assessing them, you ask them questions. You know, I like to actually find out if they're retired, if they have children, usually ask about the family. I ask who they are as a person when I am assessing them, and and [*sic*] there is also patient teaching when you're giving care, also tell them things that they should be doing, like are they doing that? So you have to condense things into your care?

Irene found time to talk and listen to patients by fitting it in when she was doing other nursing tasks. Tina also did a similar thing. She tried to fit in that extra time here and there in between tasks when she was in the room with a patient. Tina believed that it was very important to spend an "extra couple of seconds" and that it made a difference.

Tina: I try to get them involved as much as I can when I'm doing their care or bringing the medications or, you know, anything I'll try to talk, even if it's just two seconds that I'm in the room, I try to talk to them about something, about their care, what they would like to do, or how they're feeling. How they slept, you know. Yeah. And I find I'm having more time, as I become more experienced, because I have more time, because now it's quicker for me doing the other things! But it's really a time issue.

Although certain hospital routines and practices can be challenging to resist, Tina was able to overcome these hurdles through experience. Interestingly, the nurse participants in this study who were able to resist the "rush, rush" mentality, and manage their time effectively, were nurses who had practised for ten years or more. Tina, who had been qualified as a nurse for two and a half years, had less experience in nursing, but seemed to be steadily learning to manage her time effectively.

Unit Culture

Overall, when nurses resisted these discursive practices about routine and timetabling, they did so with success and to great personal satisfaction. Yet, such nursing forms of resistance came at a cost for some nurses. Irene, Marilyn and Ray explained how dealing with peers was "mentally tiring", and how they "feel spent" and "emotionally spent" dealing with certain nurse colleagues. All of the nurse participants

mentioned how working with certain peers can make it easier or more difficult for them to find time for patients.

Working with Peers

A number of nurse participants talked about peers and how working with certain nurses affected negotiation of care with some patients. Irene mentioned how some peers were good to work with, and how “working together” as a team saved her time, and she was better organized with her work.

Irene: I find, when you are working with certain staff, you could be perhaps better organized ... and if they're familiar with your patient, if you're familiar with the patient you can find time but if you're working with good co-workers and you work together, I find that saves you time, you manage the unit better, and you know.

The above indicates that knowing the patient and what the patient needed facilitated negotiation of patient care, and both nurse and patient could “work together”. However, Irene’s use of the words “working with certain staff” suggested that it was not just knowing the patient that saved her time, but also working with certain colleagues whom she described as being “good”. Irene later described these individuals as nurses who had a “positive” attitude towards patients. Irene gave an example of a nurse whom she described as being “good”, and how they worked well together. She described how they were able to joke with and cheer up patients and brighten them up.

Irene: She [referring to peer] was so good like. We had this one particular patient who was there like, for about a year and it was just like a big snowball ... he was like a cat of nine lives you know ... he should have died ten times, but he's still kicking and going strong today ... he got transferred to a long-term care facility but anyway, [she] and I would go in, and he was in isolation and you know people would say, “Oh God, not him again... ugh”, you know, and we would walk by the door and make a joke, or like call [her] names or something, and we would tell bad jokes, dirty jokes, and we would make him laugh, and you know I still see the family, and that's it, you know.

Irene seemed to enjoy working with this nurse, because they both shared similar

values and beliefs about caring for patients. They also seemed to get satisfaction knowing that they were able to make this patient laugh and they were able to build a rapport with this patient. Irene found it difficult to work with co-workers who were only interested in doing their work and not helping others. She explained how these peers were reluctant to help and very negative towards what she was doing.

Irene: it's someone that I don't enjoy working with, that is very negative, but they're good nurses, don't get me wrong, they're very smart, but you know, sometimes they're very difficult to work with because they are very negative towards what you're doing all the time, I might not tell them [to help her], there's only a few of those around.

Irene explained how she tried to avoid these nurses, and not to consult with them when possible. However, sometimes she had no choice and she had to resort to these peers to help her. Irene explained that when she called such peers, she did not let the negative attitude of others shape the type of care she gave to patients. She explained how she took control of the situation and how she resisted being rushed by her peers.

Ray also believed that it is important to have teamwork, because when there is tension between peers it “reverberates with the entire floor”. He explained that when there are tensions between staff, the atmosphere on the ward is “just drapp [sic]” and it felt like “almost like you are working in a mortuary or something. It's just, there is no life”. He also mentioned that the patients can sense the tension, and they can feel “it's not a good day”. Ray said that patients have “enough going on in their lives” and they do “do not deserve that”.

Ray: oh it does really wears me down. Like, it does. It just, beats me down so bad, like I don't wanna say makes me depressed but, but, you just leave here [unit] some days feeling defeated, because that one day goes by, when you have a crew [peers] like this, the residents feel it. It just kinda reverberates with the entire floor, you can feel the tension. They [patients] don't know what it is; they

just know that it's not a good day today. And they do not deserve that right? They're here, I mean on this floor 24/7 they don't want to know what is going on in our lives. They have enough going on in their lives. Our patients do not deserve that.

Ray felt that when there is tension between nurses, the patients can sense it.

Although Ray did not elaborate on how it affects patients, the reader may recall how some patients were very vigilant of nurses and their moods. For instance, Anne would not vocalize her needs if she felt that nurses were having a bad day for she feared retaliation. Ray believed that nurses needed to have a positive approach when working with chronically ill people and towards peers. He believed that having a positive attitude was not something that one learned at university, but it was a value that was passed on by families, "like mama taught you".

Ray: If you cannot get along with the person you're working with, and have good relations with them. I mean you do not have to like everybody. We do not like everybody, but you have to respect people that you are working with enough to know you gotta [*sic*] have their back, and to help them when they're need it because in ten minutes you might need it, and if you're not gonna [*sic*] give it [respect], you're not gonna [*sic*] get it [respect]. You know, I mean, *like your mama taught you* [emphasis added]: you treat others like you wanna [*sic*] be treated, right? [Laughs] It's basic stuff really, its stuff you do not learn in a university, its basic personality traits and stuff, that we have to get over and just try to help everybody else. The day goes by so much easier eh? If you are just willing to cooperate and help.

Ray's use of the words "like mama taught you" suggests that family values play important roles in nurses' attitudes towards patients. This suggests that negotiation of care between nurses and patients is not just influenced by institutional discourses, but also social discourses. Family values, practices and beliefs also play an important role in shaping the attitudes of nurses and how they behave when they negotiate care with patients and team members.

Task versus Patient Allocation

Just as peer support and personal values affected coordination of care between team members and negotiation of care with patients, the way nursing care was organized on the unit also played an important role. Marilyn, Lucille, Susan, and May explained that they worked with two different systems of nursing care, task allocation (where nurses are delegated tasks as their work) and patient allocation (where nurses are delegated a group of patients to look after). They mentioned how with patient allocation, they had more time to spare to get to know the patients, to discuss their needs, and, therefore, to negotiate care.

May provided many examples of patient allocation. In fact most of her interview was focused on this topic. May valued that nursing care on her unit was organized around patient allocation. She explained that she had worked with various other nursing systems including task allocation and team nursing; however patient allocation seemed to work best for her. May explained that patient allocation provided her with the opportunity to get to know her patients and their families well. She explained how she got to “know so much more” about her patients because she got to do all the nursing care, not just one particular task. She said: “You’re it, you’re their nurse, and you’re their caregiver pretty much 100 per cent”.

Unlike task allocation, patient allocation gave May more freedom to decide how to spend her time and diminished the likelihood that she would get caught up in a unit routine. May explained that it was still a busy day for the nurse; however, with patient allocation she got more opportunity to get to know patients and their needs. She would

fit in communicating with them when performing tasks, or simply “popped in” to check on them more often.

Overall, five of the nurse participants talked about and lauded patient allocation, its advantages and its potential to allow for more time to communicate with patients. Interestingly, one participant disagreed. Lisa felt that with the older system of task allocation, she had more time to talk to patients. Like other nurses, she believed that the way work was organized could detract her from finding time to talk to patients; however, she felt that the old routine of task allocation afforded her more time to spend with patients and to get to know the patient better.

Lisa explained how with the current system of patient allocation, she had to do everything herself. She believed that certain work like paper work and coordination of activities were time consuming, and such tasks, “as far as patient care goes, that time is half down”. Lisa explained how with task allocation there was a central nurse who coordinated care and dealt with mundane nursing issues like contacting doctors, and other multidisciplinary members looked after blood work and other issues that did not concern direct patient care. Lisa’s input is noteworthy. Although she was the only one to advocate for the traditional system of task allocation, she highlighted an important aspect that was overlooked by others. She pointed out that nurses may be busy and may not have time for patients, but that it was important to find out what nurses were busy doing; whether it was patient care or ancillary activities which could be done by non-nursing staff.

Chapter Summary

In order to negotiate care with patients, nurses need time to sit down with them,

find out what their needs are and exchange ideas on how to reach a mutual agreement on how care will be delivered. There was a general consensus between nurses and patients that finding time to listen to what the patient has to say facilitated negotiation of care between nurses and patients. Some patients noted how some nurses find time to listen no matter how busy they were. Some nurse participants agreed; however, they commented that institutional discourses about routine and timetabling put pressure on them to rush and get tasks finished by a certain time, rather than spend time with patients. These discourses are often reinforced by peers who have a “rush-rush mentality”. Some of the nurses were able to resist these institutional discourses by being flexible about timetabling and working around priorities rather than time. Others were able to create time to listen to patients by multitasking and by fitting in time while they were performing other tasks.

Unit culture was a significant aspect influencing care that emerged from the findings. It was found that when there was teamwork, work was done faster and nurses could spend more time with patients to negotiate care with them. In situations when there was a lack of co-operation between peers, the atmosphere on the unit was tense and patient care was affected. Some nurses did not let negative peers impinge on the way they delivered care. They were assertive and made sure that the patient care was not compromised. Certain institutional practices around organization of patient care helped to prevent and break this institutional practice of routine. Most of the nurses felt that patient allocation gave them a larger sense of control over how to spend their time and set priorities.

CHAPTER 10

DISCUSSION AND CONCLUSIONS

The aim of this study was to examine the experiences of chronically ill patients and nurses when they negotiate patient care in hospital settings. In this study, negotiation is understood as a process in which nurses and patients resort to different concessions and compromises in order to attain an agreement on how patient care will be delivered. This process is characterized by power sharing, where control is mutual or exchanged. The outcome of negotiation is presumed to be positive, however there is a potential for conflict between partners. The research questions that guided my study were: 1) How do chronically ill patients experience and negotiate their care while in the hospital? 2) How do registered nurses experience and negotiate the care they provide to chronically ill patients?

In this study, I wanted to find out what is happening during the process when patients and nurses were negotiating patient care. One of the basic assumptions that guided this study was that social and institutional discourses shape nurses' and patients' ways of thinking and behaving throughout these negotiations. In order to uncover these nuances, I needed to go beyond the participants' descriptions and pay attention to the language that the participants used when they described these experiences. This was achieved by looking at: the terminology that they used; the social construction and position of self in the relations; how power relations were negotiated; and how this affected the outcome of the negotiation. This knowledge was helpful to identify how social and institutional values, beliefs and practices shaped power relations and

negotiation of patient care. The information garnered was used to address my research sub-questions, which were:

1. What were the experiences of registered nurses and chronically ill patients about negotiation of care in hospital settings?
2. What were the social and institutional beliefs, values and practices of registered nurses and chronically ill patients when they were negotiating patient care in the hospital?
3. What were the power relations between registered nurses and chronically ill patients in hospital settings, and how were they negotiated?
4. What discourses inform the experiences of registered nurses and chronically ill patients, and how are these discourses negotiated?

The theoretical and methodological approaches used in this study were based on the precepts of Foucault and feminist post-structural theorists Butler (1992), Weedon (1997, 1999) and Cheek (2000). Foucault's precepts on knowledge, power, and discourse were used to understand how relations of power were established between nurses and patients. Foucault states that power does not always operate in overt ways; rather, it predominantly operates in subtle ways by shaping the individual's ways of thinking, feeling, and acting, through discourses. Discourses are values, beliefs, and practices that have been adopted in a particular society or institution at a particular historical time. They define the standards and norms for individuals who reside in that society. Individuals learn these discourses as they enter that society and the majority of people "accept" these values as their norm, in order to integrate within that society.

The findings from my study suggest that the discourses that shape nurse-patient relationships may be changing and moving more towards patient-centered care (Doss, DePascal & Hadley, 2011; Stoddart & Bugge 2012; Taylor, 2009; Thorne, 2008; Wellard, 1998); however, they remain deeply embedded in a hospital system that is still patriarchal in nature. In recent years, there has been a concerted effort from all health-care disciplines to move towards patient-centered care, and to ‘activate’ patients and motivate them to involve themselves in their care (Barr et al., 2003; Mosen et al., 2007). A case in point is the Chronic Care Model which has been used internationally to encourage active patient involvement in care; however change is slow and a degree of professional dominance remains.

In this study, feminist post-structuralism was used to understand how a patriarchal system could create binaries and subjectivities that could be oppressive. The findings revealed that just as the system has the potential to restrict and oppress, it also has the potential to promote the development of negotiation of care. According to Foucault and feminist post-structural theorists, individuals may be subject to these oppressive discourses; however they are not in a position of powerlessness. Every individual has the capacity to resist and challenge oppressive discourses and can use them creatively to their advantage.

In order to explore negotiation of patient care between hospital-based registered nurses and chronically ill patients, in-depth interviews were conducted with eight previously hospitalized chronically ill patients and 10 registered nurses. Five themes emerged from the analysis. These themes were:

1. *Getting to know each other*

2. *They are not the sickest patients*
3. *The two faces of patriarchy*
4. *The challenges of looking after chronically ill patients*
5. *Finding time to listen*

Some of these findings confirm what has been found in earlier studies, while others add new perspectives to the existing nursing literature. In this chapter I will: a) discuss the key findings from these themes and how they compare with those in existing research, b) discuss the strengths and limitations of this study, and c) suggest implications for nursing practice, research, education and policy.

Discussion of Key Findings

Getting to Know Each Other

One of the salient findings that emerged under this theme was that despite the various challenges that nurses and patients faced during negotiation of patient care, they also shared many positive experiences. Almost all participants commented on the special relationships that developed between nurses and patients as a result of the patient's frequent admissions to hospital. Many of the patient participants commented on how they got to know nurses on a personal level and vice versa. Some nurses and patients said this knowledge enabled them to understand each other, and to develop a friendly relationship between them, which one participant expressed was similar to that of a family.

The fact that looking after chronically ill patients can result in close connections with patients similar to those of a family, adds a new dimension to the existing nursing literature. Looking after chronically ill patients has been portrayed in the literature as an

unfulfilling task for some nurses and other health-care professionals (Murrow & Oglesby, 1996; Turner, Pugh, Budiani, 2005; Thorne, 2008) and less rewarding to health-care professionals in terms of job satisfaction (Lubkin and Larsen, 2013). The positive aspects of looking after chronically ill patients are seldom touted in the nursing literature. Only two studies were found that commented on the close connections that develop between nurses and chronically ill patients. Sahlsten, Larsson, Sjostrom, and Plos (2009) reported that “getting to know the person” was an effective tool for nurses to elicit information about the patient and to understand patients better, but did not elaborate on how it affected power relations and negotiation of care in practice. In another study, Malone (1996) looked at nurses’ perceptions of “frequent flyers” (p.3) in the emergency department. Malone said that since the emergency department tends to focus more on cure than care, “frequent flyers” can easily become a source of frustration and resentment for nurses. However, the fact that nurses got to know these patients on a personal level and became “like family” helped to bring back caring and compassion in the emergency department.

Findings from my study add to the above literature and reaffirm that that negotiating care with chronically ill patients can be a rewarding and positive experience for nurses. These findings challenge the notion that looking after chronically ill patients is boring and less rewarding than attending to the needs of acutely ill patients. A deconstruction of the binary between acute/ chronic nursing and a deeper understanding of what the word ‘rewarding’ stands for, reveals that whilst chronic care nursing may lack the hi-tech image, prestige and fast pace of acute care settings, the intrinsic rewards that nurses garnered from developing friendly relationships with patients and from making a

difference to chronically ill patients, can lead to personal gratification and makes looking after chronically ill patients worthwhile.

They are Not the Sickest Patients

A concerning issue that emerged from the findings was that patients with acute illnesses were given more importance than those with chronic illnesses in hospital settings. Although patients in this study acknowledged that there may be reasons why patients with acute illness are given priority, they identified that the waits patients with chronic illness were forced to endure created significant suffering. It has been noted before in the literature that the needs of chronically ill patients are not negotiated effectively in the emergency department (CAEP, 2001; Grudzen *et al.*, 2010; Shaw, 2007). Grudzen *et al.*, (2010) posit that since traditionally the mission of the emergency department has been to provide urgent and life-sustaining treatment for patients with acute illness, patients who present to the emergency department with these chronic situations may not have their needs adequately addressed. Grudzen *et al.*, (2012) explain that patients suffering from chronic illness require complex management, which usually differs substantially from the management of individuals who are admitted with acute conditions. The care needed does not require symptom assessment and treatment and follow-up management like some of the acute conditions that are resolved upon discharge. Rather, it requires the mobility of community support and resources to prevent exacerbation of chronic patients' condition or supportive care for those who are at the terminal stage of their illness (Grudzen *et al.*, 2010). Grudzen *et al.*, recommend further work to reorient the role of emergency medicine so that it considers changing demographics and includes chronic populations. The fact that the results of my study are

in accordance with previous literature helps to reinforce the need to address this issue, and to improve negotiation of patient care in emergency settings. Reiterating the importance of paying attention to the needs of chronically ill patients is imperative and raising awareness about the problem may urge policy makers and health managers and stakeholders to take action.

As an example of how visibility of a problem can help to minimize marginalization, was evident in the way chronic pain was managed in different hospital settings. The finding that some patient participants who were on opioids were labelled as drug abusers is also supported in nursing literature. Miner, Kruse and Biros (2003) reported that those patients whose pain remains unrelieved by analgesia were often suspected to be drug seeking by physicians, while McCaffery et al. (2005) found that nurses had preconceived ideas and misconceptions about patients who were seeking opioid/narcotic treatment and judged them to be drug addicts. Likewise, Fosnocht et al. (2005) commented that the major impediment in effective pain management is overcoming the stigma that some doctors and nurses have about patients who are on opioid/narcotic treatment.

What my study adds to nursing knowledge is that while some of the nurses' values, beliefs and practices about patients who are on opioid treatment remains unchanged in some hospitals, chronic pain was more effectively managed in hospitals where nurses had more training and experience looking after patients suffering from chronic pain. In these situations, patients were not labelled or stereotyped, they were not marginalized and positive negotiation of patient care was possible. This finding suggests that knowledge and repeated exposure to atypical situations may help to minimize

stereotypes and exclusion. According to Scott (1992), the more such discourses are brought out in the open, the more one gets used to alternative ways of looking at a particular situation. Scott (1992) noted how exposure to different experiences can help to break stereotypes and to minimize marginalization.

The Two Faces of Patriarchy

Findings under this theme revealed that hospitals are still embedded in a patriarchal system which privileges expert knowledge over patient's wisdom about management of their condition. This finding is not new. An increasing body of literature that stresses the importance of shifting nursing authority and giving primacy to the patients' expertise when negotiating care with chronically ill patients (Bodenheimer, 2003; Coleman, Austin, Brach & Wagner, 2009; Nolte & McKee, 2008; Pearson & Schaefer, 2005; WHO, 2003). A unique finding that emerged from this study was the way that institutional discourses reinforced professional authority by: privileging nurses as gatekeepers of services, not allowing patients to document on hospital records, and self-governing (i.e., a process in which patients constantly kept their own behaviors in check while they were in hospital, and made sure to comply with the hospital's rules and regulations). These findings were not found in other studies I retrieved. Although the fact that health-care professionals act as gatekeepers of services has been reported by others (Thorne, Nyhlin, & Paterson, 2000; Clark 2013) this gatekeeping privilege was mainly cited in relation to doctors, not nurses. The reality that patients were not allowed to document on their hospital records, and the actuality that patients were constantly vigilant about their behavior while they were in hospital, were also new findings.

Altogether the above experiences illustrate how certain institutional discourses reinforced unequal positions between nurses and patients. These practices created situations in which some patients were marginalized from care, or where patients had to be cautious of their behavior and expressing their needs. Interestingly though, a feminist post-structural approach challenged the notion that the institutional discourses were always oppressing. For instance, some patients were willing to take on a passive role and let nurses take the lead during negotiations of patient care. Two patient participants mentioned that they were comfortable with nurses in authority, because they were the experts and they knew what was best for them. In such situations, care planning was patient-centered and negotiation was positive because the nurses were accommodating the patient's needs. Four other patient participants said that they preferred to be a "good patient" so as not to disturb nurses; not necessarily because they felt oppressed, but because it was an effective way of negotiating their care and getting their needs met. This finding shows how the expert-patient binary can be deconstructed and interpreted in a variety of ways. It also illustrates the creative ways patients exercised their agency and navigated through potentially oppressive discourses.

The finding that patients are not passive and powerless needs to be featured more in the nursing literature. The majority of the studies that were reviewed tended to neglect the patients' contribution during nurse-patient interactions and only two studies were found that looked specifically at the patients' responses to the nurses' authority (Kettunen, Marita & Gerlander, 2002; Wheatley, 2005). This automatically places the focus on nurses and creates the impression that the patients are passive or powerless. In this study, I addressed this gap by exploring the patients' response when negotiations between

nurses and patients were in conflict. An analysis of the patients' interviews confirms that although in such situations power relations were unequal, patients were not passive and they often resisted the nurses' position of authority. Patient participants told stories of how they reported nurses to doctors or administrators, if they were mistreated by nurses. When patients were too sick to participate in their negotiation, family or others advocated for the patients and also reported nurses. Many times, action was taken and the patients' needs were met. This suggests that institutional discourses and the hierarchical structures of hospital are not always oppressive, but can also be productive.

The Challenges of Looking after Chronically Ill Patients

An important contribution that my study adds to the nursing literature relates to how nurses reacted when their position of authority was challenged by patients. Only one study was found that looked into how nurses respond to patients who are more expert in managing their illness (Wilson, Kendall & Brooks, 2006). Wilson et al., (2006) reported that nurses experienced more anxiety than physicians and physiotherapists when negotiating care with expert patients. According to Wilson et al., (2006) nurses were not effective in involving patients in their own self-care; they showed a lack of trust in the patients' capability to self-manage their illness, and tended to adopt a paternalistic approach when negotiating care with patients. Findings from my study share some similarities and differences with this study. When nurses were challenged by expert patients, some nurses did adopt a paternalistic approach to maintain control of the situation. Nurses stated that in such situations they had to act firmly with patients who were non-compliant with treatment; they tried to coax them into cooperating or reported them to administrators/doctors so that they would cooperate. These findings were not new

and have been reported elsewhere. There are numerous studies and discussion papers that comment on nurses' domineering and controlling behavior (Michie, Miles & Weinman, 2003; Paterson, 2001, Hyde et al., 2006; Perron, Fluet & Holmes, 2005; Thorne et al., 2000, Malone, 2003; Wheatley, 2005, Henderson, 2003; Crowe, 2000, Sinivaara et al., 2004, Hagbaglhery, Salsali & Ahmadi, 2004, Heartfield, 1996, Breeze & Reaper, 1998; Hamilton & Manias, 2006; Holmes, 2002, 2005; Fahy & Paratt, 2006; Liaschenko, 1997; Oudshoorn, Ward-Griffin & McWilliam, 2007). However, an original contribution of my study to nursing knowledge was to show how these experiences can be deconstructed or unpacked and show why nurses acted this way. In this study, I was able to provide some answers and show that nurses also had explanations to offer.

Unlike what was reported in some of the literature (Mohr, 1999; Maben, Adams, Peccei, Murrells & Robert, 2012; Khalil, 2009; Lowbridge & Hayes, 2013; Price, 2013; Shaw, 2007), nurses in this study did not always use labelling or authority to assert their position of power and oppress patients. There were times when some nurses stated that they acted this way because they felt this was the best way to help patients get better, or to help them out of depression so that the patient could return home to their loved ones. It is true that sometimes nurses postponed attending to the needs of demanding patients; however, it is possible this was the best way to deal with the situation. They explained that they had to act this way in order to attend to other sick patients they had to look after, and that they perceived to be more urgent. These findings offer a different perspective on nurses' use of authority and what constitutes good/bad nursing. It provides a deeper understanding of why nurses were acting in this manner. Interestingly, findings from this study indicate that when nurse participants felt the need to be firm with patients, they

emphasized the importance of being very careful about use of language and that although they were firm, they were polite with patients. It is not known how patients in this study perceived the nurses' use of politeness; however, nurses did mention that they were being “polite” towards patients because they did not want to come across as “being mean”. The above findings expose the multifaceted nature of nursing authority. These results suggest that one cannot make sweeping statements about nurses: each negotiation between nurse and patient is a unique, complex situation and needs to be interpreted in its entirety rather than as an agglomerate activity.

Further, in contrast to the findings from Wilson et al., (2006) nurses in this study did show trust in some of the patients’ capability to self-manage their illness, and did allow the patient to take the lead in difficult situations. Some nurses mentioned how they tried to deal with moments of tension by stepping back, listening to what the patient had to say and acknowledging the patients’ expertise about management of their condition. This finding raises hope that change in nursing practice is happening, and involvement in patient care is not as much rhetoric as the nursing literature claims it to be.

Finding Time to Listen

The importance of listening to patients was a salient factor that facilitated negotiation of patient care between nurses and chronically ill patients. Similar to existing literature (Khalil, 2009; Maben et al., 2012), nurses in my study seemed to have little time to sit down with the patients and listen. The majority of earlier studies attribute this to the nature of nursing work, which creates time constraints and as a result, nurses cannot afford to spend much time interacting with patients. Nurses in this study also felt

this way. They mentioned that their busy workload restricts them from spending time with patients. However, in this study it was found that it was not just the workload that put time constraints on nurses, but also a ‘rush-rush’ mentality by peers. Nurses mentioned that some peers put pressure on each other to finish nursing tasks by a certain time. Interestingly, nurse participants in this study resisted and challenged these institutional discourses, and proceeded to follow what they felt was best for the patient at the time.

These findings are in accordance with a study by Rodney (1997), who reported that one of the most pervasive cultures that influenced nurses to act the way they do was their peers. Rodney used a relational matrix to describe how she saw nurses as “connected individuals acting in concert with one another; in other words, how nurses work with each other so that they become a united force. According to Rodney, this connectedness allows nurses to support each other in practice at times when they need to act according to their moral judgments, particularly if they did not agree with what doctors or other professionals dictated. However, at times the relational matrix hindered nurses from positive enactment of their moral agency. Rodney (1997) reported that sometimes nurses applied sanctions to one another in order “to promote congruence with or resistance to predominant patterns of practice”; for example, when nurses spend time talking to patients (acting according to their own moral agency), they are punished by their peers. Nurses used messages and actions to reward one another for efficiency and “emotional strength” when nurses distanced themselves from patients (Rodney, 1997). According to Rodney, when these institutional discourses were taken for granted and left unchallenged, it led to moral distress in some nurses. In my study, nurses found it

rewarding working with peers who shared similar values, beliefs and practices, but mentally exhausting dealing with peers who had different values, beliefs and practices. However, unlike in Rodney's study, it did not seem to lead to moral distress. Nurses like Irene and Ray mentioned how they did not let certain negative attitudes from peers affect the delivery of their patient care. Instead, they proceeded to do what they believed was right for the patient irrespective of their peers' approval or lack of same.

The valuing of listening skills and getting to know patients is often associated with nursing as a female profession. It was not surprising that one of the findings that emerged from this study follows the ongoing debate in nursing about gender issues. The perception that nursing is "women's work" and therefore not as important as medicine, became apparent through words that nurses used, such as when they described their work using the word "chore" (p. 206) or that some patients looked at them as a "glorified waitress" (p.223). These words suggest that nursing is still perceived as women's work by some nurse participants. The fact that nurses commented that doctors were more interested with "blood work" (p.157) and "with numbers" (p.157) and that nurses have to be the "patient's advocate" (p.160) also suggests gendered roles. Women and seemingly 'softer' skills have historically positioned nursing as 'less important' than medicine; however, nurses and patients in this study challenged this hegemonic way of understanding nursing. Participants in this study offered powerful, personal experiences that showed how 'caring' is effective and should be considered to be just as important as technical tasks and medical discourses. It bothered some nurses when other professionals or patients devalued nursing work; however, none of the nurse participants said that they felt inferior to doctors. This suggests that although they felt others devalued their work,

nurses did not perceive themselves as less important; just different. This finding in itself suggests that nurses were already deconstructing the binary between nurse-doctor in their mind. Further, not only were nurses unabashed of these gendered roles, rather some nurses took advantage of their position as a nurse and as a female to negotiate patient care with doctors. For instance, some nurses did not feel victimized by the fact that some patients seemed to “idolize” doctors. Rather, they laughed about it and used these beliefs and values from the dominant medical discourse to negotiate care with patients. These findings provide a different twist on nurses’ position within the health-care system; nurses are not as powerless as they perceive themselves to be (Gastaldo & Holmes, 1999; Udod, 2008).

Summary of Key Findings

Most of the results in my study were to a larger or lesser degree in accordance with earlier studies; however some findings contradicted the existing literature, or provided new insights. Therefore, as a whole, in this study I have met the feminist post-structural expectations by demonstrating that discourses shaping nurse-patient negotiations are multiple, sometimes complementary, sometimes contradictory, and yet, no matter how much a topic is researched, there will always be gaps that need to be filled.

The above findings also illustrate how negotiations of care between nurses and patients are shaped by multiple factors such as hospital rules and regulations, hierarchies, interdisciplinary relations, patient characteristics and gender difference, all of which fall under the umbrella of social and institutional discourses. These factors do not operate in isolation, and they do not affect nurse-patient relations in a linear and direct way. Rather, such discourses are intertwined with each other, pushing and pulling nurse and patient

negotiations in all directions. Hence, negotiations between nurses and patients are never stable or predictable. Rather, negotiations are complex and messy, and their trajectory is indeterminate.

Collectively, the above results also indicate that I met the criteria for transgressive validity (Morrow, 2005). The reader may recall that one of the criteria that measures rigor in feminist post-structural studies is the ability of the researcher to incite discourses that transgress the established norm. In this study, I achieved this by challenging existing binaries and stereotypes by showing that patients and nurses are not passive and docile, and that they exercise power. I also demonstrated how discourses that are associated with nursing as a female profession are not inferior to medical discourses. Rather, they are different and just as important during negotiation of care between nurses and chronically ill patients. In so doing, I addressed the transgressive requirement for feminist post-structural approaches.

Strengths of the Study

The main strength of this study is the way negotiations between nurses and patients were unpacked. Most of the studies reviewed tended to look at negotiations between nurses and patients from a Marxist perspective, in which nurses were viewed as the protagonists who oppressed or empowered patients, and patients were viewed as passive recipients of care (Jarret & Payne, 1995; Kettunen, Poskiparta, & Gerlander, 2002; Hagbaglhery, Salsali & Ahmadi, 2004). Although these approaches have offered valuable information about why negotiations between nurses and patients have not yet materialized in many health-care settings, these models do not provide insights about the dynamics that are taking place during the interaction process. My contention was that to

explore negotiations between nurses and patient, one has to move beyond the individual and focus on the social and institutional discourses that shaped one's way of thinking and acting. Focusing on the moment of negotiation between nurse and patient is crucial to understanding why negotiations were successful, or not. It helped to identify how nurses and patients negotiated agreements or disagreements, how they arrived at their decisions and how social/institutional discourses shaped the trajectory of negotiation.

Another strength of the study was the richness of the data obtained. This study generated a wealth of information that could be used to identify and illuminate those nuances that may or may not be apparent to nurses, and to offer other perspectives for looking at nurse–patient relationships. Knowledge of these social and institutional discourses was pivotal in order to understand how they contribute to the outcome of negotiation. An example of this is the way current institutional discourses can create situations in which nurses' position of power was reinforced through institutional practices such as: gatekeeping of services, invisibility of the patients' voice in nursing documentation, or control of patients' behavior through self-governance. Becoming aware of how social and institutional discourses shape one's thinking and action and making them known through research is the first step in changing practice. Aston et al. (2011) explain how such knowledge can be useful to encourage self-reflexivity in practice and how it “may help nurses and clients challenge, work with, through and against social [and institutional] discourses, to change harmful beliefs and practices” (p.1191).

Further, raising awareness about the ways in which social and institutional discourses shaped negotiation of care between nurses and patients helps to shift the sole

blame from the individual to contextual influences (Aston et al., 2011). In other words, the personal becomes political. By shifting the blame from nurses not doing their jobs and patients not being cooperative to the institutional contexts, incongruences may be identified and action can be directed towards institutional practices that may be troubling negotiations between nurses and patients.

Limitations of the Study

This study is limited by its small sample size and the characteristics of the sample. Although the data generated was rich enough to address the aim of the study and the research questions, the findings cannot be generalized beyond the sample of this study. For instance, one of the main characteristics of the sample was that the majority of the patients interviewed suffered from chronic pain. This enabled me to concentrate on how negotiation of care could be better addressed in these situations; however, not all chronically ill patients suffer from pain and there are other areas in chronic illness that were not addressed. These areas deserve further exploration.

Likewise, the fact that all of the nurses interviewed mentioned that they all enjoyed looking after chronically ill patients suggests that there was a selection bias: that is, only those nurses who had positive experiences with patients came forward to be interviewed. That said, understanding the views of nurses who enjoyed looking after chronically ill patients is just as important as understanding the views of nurses who do not like to look after chronically ill patients. Both views underpin clinical reality. Another limitation is the risk of having a 'social desirability effect' in which participants respond in a way that they think the researcher wants to hear. However, my position as a researcher is not to judge the participants stories, but to get to the heart of their

experiences and what they want to convey to me as a listener. In so doing, I was minimizing the power relations between researcher and participants and by being open to what they wanted to communicate with me. The stories that participants told were an authentic expression of their experience. I could see this clearly during the interviews by the way they spoke about their experience, by their nonverbal gestures, and by the way they were emotionally moved as they recounted their stories. Whether or not these findings are amenable to generalizations can always be explored in future studies.

The sample used in this study captured a picture of how institutional discourses shape power relations and negotiation of care between nurses and chronically ill patients. Findings revealed a number of institutional discourses that shape negotiation of patient care; however, this information was not captured from the perspectives of hospital managers, administrators and policy makers. This information would have provided more insights about the hospital hierarchical structure, the experiences of those in the higher levels of the structure, and the way those shape negotiation of patient care. Still, this omission does not weaken the findings. The aim behind feminist post-structural approaches is to create awareness of a situation, and the multiple ways one can view it, rather than to provide a complete and comprehensive theory. Based on the above findings, strengths and limitations of this study, I will proceed to discuss the implications for nursing knowledge, practice, policy, education and research.

Implications for Nursing Practice

Publicizing that Looking after Chronically Ill Patients is rewarding

The fact that all nurse participants established close connections with chronically ill patients is important to recognize and needs to be publicized in nursing literature.

Such experiences can help to counteract the negative views or misconceptions that exist in the literature and in the work environment about looking after chronically ill patients. If chronic illness is continuously perpetuated as a “burden”, management of chronic illness is likely to be viewed through a negative, rather than a productive, lens. Changing one’s mindset that looking after chronically ill patients is not an encumbrance, but a rewarding experience, fosters positive attitudes. It encourages nurses to be less distant from chronically ill patients and instead to connect more with patients. Further promoting the idea that looking after chronically ill patients is rewarding may help to reduce burnout in nurses, and promote better recruitment and retention in these areas. This shifting of mentality is pressing, not only because chronically ill patients need to be treated equally and fairly, but also because chronic illness is now on the rise and the majority of patients requiring hospital services are now chronically ill patients.

Giving Chronically Ill Patients Importance in Hospital Settings

One of the most pressing issues that can facilitate negotiation between nurses and hospitalized chronically ill patients is to acknowledge that the needs of chronically ill patients may be different from the needs of acutely ill patients, but they are just as important. Changes need to be made both in terms of allocation of resources and in terms of professional attitudes towards chronically ill patients. However, before making any idealistic suggestions, I realize that there is a need to take into consideration the reality of the hospital setting, including the fact that resources are scarce, and that changing patriarchal systems takes time. The following suggestions therefore relate to a reevaluation of existing services, rather than to dramatic changes. Namely, what I suggest here is a reorganization of hospital services to address the needs of chronically ill

patients, and an adaptation to the current patriarchal system rather than a transformation. I will begin by looking at how resources within the emergency department and hospital units can be utilized so that the needs of chronically ill patients are not treated as less important.

One main observation from this study was that chronically ill patients were still resorting to the emergency department in hospital, even though their condition did not seem life-threatening. Patient participants reported that they preferred to go to hospital, possibly because it offered 24-hour access to resources that were not available in the community. Since chronically ill patients were still resorting to hospitals to address their ailments, a recommendation for practice would be to do an environmental scan of the services that exist in the community and see if an alternative exists, or if one can be put in place.

Another option would be to offer a separate service in the emergency department that caters specifically to the needs of chronically ill patients who go to hospital when they have a chronic complaint. Such a service is already in place for specific populations, such as those suffering from mental-health concerns or who require pediatric services. These services are intended to provide specialized treatment and to reduce waiting times for these populations. Perhaps a similar service could be developed for patients who present to the emergency department with chronic complaints. These services could be managed by nurse practitioners⁴ who are specifically trained in managing chronic illness, and who can provide their services in the emergency

⁴ The Canadian Nurses Association (2006) defines Nurse Practitioner (NP) as “registered nurses with additional educational preparation and experience who possess and demonstrate the competencies to autonomously diagnose order and interpret diagnostic tests; to prescribe pharmaceuticals; and perform specific procedures within their legislated scope of practice.” (p.19).

department and also on wards. In a study conducted by Martin-Misener, Reilly, Robinson and Vollman (2010), nurse practitioners were found to play a significant role with patients suffering from acute and chronic illnesses in rural areas of Nova Scotia. Martin-Misener et al. (2010) reported that nurse practitioners in these areas spent more time with patients compared to the amount of time doctors were able to spend with patients. Nurse practitioners also tended to have a holistic and family-orientated approach to patient care. Further, these researchers reported that nurse practitioners proved to be more cost effective, since they were able to offer the same services as doctors, but at a lower cost (Martin-Misener et al., 2010). Although this study looked at the advantages of employing nurse practitioners in the community area, similar advantages may prove to be effective within hospital settings. Currently in Nova Scotia there are more nurse practitioners practicing in the community than in hospitals (CIHI, 2013). A recommendation to expand the work of nurse practitioners in hospital settings is suggested.

Another pressing need that emerged in this study that relates to quality patient care concerns pain management. Findings from the study indicate that nursing practices during shift change, or the fact that in some hospitals nurses control dispensing of medicines, resulted in situations where patients were not given pain medication when they felt they needed it. As a result of this, many patients had to suffer pain unnecessarily. However, there were examples that when pain medication was prescribed on a regular basis, the needs of chronically ill patients were met with success and the patients were satisfied. Implications for practice should include changes to some of the current hospital policies and practices so that patients can get timely and appropriate pain control. Many hospitals in Canada allow patients to have their own medication at the

bedside, without requiring a nurse to dispense it. This gives the patients considerable autonomy and freedom. The introduction of such services in other hospitals is recommended. However, there are situations in which registered nurses are still required to administer medications, as is the case with the administration of opioids in hospital settings. When patients are on such medications, it is recommended to use patient-controlled analgesia for pain relief if their condition permits. If this is not possible, it is suggested pain medication be administered on an around-the-clock basis, rather than when the patients request it. These suggestions about administration of pain medications are not innovative ideas, but have been discussed for decades (Wall & Melzack, 1984; Walsh & Ford, 1989; McMahon, Koltzenburg, Tracey & Turk, 2013). However, it seems that such ideas are still not being implemented in many hospitals. Revision of current hospital policies around pain medication that will lead to more patient control and collaborative decision making around pain management is recommended. This could be in the form of a nurse-patient contract, in which the nurse and patient negotiate and discuss how the patient should receive medications when the patient is admitted into the unit

Preparing Nurses to Deal with Challenging Situations

Acknowledging the physical and emotional labor involved in looking after chronically ill patients, and providing nurses with knowledge and support about how to deal with these challenges, helps to prepare nurses to handle these difficulties when negotiating care with chronically ill patients. For instance, it is important to acknowledge that there will always be certain patients whom nurses prefer to look after more than others. During a Technology Entertainment, and Design (TED) show in 2010, Dr. Brian

Goldman, a medical physician, talked about the importance of health-care professionals acknowledging the fact that they are humans and apt to be imperfect, rather than denying it and pretending to be immaculate in their practice. He believes that only by admitting their imperfections and talking about these issues can health-care professionals learn how to handle these situations and improve practice. Although Goldman (2010) was mainly addressing doctors, his speech can be applied to nurses. He captured well the essence of feminist post-structuralism and the need to bring out into the open those discourses that are usually silenced or kept in the periphery. Nurses are not perfect, and they too make mistakes. Acknowledging rather than denying this reality will help nurses to find ways how to address these problems and prevent them from hindering negotiation of care with patients. One of the aims of feminist post-structural theory is to make such discourses visible so that we can address them.

Nurses also need to be cognizant of how institutional discourses situate them in a position of power, and how this positioning may affect their behavior when they negotiate care with chronically ill patients, especially patients who may not be pleasant to work with. Creating self-awareness through continuous professional development may reduce such tendencies. Ideally, workshops would be organized at unit or hospital level on different topics offering nurses the opportunity to reflect on their practice and critically discuss what would be the best solution in the given social and hospital milieu. By situating themselves within the social and hospital context, nurses will be going to the root of the problem, addressing the issue at its origin and possibly arriving at a solution that is realistic and achievable within a given hospital setting.

Ensuring that Patients are not Marginalized

While raising self-awareness may prevent misuse of power, it is inevitable that moments of abusive behavior will continue to occur. Khalil (2009) notes that in every profession there are “good and bad apples” and that “nursing is not an exception” (p.442). Although in this study negative incidents tended to be the exception rather than the rule, there were situations when patient care was not optimal.

Findings from this study indicate that there were a number of professional and ethical discourses within hospital settings that provided patients with opportunities to be in a position of power when they negotiated their care; however, there is still room for improvement. For instance, the introduction of a patient charter is one example of how the health-care system can ensure ethical practice is implemented and the well-being of patients is safeguarded. The patient charter has been a positive contribution for patients, because it makes them aware of their rights as a patient, and helps to place patients in a better position to reject any treatment they do not want when negotiating care with nurses. However, not all patient participants in this study were aware of their right to refuse treatment. It is therefore recommended to increase public awareness of patients’ rights through the media. Hospital administrators may also help by providing verbal and written information to patients about the patient charter when they are admitted to hospital and by explaining what measures to take if their rights are violated. In fact, some of the patients and their families in this study did take action and reported nurses when negotiations were not positive, or when patients’ needs were not met. This finding suggests that there are processes within the hospital settings that patients and families may follow if they are not happy with their care.

Health-care organizations and hospitals in Canada have a patient advocacy service that can assist patients if they have concerns about health-care services that they received (Canadian Patient Safety Institute, 2012). However, since this service may vary from province to province, specific guidelines need to be provided to patients upon admission to hospital. Patients and their families did use this service. Unfortunately, these actions always occurred after the event had taken place. This means that the patient had suffered in the interim. Findings from this study indicate that while reporting to doctors and administration face-to-face was effective; submitting an incident report in writing was not always as effective and was more likely to result in no action. Given these findings, an evaluation of the effectiveness of advocacy services within hospitals is recommended, particularly to ensure that action is always taken whether a complaint is made verbally or in writing.

Giving Patients More Voice

Patients also need to have a support system on the unit to ensure that patient advocacy takes place on the spot, not after the incident takes place. In Canada and elsewhere, nurses are expected to fulfill this role. The College of Registered Nurses in Nova Scotia (CRNNS) (2008) obliges nurses to be cognizant of their ethical and professional responsibility to treat patients equitably and fairly irrespective of color, gender, religion, age or sex, and to remind colleagues who mistreat patients about their ethical and moral obligation. Further, if some nurses mistreat patients, CRNNS has a process in place that can result in disciplinary actions against the particular nurse. However, it has been noted in the literature that some nurses are not willing to take on the role of whistleblower for fear of being isolated and rejected by peers (McDonald &

Ahern, 2000), because of trepidations about being dismissed from work (Ahern & McDonald, 2002; Attree, 2007), or because when nurses reported malpractice, the nurse managers failed to fix the problem or take action (Waters, 2008).

Given these situations, a recommendation would be to have another designated person (besides nurses) who acts as patient advocate while the patient is in hospital. This person may act as a liaison person if patients are having difficulty expressing or communicating their needs to nurses (or other health-care professionals) when they are negotiating their care. Ideally, this person would be a social worker or counsellor who is trained and skilled in dealing with such situations, and whose role is underpinned by the philosophy of human rights and social justice. According to the Canadian Association of Social Workers (2015), “the uniqueness of social work practice is in the blend of some particular values, knowledge and skills, including the use of relationship as the basis of all interventions and respect for the client’s choice and involvement”. Further, social workers are also trained in human behavior, group processes, teamwork, communication and negotiation. Therefore, they may help to resolve conflicts between patients and nurses (or other health-care professionals) when they arise.

While a social worker would prove to be ideal in situations of conflict, patients also need to be offered an opportunity to write their experiences in their own hospital records if they wish. Major steps in this direction have already taken place within some health-care settings where patients have access to their medical records (Canadian Medical Association Policy, 2000; Canadian Academy of Health Care Science, 2010). Previously, custodial practices and concerns about confidentiality prevented patients from having access to their own health records. Nowadays, advances in technology and

changes in attitude have made it possible for patients to access such information. This has been a major advance in reducing the power gap between health-care professionals and patients. While major advances towards patient participation have been made in this regards, there is still room for improvement. Institutional practices could go a step further and have a system in place where patients are given the opportunity to document in their records if they wish, or if they have any concerns.

Another way to ensure that patients have more say about their hospital experiences is to have some form of input from patients about the quality of care they received after discharge from hospital. An implication for practice would be to provide patients with a suggestion sheet and ask them to comment on positive experiences during negotiations of care between nurses and patients, and to suggest areas for improvement. Focusing on the positive aspects of care and centering on nursing situations rather than pointing a punitive finger at individual persons may lead to more constructive ways of improving patient care on a unit. These patients' suggestions can be used as opportunities for nurses to reflect on their practice and also to invigorate debate on how to addresses such quandaries when they arise. Along these same lines, patients can also be asked to nominate a nurse who made a difference and to explain why. This would help to acknowledge and reinforce good nursing practices.

Finally the reality that patients can be in a position of power also needs to be celebrated. The aim is to disrupt the existing stereotypes that patients are powerless. This stereotype is already changing with the advent of patient-centered care and patient activation. However, more stories are also needed from the patients' perspective. Narratives of how patients have resisted oppressive situations need to be made public and

disseminated through the media. By acclaiming the idea of ‘patient power’, patients may feel less vulnerable and be more willing to take an active role when negotiating their care with nurses. The organization Patients Canada is making major advances in this regard. This organization, which is patient–led and patient-governed, has been ground breaking in pushing forward the voices of patients and their families into the Canadian health-care system.

Recommendations for Education and Nursing Profession

Addressing structural and human resources is, however, a partial solution to this problem of the global crises of chronic illness. There is a need to prepare the workforce with the skills necessary to ensure positive negotiations with chronically ill patients. The Canadian Nurses Association (2012) emphasized the importance of adding information on chronic disease self-management into nursing curricula and to provide nurses with self-directed modules. This knowledge is important, and similar to what Wilson *et al.*, (2006) suggested, a recommendation for education would be to include such information in nursing curricula, and in post-basic education workshops. However it is not a matter of disseminating information to nurses, nurses also need to develop skills on how to actively involve patients in their care. Warner (2012) notes that self-care programs provide health information to patients on how to manage their condition; however, many of these literacy programs fail to provide strategies to patients on how to implement such information in real life. The importance of educating nurses on chronic disease and its management from a holistic point of view is essential if nurses are to help patients to take on a more active role in their care.

Findings from my study also confirm that some nurses need more training to

negotiate care with patients who challenge nurses' authority. Wilson mentions that although nurses' education emphasizes that patient expertise needs to be taken into consideration when negotiating care with patients, nurses need further training on how to deal with situations when their expertise is challenged. They recommend training nurses on how to learn from expert patients, rather than to feel threatened by the patients' contribution. Similarly, a recommendation for nursing education is to teach and train nurses to accept the patient as the leader in the decision-making process, rather than a passive recipient of care. This would ensure that negotiation of patient care is tailored according to the patients' priorities, rather than the nurses' agenda. In order to do so, nurses must learn to accept the patient's life experience and listen to the patients' expertise in managing their illness. The nurses' role has to shift from asking questions and offering advice to listening, probing and listening more (Doss, DePascal & Hadley, 2011).

One way of getting to know the patient's lived experience is by encouraging nursing students and qualified nurses to develop the skill of "storytelling". Storytelling is a process by which patients are encouraged to share their illness experience and how it is affecting their lives with nurses and other health-care professionals. The aim of these exercises is to provide a holistic picture of the patient, to promote individualized care, and to understand what the patients' priorities in life are. Such action will help to identify those areas that patients, rather than nurses, perceive as most important for them and the skills patients require to be more actively involved. There is a growing body of literature that is publicizing the importance of storytelling as an effective method for getting to know the patient as a person (Gidman, 2012). Frank (1998) contends that narratives and

storytelling can help health-care providers to develop a deeper understanding of a patient's illness experience, while Clark, Hanson and Ross (2003) affirm how storytelling provides an opportunity for health-care professionals to "see the person behind the patient". McLeod, Curran, Dumont, White and Charles (2014) identified benefits of first-person illness narratives delivered in video dramatizations, plays, speakers' theatre and interviews in web-based courses that included real-time voice seminar for graduate students. They found that such teaching resources had significant impacts on learners' attitudes and understanding of the experience of managing a cancer diagnosis.

Unfortunately, it is not just the patients' story that is sometimes not heard; the nurses' voice is also seldom heard during discussions with health-care policy makers, administrators and stakeholders (Weinberg, 2006). Much of this is attributed to the fact that many believe that nursing is still associated with a virtuous image, rather than a professional discipline that is backed by science (Gordon & Nelson, 2006). This public image and public expectations that nurses should act in a selfless and altruistic manner has resulted in situations where nurses undermine their own needs and well-being as a legitimate aspect of their work. These expectations have led to increasing demands on nurses, leading to poor job satisfaction and burnout in nurses, with many nurses leaving clinical practice to seek less demanding jobs (Gordon & Nelson, 2006). Hence, it is timely for nurses to assert their rights, articulate the things that they do, and to demonstrate that they make a difference (Nelson, 2002).

This is not only a matter of being self-confident and speaking up with a strong voice during discussions with health-care policy makers, administrators and stakeholders when it comes to decisions about allocation of resources. Nurses cannot avoid the reality

that we live in a patriarchal society that is dominated by economic interests that value scientific data and evidence-based practice. Clark (2006) and Nelson and Gordon (2006) stress the importance of nurses bringing scientific and economic evidence, facts and figures into the discussion if they want to support changes to practice. For example, there is an urgent need for “accurate and robust evidence” about why nurse shortages should be given a priority during discussions about budgetary issues, if nurses want to push their case forward (Tomblin Murphy, 2002, p. 1).

A recommendation for the profession is therefore to encourage nurses to use more evidence-based research to offer legitimacy for their arguments when discussing nursing or patient issues with health-care administrators and policy makers. Pringle and Doran (2003) comment that evidence related to addressing nursing and patient outcomes (i.e., nurse job satisfaction, enhancing patient satisfaction and so on) exists, it just needs to be housed together and established in databases to render its greatest impact and to make it a sellable commodity to health authorities. These databases need to have a clear definition of the outcomes being measured, as well as clear methods about how patient outcomes can be measured and quantified (Pringle & Doran, 2003). This is starting to happen with the advent of projects that specifically focus on nurse-sensitive outcomes (Doran, 2003). These projects clearly show that nurses matter and that their contribution is “appropriate, efficient and effective” (Doran, 2003, p.vii).

Suggestions for Further Research

The aim of this study was to explore the experiences of nurses and patients when they negotiate care in hospital settings. Although the focus of this study was on these two parties, the negotiation process involves a number of other individuals who play a part in

this process. Individuals such as policy makers, administrators, physicians, other health-care professionals, and families were brought into the picture. The results of this study reveal how these individuals contribute to the negotiation process between nurses and patients, but do not reveal why they act the way they do. Further research on the experiences of those who hold these positions in hospital hierarchies is merited. Similarly, the influence of medical and patriarchal discourses on negotiation of care between nurses and patients was one prominent issue. It would be interesting to explore the perceptions of physicians about nurses, and the way nurses shape negotiations between doctors and patients.

Finally, one of the concerning findings in this study was that some nursing practices resulted in marginalization of some patients. There are studies which found that nurses do not communicate effectively with patients suffering from chronic illness (Cudney, Weinert & Kinion, 2011; Iecovich, 2000; Price, 2013) and when relations between nurses and chronically ill patients were found to be tense, this led to situations where communication was experienced as disrespectful, discrediting and distressing by patients (Teeri, Leino-Kilpi & Vülimski, 2006; Thorne, 2000, 2006). However, there is a paucity of studies that deeply explored what shaped nurses' attitudes and practices towards 'unpopular' patients (Lowbridge & Hayes, 2013; Khalil, 2009). Lowbridge and Hayes (2013) comment that questioning how nurses react towards difficult patients is considered to be 'taboo'. Only a few studies have been done about this topic in the past (Conway, 1996; Stockwell, 1972; Podrasky & Sexton 1988), and when Stockwell (1972) did her study and brought the issue to the forefront, it created an 'uproar' and was not well accepted by some nurses (Allen, 2003). Findings from this study suggest that

prejudicial nursing practices such as labelling patients, or treating patients with disrespect, do exist. More research into sensitive issues that are still considered to be 'taboo' is needed. Uncovering why such practices occur, and why they are permitted is important. Bringing this knowledge out in the open is crucial, because as suggested earlier, only by exposing this information can nurses identify the social and institutional discourses that are shaping nurses practices, and offer opportunities to improve care.

Conclusion

The aim of this study was to raise awareness and to understand the complexities involved during negotiations of patient care between nurses and chronically ill patients. The scope of feminist post-structural theory is to expose the multiple discourses that exist and how these discourses play a role in shaping the negotiation process.

The main findings of this study illustrate that overall negotiation of patient care between nurses and patients tends to be positive with many rewarding moments for both patients and nurses. As a result of frequent admissions to hospital, special relations develop between patients and nurses and most of the time, power relations between the two parties were equal and negotiation of care was reciprocal and agreed upon. In line with feminist post-structuralism, I have also demonstrated that by deconstructing binaries, one finds that there is no right or wrong way of perceiving a situation, just different ways of viewing reality. For instance, nursing chronically ill patients can be different from acute care, however it does not mean looking after chronically ill patients is boring for it has its rewarding moments too. Likewise, chronic illness may not be life threatening as acute illness, however, this does not mean that the needs of chronically ill patients are not important or deserve less attention.

Another finding from this study revealed that the hospital patriarchal and hierarchical system played a principle role in shaping power relations between nurses and patients during negotiation of patient care. Yet, contrary to what one might normally expect, the hospital hierarchical structure did not always privilege nurses, and subjugate patients. There were moments when patients used the hospital hierarchical structure to get their voices heard and to subdue nurses. Through the use of feminist post-structural theory I was able to demonstrate that power relations were not always oppressive but can be productive too. Further this finding substantiates Foucault's notion that when there is power there is resistance, and substantiates feminist post-structural ideology about agency. The fact that patients challenged nurses' position of authority suggests that patients were not passive or powerless, but that they actively resisted being marginalized.

Patients were not the only ones who encountered problems when negotiating care with nurses. Nurses also mentioned that negotiating patient care with some chronically ill patients could be challenging at times. In such situations, some nurses resorted to their authoritative position to negotiate care with patients. Some nurses took on this role because they felt that their position of authority was threatened. Others chose this route because they believed that some patients were depressed and needed direction from nurses. Not all nurses took on an authoritative position when negotiating care with challenging patients. Some nurses chose to listen to the patients concerns and address their needs. This finding highlights that each negotiation between nurse and patient was a unique situation that needed to be assessed based on its own merits. This result also reveals that negotiation of care between nurses and patients was not always dominated by nurses and patients are also allowed to take control in decision making.

Finally, both patients and nurses acknowledged the importance of finding time to listen to the patient as fundamental to successful negotiation of patient care. Surprisingly, the main barrier to finding time to listen was not the nurses' workload, but peer pressure and institutional discourses about routine and timetabling. While some nurses may reinforce these discourses by putting pressure on their peers to finish work in a timely fashion, nurse participants in this study resisted such discourses and proceeded to negotiate patient care around patients' needs. These findings indicate that despite efforts to shift towards patient-centered care and patient activation, it seems that change is slow and current institutional discourses still privilege the traditional nurse-patient relationships. These institutional discourses are restricting other ways of knowing and inhibiting nurses from seeing other ways of negotiating patient care. Understanding how institutional discourses can create situations of oppression can help nurses to keep vigilant of their practice and to ensure that their practice is guided by patients' needs, not simply by traditional values, beliefs and practices. However, while such systems are hard to eradicate, the fact that nurses are resisting these discourses offers promise, and raises hope. It shows how change in nursing practice is happening but that some nurses are actively challenging the system to promote more patient centered care.

Overall, it is hoped that this study creates awareness about how nurse-patient negotiations go beyond individual interactions, and how negotiations are shaped by social and institutional discourses. It is imperative to raise awareness and to look at the positive changes that are happening in nursing practice. This will help to celebrate these accomplishments in nursing and to keep repeating them. However, it is also important to question current practice and to challenge the norm. Certain suggestions such as

allowing patients to document on their hospital records or shifting nursing education from teaching nurses how to educate patients to learning from patients may seem radical. However, only by being open to new ideas can we begin to look at how we might change current health-care values and practices. Abiding with the status quo will only produce the same results and negotiations between nurses and patients will continue to be dominated by professionals rather than being truly patient-centered. Hopefully these findings and suggestions will entice nurses to venture from the norm, to be creative and to discover new and exciting ways of negotiating care with chronically ill patients.

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APPENDIX A: INFORMED CONSENT: PATIENTS



Faculty of Health Professionals
School of Nursing

Informed Consent for Patients

Study title: The experiences of nurses and chronically ill patients when they negotiate patient care in hospital

Researchers:

Principal Investigator:

Odette Griscti (PhD student)
School of Nursing
Dalhousie University
5869 University Ave
Halifax, Nova Scotia
B3H 4R2 (902) 564 6388
odette_griscti@cbu.ca

Research Supervisor:

Dr. Megan Aston RN PhD
Dalhousie University School of Nursing

Contact Persons:

Any questions regarding any aspect of this study can be forwarded to either Odette Griscti or the research supervisor:

Dr. Megan Aston RN PhD

School of Nursing
Dalhousie University
5869 University Ave
Halifax, Nova Scotia
B3H 4R2
(902) 494-6376
megan.Aston@dal.ca

Introduction:

We invite you to take part in a research study being conducted by Odette Griscti who is a graduate student at Dalhousie University, as part of her PhD in nursing. Your participation in this study is voluntary and you may withdraw from the study at any time. Your decision to participate or not to participate in the study will not affect the health services that you are currently receiving or may be receiving in the future. The study is described below. This description tells you about the risks, inconvenience,

or discomfort which you might experience. Participating in the study might not benefit you but we might learn things that will benefit others. You should discuss any questions you have about this study with Odette Griscti.

Please read this carefully. Take as much time as you like. If you like, take it home to think about it for a while. Mark anything you do not understand, or want explained better. After you have read it, please do not hesitate to ask me questions about anything that is not clear.

The researcher will:

- Discuss the study with you
- Answer your questions
- Keep confidential any information which could identify you personally
- Be available during the study to deal with problems and answer questions

Why are the researchers doing the study?

Purpose of the Study:

The purpose of this research is to understand the experiences of chronically ill patients when they are in hospital, as well as to understand the experiences of nurses who look after chronically ill patients in hospital. It is hoped that these experiences will reveal those situations where patients felt they have power, or they felt powerless to negotiate their care with nurses.

How will the researchers do the study?

Study Design:

This research will involve tape-recorded interviews with patients and registered nurses at one hospital. I will be interviewing up to 12 patients who have at least one chronic illness and who have been hospitalized at least twice during their illness. I will also interview up to 12 registered nurses.

The interview will last about one hour. It can be conducted in hospital or in the comfort of your home, or any other place of your preference. The entire interview will be tape-recorded however all identifying information will be removed from the tape. No one else but me will be present during the interview, unless you would like someone else to be there. The information recorded will be kept confidential and no one else except my supervisor and me will have access to the tapes or to the information documented during your interview. The interview will be transcribed by myself.

If you consent to it, you will be asked to meet one more time for about 30 minutes. This meeting will be held in a week or less after the interview. We can meet at a place of your choice. In this meeting I will give you back your transcript and ask you to jot down the main points that you wanted to highlight during your interview.

Who can participate in the Study?

You can participate in this study if you:

1. are English speaking and over the age of 18 years
2. have been diagnosed with one or more chronic illnesses for over two years
3. have been admitted to hospital on at least two occasions for complications related to your chronic illness
4. are not acutely ill at the time of the interview
5. agree to be tape-recorded

What will I be asked to do?

In this interview, I will ask you to reflect on your experience, while you were in hospital. I would like to know how you felt about participating in your care and if you want to elaborate about it. Specifically I would like to learn more about what guided your decision to participate (or not to participate) in decisions relating to your nursing care. I may be using some of your quotes to give examples of the experience of chronically ill patients when they are in hospital, when I write my thesis.

What are the possible risks and discomforts?

There are no risks involved for you by participating in this study that are greater than your experience in everyday life. However since some of the discussion may delve on issues that are sensitive or of personal nature, you may feel uncomfortable talking about some of the topics. You do not have to answer any questions on these topics in this interview if you do not wish to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

What are the possible benefits?

There will be no direct benefit to you but your participation is likely to help nurses and other health care providers/stakeholders to understand better the experiences of chronically ill people when they are in hospital. I would like to learn what opportunities can be provided (or barriers removed) so that patients are in a better position to participate in their nursing care while in hospital. Such information may benefit potential patients when they are hospitalized. Studies have shown how patients who are involved in their care tend to be more satisfied with the care given and are less likely to be re-admitted to hospitals. Further, the results of this study may also be of benefit to nurses and nursing practice. Studies which show that when patients are satisfied with their nursing care, nurses have more job satisfaction, have less risk of developing burnout and are less likely to leave their jobs. This is important to consider given the current problem of nursing shortage that is currently escalating all over Canada and the entire world.

Can I withdraw from the study?

Participation in this research is voluntary. You may stop participating at any point in the study if you wish. The choice that you make will have no bearing on any of the health care services that you receive while in the community, or when you are in hospital.

You have an opportunity to withdraw from the study at any time during the interview and up to one month from the time the data is collected. If you decide to withdraw, your data will be removed and destroyed within a week. You are kindly requested to contact the

primary investigator or the research supervisor within one month from the date of the interview if you wish to do so. You do not have to give us any reason for refusing to take part in the interview or for wanting to delete any information that you have given during the interview.

Will the study cost me anything and if so, how will I be reimbursed?

Please note that you will not be provided any incentive to take part in the research. However, I will be giving you a \$20 Tim Horton's gift card, to compensate for your time and any travel expenses involved. The token will be given when the interview is completed.

How will I be informed of study results?

A summary of the research results will be available to all participants. If you would like to receive a copy of the results, please indicate on the last page of this consent form that you would like us to send you a copy.

How will my privacy be protected?

The information that I will collect from this research project will be kept in confidence. I and my supervisor Dr. Aston and possibly a research audit board will be the only one who will have access to the tape recordings and typed transcripts. Your name will not appear on the transcript or anywhere during data collection, analysis and publication and that instead a number code will be assigned to your transcript. I will be the only one who will know what your code is and I will keep this information, together with the tape recordings, in a safe place under lock and key in my office at home. All tapes and transcripts will be destroyed by the researcher, in five years from the publication of the thesis.

What will happen if the incident reported by participants suggests abuse/neglect?

If the incident reported by the participants suggests abuse /neglect and if it meets the criteria required by Nova Scotia Adult Protection Act (2011), referral to the appropriate services approved by the Department of Health and wellness or Department of Community Services will be made.

What if I have study questions or problems?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me by mail, phone or email:

Odette Griscti

School of Nursing

Dalhousie University

5869 University Ave

Halifax, Nova Scotia B3H 4R2

Phone number: 902 564 6388

Email address: odette_griscti@cbu.ca

Or my supervisor:

Dr. Megan Aston RN PhD
School of Nursing
Dalhousie University
5869 University Ave
Halifax, Nova Scotia B3H 4R2
(902) 494-6376
megan.Aston@dal.ca

This proposal has been reviewed and approved by the Cape Breton District Research Ethics Board (C.B.D.R.E), whose main aim is to make sure that research participants like you, are protected from harm. If you wish to find about more about the C.B.D.R.E. Please contact:

Chair, Research Ethics Board
c/o Cape Breton Health Research Centre
PO Box 5300
1250 Grand Lake Rd, Sydney, N.S. Canada B1P 6L2
Phone: 902-563-1833
Fax: 902-563-1856

The research proposal will also be reviewed by the The Social Sciences and Humanities Research Ethics Board (S.S.H.R.E) at Dalhousie University who is sponsoring my studies. If you wish further information of the S.S.H.R.E (Dalhousie University) please contact:

Catherine Connors, Director
Research Ethics
Dalhousie Research Services
Henry Hicks Academic Administration Building
6299 South Street, Suite 231
Dalhousie University
Halifax, Nova Scotia B3H 4R2
Phone: (902) 494-1462
Fax: (902) 494-1595
E-mail: ethics@dal.ca

What are my Research Rights?

Your signature on the form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to take part as a participant. In no way does this waive your legal rights nor release the investigator(s), sponsors, or involved institution(s) from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing the health care you are entitled to receive.

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Catherine Connors, Director, Research Ethics, and Dalhousie University at (902) 494-1462, ethics@dal.ca

Thank you, Odette Griscti

Study: The experiences of nurses and chronically ill patients when they negotiate patient care in acute hospital settings

Participant Consent

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I hereby consent to take part in this study. However I realize that my participation is voluntary and that I am free to withdraw from the study at any time up to one month after the interview without affecting my care in any way.

I consent to be tape-recorded. YES NO

I agree to have my words from the interviews used in research reports, publications and presentations as long as I am not identified YES NO

I would like to be re-contacted at a later phase in the study YES NO

Name of Participant: (Print) _____

Participant Signature: _____

Date: _____ Time: _____

STATEMENT BY PERSON PROVIDING INFORMATION ON STUDY

I have explained the nature and demands of the research study and judge that the participant named above understands the nature and demands of the study.

Name: (Print) _____

Signature: _____ Position: _____

Date: _____ Time: _____

STATEMENT BY PERSON OBTAINING CONSENT

I have explained the nature of the consent process to the participant and judge that they understand that participation is voluntary and that they may withdraw at any time from participating

Name (Print) _____

Signature: _____ Position: _____

Date: _____ Time: _____

I would like to receive a copy of the study results

Yes _____ No _____

Study results can be mailed to the following address

APPENDIX B: INFORMED CONSENT: NURSES



Faculty of Health Professionals
School of Nursing

Informed Consent for Nurses

Study: The experiences of nurses and chronically ill patients when they negotiate patient care in hospital

Researchers:

Principal Investigator:

Odette Griscti (PhD student)
School of Nursing
Dalhousie University
5869 University Ave
Halifax, Nova Scotia B3H 4R2
odette_griscti@cbu.ca

Research Supervisor:

Dr. Megan Aston RN PhD
Dalhousie University School of Nursing

Contact Persons:

Any questions regarding any aspect of this study can be forwarded to either Odette Griscti or the research supervisor:

Dr. Megan Aston RN PhD

School of Nursing
Dalhousie University
5869 University Ave
Halifax, Nova Scotia B3H 3J5
(902) 494-6376
megan.Aston@dal.ca

Introduction:

We invite you to take part in a research study being conducted by Odette Griscti who is a graduate student at Dalhousie University, as part of her PhD in nursing. Your participation in this study is voluntary and you may withdraw from the study at any time. Your decision to participate or not to participate in the study will not affect your current or future work positions in health care.

The study is described below. This description tells you about the risks, inconvenience, or discomfort which you might experience. Participating in the study might not benefit you but we might learn things that will benefit others. You should discuss any questions you have about this study with Odette Griscti.

Please read this carefully. Take as much time as you like. If you like, take it home to think about it for a while. Mark anything you do not understand, or want explained better. After you have read it, please do not hesitate to ask me questions about anything that is not clear.

The researchers will:

- Discuss the study with you
- Answer your questions
- Keep confidential any information which could identify you personally
- Be available during the study to deal with problems and answer questions

Why are the researchers doing the study?**Purpose of the Study:**

The purpose of this research is to understand the experiences of chronically ill patients when they are in hospital, as well as to understand the experiences of nurses who look after chronically ill patients in hospital. It is hoped that these experiences will reveal those situations where patients felt they have power, or they felt powerless to negotiate their care with nurses.

How will the researchers do the study?

Study Design:

This research will involve tape-recorded interviews with up to 12 patients and 12 nurses. I will be interviewing patients who have chronic illness and who have been hospitalized at some point during their illness. You have been chosen as a potential participant for this study because I feel that your experience as a nurse looking after chronically ill patients, can contribute to nursing practice and education.

The interview will last about one hour. It can be conducted in hospital or in the comfort of your home, or any other place of your preference. The entire interview will be tape-recorded but all identifying information will be removed from the tape. No one else but me will be present during the interview, unless you would like someone else to be there.

The information recorded will be kept confidential and no one else except myself will have access to the tapes or to the information documented during your interview. The interview will be transcribed by myself.

If you consent to it, you will be asked to meet one more time for about 30 minutes. This meeting will be held in a week or less after the interview. We can meet at a place of your choice. In this meeting I will give you back your transcript and ask you to jot down the main points that you wanted to highlight during your interview.

Who can Participate in the Study

You may participate in this study if you:

1. are registered with CRNNS
2. have been employed as an RN for more than two years
3. work/have worked in a hospital for at least a year; have nursed chronically ill adult patients for at least one year and agree to be tape-recorded

What will I be asked to do?

In this study, I will also be conducting twelve separate interviews with nurses who looked after chronically ill patients in hospital. You have been chosen as one of the nurses that I would like to interview because I feel that your experience as a nurse can contribute much to our understanding and knowledge of local health practices.

During the interview, I will be asking you about your experience looking after chronically ill patients while they are in hospital. I would like to know how you feel about it. Specifically I would also like to learn about what influences your decisions to involve (or not involve) patients in their care while they are in hospital. If you do involve (or not involve) them, how you do this and what are the challenges and successes you experience. I may be using some of your quotes to give examples of the experience of nurses looking after chronically ill patients, when I write my thesis.

What are the possible risks and discomforts?

There are no risks involved for you by participating in this study that are greater than your experience in everyday life. However since some of discussion may delve on issues that are sensitive or personal nature, you may feel uncomfortable talking about some of the topics. You do not have to answer any questions on these topics in this interview if you do not wish to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

What are the possible benefits?

There will be no direct benefit to you but your participation may help nurses and other health care providers/stakeholders to understand better the experiences of chronically ill people when they are in hospital. I would like to learn what opportunities can be

provided (or barriers removed) so that patients are in a better position to participate in their nursing care while in hospital. Such information may benefit potential patients when they are hospitalized. Studies have shown how patients who are involved in their care tend to be more satisfied with the care given and are less likely to be re-admitted to hospitals. Further, the results of this study may also be of benefit to nurses and nursing practice. Studies which show that when patients are satisfied with their nursing care, nurses have more job satisfaction, have less risk of developing burnout and are less likely to leave their jobs. This is important to consider given the current problem of nursing shortage that is currently escalating all over Canada and the entire world.

Can I withdraw from the study?

Participation in this research is voluntary. You may stop participating at any point in the study if you wish. The choice that you make will have no bearing on your work position.

You have an opportunity to withdraw from the study at any time during the interview and up to one month from the time the data is collected. You are kindly requested to contact the primary investigator or the research supervisor within one month from the date of the interview, if you wish to do so. If you decide to withdraw, your data will be removed and destroyed within a week. You do not have to give us any reason for refusing to take part in the interview or for wanting to delete any information that you have given during the interview.

Will the study cost me anything and if so, how will I be reimbursed?

Please note that you will not be provided any incentive to take part in the research. However, I will be giving you a \$20 gift card from Coles Bookstore to compensate for your time and any travel expenses involved. The gift voucher will be given after the interview is completed.

How will I be informed of study results?

A summary of the research results will be available to all participants. If you would like to receive a copy of the results, please indicate on the last page of this consent form that you would like us to send you a copy.

How will my privacy be protected?

The information that I will collect from this research project will be kept in confidence. I and my supervisor Dr. Aston and possibly a research audit board will be the only one who will have access to the tape recordings and typed transcripts. Your name will not appear on the transcript or anywhere during data collection, analysis and publication and that instead a number code will be assigned to your transcript. I will be the only one who will know what your code is and I will keep this information, together with the tape recordings, in a safe place under lock and key in my office at home. All tapes and transcripts will be destroyed by the researcher, in five years from the publication of the

thesis.

What will happen if the incident reported by participants suggests abuse/neglect?

If the incident reported by the participants suggests abuse /neglect and if it meets the criteria required by Nova Scotia Adult Protection Act (2011), referral to the appropriate services approved by the Department of Health and wellness or Department of Community Services will be made.

What if I have study questions or problems?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact me by mail, phone or email at:

Odette Griscti
School of Nursing
Dalhousie University
5869 University Ave
Halifax, Nova Scotia B3H 4R2
Phone number: 902 564 6388
Email address: odette_griscti@cbu.ca

Or my supervisor at:
Dr. Megan Aston RN PhD
School of Nursing
Dalhousie University
5869 University Ave
Halifax, Nova Scotia B3H 4R2
(902) 494-6376
megan.Aston@dal.ca

This proposal has been reviewed and approved by the Cape Breton District Research Ethics Board (C.B.D.R.E), whose main aim is to make sure that research participants like you, are protected from harm. If you wish to find about more about the C.B.D.R.E. Please contact:

Chair, Research Ethics Board
c/o Cape Breton Health Research Centre
PO Box 5300
1250 Grand Lake Rd, Sydney, N.S. Canada B1P 6L2
Phone: 902-563-1833
Fax: 902-563-1856

The research proposal will also be reviewed by The Social Sciences and Humanities

Research Ethics Board (S.S.H.R.E) at Dalhousie University who is sponsoring my studies. If you wish further information of the S.S.H.R.E (Dalhousie University) please contact:

Catherine Connors, Director
Research Ethics
Dalhousie Research Services
Henry Hicks Academic Administration Building
6299 South Street, Suite 231
Dalhousie University
Halifax, Nova Scotia B3H 4R2
Phone: (902) 494-1462
Fax: (902) 494-1595
E-mail: ethics@dal.ca

What are my Research Rights?

Your signature on the form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to take part as a participant. In no way does this waive your legal rights nor release the investigator(s), sponsors or involved institution(s) from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing the health care you are entitled to receive.

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Catherine Connors, Director, Research Ethics, and Dalhousie University at (902) 494-1462, ethics@dal.ca

Thank you, Odette Griscti

Study: The experiences of nurses and chronically ill patients when they negotiate patient care in acute hospital settings

Nurses Consent

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I hereby consent to take part in this study. However I realize that my participation is voluntary and that I am free to withdraw from the study at any time up to one month after the interview without affecting my work position.

I consent to be tape-recorded. YES NO

I agree to have my words from the interviews used in research reports, publications and presentations as long as I am not identified YES NO

I would like to be re-contacted at a later phase in the study YES NO

Name of Participant: (Print) _____

Participant Signature: _____

Date: _____ Time: _____

STATEMENT BY PERSON PROVIDING INFORMATION ON STUDY

I have explained the nature and demands of the research study and judge that the participant named above understands the nature and demands of the study.

Name: (Print) _____

Signature: _____ Position: _____

Date: _____ Time: _____

STATEMENT BY PERSON OBTAINING CONSENT

I have explained the nature of the consent process to the participant and judge that they understand that participation is voluntary and that they may withdraw at any time from participating

Name (Print) _____

Signature: _____ Position: _____

Date _____ Time: _____

I would like to receive a copy of the study results

Yes _____ No _____

Study results can be mailed to the following address

APPENDIX C: INTERVIEW SCHEDULE: PATIENTS

Study: The experiences of nurses and chronically ill patients when they negotiate patient care in hospital

Demographic form:

Age:

Sex:

Ethnicity:

Occupation:

Current chronic illness (es):

First Diagnosed:

Number of time admitted to hospital:

Interview Schedule: Patient

Introduction

Thank you for participating in this study. Today I would like to hear about your latest hospital experience. There are no right or wrong answers. The purpose of this interview is to explore how you felt and experienced all aspects of your care while in the hospital. More specifically I want explore your experience with nurses and other health care professionals while in the hospital. I will start with some general overall questions and then ask more specific questions. Your story will help us to better understand what it is like being a patient in the hospital who has a chronic illness and the day to day care that you received. The information that you, other patients and nurses share with us will be used to improve practices in the hospital.

Opening questions

Can you tell me why you wanted to participate in this study?

Patient's experience about living with chronic illness

Tell me about your chronic illness

Probes:

- How long have you lived with this condition?
- How has it affected your life?
- How many times have you been in the hospital due to this chronic illness?
- How knowledgeable do you feel about your condition?
- Do you seek knowledge about your condition on your own?

Sub Question 1:

How are relations of power experienced and negotiated by chronically ill patients and nurses in a hospital setting?

Patient's experience with nurses and other health professionals while hospitalized

Tell me about this hospital admission.

- What did you like or not like about the experience?

Tell me about the nurses who took care of you

- What did the nurses do for you?
- Tell me about specific relationships you had with nurses
- What did you find helpful about that they did or how they provided care?
- What did you not find helpful?

Tell me about other health care professionals who took care of you

- Who were they? What did they do for you?
- What worked well?
- What did not work well?

Involvement in care

Tell me about your care in hospital, specifically to situations when nurses included or not included in your care.

- Did you feel that knowledge about your condition was respected?
- Were you asked for your opinion about care? Please elaborate
- Did you want to be asked for your opinion? Please elaborate
- Were you asked to do certain things? Why or why not? How did this make you feel?

Power relationships: subjectivity, agency and resistance

Tell me about one particular interaction with a nurse. A nurse who stands out in your mind for any reason at all.

- How did you work together?
- How were decisions made about your care?
- Did the nurse make decisions for you? If so, tell me about this.
- Did you tell the nurse what you wanted? If so, tell me about this.

Sub question 2

What discourses inform the experiences of chronically ill patients and how are these discourses negotiated?

Personal discourses of empowerment and/or disempowerment

Tell me about a nurse (or two) who took in consideration the kind of care you wanted.

- What happened? How did it make you feel?
- What was good about it?
- What happened in the end?

Tell me about a nurse who did not take in consideration the kind of care you wanted.

- What happened? How did it make you feel?
- What was not so good about it?
- What happened in the end?

Sub question 3: What are the personal, social and institutional beliefs, values and practices of chronically ill patients, about negotiation of patient care in the hospital?

Social and institutional discourses of empowerment and/or disempowerment

Tell me how:

- You feel about being a patient in hospital affects the extent to which you are be involved in your care.
- You feel about being from this society affects the extent to which you ask / do not ask to be involved in your care.

APPENDIX D: INTERVIEW SCHEDULE: NURSES

Study title: The experiences of nurses and chronically ill patients when they negotiate patient care in hospital

Demographic form:

Age:

Sex:

Ethnicity:

Number of years as a registered nurse:

Clinical experience as a nurse

Clinical experience working as a nurse with chronically ill patients:

Interview Schedule: Nurses

Thank you for participating in this study. Today I would like to hear about your experience of providing care for chronically ill patients in the hospital. There are no right or wrong answers. The purpose of this interview is to explore how you interact with chronically ill patients and how you negotiate their care with them or for them. I will start with some general overall questions and then ask more specific questions. Your story will help us to better understand what it is like working with and providing care to chronically ill patients in the hospital. The information that you and chronically ill patients share with us will be used to improve practices in the hospital. For example, what works well and what doesn't work well.

Opening questions

Can you tell me why you wanted to participate in this study?

Nurse's experience looking after chronically ill patients

1. How long have you been a nurse and how long have you been working with chronically ill patients?
2. What types of chronic illness do most of your patients have?
3. Tell me about a typical workday. What is expected of you in your role as a nurse who works with chronically ill patients?

Sub Question 1: How are relations of power experienced and negotiated by chronically ill patients and nurses in a hospital setting?

Involvement in care

Tell me about looking after chronically ill patients in hospital, specifically to situations when patients were included or not included in their care.

- Do patients want to be involved in their care? Please elaborate
- Do patients give their opinion about care? Please elaborate
- Do patients ask to do certain things his/her way? Why or why not? How did this make you feel?

Power relationships: subjectivity, agency and resistance

Tell me about one chronically ill patient you have worked with. A patient who stands out in your mind for any reason at all.

- How did you work together?
- How were decisions made about this patient's care?
- Did you have to make decisions for the patient? If so, tell me about this.
- Did the patient tell you what he/she wanted? If so, tell me about this.

Sub question 2: What discourses inform the experiences of chronically ill patients and how are these discourses negotiated?

Personal discourses of empowerment and/or disempowerment

Tell me about a patient (or two) who was able to tell you what kind of care they wanted.

- What happened? How did it make you feel?
- What happened in the end?

Tell me about a patient who could not or did not tell you what kind of care they wanted.

- What happened? How did it make you feel?
- What happened in the end?

Sub question 3: What are the personal, social and institutional beliefs, values and practices of chronically ill patients, about negotiation of patient care in the hospital?

Social and institutional discourses of empowerment and/or disempowerment

Tell me how decisions are made about how to care for chronically ill patients in the hospital.

- In what ways do hospital protocols or policies that affect your interactions with patients?
- In what ways do values, beliefs or practices from your society affect how you interact with patients?
- How do you work with other nurses and other health professionals?
- How does your relationship with other health professionals affect the way you deliver patient care?
- How do organizational factors affect the amount of time you interact with patients?

APPENDIX E: POSTER FOR PATIENTS



Faculty of Health Professionals
School of Nursing

**PERSONS SUFFERING FROM CHRONIC ILLNESS
NEEDED TO PARTICIPATE IN A RESEARCH STUDY**

We are looking for volunteers to take part in a study on the experiences of and chronically ill patients when they negotiate their care with nurses in hospital

You can participate in this study if you:

- are English speaking and over the age of 18 years;
- have been diagnosed with one or more chronic illnesses for more than two years;
- have been admitted to hospital on at least two occasions for complications related to your chronic illness;
- are not acutely ill at the time of the interview;
- agree to be tape-recorded.

As a participant in this study, you would be asked to participate in an interview which will last for approximately 60minutes.

Interviews will be conducted at a place of your choice or in a private room at the Cape Breton Regional Hospital.

In appreciation for your time, you will receive: A gift token of \$20 from Tim Horton's

For more information about this study, or to volunteer for this study,
please contact:

Odette Griscti

Phone: 902 564 6388

Email: odette_griscti@cbu.ca

This study has been reviewed by the Office of Research Ethics, Dalhousie University and the Cape Breton Regional Health District Authority.

APPENDIX F: POSTER FOR NURSES



Faculty of Health Professionals

School of Nursing

NURSES NEEDED TO PARTICIPATE IN A RESEARCH STUDY ON CHRONIC ILLNESS

We are looking for volunteers to take part in a study on the experiences of nurses and chronically ill patients when they negotiate patient care in hospital

You may participate in this study if you:

- are registered with CRNNS;
- have been employed as an RN for more than two years;
- work/have worked in a hospital for at least a year;
- have nursed chronically ill adult patients for at least one year;
- agree to be tape-recorded.

As a participant in this study, you would be asked to participate in one interview which will last for approximately 60minutes.

Interviews will be conducted at a place of your choice or in a private room at the Cape Breton Regional Hospital.

In appreciation for your time, you will receive a gift token of \$20 from Coles Book Store

For more information about this study or to volunteer for this study,

please contact:

Odette Griscti

Phone: 902 564 6388

Email: odette_griscti@cbu.ca

This study has been reviewed by the Office of Research Ethics, Dalhousie University and the Cape Breton Regional Health District Authority.