Patients' voices and experiences of "being a patient" on an internal medicine unit in an urban hospital: A qualitative inquiry

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Abstract

In this qualitative inquiry, I focus on understanding the meanings of “being a patient” on an internal medicine ward in an urban hospital in Montreal, Quebec. I use open-ended, conversational style interviews with four hospitalized patients to understand their diverse patient voices. I define voice as the diverse ways patients express their meanings of lived experiences on this ward. I draw from two social science theorists to frame my inquiry: French phenomenologist Merleau-Ponty and Russian literacy critic, Bakhtin. I also draw from applied researchers Maguire and Cordella, who work in voice-related methodologies. The participants express their preferred voices as patients and the type of voices they preferred their health care providers to use during medical encounters and dialogues. They describe their lived experiences as hospitalized patients, express what they wished they knew before their hospital admission, and provide their recommendations for future hospitalized patients. Their utterances offer implications for medical and health educators, physiotherapists and health care providers, and health care qualitative researchers in listening for and responding to patient voices.

Keywords: Qualitative health research, Patient voice, Patient-centered care, Patient Education, Medical Education.

Résumé

Dans cette recherche qualitative, je cherche à comprendre les interprétations “d’être un patient” sur un étage de médecine interne dans un hôpital urbain à Montréal, Québec. J’ai utilisé des entrevues à questions ouvertes, style de conversation avec quatre patients hospitalisés afin de comprendre leurs diverses voix comme patient. Je défini voix en étant les manières diverses dont les patients expriment leurs interprétations de leurs expériences sur cet étage. Je m’inspire de deux théoriciens en sociologies pour encadrer ma recherche: le phénomologiste français Merleau-Ponty et le critique littéraire russe, Bakhtin. Je m’inspire également des chercheurs appliqués Maguire et Cordella, qui travaillent avec des méthodologies apparentées à la voix. Les participants ont exprimé les voix qu’ils privilégient comme patients, et les voix ils préféreraient que leurs professionnelles de la santé utilisent durant leurs rencontres et discours médicaux. Ils décrivent leurs expériences en tant que patients hospitalisés, expriment ce qu’ils auraient aimé savoir avant leur admission à l’hôpital, et offrent des recommandations aux futurs patients hospitalisés. Leurs déclarations fournissent des implications pour les éducateurs médicaux et en soins de santé, les physiothérapeutes et professionnelles de la santé, et les chercheurs qualitatifs en santé afin de bien entendre et répondre aux voix des patients.

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Chapter 1. Introduction

> *Jean: Être un patient, ce n'est pas agréable être un patient. Il fallait mieux qu'on ne le soit pas. Ni moi ni personne. Ça serait un bon signe…le sentiment d'être un patient n'est pas bon. Parce que personne aime être malade.*

> *Jean: Being a patient, it is not enjoyable being a patient. It's better not to be. Not for me not for anyone. That would be a good sign…the feeling of being a patient is not good. Because no one likes being sick. (Jean, 72y, Int 2, 09/06/2010)*

This excerpt emerged from my interview with Jean, a 72-year old French-speaking man. I met him in a small, white-walled private hospital room with a family member sitting in a high-backed chair in the corner of the room. He was admitted to the internal medicine ward due to a constriction in his oesophagus which made it difficult for him to swallow.

In my role as a physiotherapist, as I rotated from room to room to see patients, I wondered what it was like to be the person waiting for me to arrive. What were they doing before I arrived? Did my treatment affect their day? What else were they doing with their time? I especially developed an interest in the experiences of geriatric independent persons, or persons with cognitive deficits, and the health and psychosocial complexities involved around their care. I define "geriatric" as an individual over 65 years of age in accordance to Health Canada (Health Canada, 2006, p. 157), although I personally feel this age limit is fifteen years too low.

My aims in undertaking this inquiry are threefold: 1) to examine how a selected group of patients perceive and voice their experiences of "being a patient" on an internal medical ward in an urban hospital setting; 2) to determine what these hospitalized patients would recommend to future hospitalized patients; and 3) to determine what kind of information these patients would have liked to receive at the start of their hospital stay. I view these aims as three different but interrelated phenomena. In this chapter, I situate myself in the inquiry to contextualize my personal interests and describe a selection of the key sensitizing concepts I chose to frame my inquiry.

Situating Myself in the Inquiry

As a new qualitative researcher, I appreciate that I influence the understandings and interpretations that emerge from this inquiry in many ways: first as an outsider looking at patient experiences, as a health care professional, as a published quantitative researcher, and as a graduate student in the Department of Educational and Counselling Psychology. I believe my experience and values as a physiotherapist working with patients is my largest source of influence. I begin with my journey in becoming a physiotherapist and how my Master's degree forced me to change the way I think about health care from a quantitative to a more qualitative view.

My journey as a physiotherapist.

My studies in physiotherapy were prompted by a desire to help and educate people to take better care of themselves. I began my studies in 2003 at the University of Ottawa, and became quickly aware that physiotherapy was a profession with multiple roles in patient care. Initially I had no idea that, besides orthopaedics, physiotherapists were involved in areas such as neurology, cardio-respiratory therapy, vestibular rehabilitation, oncology, paediatrics, seniors' health, and women's health, for example. In addition to the medical aspects of my learning, my years of studying physiotherapy also sensitized me to the person who is hidden behind a disease and how society treats its most vulnerable populations, more specifically the elderly. Whether positive or negative, the physiotherapist I am today is greatly influenced by the professors, classmates, patients and supervisors I met along my journey.

NARRATIVE SCENARIO: KNOWING MY ROLE

> My last physiotherapy placement before graduation was done in in-patient cardiac rehabilitation. I would visit patients in their hospital rooms the day after surgery to assist them in sitting, standing, or walking, among other things. Patients remained in hospital for three days before going home. I was trained to provide patients with orthopaedic exercises in order to maintain their physical strength and mobility, if they needed it, and wanted to do so in this placement. After discussing the treatment plan with me, my supervisor let me know that we were not in an orthopaedic setting and that it was not my role to provide the patient with exercises. All I needed to do was to provide cardio-respiratory treatments, maintain their walking endurance, educate them on post-surgery restrictions, and prepare them for discharge home. Nothing else! (Cardio-respiratory placement, 05/2007)

Other than trying to do too much with my patients, the second most common feedback comment in my evaluations was that I spent too much time talking to my patients, which limited the number of patients I could see in a day. As a student, I felt that my role was limited to my supervisor's requirements. As an independent practitioner, I could finally develop my "inner physiotherapist". By "inner physiotherapist", I refer to the physiotherapist I want to be, based on my personal values and beliefs. I could provide my patients with exercises if I wanted to and talk to them as much as I wanted, while managing my own time and caseload.

Upon graduation in 2007, I began my career in a 400-bed long-term care home in Ottawa, Ontario. This residence had wards for independent seniors and wards for seniors with dementia and various debilitating physical conditions. I was part of a multidisciplinary team of occupational therapists, doctors, registered nurses, auxiliary nurses, assistant physiotherapists, recreational therapists, social workers, pastoral services, and pharmacists, to name a few. I was responsible for three of the four floors of the residence and had a caseload of about 100 patients.

I learnt more about life and aging during this time than I had during my entire studies. I observed a large number of my patients decease, fall, require surgery, lose their mobility, and degenerate either physically or mentally. The complexity of seniors' health became my new passion. I spent a large amount of my time talking to my patients about their health conditions, or anything else they wanted to know more about. I realized just how empowering knowledge can be, but I wanted to know more about it, thus my plan to enter graduate studies in Education.

While I was working as a physiotherapist, I was also employed as a research assistant for a physiatrist at The Rehabilitation Center in Ottawa. Within my first year of graduation I published an article in *The Canadian Medical Association Journal* and was preparing two other manuscripts. With a new sense of contributing to the medical world, I became sensitive to the works of other authors who have since inspired me by their passion for writing and patient-centered care. Such authors and subjects include Chris Winkleman's work on inactivity in the chronically ill; Margaret Herridge on the long-term outcomes of critical illness; and Peter Morris on early intensive care unit mobility. I created a list of personal research topics that interested me enough to pursue my own research and guide me through my graduate admission process to McGill University. My thesis topics revolved around seniors, mobility, the impact of an interdisciplinary team on a patient's level of mobility, and the physical impacts of immobility. I left Ottawa for Montreal with lifelong lessons about aging well, and with clinical and research experience. For aging, I learnt about the importance of remaining active physically and mentally throughout one's lifespan because, as I observed first hand, this will greatly affect how a person will age. My clinical experience taught me how to apply my physiotherapy knowledge, work alongside a multidisciplinary team, manage a caseload, and interact with patients. My research experience provided me with invaluable knowledge about creating a research project from a mere thought and idea, all the way to a manuscript publication and national conferences.

Thinking qualitatively.

I began my graduate studies in the McGill University Faculty of Education in September 2008. It did not take long for me to realize that my medical, systematic way of thinking was hindering more than helping my studies. In medicine, if someone were to pose the question "What is learning?", for example, the answer might revolve around the idea that it is what it is: learning. In education, volumes of books and papers elaborate on that sole question. My medical mind was unable to comprehend why the question was so complicated. In order to grasp education and a qualitative way of thinking, I had to ignore my background in health care. Suspending my previous knowledge took me a year.

I began my thesis journey thinking about seniors' health. I visited professors, explaining my ideas that revolved around a multidisciplinary team and patient immobility, leaving with feelings of dissatisfaction with my topic. After months of inner searching, I realized that what I fundamentally wanted to do was to ask patients about their hospital stay. I wanted to know what it was like to be a patient, how patients felt about being in the hospital, a rehabilitation center, or anywhere else they were admitted. My ultimate goal was to understand how patients perceived their hospital experience and use this information to positively influence the hospital stay of other patients. It took many encounters with professors before I randomly met with Dr. Jeffrey Wiseman, now my co-supervisor, before the start of my Health Professions Education course. He immediately took an interest in my topic and provided me with great feedback on how to clarify my own thoughts. He suggested I speak to Dr. Mary H. Maguire, my other co-supervisor, who also took an interest in my topic. I finally felt confident and ready to start the thesis process. I narrowed my inquiry and began the ethics submission process.

Refocusing the Inquiry

From my personal experience in health care experience, I find there to be a misunderstanding between what means to be a patient and what patients are actually experiencing. I aim to create a better understanding of the experience of "being a patient" from patients' perspectives and define the term "voice" as it may be conceptualized in health care. The understandings and knowledge generated from this qualitative study may be used to better understand the patients' voice and their perceived personal experiences in hospital. These understandings may help physiotherapists in their practice and other health care professionals to understand the implications of patient voice within the medical discourse. My research questions are:

1. How do a selected group of patients on an internal medicine ward perceive and voice their experiences of "being a patient"?
2. What would these hospitalized patients recommend to other patients?
3. When invited to reflect back on their experiences, what kinds of information do these patients articulate that they would have liked to receive during their hospital stay?

My research questions draw on phenomenology to understand the lived experiences of patients on the internal medicine ward of an urban hospital.

As the act of researching is recursive, my questions changed during the data collection process and when I began interpreting the emerging thematic understandings. My initial questions and research aims reflected the perceived educational needs of geriatric patients in relation to physiotherapy and the type of education that was provided to patients. As I asked my participants these questions, I found that some were not seen by a physiotherapist, and many were unable to pin-point what would classify as an "educational need", and much less what "educational information" meant. Therefore, I decided to focus solely on patients' tangible experiences.

Key Sensitizing Concepts

Throughout this inquiry, I use the following key concepts and definitions to explore the meaning of "being a patient".

Phenomenology: A social theory that aims to understand the lived experiences of individuals from their perspectives. It aims to describe the everyday lives of individuals as internalized by them in particular contexts. It renders "explicit the taken-for-granted presuppositions of everyday life and, particularly, to bring to the fore one's consciousness of the world" (Toombs, 2001, p. 2).

Voice: It is the "speaking personality that is recognized, heard, or valued in an utterance or text in a particular context" (Maguire & Graves, 2001, p. 564). This concept emphasized the importance of attending to the ways in which people "explain, from their perspectives, [and] how they find their own expressions of meaning and inquiry in different contexts" (Maguire, 1999, p. 142).

Patient-centered care: An approach that empowers patients by bringing "into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured" (Kitwood, 1997, p. 135). This concept would be inexistent without the core necessity of first listening to the patient's voices in order to understand their uniqueness and experience from their points of view.

Chapter Summary

In this chapter I introduced my qualitative inquiry on the meaning of "being a patient". I described my journey as a physiotherapist, and presented the key sensitizing concepts that frame my inquiry: voice and patient-centered care. In Chapter 2, I describe my literature review on voice in medicine, as well as my theoretical framework.

Chapter 2. Literature Review and Theoretical Framework

Literature Review

What does it mean to "being a patient"? Frank (1991) describes it as "being colonized as medical territory and becoming a spectator to your own drama" where lab results dictate how you should feel (Frank, 1991, pp. 56-57). A simple internet search reveals numerous stories on doctors, and other health care professionals, who become patients themselves. They recount how they navigated and experienced the medical system from a hospital bed. As insiders of being patients with outsider experience as health care professionals, they use their knowledge as professionals to recount and analyze their experiences of "being a patient" as a phenomenon they knew existed, but never quite understood. In most cases, the experience changes their medical practice and reveals new meanings for patient-centered care. For two well-cited authors in this thesis, S. Kay Toombs and Mary H. Maguire, discuss the complexities and challenges of "being a patient".

S. Kay Toombs, Ph.D., is an Emeritus Associate Professor of philosophy at Baylor University in Texas. She states that her interest in exploring doctor-patient relationships grew out of her own personal experience as a patient living with multiple sclerosis. During her discussions with the doctor, she noticed that they were "never quite reaching one another", not out of inability to communicate, but because they were living two different realities (Toombs, 1992, p. xi). In *The Handbook for Phenomenology and Medicine*, she recounts living with this incurable disease, and how phenomenology can provide "a powerful means to illuminate the experience of loss of mobility…[in] particular, in rendering explicit the dynamic relation between body and world" (Toombs, 2001, p. 247). In the 2009 newsletter of the McGill Nursing Alumni Association, Maguire recounts "appreciat[ing] the insights the journey from illness to well being has provided [her] about the meanings of care from diverse perspectives" (Maguire, 2009, p. 1).

Surprising, and striking is the relative absence of the concept of patient "voice" in health care literature. Unless recounted informally by the professionals who experience "being a patient", little actually exists on patient voice from the patients', rather than professionals', point of view. Interchangeable terms, such as Patient Experience, Patient Opinion, Patient Satisfaction, Patient Perception, Patient Words, are used to describe voice, but they do not always deal with the real concept of Patient Voice as voice is and can be understood (Maguire & Curdt-Christiansen, 2007, p. 7). The literature that does exist is scarce, confusing, and absent in major medical journals.

In physiotherapy, the concept of patient voice is often depicted either by the therapists' opinion on patient care, or on the use of patient perception to create problem-based cases for students (Ottewill, Demain, Ellis-Hill, Greenyer, & Kileff, 2006; Brown, Humphry, & Taylor, 1997; Litchfield & MacDougall, 2002). Other health care fields that publish on voice can be found in psychiatry (Chur-Hansen & Koopwitz, 2004), palliative care (Teno, 1999), social work (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010), speech and language pathology (Hengst, Duff, & Prior, 2008; Barrow, 2008), cardiology (Rauen & Rauen, 2006), nursing (Jackson & Mannix, 2004), paediatrics, and even management (Hsieh, 2009). Jurate A. Sakalys, a practicing nurse with a PhD, publishes on illness narratives as a form to "restore" a patient's voice (Sakalys, 2010; Sakalys, 2003). She writes how autobiographical accounts can be an "important way [patients can] make sense of an illness episode, to restore personhood and connectedness, and to re-claim the illness experience" (Sakalys, 2003, p. 228). She recommends to other nurses who wish to use narrative to "give primacy to the patient's voice, to listen for meaning rather than for facts, and to provide a relationship enabling the evolution of the patient's story" (Sakalys, 2003, p. 228).

The Division of Health Care Communication of the University of British Columbia titled their first international conference: *Where's the patient's voice in health professional education?* (Farrell, Towle, & Godolphin, 2006). Their objectives were to promote ways in which patients could be more involved in the curriculum planning for health care professional students. Farrell et al. reinforce the need to place patients in more active health care roles and to better design studies that might capture their involvement. John Spencer, from the department of Medical Education of Newcastle University, emphasizes that patient participation can enrich medical education with "specialty-knowledge", or in discussing the "bigger picture" of an illness (Spencer, 2010, p. 11). He concludes by saying that "The 'patient's voice' is not singular; it is in reality a cacophony!" (Spencer, 2010, p. 11). Voice is not singular and needs to be captured holistically in order to understand the expressed needs of patients. A systematic review in 2009 concluded that studies involving "real" patients in medical education was "recommended in order to bring the patient voice into education" (Jha, Quinton, Bekker, & Roberts, 2009, p. 10). Unfortunately, patient voice was solely defined as any form of active participation for teaching or curriculum development on the patient's behalf.

Based on the references above, there appears to be an agreement in medical education that involving real patients in health care curriculums is a good idea. And yet, that is not quite what "patient voice" is. Although I do believe patient involvement is crucial in medical education, voice in these instances does not promote voice as voice is, or can be understood. There is little focus on the meaning of the utterances or experience from the patients' perspectives to understand the experiences as experienced and expressed by patients. Rare are the studies that represent patient voice as a means to explore the uniqueness of each patient and their actual lived experiences as they perceive them to be.

So what is voice? Voice is the "speaking personality that is recognized, heard, or valued in an utterance or text in a particular context" (Maguire & Graves, 2001, p. 564). Listening to the various voices a person can use can focus attention to the different ways "they explain, from their perspectives, [and] how they find their own expressions of meaning and inquiry in different contexts" (Maguire, 1999, p. 142). With all best intentions, medical studies that attempt to understand patient voice, unfortunately restrain it, or even misinterpret the actual concept, conflating it with patient opinion or self-reports from surveys.

For example, Hundt, Carayon, Springman, Smith, Florek, Sheth et al. conducted a telephone survey to obtain post-operative perspectives from patients. Although they entitle the study "Outpatient surgery and patient safety: The patient's voice", they do not explain or comment on voice in the text (Hundt et al., 2005). In family medicine, Scott et al. "strive" to capture the patients' voice by sending them electronic surveys prior to their medical appointments as a means to bring "patient-reported outcomes into clinical care" (Scott, 2010). A similar survey, also titled "patient voice" (Wolosin, 2005), was conducted, again in family medicine, to determine patient satisfaction with care. Slade, Malloy and Keating (2009) described the use of a grounded theory qualitative study to "investigate participant experience of exercise programmes for non-specific chronic low back pain" (p. 270). They conducted focus groups where "patients were encouraged to give personal opinions" with a series of 11 predetermined questions (Slade, Molloy, & Keating, 2009, p. 270). Unfortunately, focus groups with a priori structured questions do not leave much room for an exploration of each participant's voice to emerge. These articles liberally use the word "voice", yet misinterpret it.

Seemingly good medical qualitative studies fail to use appropriate qualitative methodologies. Nowhere in the previously discussed definitions of voice is it defined that voice needs to be surveyed, tabulated, or peer reviewed in order to be understood. It is too common to see medical "qualitative" studies that produce quantitative results. Many use brief excerpts from the participants with a tally of how many times a certain word was repeated, which are reviewed by an expert panel to determine their relevance. Lattanzi, Giuliano, Meehan, Sander, Wootten & Zimmerman explored the experience of physical rehabilitation using a phenomenological qualitative study, yet triangulated, peer reviewed and confirmed the relevance of what their participants said with experts (Lattanzi et al., 2010, p. 257). That is not phenomenology. Teh, Karp, Kleinman, Reynolds, Weiner & Cleary (2009) designed a grounded theory qualitative study to "explore the experiences of older adults seeking treatment for chronic pain" (p. 521). They conducted individual interviews of 45-60 minutes in length with three or four main questions to "allow the respondents to speak freely about their experiences" (Teh et al., 2009, p. 522). Although their approach might seemingly look like they intend to allow participants to freely express their voices, yet grounded theory, which is used commonly as a qualitative "framework" in medicine, is actually not a theory or a framework, but a strategy for describing emerging themes. There appears to be a mysterious "sexiness" in doing qualitative studies in medicine, without knowing what to do, how to interpret, how to report, or locate these inquiries within the complexities of qualitative traditions (Denzin & Lincoln, 2000, pp. 9-11).

More promising directions might be in the literature on medical discourses and dialogues between the patient and the health care professional. In her work on critical transformative dialogues, Franziska Trede, a physiotherapist, argues the "value of dialogue in transcending a fusion of understandings to achieve transformative action" (Trede, Higgs, & Rothwell, 2009; Trede, 2008). She describes "[the] importance of critical dialogues is that they focus on freeing speech partners from their limited horizons by exposing their unreflected prejudices and the preconceived ideas that they bring to the dialogue" (Trede et al., 2009, p. 136). Marisa Cordella, a senior lecturer in Spanish Linguistics in the School of Languages, Cultures and Linguistics at Monash University, Australia, and has written extensively on dialogues and different type of voices. The ideas discussed in her book, *The dynamic consultation: A discourse analytical study of doctor-patient communication*, are based in an outpatient public teaching hospital in Santiago, Chile. She acknowledges the varied voices doctors and patients use during a clinical encounter in medical discourse. Her work and classifications of preferred voices patients appear to use and prefer from the health care professionals is the main source of reference for my inquiry.

The lack of health care literature on patient voice relating specifically to the lived experiences of patients themselves, and the quality and thoroughness of qualitative inquiries, is striking. I propose to use a phenomenological methodology to understand the phenomenon of "being a patient". I draw from French scholar Merleau-Ponty's stance in phenomenology that "tries to give a direct description of our experience as it is [while offering] an account of space, time and the world as we 'live' them" (Merleau-Ponty, 1962, p. vii). Phenomenologists focus on the lived experiences of individuals by allowing them to reflect on and disclose the meanings of their experiences (Toombs, 1992, p. xi). Svenaeus describes phenomenology as a means to "enrich our understanding of health in adding to the disease-level analysis that addresses the questions of how the physiological states are lived as meaning in an environment" (Svenaeus, 2001, p. 87). I aim to understand the meanings of "being a patient" from the patients themselves during their hospital stay in an academic hospital setting. I aim to understand and more clearly define patient voice, how it can be applied, and especially how it may be understood in a medical setting. I also aim to describe how the patient-centered care approach presently encouraged in medical settings cannot exist without patient voice.

Theoretical Framework

In this section, I present my theoretical framework on voice and patient-centered care, which shapes the way I interpret the utterances of my participants. I draw on theoretical perspectives located within a phenomenological approach. Merleau-Ponty's work shows a "passionate commitment to the interrogation of philosophical and social concerns" (O'Neill, 1974, p. v). His elaboration of the body within a world shapes my theoretical framework of voice. I argue that voice is used by individuals in their interactions with the world, in that a person's "body and language are inter-nested" (Svenaeus, 2001, p. 100).

Patient voice.

From a medical perspective, the body "assumes the status of a scientific object...[where] a particular body is simply an exemplar of *the* human body and, as such, it may be viewed independently from the person whose body it is (Toombs, 2001, p. 8; Toombs, 1992, pp. 76-81). Merleau-Ponty (1962) argues that the body is an "incarnate form which the self assumes when it ceases to regard itself, first and foremost" as a scientific neurophysiological organism filled with cells, tissues and organs (Macann, 1993, p. 170; Toombs, 2001, p. 8). It is evident that the medical and phenomenological definitions of body do not resemble each other at all. I use Merleau-Ponty's definition of body that views the person and the body as one, rather than two separately treatable entities.

One's body is more than an object moving in the world, but a vehicle to see, communicate, and perceive what exists (Merleau-Ponty, 1962, p. 92; O'Neill, 1974, p. xvi; Toombs, 2001, p. 248). One's perception is "constantly filled with a play of colors, noises and fleeting tactile sensations" which are presupposed uniquely by the person experiencing them

(Merleau-Ponty, 1962, p. x). The body yields sensations to inform a person about their perception of the world they are in. A world is what a person lives through and perceives (Merleau-Ponty, 1962, p. xvi-xvii). The perceived things exists only insofar as they are perceived in the unique way the person perceives them, and are never exhausted by the way they are viewed (O'Neill, 1974, p. xvii). The objects of a person's perception are, in themselves, phenomena (O'Neill, 1974, p. xvii).

The constant interaction the body has with the world "reflects the fact that the lived body represents not just one's bodily being but one's contextual Being-in-the-world" (Toombs, 2001, p. 6). Being-in-the-world is a "bodily state where the consciousness reveals a dynamic relation between the body and the world where the lived body is an embodied consciousness that simultaneously engages, and is engaged in, the surrounding world" (Merleau-Ponty, 1962, p. 79). A person's needs, behaviours, or "acts must be understood in terms of their being acts which take place within a certain situation having a certain practical significance for the embodied subjects" at a particular time and space (Toombs, 1992, p. 53).

There are numerous ways a person can express his or her needs, behaviours, or acts to another human being. The most commonly used method is through language. In his book, *The Phenomenology of Perception*, Merleau-Ponty beautifully describes how language plays a central role in a dialogue between two people.

> In the experience of dialogue, there is constituted between the other person and myself a common ground; my thought and his are interwoven into a single fabric [...]. We have here a dual being, where the other is, for me, no longer a mere bit of behaviour in my transcendental field, nor I in his; we are collaborators for each other in consummate reciprocity. Our perspectives merge into each other, and we co-exist through a common world. In the present dialogue, I am freed from myself, for the other person's thoughts are

> certainly his, they are not of my making, though I do grasp them the moment they come into being, or even anticipate them. And indeed, the objection which my interlocutor raises to what I say draws from me thoughts which I had no idea I possessed, so that at the same time that I lend him thoughts, he reciprocates by making me think too. It is only retrospectively, when I have withdrawn from the dialogue and am recalling it that I am able to reintegrate it into my life and make of it an episode in my private history... (Merleau-Ponty, 1962, p. 354)

Merleau-Ponty describes language as a discourse that involves collaboration, a merge, a co-existence and reciprocity between two people talking. He adds that it is a "phenomenon of articulation, of sound, or the consciousness of such a phenomenon, but in any case language is but an external accompaniment of thought" (Merleau-Ponty, 1962, p. 177). How fortunate are those who can listen to another person's thoughts!

Mikhail Bakhtin is one of the leading thinkers on dialogue and dialogical approaches. He states, "Form and content in discourse are one, once we understand that verbal discourse is a social phenomenon – social through its entire range and in each and every of its factors, from the sound image to the furthest reaches of abstract meaning" (Bakhtin, 1981, p. 259). It is important to note that as a social phenomenon, the relationship between a person's utterances and languages has multiple factors which can vary in multiple contexts and situations. Bakhtin notes how the "diversity of social speech types and [the] diversity of individual voices" can be "[t]he internal stratification of any single national language into social dialects, characteristic group behaviour, professional jargons, generic languages, languages of generations and age groups, tendentious languages, language of the authorities, of various circles and of passing fashions, languages that serve the specific socio-political purposes of the day, even hour" (Bakhtin, 1981, pp. 262-263). Each speech type "permits a multiplicity of social voices and a wide variety of their links and interrelationships" (Bakhtin, 1981, p. 263). Bakhtin emphasizes how words have their "own expression and evaluative tones" and convey a deeper meaning in a voice (Maguire & Graves, 2001, p. 566).

In drawing from the works of Bakhtin and other theorists, Maguire uses his concept in her work with multilingual children's literacy development. Maguire and Curdt-Christiansen (2007) note how the texts of multilingual children indicate how they "assert their own ideological stances towards prevailing authoritative discourses, give visible voice to their own sense of agency and internally persuasive discourses, and respond to the various ideological resources that mediate their multilingualism and linguistic repertoires" (Maguire & Curdt-Christiansen, 2007, p. 75).

Cordella (2004) describes how patients and doctors can have multiple voices in the course of a dialogue with each other. She describes patients as having four possible voices: *Health-related Storytelling*, *Competence*, *Social Communicator*, and *Initiator*. The voice of *Health-related Storytelling* is used in "functional relationship with the doctor voice […] usually triggered by a doctor's question" (Cordella, 2004, p. 154). Patients who prefer the voice of *Competence* "show familiarity with the medical process and understand their health condition", and is subdivided into three more voices: *Compliers* who understand the instructions and carry out the task, *Apologizers* who understand the instructions but were unable to carry out the task, and *Challengers* who become responsible for their health and begin to contest the doctor's recommendations (Cordella, 2004, p. 157). The voice of the *Social Communicator* arises during the course of the conversation with the doctor when issues related to social identities and experiences arise (Cordella, 2004, p. 165). And lastly the voice of the *Initiators* "seek information about their health condition [...] and indicate a desire to understand more about their health in order to take better care of it" (Cordella, 2004, p. 171).

Cordella then describes the doctors, or health care professionals, as having three possible voices: *Doctor*, *Educator*, and *Fellow Human*. The *Doctor* voice is used mainly to “find out informative data about the patient’s health condition that will enable [the doctor] to make a diagnosis and/or to assess changes” (Cordella, 2004, p. 63). The *Educator* voice “shares information with patients in order to help them better understand their health condition and appreciate the benefits of the recommended treatment” (Cordella, 2004, p. 87). The *Fellow Human* voice “show[s] empathy and encourage[s] patients to tell their stories [while] complement[ing] the doctor voice in exploring the whole picture of the patients as a way of understanding the health problem” (Cordella, 2004, p. 121). Whereas the *Doctor* and *Educator* voices reinforce a certain hierarchy in which the health care professional is dictating to the patient, the *Fellow Human* voice connotes a shared partnership in the consultation (Cordella, 2004, p. 147). Although I do not explore the Doctor voices, the participants alluded to the type of voices they would have preferred from the health care professional.

In this inquiry, I draw on Merleau-Ponty’s view of the body and being-in-the-world, Bakhtin’s view of language and discourse, and Maguire and Cordella’s views of multiple voices as my theoretical framework to help me understand and interpret the voices of my participants.

Patient-centered care.

“World is not in man but man *in* the world” (Merleau-Ponty, 1962, p. xi). In this quote, Merleau-Ponty represents what I think patient-centered care should strive to be. Patient-centered care reflects how everyone influences the lives of others through their actions or words. It also reflects my personal belief that humans need one another, are interconnected, and should strive to treat others as they would like to be treated. As many possible interpretations can arise from this cryptic statement, my interpretation is but one of many. Maguire interprets this statement by

Merleau-Ponty as how human utterances cannot be fully understood in isolation from the nested contexts they are living in (Maguire & Graves, 2001, p. 566).

Like voice, patient-centered care is a much used term with different meanings. It is a complex concept that is alternatively phrased as Family-centered Care, Patient Education, Patient Autonomy, Patient Compliance, and Patient Management. The CanMeds Physician Competency Framework identifies patient-centered care under the "collaborator" competency of physicians. The authors of this document describe collaboration as "increasingly important in a modern multi-professional environment, where the goal of patient-centered care is widely shared […] for the provision of optimal care, education and scholarship" (Royal College of Physicians and Surgeons of Canada, 2005, p. 4). Similarly, the Canadian Physiotherapy Association (CPA) "supports interprofessional practice for physiotherapists and believes that interprofessional collaboration is an essential prerequisite for effective and efficient client and family-centered care" (Canadian Physiotherapy Association, 2006). These documents refer to and call for patient-centered care as an important goal, but offer no definition for it. Despite the popularity of "patient-centered care", it remains ill-defined, diffuse, and poorly conceptualized in the way it is presently used in health care literature (Maguire & Wiseman, 2009). Although collaboration and interprofessional practice are key enablers for patient-centered care, their presence is not a guarantee that patient-centered care will actually occur. The extent to which the patient has freedom and support to collaborate with other health professionals and, in effect, act as the most important of the multiple "professionals" designing his/her own care, is the extent to which care is truly patient-centered.

In 1986, Ian R. McWhinney asked the world of family medicine *"Are we on the brink of a major transformation of clinical method?*" He argued that the traditional methods used to serve medicine appeared to be failing the contemporary needs of patients (McWhinney, 1986, p.

873). In particular, he states how the methods of the time have "no means for understanding the inner experience of patients" (McWhinney, 1986, p. 873). It is "strictly objective" (McWhinney, 1986, p. 874). He questions empirical studies and pushes for an epistemological change in medicine to use other forms of methodologies if empirical authors really want to understand the meaning of illness. He specifically mentions the use of phenomenology. The transformed clinical method, as he calls it, is the start of a patient-centered care reform. Where a doctor-centered care brings the "patient's illness into [the doctor's] own world and to interpret the illness in terms of [the doctor's] own pathological frame of reference", patient-centered care brings the doctor into the "patient's world and to see the illness through the patients eyes" (McWhinney, 1986, p. 876). McWhinney adds that this approach may encourage openness by the patient, understanding of their expectations, feelings, and fears as they are specific for each person, and reflect a unique meaning of illness in unique situations and experiences of life (McWhinney, 1986, p. 876). McWhinney appears to draw from Merleau-Ponty or another similar theorist for his definition of patient-centered care, as Merleau-Ponty similiarly writes how a person understands facts to be reality in the way that person experiences them to be true (Merleau-Ponty, 1962, p. 358).

In 1997, Tom Kitwood became a pioneer in patient-centered care the domain of dementia care with his book, *Dementia reconsidered: The person comes first*. Similar to McWhinney, he defines patient-centered care as an approach that "brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured" (Kitwood, 1997, p. 135). He add that "it reinstates the emotions as the well-spring of human life, and enjoys the fact that we are embodied beings" (Kitwood, 1997, p. 135). This is similar to Merleau-Ponty's view of "being-in-the-world" as described in the previous section. Together, McWhinney and Kitwood describe a philosophical mind shift for seeing a human being, and how health care professionals could come to understand the person on an entirely new level if they paid closer attention to respond to the needs, or unmet needs, of their patients.

Adopting a patient-centered care approach "requires that the [health care professional] get rid of preconceptions and prejudgements, including those derived from theories and schemata of human behaviour" in order to understand their patients (McWhinney, 1986, p. 876; Waksler, 2001, p. 74). To be healthy or ill is certainly not the same as having a "good or bad feeling" (Svenaeus, 2001, p. 94). Illness "is not simply a problem with the isolated physiological object-body but, rather, a problem with the whole embodying organism/environment (Toombs, 2001, p. 6). "Illness pervades existence" (Svenaeus, 2001, p. 97). If health "is to be understood as a being at home" and illness is "not being at home", the very nature of being ill transforms the patient's world into "pervasive homelessness" (Svenaeus, 2001, p. 94). When the difference between health and illness is recognized, the "*attunement*" of one's being-in-the-world becomes the phenomenon to focus on (Svenaeus, 2001, p. 94).

McWhinney originally challenged that medical education does not promote certain qualities such as "self-knowledge, moral awareness, a reflective habit of mind and a capacity for empathy and attentive listening" (McWhinney, 1986, p. 876). Although he comments that the present medical model "may help both the physician and the patient understand aspects of the illness...it is not a substitute for knowing the patient as an individual" (McWhinney, 1986, p. 876; McWhinney, 2001, p. 331). This remains as true in 2011 as in did in 1986. Applying patient-centered care to medical practice involves much more than collaboration, as described in the CanMeds and by the Canadian Physiotherapy Association. Svaneaus (2001) argues that "the world I live in is certainly first and foremost *my* world" (p. 94) and needs to be understood as such.

Chapter Summary

In this chapter, I describe how voice remains an abstract, absent and ill defined concept in medical and physiotherapy literature. I argue that patient voice needs to be at the centre of patient-centered care, where both these sensitizing concepts can be used conjointly as the foundations to my theoretical framework. With the help of key theorists and authors, I argue that the medical treatment plan and entire approach towards patients should be tailored, based on their unique needs. In Chapter 3, I describe the methodology, data collection, and tools of inquiry that I use to explore the phenomenon of "being a patient" from the perspective of four in-hospital patients.

Chapter 3. Methodology, Data Collection Process, and Tools of Inquiry

I begin with excerpts from transcribed interviews of three participants who were admitted to an internal medicine ward of an academic quaternary referral hospital in Montreal, Quebec.

Heidi: How would you define being a patient?

Jean: Être un patient, ce n'est pas agréable être un patient. Il fallait mieux qu'on ne le soit pas. […] Le sentiment d'être un patient n'est pas bon. Parce que personne aime être malade…	*Jean: Being a patient, it is not enjoyable being a patient. It's better not to be. […] The feeling of being a patient is not good. Because no one likes being sick... (Jean, 72y, Int 2, 09/06/2010)*

Mary: (10 sec pause) I would, it would have to be, like I just said, coming in, being treated with respect and being spoken to...not sarcastically or anything like that...but being spoken to nicely...and that would be about it. (Mary, 72y, 06/30/2010)

Un patient – celui qui reçoit des soins. De façon subjective – Une personne impatiente en détresse qui doit être en bonne santé pour se mouler à toutes les contraintes et agressions du système hospitalier et en sortir guérie de maux qui l'affligent et l'inquiète!!!	*A patient – the one who receives care. Subjectively – An impatient person in distress who needs to be in good health to mould to all the constraints and aggressions of the hospital system and to exit healed of the pains that afflict and worry them!!! (Marie-Ange, 65y, Int 1, 09/03/2010)*

The range of responses reflects the diversity of their perceptions of their lived experiences as patients. Jean describes a patient's feelings of vulnerability and how being in hospital is "not always easy". Mary talks about attributes health care professionals should or should not have. Marie-Ange provides a view of a patient as one who receives care and alludes to systemic issues a patient can experience when in hospital.

In this chapter, I situate myself in the inquiry and reflect how I have changed as a qualitative researcher throughout the course of my data collection process and writing this thesis. I draw from several key understandings and principles from French phenomenologist Merleau-Ponty and Toombs' view of medical phenomenology. I use the concept of patient voice to explore these patients' meanings of "being a patient" on an internal medicine ward in this academic urban hospital. I provide contextual information on the patient and physiotherapy participants. I describe my data collection process and my rationale for the tools of inquiry I selected, and I include examples of my data sources interviews, observations, and documents.

Background and Role of the Researcher

I am an allied health care professional, a physiotherapist, working with a team of multidisciplinary professionals for the welfare of people who have experienced an illness, or require treatment as a consequence of some disabling circumstance. My primary roles are to improve and maintain physical mobility and independence, prevent, manage and reduce pain, physical limitations or disabilities that may limit the clients' activities, and improve overall fitness, health and well-being (Canadian Physiotherapy Association, 2010).

When I first meet a patient, I conduct a detailed interview in order to determine the nature of the problem, what treatment is best, and if I am the appropriate health care professional to treat them. The patients' actions, reactions, words, and response to my evaluation and treatment all become pieces to a larger diagnostic puzzle and treatment plan. For example, when a person presents with shoulder pain, I consider: their age, hobbies or sports, their posture, past injuries, the way they describe the pain, and its location, what makes it increase or decrease, the duration of the pain, and numerous other factors to determine why they are in pain. The difference between a medical interview and phenomenological interview is that the latter takes a deeper approach to understand a person's perceptions and lived experiences from his or her perspective. Health professionals, me included, can be very preoccupied by the answers that fit into a routine pattern and omit listening to more nuanced words that may not fit the diagnostic pattern. The interview then becomes very selective. Some patients are themselves direct and may provide explicit answers; others may be more shy and reluctant. However when the problem persists, when the patient is readmitted more than once, or when the treatment seems to be rendering no results, there may be deeper existing problems, or reasons that are creating a barrier that cannot always be found by the typical perfunctory medical interviews. For example, patients living with chronic depression, post-traumatic stress disorder, physical or mental abuse, or chronic pain (Meagher, 2004; Polatin, Kinney, Gatchel, Lillo, & Mayer, 1993; Jain, 2009; Sharp & Harvey, 2001).

Waksler (2001) describes the phenomenological approach to an interview as an "exploration of one's taken-for-granted 'knowledge' [and] discloses a mixture of ideas - not only what one might view as verified truth but also unexamined tradition, guesses, suppositions, beliefs, and hopes" (p. 69). Ideally, a medical interview would do more than just ask medical questions, and place the interviewer in the interviewee's "situation and think about how one might feel" (Maguire, 2009, p. 5). The interviewer should be engaged in the conversation by "critically reading and interpreting a patient's words and worlds and to act upon those words by being present in the clinical encounter" (Maguire, 2009, p. 5). A medical interview where the approach relates to the patient as a unique individual with a voice can be a very liberating experience for the interviewee.

Methodology

In this qualitative inquiry, I aim to examine the meanings of "being a patient" for a selected group of patients admitted to an internal medicine ward of an urban quaternary care academic hospital. I base my inquiry on phenomenological theorists and approaches, which means that I aim to understand the lived experiences of individuals from their perspectives.

In adjunct, I use the medical approach of patient-centered care which emphasizes placing the patient at the forefront of their care, and the interview. Patient-centered care promotes an environment of sharing where the patient is the lead decision-maker in their own care. I believe that the only way patient-centered care can be achieved is by reinforcing communication as a dialogue between the health care professional and the patient, rather than a monologue. Being ill does not imply being unable to express your needs, be it vocally, in writing, or through body and facial expressions. As described by McWinney (2001), patient-centered care can "make possible a medicine which can see illness is an expression of a person with a moral nature, an inner life, a unique life story which enable medicine to heal by a therapy of the word and a therapy of the body" (p. 15).

Epistemology.

Therefore, my epistemological stance is that the experiences, needs, and perspectives of people are unique, and that each person should be approached and cared for based on their unique preferences. I believe that voice is a powerful form of expression that is at the center of patient-centered care. Every word, or facial expression, everything that the person says or does is a reflection of his or her needs. Health care professionals who practice patient-centered care also need to make sure that they take the time to listen to their patients as human beings with unique and varied voices. I believe that patients have preferred health professional voices that need to correspond to their own voices in order to promote a caring harmony. Some might prefer a more empathetic *Fellow Human* voice; "*To be a doctor and to be human being"* (Marco, 79y, 06/24/2010), whereas others might prefer a more informative *Educator* voice; "*They explained, that was the important part"* (Mary, 72y, 06/30/2010*).* When the voices in the dialogue correspond to the patient's needs, the two parties become attuned to one another. The dialogue then promotes a deeper rapport, trust, and understanding between the patient and the health care professional.

I believe that patients have a different understanding and perception about the hospital "world". A health care world is typically a sterile and hostile environment. The participant Marie-Ange describes her hospital experience as *"the patient is at the service of the hospital system and not the other way around" ("Le patient est au service du roulement hospitalier et non l'inverse";* Marie-Ange, 65y, Int 1, 09/03/2010). Therefore, not only does the person need to adapt to their body in illness, they also need to adapt to a medical world which they may not have control over or knowledge about. In order to adopt patient-centered care, health professionals need to acknowledge that patients do not always understand the implicit functions of the medical environment. Each individual's background, perceptions, upbringing, and other factors will affect the way they adapt, experience, and interpret being in this unfamiliar medical world (Svenaeus, 2001, p. 87). In order for health care professionals to promote a shared partnership, they need to understand that each patient has their own interpretation of being-in-the-world which may also affect the way they view their care. Therefore, when health professionals visit many patients a day, they are entering many different worlds and need to adapt themselves to each patient's reality or multiple realities. And not only adapt themselves to each patient, but also to suspend all their own beliefs and acknowledge that the patients' perspective is primordial, and that these perspectives might not reflect your own (Waksler, 2001, p. 70).

To me, patient-centered care encompasses the concepts of voice, perception, and being-in-the-world. Each of my research questions explores this link:

1. How do a selected group of patients on an internal medicine ward perceive and voice their experiences "being a patient"?
2. What would these hospitalized patients recommend to future hospitalized patients?
3. When invited to reflect back on their experiences, what kinds of information do these geriatric patients articulate that they would have liked to receive during their hospital stay?

Nested Contexts: Situating my Inquiry

More than one medical context can influence a patient's experience of "being a patient". To understand the nested medical contexts of a patient's hospital experiences, I briefly describe the larger University Health Center network, the teaching hospital used in this inquiry which is member of this network, the internal medicine ward within this hospital, and the interprofessional rounds that take place on this ward.

The University Health Centre.

The University Health Centre comprises six teaching hospitals located in Montreal, Quebec. These hospitals are located around downtown Montreal and Lachine. The mission statement of the University Health Centers is to provide "The Best Care for Life".

The study teaching hospital.

The study teaching hospital is located in downtown Montreal. It is a quaternary academic referral hospital that offers a wide range of highly specialized services such as internal medicine, women's health, various types of surgeries, a cancer care unit, a geriatric care unit, etc.

The internal medicine ward.

The ward where my inquiry was centered upon has 24 beds reserved for patients with acute internal medicine problems needing diagnosis and/or treatment. It looks like a long rectangle with stairs at both ends and with an elevator at one end with a family lounge. The nursing station is in the center. Most patients on this ward have multiple simultaneous acute medical, social, psychosocial, and chronic problems. Ninety-five percent of patients are admitted to this ward from the emergency room.

During a regular day, the ward is buzzing with a large staff of multiple health care professionals from many disciplines, patients walking about in the halls, and other staff cleaning or transporting patients to appointments. It is busy! For people not in the medical field, imagine a shopping mall on a Boxing Day. For people in the medical field, this internal medicine ward resembles any other ward in a busy urban hospital: the way health professionals move, the movement in-and-out of rooms, the patients, the discourses between professionals, body language of the team, the position and look of the charts. The physical space of this ward is not atypical, the health professionals or other professionals present are not atypical and the clutter around the ward is not atypical. The differences, however, are the team culture, dynamics, and past history of the ward. According to the ward Medical Director, this ward has experienced years of difficulty with administrative support (physical environment, equipment and human resources, staff turnover) and nursing leadership (support, numbers, competence, and teamwork). Combined with a drastic demand to admit sicker and more complex patients and the pressures to discharge patients faster to facilities that do not exist, or are also severely restricted by Government resource allocation decisions, the ward team is forced daily to rethink what the real definition of “The Best Care For Life” means for their patients’ care.

The team on this internal medicine ward consists of nurses, pharmacists, physiotherapists, occupational therapists, social workers, dieticians, pastoral service providers, respiratory therapists, orderlies, support staff, and physicians. The physicians include an internal medicine resident in his/her third year of training, a resident in his/her second year of training, one or two residents in his/her first year of training, two medical students (also known as clinical clerks), and an attending doctor (also known as the physician). A resident is a doctor who graduated from medical school and who is pursuing further post-graduate training by practicing medicine under the supervision of fully licensed physicians, usually in a hospital or clinic. The General Internal Medicine Residency consists of three years' of core internal medicine training and an additional two years' of fellowship training in General Internal Medicine or another subspecialty.

Although there are many professionals on the ward at one time, their working schedules vary. For example, the nurses, physiotherapist, occupational therapist, social workers, support staff, and pharmacist only treat the patients on this ward and do not rotate to other wards. In contrast, the dietician, pastor, and respiratory therapist see patients on this ward and rotate to others. Completely independent of these schedules is the medical team of attending physicians, residents, and medical students. Although there is always an attending physician on the ward, this person changes every two to four weeks, and the residents, and students change every month.

When I arrived on the ward for the first interview in the evening, my initial impression of the ward was how quiet it was as compared to my day visit.

> It is 5h00pm. I see about four staff on the floor. All patients are in their rooms. The atmosphere is peaceful, calm and serene. The halls are clean. I was nervous walking in for my first interviews but the quietness of the ward makes me feel much more relaxed. (Ward field notes, 05/20/2010)

I was introduced to the evening head nurse by the day head nurse; this was actually a complete coincidence. I also introduced myself to the ward clerk in order to advise him (or her) as to who I was and that I would need access to the medical charts. Although it is best for an “intruder” to advise the head nurse of their presence before seeing the patients, I never knew who that person was and was rarely approached for identification. On most visits, I introduced myself only to the ward clerk and visited the patients at my will. I may have blended in with the visitors since I was on the ward in the evenings between four and seven o’clock, and between ten o’clock and noon on Saturdays. In total, I visited the ward on six separate occasions.

The rounds, interdisciplinary meetings.

Multidisciplinary rounds are team meetings where doctors, nurses, physiotherapists, occupational therapists, social workers, dieticians, respiratory therapists, and other health professionals meet once per week to systematically and formally discuss each patient’s treatment and discharge plans. On this ward, rounds also include the Navigator nurse, a senior medical resident and occasionally a pharmacist, pastoral services, and students from various health care sectors (nursing, medicine, physiotherapy, etc). Rounds on are held weekly, on Wednesday mornings.

I attended at total of nine rounds. My primary goal for the first rounds was to determine the feasibility of my recruitment strategy and to determine the discharge dates of the patients. Discharge is a term that means the patient is leaving the hospital to go home, or to another facility. I found out that discharge dates are never mentioned or predicted unless the patient is going to a rehabilitation centre, or moving to another ward. When I asked the head nurse if she knew when the patients would be discharged, she comically said: “If you find out, please let me know.” The discharge date is often spontaneous, or fluctuates, based on the health of the patient. What I did find evident, however, was identifying which patients were too “unstable” to be interviewed and which were “doing better”. I was able to determine this by the way the team was describing the patients: if the patient was alert and oriented, mobilizing or independent with some tasks, if the treatment was going well, if the discussion was shorter, or if they directly said that the patient was “going home soon”. Then I knew that I needed to visit the patient before the weekend because they would not be in hospital the following week. On average, 23 patients are discussed at rounds; about 13 of these are over 65 years of age. I selected one to four patients per rounds who corresponded to my thesis criteria.

Each round is unique. The setting, pace and liberty of expression of each professional directly reflects the philosophy of the ward and who is leading the meeting. On this ward, the meetings look the same, in that each professional sits in the same spot and all are directed by the same people.

> As I walk into the meeting, the head nurse and other specialty nurses are present at the long rectangular table. The front (right side from the door) of the room has a large white board and an antique x-ray reader. The left side is just a plain white wall with chairs. I sit on the right side of the room near the head of the table. The rest of the team arrives and takes their seats. The senior resident arrives last and sits to my left at the head of the table. The nurses appear to be sitting on the side of the table the doctor is sitting on, whereas the other professionals sit at the opposite end. The resident begins the meeting, but the head nurse intervenes commenting that she is the one who directs which patients are discussed. He agrees, and the nurse continues. She identifies a patient and then the resident takes on the discussion about their medical status, treatment plan, and discharge plan. The order of the patients discussed varies, depending on the nurses who come in and out of the room as they are the ones tending to the patient. The rest of the team appears to be consulted as needed. (Rounds field notes, 05/19/2010)

This description of rounds resembles the general schedule of the other rounds where the head nurse identifies the patient order and the attending physician continues the discussion. What differs from other rounds is the pace of the discussion which is dictated by the senior resident and attending doctor. In the nine weeks I attended rounds, I observed three different senior medical residents and three different attending doctors. Each varied greatly from the next. The variety of the doctors helped me understand the culture of the ward and the relationship among the members of the health professional team, and the comments my participants made regarding the impressions of their patients' hospital stay.

Negotiating Access to the Health Care Sector and a Research Site

It took me nine months to obtain ethical approval. As my thesis is in a medical setting, it needed to be approved by the research ethics boards of a medical institution and not the McGill University ethics board. I began the ethics submission process in a rehabilitation center. I visited the site, met with the three physiotherapists who would help during data collection, contacted the ethics board and submitted my first ethics proposal in August 2009 (Table 1). My study setting was on a cerebrovascular accident (CVA) or stroke ward. The Center for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR) is the overseeing ethics committee for this rehabilitation center, and many other Montreal rehabilitation centers. Prior to a CRIR approval, each rehabilitation center must institutionally approve a project for feasibility in their centre. Given the usual four to six-week wait time, I expected to begin data collection in December 2009.

In October 2009, the rehabilitation center informed me that, due to institutional changes and a large number of research requests for patients having sustained a stroke, my project could be expedited if I changed my population. I therefore modified my criteria for patients having experienced an orthopaedic hip or knee surgery. In November 2009, the same rehabilitation center notified me that I was not covered for institutional insurance and was refused access. After discussing this incidence with the CRIR, they recommended I submit to a second rehabilitation center which they also ethically govern. I submitted a third proposal with the same population. In the meantime, I submitted another proposal to Villa Medica Hospital, which is an entirely separate institution not affiliated with the CRIR, in hopes of increasing the speed of an approval.

In December 2009, the second rehabilitation center notified me that I was also denied access. As neither I nor my supervisors were affiliated with the CRIR, I had no insurance to do research in a CRIR facility. Distraught, I contacted the CRIR once again to discuss this issue. Why was the CRIR directing me to pursue institutional approval if the institutions were wondering why the CRIR was letting me pursue research submissions? The CRIR was unaware of why this was taking place and commented that such a situation had never occurred in the past. My entire proposal for the CRIR was thus withdrawn.

After discussing with my supervisors, I was advised to cancel the ethical submission I had made to Villa Medica and to concentrate on the acute care internal medicine ward at the academic hospital where Dr. Wiseman is an attending physician. This required an entirely new ethics submission. My fourth and last ethical proposal was submitted to the Research Institute of that hospital in February 2010. I proposed a population of English or French-speaking patients over 65 years of age with no cognitive disorders, admitted to an internal medicine ward. The project was expedited and approved eight weeks later.

The barriers I faced in attempting to gain ethics access were challenging, frustrating, and confusing. Both my supervisors and I knew that any patient risk engendered by my thesis study was very minimal, if not nonexistent; thus the delay is constant ethical refusals was frustrating. Confusing, and perhaps disturbing, was the approbation of the CRIR to submit my project, but followed by the refusals of their own rehabilitation facilities. Each facility rejected my entry, confused as to why the CRIR was even submitting them my project. The ease with which the academic hospital approved my project may have been due to the academic institution's prior experience with approving medical education and educational psychology studies, and the presence of Dr. Wiseman, along with the assurance that he would be present on the ward while I was conducting the interviews.

Many gatekeepers closed doors to me in the submission process of this project, especially the rehabilitation centers that are perhaps unfamiliar with the process of qualitative studies. Ultimately, the best decision was to take advantage of the infrastructure that could support my project, such as this academic hospital. As patient voice does not emerge in the medical literature, it is unfortunately not surprising that it is so difficult to again access to a medical site.

Table 1

Time Line of Ethics Submissions and Data Collection Process

Time line	Ethics submission
August 2009	First submission to the CRIR
October 2009	Resubmission of first submission to the CRIR with modifications
November 2009	Cancellation of first CRIR submission
	Second submission to the CRIR
	Submission to Villa Medica Ethics Board
December 2009	Cancellation of second submission to the CRIR
	Cancellation of submission to Villa Medica Ethics Board
February 2010	Submission to the Research Institute of the academic hospital
May 2010	Final approval from the Research Institute of the academic hospital
	Start of data collection process
October 2010	End of data collection process

The internal medicine "Patient Discharge Navigators".

Gaining access to the academic hospital was a simple task, compared to the struggles of submitting to the CRIR. The presence of my co-supervisor and the internal medicine Patient Discharge Navigators no doubt facilitated my access to this research facility.

The Patient Discharge Navigators is an innovative pilot program initiated with the aid of a grant from the McGill Initiative for Interprofessional Patient-centered Education and Practice. It consists of an interprofessional team with a ward nurse, administrative assistant, and physician. They detect and address patients' understanding of ward discharge plans, provide additional guidance, educational resources, and needed support. The Navigators program offers a free service to contact and maintain communication with the patients after hospital discharge to assure a safe return home. The service is continued until the patient meets with a general practitioner, or has a medical follow-up, in the community. All personnel on the internal medicine ward are aware of and support the existence of this project. The Navigators program is open to all patients admitted solely to this particular general internal medicine ward.

Due to the existing infrastructure of this program, I was graciously provided with the help of the Navigator's administrative assistant, Emily, to recruit participants for me, obtain direct contact with the entire ward team, participate in the weekly medical rounds, and arrange access to medical charts. It is not usual for a student project to have this much access to medical information of a ward; that is normally restricted to the professionals who tend to the patients. An additional advantage in obtaining access at this academic hospital may have been my studentship at an affiliated university and my professional code of ethics as a licensed physiotherapist. As a physiotherapist, I practice the strict confidentiality policies similar to the health care professionals on working in the hospital. Therefore I entered the ward as both an outsider researcher, and an insider health care professional representing a practice and oath.

Gaining access to patients on the ward.

Gaining access to the patients on the ward would not have been possible without numerous people. Prior to the start of the project I met the head nurse, the Navigator nurse, and the Navigator medical secretary and my recruiter, Emily. At my first rounds, I was introduced to the rest of the ward team. All were made aware of my project, that I would be attending their rounds, and when I would meet the patients. Here, the physiotherapist of the ward, Anna, introduced herself to me and agreed to help me select participants since she knew them.

My weekly recruitment strategy was as follows. Every Wednesday morning from May to July 2010, I attended the medical rounds of the ward. I selected between two to four patients per week. I confirmed the patients I selected with Anna who would remove, change, or add participants. I submitted this list to Emily after rounds. She visited the patients in their rooms between Wednesday afternoon and Friday morning of that same week. She would describe me as a McGill student and physiotherapist who wanted to ask patients about their stay on the ward. If the patient agreed to participate, she would leave them an information form and make an appointment for the interview. If the patient was reticent, but did not refuse, she would leave the information form and return at a later time, either the same day or the day after. Emily sent me all interview times via email. Interviews were always after four o’clock on week nights, or on weekends before noon. Once I was informed of the interview date and time, Emily was no longer involved with the participants. I interviewed all participants in their rooms. Once I finished the interview, I reviewed their medical chart for the admission date and diagnosis, co-morbidities and functional status (i.e., if they walk independently, or use a walking aid). Each participant was assigned a study code so that no medical information could be related to a specific participant.

To recruit the physiotherapist participants, I discussed my project with Anna who agreed to be interviewed. I later met Lili, Anna’s physiotherapy student for seven weeks, who also agreed to be interviewed. A date and time for these interviews was determined through Anna. Both were interviewed in the ward stock room.

Participants and their Interview Location

Heidi: Qu’est-ce que tu voudrais savoir, disons c’est la première fois que tu vois le médecin, ou t’est pas trop sûre c’est qui le	*Heidi: What would like to know, let’s say if it was the first time you saw the doctor, or you’re not too sure who the doctor is.*

médecin. Qu’est-ce que tu ferais en premier?	*What would you do first?*
Lili: Ben…euh…	*Lili: Well…euh…*
Heidi: Pour finalement prendre plus de charge?	*Heidi: To take more control?*
Lili: Ça c’est une bonne question [un préposé de l’étage entre dans la pièce pour chercher un item de chambre, Lili arrête de parler]… prendre plus de charge sur ma santé?	*Lili: That is a good question [an orderly from the ward enters the room to get an item for a room, Lili stops talking]…take more control over my health? (Lili, 25y, 07/30/2010)*

Jean, Marco, Mary, and Marie-Ange are the four patient participants who agreed to meet me. All were admitted to the internal medicine ward of the academic hospital for various medical conditions. Lili and Anna are the two physiotherapy participants who agreed to meet me. All names are pseudonyms. In this utterance, Lili is about to answer my question when the interview is interrupted by someone entering the room. With no available conference or closed room, we met in the storage room of the ward. On two occasions during our conversation, someone entered the room for items. With the reality of busy wards, I found it difficult to obtain complete privacy when I met with all the participants.

I initially used the following criteria for including patients in this inquiry: English or French-speaking, over 65 years of age, admitted to the internal medicine ward of the academic hospital, no apparent cognitive disorders or aphasia. I excluded patients who were below 65 years of age, spoke another language than English or French, were aphasic, or were disoriented in time and space. I selected these criteria in order to meet with patients who wished to express and share their perspectives about being a patient on an internal medicine ward. Physiotherapists were included if they were presently treating patients on this ward, or had done so in the past.

Table 2

Information on Participants, Hospital Admission, Discharge and Interview Dates

Name	Age	Sex	Language	Admission date[a]	Discharge date[a]	First interview	Second interview
Jean	72	M	French	06/12/2010	06/25/2010	06/17/2010	09/06/2010
Marco	79	M	English	06/10/2010	06/25/2010	06/24/2010	
Mary	72	F	English	06/16/2010	07/05/2010	06/30/2010	
Marie-Ange	65	F	French	07/20/2010	07/28/2010	09/03/2010	10/14/2010
Lili	25	F	French			07/30/2010	
Anna	26	F	English			08/06/2010	

[a] To/From this internal medicine ward.

Jean.

Jean is a 72-year old, French-speaking, man. When I met him, his wife had just exited the room, his nurse was tending to him, and a family member was sitting in a chair in the corner of the room, next to the window. Jean was admitted due to an esophageal stenosis, a narrowing of his esophagus, and remained on the ward for a total of 17 days. Figure 1 shows the arrangement of his private room as he was in full isolation at the time I met him. From the doorway, the bathroom was on the right and a hamper for the isolation gowns was on the left. Jean was lying in bed with an intravenous pole at his side to hold his nasal feeding bag. During the interview, I stood to Jean's left wearing a gown, gloves, and a mask. His guest was using the chair and due to isolation contact protocols, I was unable to exit the room to obtain another chair.

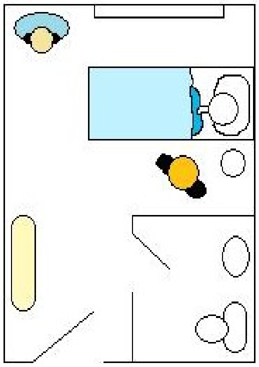

Figure 1. Jean's private hospital room. This figure illustrates Jean lying in bed, while I stood to his left.

Marco.

Marco is a 79-year old, English-speaking man. When I met him, he was lying in bed with his wife at his side. Marco was admitted for calciphylaxis, vascular calcification and skin necrosis. He spent 14 days on the ward before going home with his wife. Figure 2 shows the arrangement of his shared room during the interview. Two other patients shared his room and one of them had a visitor. One bed was unoccupied. The yellow curtains used for privacy were drawn. Marco's were open. The room had one bathroom at the right of the door, and one free-standing sink at the end of the room between two windows. Marco's bed was in the back right corner of the room. His wife sat to his left during the interview.

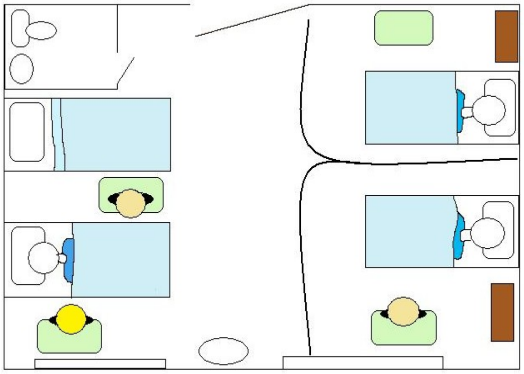

Figure 2. Marco's shared hospital room. This figure illustrates Marco lying in bed, while I sat to his right.

Mary.

Mary is a 72-year old, English-speaking, lady. She remained on the ward for 14 days due to iron deficiency anaemia, and was transferred to another ward one week after our interview for further investigation about a possible colon cancer. Figure 3 shows her shared room during the interview. Two other patients shared her room and one of them had a visitor. One bed was unoccupied. The yellow curtains used for privacy were drawn. Mary's were open. The layout of the room is identical to that of Marco's, but Mary's bed was the first one on the right. Mary was already sitting in a high-backed chair when I arrived, and I sat in a similar chair in front of her. Her bedside table was used to hold her dinner and the audio-recorder.

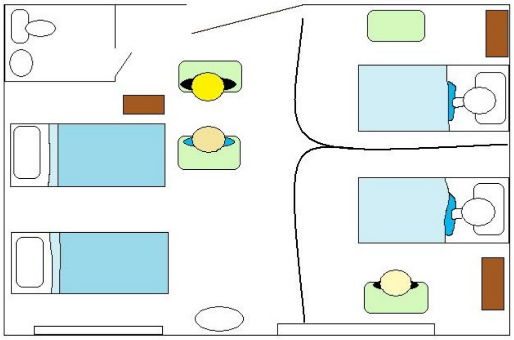

Figure 3. Mary's shared hospital room. This figure illustrates Mary and me facing each other in chairs.

Marie-Ange.

I did not meet Marie-Anne in the same way as I met the other participants. Through Dr. J, I contacted Marie-Ange by telephone after her discharge from the ward. She had remained on the ward for eight days due to a diagnosis of Churg Strauss Syndrome. This is "a rare systemic autoimmune disease characterized by inflammation of small to medium-sized arteries, arterioles and venules" (Churg Strauss Syndrome Association, 2003). Its cause is unknown; it is neither contagious nor hereditary; affects 1 in 100 000 people; and has no cure (Churg Strauss Syndrome Association, 2003). Although I did not observe Marie-Ange's room, she makes reference to a room shared with two other patients, which would resemble the rooms Marco and Mary had during their hospital stay on the ward.

Il s'est rapidement dégagé une dynamique d'entraide entre les trois patients de notre chambre…	*A dynamic of mutual aid was quickly developed between the three people in our room...* *(Marie-Ange, 65y, Int 1, 09/03/2010)*

Lili and Anna.

Lili and Anna are the physiotherapy participants. Lili is a bilingual physiotherapy student who started her studies at McGill University in 2007. At the time of the interview she was at the end of the first year of her Master's in physiotherapy. I met her one week before the end of her placement with Anna, on this internal medicine ward. Anna is a bilingual physiotherapist. She has been a physiotherapist for a total of four and a half years. She worked as a "float" (i.e., not assigned to one ward) for this academic hospital for two years, and has been permanent on this ward for six months. She did her Bachelor's in physiotherapy right after CEGEP, and has a special interest in geriatrics and interdisciplinary care. Both interviews were done in the physiotherapy and occupational gym, which is used mainly as storage for unused or broken hospital equipment. Figure 4 depicts the storage room. It contains a Bobath bed (low and large rectangular bed) for therapy, broken lounge chairs, numerous intravenous poles, two unused hospital beds, many bedside tables and unused hamper baskets. It has one bathroom and one free-standing sink between two windows, similar to the other shared functional rooms. For the interview, I brought in two lounge chairs from the resting area of the hallway. I placed a clothing hamper basket between us to hold the audio-recorder.

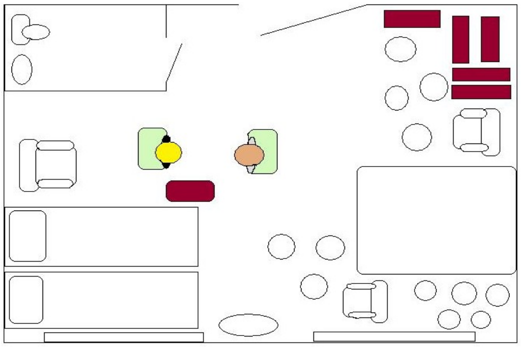

Figure 4. Lili and Anna's interview location. This figure illustrates Lili, or Anna, and me sitting in chairs.

All patient participants were exposed to the phenomenon of being a patient, as described in Chapter 1 and 2. In other words, they were exposed to various health care professionals who depicted a successful, or lack of, patient-centered care during the course of their hospital stay. They also experienced instances of dialogue with health care professionals where they were prompted to use their own various voices, and communicate with the many voices of the professionals, as described in the Methodology section of this Chapter.

Data Collection and Tools of Inquiry

I spent three months on the internal medicine ward of this academic hospital collecting data from various sources. Here I present my three data sources which include: 1) interviews, 2) observation notes, and 3) documents, as well as my tools of inquiry.

From interviewing to conversations.

My social interactions with patients shifted from interviews to engaging conversations after I realized that interviews were slightly confining to capture patient voices. In my conversations I aimed to "bring into focus the uniqueness of each person" and be respectful of what they "endured" during the course of their hospital stay (Kitwood, 1997, p. 135). Specifically in the first part of the conversation, I focused on questions that encouraged the patients to reflect on their personal hospital experiences, such as: "Can you describe to me your hospital admission?" or "Were there people, events, or situations that challenged (or impacted) you during your hospital stay?" In the second part of the conversation I asked participants more complicated questions, such as: "Now that you are about to go home, what would you have liked to know at the start of your hospital stay?" or "What would you recommend to future patients who are about to be admitted to hospital, to help them?" or "How would you describe 'being a patient'?" However, the more I really listened to what the patients said, more questions emerged during the interview, based on what they wanted to talk about. When possible, I met the participants within seven days prior to their hospital discharge. We engaged in a conversation which lasted approximately 35-60 minutes, in their hospital room. If a participant was in a shared room, the conversation was continued with as much privacy and discretion as possible. The reality in hospitals is that three to four people share a room, which constrains their freedom of expression, knowing that their room-mates may be listening.

At Marie-Ange's request, I sent her my questions in French, via email. These questions resembled the ones in English, but were more detailed, with follow-up questions to cue her into developing her answers. For example, "Pouvez-vous me décrire comment vous avez vécu votre séjour à l'hôpital (i.e.: vos impressions, vos relations avec le personnel, relations avec les autres patients, vos impressions du travail de l'équipe)?"

In my conversations with Anna and Lili, I first focused on understanding the dynamics of the ward and in rounds, and in the second part of the conversation I asked them to reflect on what they recommend to future hospitalized patients, and to describe some of their patients' hospital experiences. We engaged in a conversation which lasted approximately 60 minutes.

In total, I collected interview data from six participants: four patients, one physiotherapist, and one physiotherapy student.

My interview style.

I began my interviews with a rather perfunctory and direct style, but had to switch to more open-ended questions and conversations to really capture what the participants needed to express and talk about. For example, I began my interview with Mary with a more direct style:

> *Heidi: Could you tell me a little bit about why you're here in the hospital?*
>
> *Mary: Because my general practitioner sends me every couple months because I'm a diabetic, for bloods tests and she suddenly discovered, within a matter of weeks that my haemoglobin went from 124 to 72. And she sent me in here with papers to have me tested. To see what was happening because I wasn't bleeding anywhere. So, that's why I came in.*
>
> *Heidi: And did you find out why?*
>
> *Mary: Uh huh, they, they discovered that I have colon cancer, some colon cancer, not a lot they said, but some.*
>
> *Heidi: And did you just find out today?*
>
> *Mary: No, I found out, what is today? Tuesday, Thursday I think it was.*
>
> *Heidi: And is Thursday the day that you were admitted?*
>
> *Mary: No, I've been here for 14 days.*
>
> *Heidi: On 6 medicine, or...*
>
> *Mary: On 6, well I was down stairs in emergency, and then they sent me up here.*
>
> *Heidi: Ok. Quite a while!*
>
> *Mary: Yep, and they did a lot of tests. (Mary, 72yd, 06/30/2010)*

As the conversation progressed, I switched to a more conversational style:

Heidi: So if someone, say, was coming into the hospital, so if you can think back to your experience with your admissions, what would you recommend to these people? If you knew them before they were about to be admitted...to help them.

Mary: (long pause) I really don't know 'cause I think it's different for each person, you know, everybody comes in, it's it's different. Ah, you're coming in you have no idea what is gonna happen...(louder) just, just, just, treat the people with respect, like, uhm, don't rush them, like don't hurry them, to do things, you know...

Heidi: You mean, you mean the patient hurry or the health professional?

Mary: The health professional... (Mary, 72y, 06/30/2010)

Everyone's conversational style is unique. Mine is largely influenced by my experience as a physiotherapist and by patients I have met in my career. My style was also influenced by the whether the room was private or shared, who was present in the room, and whether I was sitting or standing. Questions also varied, depending on my background knowledge of the patients' medical care, which I obtained during rounds. In all conversations with the participants I attempted to create conversational spaces in which they feel they could express and voice their meanings of being a patient.

Observations.

My descriptive field notes included "detailed accounts of [my] initial impressions, key events and incidents observed in the setting along with [my] personal reactions, what people in the setting treat as especially important, and any unusual happenings that depart from the routing and ordinary" (Emerson, Fretz, & Shaw, 1995, p. 229). My field notes also included the dynamics of the health care professionals on the ward and in rounds. I used the rounds field notes to better understand the ward field notes and then the overall patient interviews. I wrote reflective notes before and after each conversation with the participants noting the resonating ethos, patient behaviours and their disposition, the hospital room.

Cordella (2004) explains: “[T]he performance realized in a micro setting is unlikely to be independent of socio-cultural relationships at the macro level. For example, the exercise of power is not necessarily peculiar to the medical consultation, but may be representative of an asymmetrical interaction in discourses of other social contexts as well” (Cordella, 2004, p. 6). In other words, the micro-dynamics of rounds is unlikely to be independent of the macro-dynamics of the health care professionals who are on the ward. The micro and macro-dynamics of the team may then affect the interactions with the patients, and the patients’ satisfaction with their hospital stay and the professionals who tended to them. For example, the discussions that were held during rounds about the participant Marco are the perfect example of how the micro-dynamics’ can influence the patients.

> Rounds field notes, June 23rd, 2010:
>
> Today, the case of a particular patient was discussed longer than usual. A 20-minute heated discussion was held between the senior resident, the head nurse, and the social worker around a patient to whom a very expensive treatment for his lower leg necrosis was being administered. This particular medication is not part of the free drug plan; therefore special approval was required from the hospital. The social worker was very involved because the patient can receive the treatment as an outpatient three times a week. This conversation was particularly long because the patient had no method of getting to the hospital. Obtaining assisted transportation takes about three weeks and they could not keep the patient in hospital in the meantime. The social worker said that the patient was being “cheap” and didn’t want to pay for a taxi. She said she could say that, since she was of the same [Greek] culture as the patient.

Interview with Marco, June 24th, 2010:

Marco: …Uhm, they trying a new medication. Also they try newer medication and I have to continuously do that every other day three times a week.

Heidi: Do you know how long this is going to take?

Marco: I have this problem since January. And they told me it's a long processing, maybe take 6 months. But I have to follow the treatment […] Even I had a little bit discussion today, last week they gave me the option about this new medication. Its new medication and I don't know what it does. Doesn't seems to be any guarantees but they said it's a good meds and I will do better. I accept it. In the meantime, it was bothering my transport, it's not easy for me to access transport three times a week, and they told me they would take care of it. They would take care of the cleaning, take care of the transport. All of a sudden they said today, they cannot provide the transport […] I was quite upset. And they tell me, yes, I can go home, but come back three times a week.

The discourse between the health professionals about his expensive treatment occurred on two separate occasions in rounds. Alone, the rounds field notes depict Marco as difficult and "non-compliant" patient. From the transcript from the interview, it appears that Marco is more unaware and does not understand much about the expensive medication the medical team is trying so hard to get him to use. This example illustrates how I use the rounds field notes to understand the context of the conversation I had with Marco. These notes also help me understand the full circle of patient care and how health care professionals have an impact on a patient's stay. They also enable me to understand my participants' comments about health care professionals who are perhaps more brisk in their care, and whom I have noticed to be more derogatory towards patients during rounds.

Documents.

Documents such as charts or written records were another source of data and tools of qualitative inquiry that I used. After each conversation, I reviewed the patients' medical chart for information on their admission date and diagnosis, co-morbidities, function, date of birth, discharge location and phone number, if they agreed for a second interview. I collected this information from the medical charts to understand more about what their experience was like during their stay on the ward, and for demographic purposes. I obtained the discharge date through the ward clerk after the patient was discharged.

Study Number:	104
Gender/Language:	Male, English
Date of birth:	03/14/1931
Admission Date:	To ER on 06/07/2010. To internal medicine on 06/10/2010
Diagnosis:	Calciphylaxisis.
Discharge Date:	06/25/2010 Location: Home with wife
Co-morbidities:	CAD, CHF, GI polyps, HTN, incr chole, Afib, asthma, BPH, GI bleed in 2007, cholecystectomy.
Function:	4ww in room. Pt says he is at his normal strength but was always limited 2 to his heart problems.

Figure 5. Data Collection Form. This figure illustrates the data that I extracted from the participant's medical chart.

Noteworthy are the abbreviations and short sentence which reflect the way the medical written language reflects a patient's medical history.

Ethics and Ethical Issues

Patients knew that I was a graduate student from McGill University and a physiotherapist not employed by this academic hospital. It was made clear that the risk involved in this study was solely the use of their valuable time and that they would receive the same standard care and treatment considered best for them, irrespective of their participation in the study. Although the risks are minimal, Dr. Jeffrey Wiseman or a head nurse would be present on the ward during the time I met with the patients as a safety monitoring plan, should any complications arise during the course of the interviews.

To maintain patient confidentiality, the patient's name was never mentioned during the recordings, nor did it appear on paper documents that exited the hospital. The patient was given a numerical study code (e.g., V103) as soon as the interview was scheduled. The patient's phone number was noted only if he or she agreed to participate in the second interview. All demographic data were transcribed into a password-protected Microsoft Word document. I am the only person to know the password to these documents. All paper documents were shredded once they were transcribed.

Chapter Summary

In this inquiry, I aim to create a better understanding of the meaning of "being a patient", more specifically in patients over 65 years of age admitted to the internal medicine ward of an academic hospital. In this chapter I explained my methodology and epistemological stance, my data collection process and tools of inquiry. Chapter 4 will discuss the thematic understandings I draw from my conversations with three of the four participants.

Chapter 4. Thematic Understandings of the Diverse Meanings of "Being a Patient": Patients' Voices

> *Un patient – celui qui reçoit des soins. De façon subjective – Une personne impatiente en détresse qui doit être en bonne santé pour se mouler à toutes les contraintes et agressions du système hospitalier et en sortir guérie de maux qui l'affligent et l'inquiète!!!*

> *A patient – the one who receives care. Subjectively – An impatient person in distress who needs to be in good health to mould to all the constraints and aggressions of the hospital system and to exit healed of the pains that afflict and worry them!!! (Marie-Ange, 65y, Int 1, 09/03/2010)*

Marie-Ange describes a patient as "an impatient person in distress" who needs to be in good health to mould to the many constraints and aggressions of the hospital system. She alludes to the challenges a person faces in meeting the physical and systemic "aggressions" of the health care system and to a patient's desire to exit a hospital completely healed of their pains. Although she alludes to harsh systemic issues, Marie-Ange was still impressed with the "philosophy" of care she received on the ward.

In this chapter, I present three of the four participants' reflections about their lived experiences as patients on this internal medicine ward. I present their voices in key moments in which they describe personal instances that impacted them as patients, either positively or negatively. I begin each section by presenting an utterance by each individual, Jean, Marco and Mary. The utterances I present in this chapter capture what these participants express as their meanings of "being a patient", and reflect their voices as a "speaking personality" (Maguire & Graves, 2001, p. 564). The participant Marie-Ange will be discussed separately in Chapter 5.

Jean: "I Was Very Well Received, Well Served"

Heidi: Pouvez-vous me décrire votre admission ici à l'hôpital?	*Heidi: Could you describe to me your admission at the hospital here?*
Jean: Oui ben mon admission à l'hôpital ici a été très bien. Je suis entré à l'urgence…j'ai été très bien reçu, très bien servis là bas pendent le temps que j'étais…	*Jean: Yes well my admission to the hospital here went very well. I went to the emergency…I was very well received there, very well served in the time that I was there… (Jean, 72y, Int 1, 09/06/2010)*

This excerpt emerged from my second interview with 72 year-old Jean on the ward. Jean went to the hospital because of an increasing difficulty in swallowing. Here, he talks about his admission process through the emergency room and alludes to the ways in which he was "received" by the health care professionals working there. This theme of "being served and received" captures his instrumental view of the meaning of being a patient.

Jean was diagnosed with an oesophageal stenosis, that is his oesophagus is constricted, which explains his difficulty swallowing. He has also been managing a past medical history of non-Hodgkin's lymphoma (NHL) and diffuse large-B cell lymphoma (DLBCL), rheumatoid arthritis (RA), and chronic migraines for the past 25 years. When I first met Jean, he appeared calm and comfortable lying in bed in a hospital gown. He had a nasal feeding tube in place, a tube that goes through the nose to the stomach to feed the person with a nutrient-rich liquid. He kindly welcomed me into his private hospital room. Patients are usually placed in private rooms when they may contaminate other patients, or have very weak immune systems. Jean had to remain in full isolation for a few days due to a bacterial contamination from another patient, a systemic occurrence frequently reported in hospitals. A full isolation room means that all people entering the room need to wear a mask, gloves, and a long yellow gown with long sleeves that are tight at the wrist. Before exiting the room, the gloves and mask must be thrown away in the garbage and the gown must be placed in a special hamper for cleaning. The person must then immediately wash his or her hands and leave the room. Talking with Jean at this time and in this isolation room presented conversational challenges in establishing a rapport in an already uncomfortable health care setting.

My first interview with Jean was very short. Within eight minutes, I asked him my questions, awkwardly standing next to his bed in a mask and gown, with the audio-recorder in a rubber glove to avoid contact contamination. I was nervous. I felt like a health care professional standing at his bedside asking him quick medical questions. I felt pressure as a researcher trying to lead a patient-centered interview. I quickly jumped from one question to the next, unconsciously ignoring key issues he had just raised, as indicated in the next excerpt:

Jean: J'étais sceptique oui, j'étais sceptique à partir du jour ou j'ai passé une endoscopie. À partir là. [Heidi: Uh hum.] Aujourd'hui je ne suis plus sceptique.	*Jean: I was sceptical, yes, I was sceptical from the day I had an endoscopy. It started there. [Heidi: Uh hum]. Today I am no longer sceptical.*
Heidi: Excellent, donc qu'est ce que vous auriez à suggérer à autres patients, comme vous, qui sont admis à l'hôpital?	*Heidi: Great, so what would you suggest to other patients who, like you, are admitted to the hospital? (J, 72y, Int 1, 06/17/2010)*

In retrospect I now realize that, by asking Jean closed-ended questions at a rapid pace, I was not attempting to create a conversation with Jean in order to understand his voice. I should have asked him more about his feelings of being sceptical and why the endoscopy made him no longer feel sceptical. Being used to short "medical interviews", Jean cued into my rapid questions immediately and kept his answers short. In mid-interview, he asked me:

Parce que moi ça faisait dix jours que je ne mangeais plus. Et qu'est ce que vous voulez savoir d'avantage?	*Because me it had been ten days that I wasn't eating anymore. And what else do you want to know? (J, 72y, Int 1, 06/17/2010)*

His question led me to my own reflective questions. Was he attempting to place me back on track so that I was not using any more of his time? Was he making sure that I had completed everything I needed for my project? But one question that stands out, considering the quick pace of this interview, was whether he answered the questions just to satisfy my needs? Jean's question brings me back to my time as a clinician and makes me wonder how many of my patients may have been telling me what I needed to know, intentionally limiting their answers? In eight minutes, I accomplished what I needed to know physiologically. However in retrospect, I did not give Jean, or even my patients, enough time to express their voices and concerns. How could eight minutes even begin to fulfill all their needs? Jean's succinct responses to my questions are accentuated by the last comment he made in the first interview. I asked if he wanted to add anything else before the end of the interview, and he replied:

Moi, je ne vais pas chercher les choses. Pas dire des imbéciles pour rien. J'ai dis tout ce que j'avais à dire, tout ce que c'était vrai, c'est tout.	*Myself, I don't create things. I don't say silly things for nothing. I said everything I had to say, all that was true, that's it. (J, 72y, Int 1, 06/17/2010)*

This comment provides some insight about how patients, like Jean, may respond or think they need to respond in health care contexts when speaking to health care professionals. Is this his preferred way of interacting? Or do his previous experiences interacting with health care professionals make him think he needs so keep his answers short? Cordella (2004) argues that a patient like Jean might prefer speaking with a *Health-related Storytelling* voice. A *Health-*

related Storytelling voice corresponds closely to the close-ended questions of the *Doctor* voice, where direct questions are posed for assessment and diagnostic purposes and succinct answers follow. To answer, patients use the “past tense for the event(s) being described by a comparison of [his] past and present states of being” (Cordella, 2004, p. 154). *Health-related Storytelling* voice also relates to patients who “present themselves...as people who seek assistance for a personal problem they lack the expertise to manage on their own” (Cordella, 2004, p. 154).

Before I contacted Jean for the second interview, I had reviewed the first transcript and I realized my numerous “mistakes in interacting” with this participant. I contacted Jean on a Monday morning. He was at home with his wife and remembered our conversation from his time in hospital. Immediately, he began retelling me about his experience as a patient, even before I even had the chance to turn the audio-recorder on. It was only after I spoke to him a second time, and as a result of how he recalled his hospital stay in retrospect, that I could understand the meanings of his utterances in that first interview. These interviews reflect the recursive nature of interviewing in a research context and how health care professionals may better understand the meanings of their patients’ utterances, which may not always be apparent on the first encounter. To critically reflect on my own conversational role in the interviews, I thus worked recursively with Jean’s first and second interview simultaneously to better understand his answers and experience of “being a patient”. In this process, I also purposely identified questions I should have asked.

Being well served and well received.

At the end of the first interview, I understood that Jean had a positive hospital stay and felt satisfied towards with the care he received. He appeared to pay close attention to the hospital service from the first day he presents himself at the emergency room. In the first minute of the first interview, when I ask him to explain his admission process, he immediately connects my question to the metaphor of service and being well received.

Heidi: Pouvez-vous me décrire votre admission ici à l'hôpital?	*Heidi: Could you describe to me your admission at the hospital here?*
Jean: Oui ben mon admission à l'hôpital ici a été très bien. Je suis entré à l'urgence…j'ai été très bien reçu, très bien servis là bas pendent le temps que j'étais…	*Jean: Yes well my admission to the hospital here went very well. I went to the emergency…I was very well received there, well served while I was there… (J, 72y, Int 1, 06/17/2010)*

He describes his admission process to emergency room as a positive experience. Frequently when patients reflect back on their admission process they may describe many challenges such as waiting for a bed, waiting for care, or waiting to see a doctor in the emergency room. Perhaps the triage nurse recognized the seriousness of his problem and admitted him immediately. In the larger discourse of patient-centered care, I wonder how patients expect to be treated when they present themselves in emergency. Why do some people worry they will not receive "service" in emergency? Is the media, rightly or wrongly, exposing the emergency room as a place that warrants fear?

Only after the second interview when Jean makes frequent referrals to a person's "desire" to seek medical attention, did I realize the "service" metaphor in his perception of "being a patient". This was a turning point in my interpretation of Jean's utterances. It made me realize how he believes people consciously choose to go to the hospital to receive a specialized service.

…et qu'on aller à l'hôpital pour ce faire soigner…c'est un désire que nous avons et tout le personnel de l'hôpital s'engage à	*…and when we go to the hospital to get treated…it's a desire we have and all of the hospital personnel pledges to help us,*

nous aider, pour nous soulager et nous aider.	*to make us better and to help us. (J, 72y, Int 2, 09/06/2010)*

Jean appears to be speaking on behalf of other patients describing how going to the hospital is a desire "they" have to get treated for medical attention, not pleasure. Not only is getting treatment a conscious decision for him, but he has such confidence in the hospital personnel, stating how they "pledge" to make him better. In a way, Jean is right. Upon graduation, all health care professionals do take an oath towards the population to do just that: to help. Jean is fully prepared to allow the medical team to treat him the best way they know how because he trusts them. In the larger discourse of patient-centered care, health care professionals need to be cognizant that it is their duty to help people. In the busyness of a hospital day, it can be easily forgotten that health professionals are there to serve the people. Jean's trust in the health care team may be because he is experienced as a patient and had satisfying experiences in the past. Although he refers to patients in general, not all patients trust the hospital system like he does. Some people may become defensive and demanding when they enter the hospital in order to assure that they, or their family member, receive proper care or "service".

Leitmotifs of "being well served and received" are also reflected in the way Jean did not appear to be concerned by the numerous health care professionals who entered his room and the questions they posed. Actually, the more questions that were asked, the better cared for he felt.

Les gens ici se sont bien occupés des patients. On venait toujours me poser des questions de ceci et de cela.	*The people here care well for the patients. They would always come ask me questions about this or that. (J, 72y, Int 1, 06/17/2010)*

The fact that he is being asked many questions, to him, means that the health care team is fulfilling their role and caring for patients. He apparently did not mind the type of questions either as he refers to them as *"about this or that"*. Nor does he seem to mind the number of health care professionals he might have seen during his stay. Here, I should have asked him what the health care team did to make him feel "well" cared for. As just another person seeing him in his hospital room and asking him many questions, I might have resembled any other health care professional who was tending to his care. This possible inference is connected to this excerpt from his second interview.

Heidi: Est-ce que vous avez reçu assez d'information? Donc est-ce que quelqu'un, s'est assis avec vous pour vous expliquer ce qui ce passait?	*Heidi: Did you receive enough information? So did someone sit with you and explain what was happening?*
Jean: Euh…non…je ne me souviens pas. Sincèrement je ne me souviens pas, mais…[Demande à sa femme: Madame me demande si à l'hôpital on m'a donné assez d'information concernant mon œsophage, ce que j'avais, euh]. Je sais pas mais je demande si j'ai quelques choses dans l'œsophage, peut-être que vous le savez, non? Est-ce que j'ai quelques choses dans l'œsophage? Savez-vous si j'ai quelques choses de mauvais de désagréable dans l'œsophage? Parce que je ne sais pas si on me l'a dit, je ne me souviens pas.	*Jean: Euh...no...I don't remember. Sincerely I don't remember, but...[Asks his wife: The lady is asking me if I was given enough information about my oesophagus in the hospital, what I had, euh]. I don't know but I am wondering if I have something in my oesophagus, maybe you know, no? Do I have something in my oesophagus? Do you know if I have something bad something unpleasant in my oesophagus? Because I don't know if someone told me, I don't remember.*
	(J, 72y, Int 2, 09/06/2010)

Jean points out that the myriad types of health care professionals who enter a patient's room may all resemble each other from a patient's perspective. Jean knew that I was a student and a physiotherapist, but by my interviewing him in his room and then calling him at home, he might not have differentiated me from any other professional. In his mind, I could be calling because I spoke to his doctor and read his medical chart. Jean's awareness that I was merely a student surfaced within three minutes after the interview began. Thus for part of the interview he might have thought I was working for the hospital. He was freely divulging all his medical information to me over the phone because he remembered me, but in reality my role may have been obscure to him. Unfortunately, patients may easily fall victims to false treatments or place themselves in danger with those they perceive to be "health care professionals" and whom they thus trust because of appearances, when in reality these people have no medical training. Jean was fortunate that he was divulging his information to me and not a stranger. This willingness to be helped reflects how trusting Jean is of the medical system and medical team. This also reinforces the crucial importance of clear introductions of roles and names when a health care professional enters the patient's room. In Jean's case, he was not concerned by who visited him, but in this excerpt he goes through a small moment of panic when he wonders if he has something "unpleasant" that he might not have known before, or could not remember if he had been told about. Although in the rest of the discussion he tells me that he is receiving treatment to open his oesophagus and that he understands his care, it is apparent here that Jean may not understand his treatment plan as much as he thought he did.

Despite his apparent acceptance and willingness to be cared for, Jean still describes himself as once being very sceptical and suspicious about his medical condition. These feelings quickly dissipate when he receives the official diagnosis for his swallowing problem.

Heidi: Et qu'est-ce qui vous a aidé le plus?	*Heidi: What helped you the most?*

> *Jean : Ce qui m'a aidé? Au début moi j'étais très sceptique concernant ma maladie pourtant euh, tout en étant sceptique je suis méfiant…*
>
> *Heidi: Uh hum.*
>
> *Jean : …méfiant concernant ma maladie, ici. Parce que j'ai passé (endoscopie). Aujourd'hui tout ça c'est partit parce que je n'ai rien d'après ce que je sais sur toutes les tests qui ont été fait, tout à bien marché, tout a bien, a bien réussit. Alors, question de services, comme je vous ai dit, tout a été fait très bien. Pas question de quoi, de quoi que ce soit.*

> *Jean: What helped me? At first I was very sceptical concerning my disease yet, euh, while being sceptical I am suspicious...*
>
> *Heidi: Uh hum.*
>
> *Jean: ...suspicious about my disease, here. Because I passed (endoscopy). Today all that is gone because I have nothing based on what I know from the tests that were done, everything worked, was a good, a good success. So, question of service, like I said, everything was done very well. No worry about anything. (J, 72y, Int 1, 06/17/2010)*

Noteworthy here is that Jean is used to managing his illnesses, which might explain why he waited ten days before going to the hospital. With the support of his wife, he might have attempted to puree his food, or restrict himself to liquid in order to manage this new illness on his own. This scepticism and suspiciousness, one could infer, was because he tried to manage on his own and failed. He tried to assume some sense of personal control over his illnesses. However, the fact that he waited so long demonstrates that he might be unaware of the signs that make a medical problems life threatening. Perhaps he did not want to wait in the emergency room for a problem he thought would go away on its own. Quebec's busy emergency rooms with wait times of over twelve hours are frequently discussed in the media. I clarified with Jean whether he was sceptical about his medical condition or the hospital, because patients often express frustrations about the available services within the province of Quebec. Especially accentuated by the media, public discourses frequently highlight the lack of medical professionals in all spectrums of care, the lack of nurses, and the lengthy wait times in the emergency rooms. He was only sceptical about his illness.

After the endoscopy, he states that *"Today, all that is gone"*. The endoscopy appeared to be a defining moments in his stay as a patient. However, his comment of *"based on what I know"* could mean a lot, or very little, depending on how much the person receiving the information wants to know. There is a possibility that his diagnosis was actually described to him, but he forgot. There is also a possibility that he may have been given very little information, but he did not feel like he needed to know more. Knowing that everything was being taken care of might have been enough information for him. However, when relating his comment "*everything worked, was a good, a good success*" to the previous utterance, it is more evident that he did not understand his diagnosis. He spent thirteen days in hospital and was still receiving treatments three months after his discharge; I wonder how everything was such a "good success". Still, he is satisfied that everything was well taken care of. Based on his trust in the hospital, he might not be the type of patient who requires much information to be satisfied and feel confident in the care received in the first place.

The last instance reinforcing Jean's overall satisfaction with his hospital service appears to be connected to the medical team who addressed more than just his swallowing problem. Jean's modesty towards his experience as a patient is interesting to explore. He states: *"…et aussi on m'enlevé la douleur que j'avais à ma poitrine…Ça valu beaucoup la peine" ("…and they also got rid of the pain that I was having in my chest…it was really worth it"; J, 72y, Int 2, 09/06/2010).* He chose to go to the hospital for one problem among the many that he had, and expected only that problem to be treated. Jean had goals and the medical team unknowingly met those goals and exceeded them by addressing other illnesses that were also affecting his health. Although treating the reason for the hospital admission is obvious, some patients may have other goals for their hospital stay. If the goals are not met, patients may not, therefore, be satisfied with their care. This makes me wonder how patients establish their goals, or whether they may have unrealistic goals. What do patients expect from the medical team? What do they expect from the doctor and the rest of the health care team? What do they expect from the overall hospital stay? Do they expect a private room? How long do they expect to be in hospital for? The hidden truth about being in the hospital is that a patient will remain in hospital no longer than they need to and may go home before they feel completely better. A patient may not know this unless they are explicitly told. Does this relate to their hospital satisfaction? What makes the hospital "worth it"? One might wrestle with the issue of what are reasonable expectations for patient in a patient-centered care model and within the realities of the Quebec health system.

Being a patient "is not enjoyable".

Notwithstanding his satisfaction with the service he received during his hospital stay, Jean admits that being a patient is not enjoyable.

Heidi: Quand je vous avais rencontre, je vous avais demandé votre définition d'être un patient. Maintenant que vous avez du recul, est-ce que vous pourriez me décrire c'est quoi être un patient?	*Heidi: When I met you, I had asked you your definition of being a patient. Now with some reflection, would you be able to tell me what it is like being a patient?*
Jean: Être un patient, ce n'est pas agréable être un patient. Il fallait mieux qu'on ne le soit pas. Ni moi ni personne. Ça serait un bon signe. […] Mais…le sentiment d'être	*Jean: Being a patient, it is not enjoyable being a patient. It's better not to be. Not me not anyone. That would be a good sign. [...] But...the feeling of being a patient is not good. Because no one likes being*

un patient n'est pas bon. Parce que personne aime être malade…	*sick... (J, 72y, Int 2, 09/06/2010)*

I am not sure if Jean answers this question based on his admission to the ward or on other perspectives as a patient, but he is definitely speaking from experience. The way he describes being a patient as "not enjoyable" may seem evident, but the use "joy" speaks loudly about the sacrifices that patients must make when they become patients, such putting their life, their activities and everything that brought them joy on hold to tend to the afflictions that are bothering them. Jean's says it best, that no one likes being sick and that no one chooses to be sick. How can health care professionals help patients through a time in their lives that they do not wish for but must endure? How can care be adapted to ease a hospital stay so that patients are not afflicted by unnecessary worries? He expresses his meaning of being a patient once again just as the second interview ends.

Heidi: Oui. Et c'est (l'entrevue) pour comprendre l'expérience d'être un patient.	*Heidi: Yes. And it's (this interview) is to understand the experience of being a patient.*
Jean: Ah. L'expérience d'être un patient n'est pas toujours beau. Parce que personne n'aime être patient. Vous comprenez? [Heidi: Oui.] Tout le monde aime être en bonne santé. C'est ça la vie. Ce n'est pas toujours facile. Maintenant je me prépare la semaine prochaine pour aller voir mon oncologue. Parce que j'ai un lymphome, et je vais aller voir une autre fois…le…le (inaudible), la dilatation.	*Jean: Ah. The experience of being a patient is not always nice. No one likes being a patient. You understand? [Heidi: Yes.] Everyone likes to be in good health. That is life. It is not always easy. Now I am preparing for next week to go see my oncologist. Because they found a lymphoma and I will go see another time...the...the... (inaudible), the dilatation.*

(J, 72y, Int 2, 09/06/2010)

Jean is the only participant where I adapted the question to ask the *experience* of "being a patient", rather than the *meaning*. Changing the word seemed to help Jean better understand the question. He adds that being a patient is not nice. Why nice? Usually, when someone discusses a situation, they say that it is easy or difficult. Although I did not investigate Jean's culture, referring a situation to "beau" in French or "bueno" in Spanish may mean something different than "nice" in English. Being from a French Canadian culture myself, I know that the most common expression is "Ce n'était (or il n'était) pas très beau à voir". This is meant to say "It (or he or she) was not a sight see. Jean may have been referring to this expression, stating that he was not well and looked very ill, or literally meant that the overall experience is not "nice" or "beautiful". In patient-centered care, this pinpoints the importance of understanding the patients' culture. This also demonstrates how questions need to be adapted for each patient as they may understand some words better than others.

Interestingly, Jean mentions his upcoming medical visit with an oncologist and another to continue dilating his oesophagus. This adds volume to the length time patients remain patients, and how long care is continued after discharge. He was "preparing" for these visits one week in advance. In mentioning beforehand that being a patient is "not always easy", Jean is also describing how much mental and physical energy is needed to be a patient, not only in hospital, but after discharge as well. Here, I could have asked how he prepared for his medical visits and the steps he took to make sure he was ready for his appointment.

Jean was serving as an advocate for other patients by describing his perspective of being a patient and speaking spontaneously on behalf of all patients. I asked him what he would suggest to other patients. In his first interview he states:

Heidi: Qu'est ce que vous auriez à	*Heidi: What would you suggest to other*

suggérer à d’autres patients, comme vous, qui sont admis à l’hôpital?	*patient, like you, who are admitted to the hospital?*
Jean: Qui sont patient comme moi?	*Jean: Who are patients like me?*
Heidi: Oui.	*Heidi: Yes.*
Jean: Qu’ils ne soient pas trop sceptique…	*Jean: That they shouldn’t be so sceptical...*
Heidi: Ok	*Heidi: Ok.*
Jean: Même si je ne l’ai jamais démontré, et qu’il ait du courage et qu’il sache attendre parce que le meilleur jour (inaudible) les meilleurs (inaudible) vont arrivés, non?	*Jean: Even if I never showed it, and that they have courage and that they know to wait because the best days (inaudible) the best (inaudible) are to come, no?*
Heidi: Uh hum. Et si, disons, vous sortez d’ici et vous rencontrez, eu, une personne qui a les mêmes conditions que vous et qui veut vos conseils. Donc en plus du courage et d’être patient, qu’est ce que vous leurs diriez, pour les aider de plus?	*Heidi: Uh hum. So let’s say, you leave here and meet someone who has the same condition as you do and who wants advice. So with being courageous and having patience, what would you tell them to help them more?*
Jean: J’sais pas, euh, tout ce que j’ai parlé est mon expérience ici et assurer la personne que de ne pas s’inquiéter parce que parfois on s’inquiète pour rien et que tout ça va bien marcher. C’est ça.	*Jean: I don’t know, euh, everything I said is my experience here and to reassure the person not to worry because sometimes we worry for nothing and everything works out. That’s it. (J, 72y, Int 1, 06/17/2010)*

In his recommendations to other patients, he mentions again how sceptical he was on his admission. However, here he cautions other patients not to be sceptical like he was. Why did he hide his scepticism? Jean's hospital experience and sceptical feelings reinforce the need for patients to be reassured about their medical diagnosis and kept well informed about their care in order to relieve any evident, or not so evident, anxieties. He recommends other patients not to worry so much and to always keeping sight of better days to come. As described earlier, this reinforces Jean's trust and optimism towards the hospital system and towards life in general. It takes a lot of wisdom and self-assurance to know that even if one cannot swallow for ten days and has had migraines for the past 25 years, the best days are still to come and that everything works out in the end. "That's it!" he affirms. Perhaps his secret ingredient to being a patient is courage, the courage he has demonstrated throughout all of his illnesses, and positivity even after a lengthy hospital stay. He provides additional advice in his second interview:

Heidi: Et autre que l'importance de manger, qu'est-ce que vous recommandiez, disons un ami qui s'en va à l'hôpital. Qu'est-ce que vous lui diriez pour l'encourager?	*Heidi: And other than the importance of eating, what would you recommend, let's say to a friend who was going to the hospital. What would say to encourage him?*
Jean: Qu'est-ce que vous voulez que je dise?	*Jean: What do you want me to say?*
Heidi: Autre que manger.	*Heidi: Other than eating.*
Jean: Autre que manger?	*Jean: Other than eating?*
Heidi: Oui. Des mots d'encouragement.	*Heidi: Yes. Words of encouragement.*
Jean: (expire) Bon…vous savez que, des mots d'encouragement…qu'il soit persistant, qu'il ne perde pas le courage, que le personnel de l'hôpital sont l'a pour	*Jean: (exhales) Well...you know, words of encouragement...that he be persistent, not to lose courage, that the hospital personnel are there to help him and that, the, the best days are to come and that you can't let*

> *l'aider et que les, les, les meilleurs jours vont venir et il ne faut pas se laisser abattre pour ça. C'est que je peux dire à un patient quelconque. Et quoi dire sur le personnel, sur les infirmières, sur tous le personnel de l'hôpital?…Tous sont là pour nous aider.*

> *yourself down for this. That is what I want to say to a patient. And what to say on the personnel, the nurses, all the personnel from the hospital?...All are there to help us. (J, 72y, Int 2, 09/06/2010)*

In relating to his admission diagnosis, he first recommends that other patients should make sure they eat. When I asked how he would encourage future patients other than eating, he seemed at a loss for words. But true to his words three months prior, he repeated what he said in the first interview. He reaffirms that patients should have courage and persistence. He alludes to the time that is needed to heal after a hospital stay and the persistence patients need throughout the healing process. He encourages patients to trust that the hospital personnel will help them. After a positive hospital experience such as his, it might be easier for Jean to advise patients to have so much faith. In patient-centered care, eliciting a rapport of trust and faith between the health care professional and the patient only comes when a patient's voice and utterances are heard and acknowledged. Jean felt listened to and cared for, which might have made it easier for him to advise others to trust in the health care system. As a health care professional, I wonder if individuals I have treated trusted me with their care. What do I do to make sure they feel valued as individuals? How does this relationship affect the care I provide? My favourite quote from Jean is the following: *"the best days are to come and that you can't let yourself down for this."* Such words of wisdom could be related to every aspect of life.

Needing help and support.

The importance of Jean's support system is evident in both interviews. When I met him on the ward, his wife had just left the room and another family member was keeping him company.

> *Euh…non…je ne me souviens pas. Sincèrement je ne me souviens pas, mais… (Demande à sa femme : Madame me demande si à l'hôpital on m'a donné assez d'information concernant mon œsophage, ce que j'avais). […] Ben moi, je ne sais pas, je ne me rappelle pas si on m'a dit ce que j'avais dans l'œsophage, je me souviens pas. Ce que j'étais voir…euh [Sa femme lui dit quelques choses]…ah c'est vrai. J'avais un virus aussi, on m'a donné… [Epouse: Antiviral] antiviral à l'hôpital. Un antiviral liquide, à l'hôpital, pendant longtemps. Et maintenant je continus à prendre cet antiviral à la maison. [Sa femme lui dit quelques choses]. Le médecin il a dit que c'est disparu, mais pour renforcir plus, pour pas que ça revienne, il m'a donné encore un mois de plus avec antiviral.*

> *Euh…no…I don't remember. Really I don't remember, but...(Asks his wife: The lady is asking me if I received enough information about my oesophagus while I was in hospital, what I had). [...] Well me, I don't know, I don't remember if I was told what I had in my oesophagus, I don't remember. What I was going for…euh [His wife says something to him]…oh it's true. I had a virus too, they gave me… [Wife: Antiviral] antiviral at the hospital. A liquid antiviral, in the hospital, for a long time. And now I still take the antiviral at home. [His wife says something to him]. The doctor said it went away, but to make it stronger, so that it doesn't come back, he gave me another month of antiviral. (J, 72y, Int 2, 09/06/2010)*

In the first segment, he relies on his wife to remind him of the information the medical team provided him with while he was in hospital. After his wife reminds him of the virus he developed in hospital and the antibiotics he was taking as a result. On the ward, Jean was physically able to walk and attend to all of his daily cares, but remained there to ensure that he was eating because of the restricting stenosis. After a weekend home, he decided no longer needed the services of the hospital.

Heidi: Est-ce que vous saviez quand vous alliez être, avant de partir de l’hôpital est-ce que quelqu’un vous avait prévu de la date de votre congé?	*Heidi: Did you know that you were going to be, before leaving the hospital did someone warn you about your discharge date?*
Jean: Euh…non. C'est-à-dire, on m’avait donné à la maison passer la fin de semaine [Heidi: Ok] pour essayer. Pour voir si ça allait bien. Je suis venu la fin de semaine à la maison, ça été bien alors…je suis retourné à l’hôpital pour dire que je resterai à la maison. Je voulais rester à la maison. Personne m’a forcé à quitter l’hôpital.	*Jean: Euh...no. That is, I was told that I would be given a weekend pass [Heidi: Ok] to try. To see if it went well. I went home for the weekend and everything went well so...I went back to the hospital to tell them that I would be staying at home. I wanted to stay home. No one forced me to leave the hospital.*
Heidi: Avant de partir est-ce que vous vous sentiez confortable avec tous vos médicaments.	*Heidi: Before leaving, did you feel comfortable with all your medications?*
Jean: Oui, oui. J’avais tout ce qui fallait. J’avais tous mes médicaments, oui.	*Jean: Yes, yes. I had everything I needed. I had all my medications, yes. (J, 72y, Int 2, 09/06/2010)*

What does not surface in this segment is that his wife may have played a key role in her husband's early discharge. In hospital, he was receiving an adapted meal, but at home, his wife was preparing and adapting all of his meals to facilitate swallowing. This no doubt facilitated his decision to remain home under the care of his wife.

I consider this a rapid discharge because he may not have had the time to meet with the medical team before he went home. His oesophagus still restricted: *"And now I eat much better, not...not enough like I wanted to, but better enough" ("Et maintenant je mange beaucoup mieux, pas…pas assez comme je voulais, mais assez mieux"; J, 72y, Int 2, 09/06/2010).* He presented himself at the hospital on Monday morning to let them know he would be staying home, and left that same day. For patient-centered care, this reinforces the importance of involving family members or the patient's support system into the treatment and discharge plan, if possible. When a patient is ill, on medication, and in an uncomfortable situation such as lying in a hospital bed, any information or details about their care become difficult to pay attention to. When a family member or friend is present in an advocacy role, that individual may be better able to communicate the information to the health care team, and to the patient. The fact that he did not have any questions before discharge, or could not remember if he met with anyone before discharge, reinforces the necessity of clear and individualized discharge information to patients. Although Jean states that he did not have any questions before discharge, the rapidity of the discharge and the anticipation of going home may have blurred any questions he had. Not to mention that he was in hospital for thirteen days, was in full isolation, contacted a virus and needed nasal feeding. One might speculate as to why he did not have any questions.

Jean also relied on the direct or indirect support of his nurses. When I asked him about his most difficult hospital moments, he described to me there was vomiting as a result of the migraines.

Jean: Oui, c'était quand je vomissais beaucoup. Je vomissais beaucoup quand j'avais beaucoup de migraine.	*Jean: Yes, it was when I was throwing up a lot. I was throwing up a lot when I had a lot of migraines.*
Heidi: Est-ce que vous vous sentiez soutenu? Est-ce que l'équipe était là pour vous?	*Heidi: Did you feel supported? Was the team there for you?*
Jean: Des fois les infirmières étaient là. Des fois elles étaient très occupées. Mais c'était pas vraiment nécessaire à ce moment là. Quand j'avais la migraine, je demandais de me donner de la codéine, et elles me le donnaient. Quand je…je voulais vomir, personne ne pouvait m'empêcher. Il fallait que je vomisse. Pourtant seul. Non. J'ai toujours eu support. J'ai toujours eu support.	*Jean: Sometimes the nurses were there. Sometimes they were very busy. But it wasn't really necessary at that time. What I had migraines, I asked for codeine and they gave it to me. When I...I wanted to throw up, no one could stop me. I needed to throw up. Even alone. No. I always had support. I always had support. (J, 72y, Int 2, 09/06/2010)*

When I posed this question to other participants, they mentioned situations involving certain members of the health care team. Having considerable experience with his migraines, he knows that there is not much his nurse could do, but knowing that he or she was close by may have been all he needed to feel supported through those difficult times. He does comment that he vomited "a lot" and did not necessarily want to bother the nurses every time. However if a patient has less hospital experience, being left alone to vomit may be viewed as a lack of care or ignorance. If health care professionals want to make sure they respond a patient's needs, the best thing to do is ask them how they manage these conditions at home and what they could do to help. Just because they are in hospital does not mean patients do not know how to manage some illnesses, especially when they have been managing them for 25 years. In Jean's case, it appears his nurse respected his needs. With his nurse and the rest of the health care team, Jean reinforces that *"Without the team to help us, we [patients] couldn't make it" ("Sans l'équipe pour nous aider, on [patients] n'arrivera pas"; J, 72y, Int 2, 09/06/2010).*

Jean and I then discussed the importance of the medical team in his care. Again, this reinforces the pivotal role the health care team plays in the care of patients.

Heidi: Est-ce que leur influence fait grande partit de votre séjour?	*Heidi: Does their influence play a large part of your stay?*
Jean: Euh…leur influence…du personnel de l'hôpital?	*Jean: Euh...their influence...from the hospital personnel?*
Heidi: Oui.	*Heidi: Yes.*
Jean: Si…j'ai pas bien saisi.	*Jean: If…I didn't understand.*
Heidi: Si le type d'équipe, donc les types de professionnels qui vous aident, est-ce qu'ils font la différence dans votre séjour?	*Heidi: If the type of team, so the type of professionals that help you, do they make a difference in your stay?*
Jean: Mais oui. Certainement. Il fallait, il fallait parce que moi, moi, je n'arrivais pas. Avec leurs aides, avec leurs compétences qu'on arrive à s'en sortir. Parce que par moi seul je n'y arriverais pas.	*Jean: But yes. Absolutely. They must, they must because me, me, I wouldn't be able. With their help, with their competence we can get out of it. Because me on my own, I wouldn't be able. (J, 72y, Int 2, 09/06/2010)*

At first Jean had difficulty understanding my question, perhaps because I was not speaking loudly enough on the phone, or because my question was ill-formulated. After he signals how crucial health care professionals are to help patients out of their illness, to guide them to get better. I asked Jean what he thought the best qualities were for a health care team.

Jean: Les meilleures qualités sont être patient. C'est ça hein? Toujours une bonne ambiance et avoir tout nécessaire à nous donner, pour nous guérir, nous aider.	*Jean: The best qualities are to be patient. That's it hein? Always a good atmosphere and to have everything necessary to give us, to heal us, to help us.*
Heidi: Et ça est-ce que c'est une expérience que vous avez vécu personnellement?	*Heidi: And is that an experienced you lived personally?*
Jean: Oui, j'ai vécu, oui. Les gens ont été super, très très gentil. Très bien.	*Jean: Yes, I lived it, yes. The people were great, very very nice. Very good. (J, 72y, Int 2, 09/06/2010)*

He feels that a health care team needs to be patient, above all other qualities, and to create the appropriate atmosphere for patients to heal. Ironically, he identifies this as the most difficult personal quality to possess in a stressful, busy environment. One might speculate whether this could be accomplished by the health care professional taking the time to meet and speak to each individual patient, or looking at the way they speak or the way they tend to patients. Interestingly, Jean recommends that the ward should have everything necessary to heal the patient, which is exactly the opposite of the situation the Medical Director described they had in Chapter 3, due to governmental budget costs. Jean might mean being able to "offer" patients the best material objects such as better beds and unbroken chairs, but also being in a position to offer the best of themselves. Unfortunately, with budget cuts, comes a lack of nurses and doctors. Nurses are forced to work twelve-hour shifts; doctors are forced to treat more patients in shorter amounts of time. Still, these professionals push themselves to continue to offer the best care, and the best of themselves, to their patients. Jean's positive outlook may be due, in part, to the remarkable care he received from his health care team. However, with little governmental support, these remarkable professionals are now at the end of their ropes. Patients have the right to demand exceptional care and “everything necessary to heal” them. Why don’t those treating the patients also have the right to demand “everything necessary”?

Being well “disposed”.

Approximately twenty minutes into the second interview, I first learnt that Jean had been suffering from migraines for the past 25 years. That day, he had a particularly bad migraine and the medication he had taken earlier that morning was wearing off. Still, he dedicated his time to me and commented, just before hanging up, how important it was for him to be well disposed when speaking.

Jean: Alors je vous souhaite bonne chance dans votre étude.	*Jean: So I wish you good luck with your study.*
Heidi: Merci. Est-ce qu’il y autre chose que vous vouliez rajouter.	*Heidi: Thank you. Is there anything else you’d like to add?*
Jean: Non, je n’ai plus rien à ajouter. Ça va. Ça été, ça été…et quand je parle j’ai être bien disposé pour parler, et aujourd’hui ce n’est pas tellement bien ma journée [Heidi: Oh! Ok.] Donc, en tout cas ça été bien.	*Jean: No, I have nothing else to add. It’s fine. It was, it was...and I like to be well disposed when I talk, and today it is not really my day [Heidi: Oh! Ok.] So, anyways it went well. (J, 72y, Int 2, 09/06/2010)*

Although twenty minutes is short for a qualitative interview, it would have been unethical and irresponsible to continue the discussion and leave him with an intense migraine, just to satisfy my researcher agenda. The timing of interviews with patients is a crucial issue in patient-centered care, be it with a health care professional or a researcher. He adds:

> *Jean: …Ça me manque beaucoup la mémoire surtout quand je suis atteint avec la migraine. Aujourd'hui c'est une journée que j'ai une grosse grosse migraine. Et…si je vous ai parlé l'autre fois, c'est parce que j'avais pris des comprimé pour la migraine. J'avais pris, parce que la migraine que j'ai c'est chronique. Je prends toujours des comprimer. C'est certain que dans 15-20 minutes faudrait que je prenne parce que ceux que j'ai déjà pris ne font plus effet… Je prends quatre à six comprimés par jour. Par jour depuis 25 ans.*

> *Jean: ...I lose a lot of memory especially when I get a migraine. Today is a day that I have a big migraine. And...if I spoke to you last time, it's because I had taken a pill for the migraine. I took it, because the migraine that I have is chronic. I always take pills. It's certain that in 15-20 minutes I will have to take another one because those that I took don't have an effect anymore...I take four to six pills a day. A day for the past 25 years. (J, 72y, Int 2, 09/06/2010)*

This excerpt illustrates how circumstances might not provide the most opportune times for patients to talk, even if they are opportune for the health care professional. I wonder about the typical hospital routine of a doctor's early morning or late night visits and how "disposed" the patient is to communicate at that time. I also wonder about patients who are awakened at all hours of the night for medical interventions. Unfortunately, the hospital system is not malleable when it comes to accommodating patients, which contradicts and poses challenges to really implementing a patient-centered care approach, and raises the question of whose interests are actually "being served".

Understanding Jean and Jean's Voices

Jean's utterances, and voices, provide various views about the meaning of "being a patient", from being well received and well served, to the importance of being well supported and well disposed when talking. He describes how being a patient is not enjoyable, but with the right support system and a positive attitude, hope and better days are possible. His direct answers to my questions allude to his preference for a *Health-related Storytelling* voice, and his comfort in being well cared for when health care professionals use a more typical *Doctor* voice to ask questions. When I ask Jean if he has anything else to add before concluding the interview, he presents his preferred voices one last time.

Non. Moi, je ne vais pas chercher les choses. Pas dire des imbéciles pour rien. J'ai dis tout ce que j'avais à dire, tout ce que c'était vrai, c'est tout.	*No. Me, I don't look for things. Don't say nonsense for nothing. I said everything I had to say, all that was true, that's all. (J, 72y, Int1, 06/17/2010)*

Marco: "To Be a Doctor and to Be a Human Being"

> *Heidi: If you knew someone, who was about to be admitted to the hospital [Marco: Yes] what would you suggest to them?*
>
> *Marco: I suggest him, first of all, have a good doctor. To be a doctor and to be human being. (Marco, 79y, 06/24/2010)*

This excerpt emerged from my interview with 79-year old Marco, who was in the hospital due to vascular calcification and skin necrosis of both his lower legs. This syndrome is medically referred to as calciphylaxis. In this excerpt, he elaborates and refers to two aspects of health care for a patient: a professional competence "to be a doctor" and an empathetic quality "to be a human being".

Marco has been in and out of hospitals for the past five years for various medical conditions. On this admission, he remained in the emergency room for four days before being admitted to the ward, where he remained for another fifteen days. Aside from the calciphylaxis, Marco's past medical history includes coronary artery disease (CAD), chronic heart failure (CHF), gastro-intestinal (GI) polyps, elevated cholesterol, atrial fibulation (Afib), asthma, benign prostatic hyperplasia (BPH), cholecystectomy, and a GI bleed in 2007. Functionally, he says he walks on his own, but with great difficulty due to the calciphylaxis and his heart problems. He lives at home with his wife in the Montreal area.

I interviewed Marco the day before he was discharged. He was in a large, white-walled shared hospital room. Talking with Marco in this context presented conversational challenges in establishing participant privacy. When I entered the room, Marco was resting in bed in a hospital gown with both lower legs bandaged. The head of his bed was halfway up and the foot portion was slightly bent. A four-wheeled walker was next to his bed. His wife sat to his left in a straight-backed chair. After I introduced myself, I sat in a similar chair to his right. I placed the audio-recorder next to his head on the pillow. After my experience with Jean, I made an effort to pace myself with this interview and attempt to ask more questions that would enable me to understand more about his experience as a patient from his viewpoint. The interview lasted only 27 minutes. He stated that he did not want to be interviewed again after discharge.

Fellow human being voice.

This theme of "being a human being" appears to capture what Marco believes is what patients need from their health care providers during a hospital admission. He provides some insights about the type of voices some patients may prefer from health care professionals, in addition to the usual *Doctor* voice used for clinical questions. Cordella (2004) argues that a patient, like Marco, might prefer the *Fellow Human* voice which is used to "show empathy, and to encourage patients to tell their stories" (Cordella, 2004, p. 121). The *Fellow Human* voice keeps "with a holistic approach to medicine, which recognizes that a person's condition can sometimes be understood by looking at social factors that affect health" (Cordella, 2004, p. 121).

Throughout the interview, Marco felt it was important to reinforce that doctors need to be “human beings”, as he often returned to this theme, no matter what he was describing or referring to. One might ask why Marco needs to explicitly state that he prefers to be treated by health care professionals who are “human beings?”

He alludes to many systemic issues by describing his hospital experiences as a patient and that may provide insights into why he considers this voice to be so important.

> *Marco:…With the system it works, I think should work, uhm, you have a problem, you come to emergency because there is no other solution. You stay in emergency four days, three-four days in the hall...that breaks the patient automatically...[Heidi: Yeah] and he doesn't know who the doctor is. The doctor this week is Joe Blow, next week another doctor. You have nobody to discuss anything with you because the doctor has something else on his mind. Like I tell you, maybe I'm wrong.*
>
> *Heidi: No, that's a very valid point.*
>
> *Marco: Yeah. Oh, I don't want you to sympathize with me, it's what I've been through here. You don't feel good you, so take the ambulance. It's...I don't know the system is breaking down, for the better? (Mc, 79y, 06/24/2010)*

He begins by describing his experience and feelings of being “broken” from his stay in the emergency room. We can infer that Marco, like Jean, made the decision to go to the hospital on the assumption that he would receive immediate care for his problem, not knowing that he would remain there for four days. Discouraged, he states that this *“breaks the patient automatically”*. “Break” is an interesting word choice. He alludes to situations where the patients may be strong when they decide to the go the emergency room, but after waiting for care, they eventually become weak and break from the frustrating systemic issues they encounter. What might be the signs of a patient “breaking”? Some possible consequences may be: leaving the emergency room untreated, losing the will to get better, sinking into a depression, increased anger or moments of sadness. Once a patient's persistence fades, it can be difficult for them to regain it from within the institutional hospital walls.

Note that even if a patient remains in the emergence room for four days, a transfer to a ward is still considered as a new admission. They usually receive new evaluations from all health professionals on that ward. Their medical chart will note if they were on another ward or in the emergency room beforehand. However, if a health care professional does not take into consideration the total length of time a patient has been in the hospital, this "new admission" could be labelled as lazy or non-compliant if they present a lack of persistence or will to get better. This creates a vicious cycle of care as patients may feel "broken" after an emergency room experience, the patient may be labelled by some of the health care team who may provide him or her with less attention, and the patient then feels less resilience and more frustration over feelings of not being well cared for. Patients who seem defeated or less resilient present challenges to health care workers who must summon their own physical energy to be uplifting for the patient. In Marco's case, he alludes to the fact that his willingness to get better faded in the emergency room. In patient-centered care rhetoric, a discussion would be held with patients immediately upon their arrival on the ward to address any feelings of defeat or frustration so as to encourage them to become proactive in their care.

While waiting in the emergency room, Marco's main concern appears to be that he does not know who his doctor is; he is uncertain about what is happening for his care, or who is to be tending to his needs. Appreciating that *"the doctor has something else on his mind"* presents a noteworthy statement about what patients observe when in hospital. Health care professionals may or may not be aware of how intuitive and observant patients are about those who treat them. Epstein describes the health care professionals' mental process during everyday tasks as mindful or mindless practice. Mindful practice is when a health care professional has the “means to enhance the ability to engage in moment-to-moment self-monitoring” and become in tune to the moment they are in with the patient they are speaking with (Epstein, 1999, p. 833). In contrast, “mindlessness may account for some deviations from professionalism and errors in judgment and technique” or lack of empathy (Epstein, 1999, p. 833). Marco alludes to a mindless practice by a doctor who was speaking to him, but did not seem to be paying attention to what he was saying.

Marco’s story is not uncommon. I recall a friend of mine who was brought to the emergency room as she overtly verbalized suicidal ideation and intention. She remained there for two days before being transferred to a different hospital, where she waited another two days in that emergency room. Her hospital bed was in a hallway and she had to be given permission to shower with supervision. Aside from the disrespectful comments of a nurse who asked her if she was suicidal because of “Catholic guilt”, contact with a health care professional was minimal. As the days passed, her motivation rapidly waned. When she was finally transferred to the psychiatric unit, she had to find and rebuild the energy to receive care in order to get better, energy that she would need to sustain for the four weeks she remained in hospital.

Lengthy wait times in emergency rooms have become sad reality in Quebec hospitals. Horror stories from the media and even from friends have led people to make terrible assumptions about our emergency rooms. It might be inferred that going to the emergency room has become intolerable and unsanitary, especially for those who have no choice but to wait on gurneys in hallways. Because patients like Marco may speak up about these conditions, there is more media coverage about the efforts that are, or need to be implemented to make emergency rooms better for patient care. However, with his insider experience, Marco questions if the situation is really getting better. He recalls previous emergency room experiences:

> *…But five years experiences and I came with angina…I came three times [to the emergency room], the last time I had a wonderful doctor at least he came and sit with me to explain to me because always they were telling me well do this, do that, well have open heart. And in the end I come to the ward and they tell me you can't have an open heart...I don't understand...I'm not a doctor. And since then I have an operation for a polyp and gallbladder. From that time it's bad to worst. I can't stand on my feet. I don't say they destroy me. Oh, I don't know. (Mc, 79y, 06/24/2010)*

Marco refers to the frequency of visits one patient can make to the emergency room, returning three times because of his heart problems. Unfortunately, it occurs quite often that a patient will return to the emergency room on numerous occasions for the same problem. Out of all his admissions, he recalls one "wonderful" doctor who took the time to sit with him and explain the treatment plan. Although the surgery was changed for reasons unknown, there appears to have been a lack of communication between the health care professional and Marco, who explains that he does not understand what happened. The lack of communication or explanations provided to Marco may be the reason he feels that his health has degraded. His confusion might have been avoided if he would had received more information about his condition, about the treatment plan, about why the surgery was changed, and had had more contact with the doctor, who Marco feels is the most important person in his care. Since many professionals are involved in the care of one patient, presuppositions may occur as each assumes that the other is taking charge, or that someone else is providing the needed care. Marco alludes to the lack of communication between health care professionals, the disorganization that can occur when more than one professional is responsible for a patient, and the confusion, disconnect and dismay a patient may feel as a result. However, Marco does not describe himself as being confused; he uses a stronger descriptor: feeling "destroyed".

He repeats feeling "destroyed" again later in the interview: "*But again I come back and stay three-four days, never less than that in emergency. That's terrible. They destroy you before you come in.*" He appears to relate his feeling of being "destroyed" more to the days he spent in emergency than the time he was on the ward. This remark is similar to his previous metaphor when he described the emergency room as "breaking" the patient. Why may a patient feel "destroyed" and "broken" after being admitted to the emergency room? How can anyone expect to get better when feeling this way? Marco alludes to the most frequently reported systemic issues such as the lack of beds on wards to accommodate patients and the lack of health care professionals who, as a result, do not have the time to tend to the psychological needs of their patients and provide one-on-one attention. The feeling of not being listened to might explain why Marco felt "destroyed". He might feel that he was not given the opportunity as a speaking agent to express his concerns and needs as an independent person.

In order to help me understand more about his hospital experience, Marco then leads me into a conversation about his stay on the ward. He describes the difficulties he experienced with an expensive medication that was used to treat his leg ulcers and his impressions of receiving hospital service like the service "in a restaurant."

The new medication, "I accept it but I was not ready to accept it".

> *Marco: Well...I don't know...(mumbling)...you hope, you do everything they told you. Whatever they [medical team] tell me I accept it, but this one, I was not ready to accept it, this treatment but I accept it. But they were telling me, we'll do that, I say that's fine you will do that, I say that's good. And I had much hope, and instead of getting better it coming worst. (Mc, 79y, 06/24/2010)*

An important aspect of Marco's hospital stay is the treatment plan that was created for his bilateral lower leg ulcers, which involves a new and expensive medication. This new medication is covered by the government of Quebec, but needs a special approval from the hospital to be used. It is difficult to determine how Marco feels about this new medication because he alternates from accepting to not accepting it, and from saying he understands and to not understanding it. One could infer from his uncertainty that there might be a lack of consistency among the health professionals who explained the medication to Marco. He notes *"whatever they tell me I accept it"*. He may be alluding to a *Doctor* voice that was used to reinforce the use of the medication, and his impression of needing to comply. Explaining the new medication using an authoritative voice does not correspond to the *Fellow Human* voice Marco appears to prefer. This may explain why he continues from this utterance to state that, after all that was explained about the new medication, he still *"was not ready to accept it"*. Another reason why Marco may be reticent about accepting this new medication is the strict protocol.

> *Marco: I admitted because I have a leg with wounds in the back, on both legs you have that. On one leg they cured it up, but on the other it takes much longer and I had a very severe pain which I used to come every second week. In the beginning I come every week, and the second I come every second week and they would debrid the wound. On the leg there were black spots on it.*
>
> *Heidi: Is it better now?*
>
> *Marco: It is better. Uhm, they trying a new medication. Also they try newer medication and I have to continuously do that every other day three times a week.*
>
> *Heidi: Do you know how long this is going to take?*
>
> *Marco: I have this problem since January. And they told me it's a long processing, maybe take six months. But I have to follow the treatment. (Mc, 79y, 06/24/2010)*

Marco's discharge plan involves his returning home, but travelling to the hospital three times a week for treatment. As he mentions this requirement, he changes the conversational tone. Marco feels unable to return to the hospital so often, which makes it difficult for the medical team to discharge him home as quickly as anticipated on a medication that requires diligent and frequent administrations. Although Marco still appears uncertain about this new medication, he states that he *"has to follow the treatment."* Out-of-hospital care can present several physical and financial burdens for patients. On one hand, he might have remained in the hospital had there been more available beds, but on the other hand he is well enough to go home and it is important for patients to be proactive in their care. Such a situation presents a moral and ethical dilemma for health care workers who need to ensure that if the patient is discharged, he or she still receives the necessary care, or does not fall between "the cracks" of the hospital system. This reinforces the importance of the links between the hospital and the community organizations that follow patients after discharge (i.e., the CLSC). Marco continues to discuss this difficult issue:

> *Marco: Even I had a little bit discussion today [with the medical team or social worker]. Last week they gave me the option about this new medication. Its new medication and I don't know what it does. Doesn't seems to be any guarantees but they said definitely it's a good medication and I will do better. I accept it. In the mean time, it was bothering my transport, it's not easy for me to access transport 3 times a week, and they told me they [the social worker] would take care of it [with ParaTranspo]. They would take care of the cleaning, take care of the transport. All of a sudden they said today, they cannot provide the transport...I was quite upset. And they tell me, yes, I can go home, but come back 3 times a week.*
>
> *Heidi: Did they explain to you when you might be going home?*
>
> *Marco: According to what was discussed, they discussed tomorrow, then they come to tell me not tomorrow. I tell them, guys, make a decision. You know, make a decision.*

You put me up with this stuff you make a decision. I'm not going to sit here for 3 treatments a week. It's basic story. (Mc, 79y, 06/24/2010)

The initial discharge plan was to provide Marco with Para-Transportation. This is a bus service that brings people with functional limitations from their home to a specific location, such as medical appointments. However, when the submission process was initiated by the social worker, they discovered that it takes three weeks to obtain this service. This is why Marco states *"all of a sudden, they cannot provide transport"*. So who is now responsible for the transportation? This lack of accessibility means that Marco would have difficulties obtaining the new medication which puts a strain on the medical team's plans. This issue prompted many heated discussions during rounds, which Marco was unaware of. In two separate rounds, I observed about fifteen minutes of discussion, simply on the issue of administering the medication and transportation. The medical team was concerned as they had leveraged a lot with the hospital system to obtain this medication for Marco, and the social workers were concerned because they could not find a common ground with Marco to help him get access to the treatment. Irritated, the discussion ended after one of the social workers excused herself and said that Marco was being "cheap" because he did not want to pay for a taxi. She said she could say that since they shared the same culture. The assumption around the table was that Marco had the money, but did not want to be bothered to spend it for this treatment.

Cordella (2004) argues that a patient, like Marco, may prefer using a mixture of voices that alternative between an *Apologizer* and *Challenger* voice. An *Apologizer* voice is used when a patient "understand[s] the doctor's instructions, but somewhere along the line their good intentions to carry them out had broken down" (Cordella, 2004, p. 157). This may be patients who are quick to make apologies for why they were unable to follow through with treatments that were given to them. A *Challenger* voice is when patients have "developed some expertise of their own and become competent and responsible for their health, and contest the doctor's recommendations and authority from their new power base of knowledge" (Cordella, 2004, p. 157). This is particularly the case when the "prescribed treatment is proving ineffectual or problematic" (Cordella, 2004, p. 162), which one might infer is what Marco feels is happening. This also presents an interesting issue for health care professional communication with internet savvy patients and patients with chronic conditions. Both groups may search for information independently in order to better understand the condition they have lived with it for so long, or feel that the professional is not offering them enough information in person. In order to be attuned to Marco's voices, health care professionals should begin the discourse with a *Fellow Human* voice to first establish rapport, and then perhaps adopt an *Educator* voice to explain and reinforce what is needed medically. An *Educator* voice "shares medical information with patients in order to help them better understand their health condition and appreciate the benefits of the recommended treatment" (Cordella, 2004, p. 87). The lack of attunement between Marco's voice and the medical team's voice can make it difficult for both parties to communicate with one another regarding treatment and discharge planning. Attunement "means working together in harmony with a patient in helping her to express what she is experiencing, enduring, dealing with at a particular moment in her life trajectory" (Maguire, 2009, p. 4). It appears that at the time I met Marco, he did not feel that his needs, medical or emotional, were being met.

Marco's hesitation about this treatment, and perhaps his use of both an *Apologizer* and *Challenger* voice, may be a result of the lack of education he was given regarding the medication and other intertwined systemic issues. I pushed the issue further and asked him about the information he received in hospital:

> *Heidi: Do you feel like you've received enough information on everything that involves your treatment?*
>
> *Marco: Uhm...yes but it took a long time to get information. And still I'm not sure. Still they not 100%. This medication they give me now, it's ah, to clean the veins. Some kind of medication they tell is very expensive. I don't know. What can I say? What do you want to ask about it?*
>
> *Heidi: Well some patients they come and they feel like they receive a lot of information, and some patients feel like they don't get enough. I wanted to know if you feel like you've gotten enough or not enough.*
>
> *Marco: I feel personally I [mumbling that sounds like "was jaded"] but I shouldn't use those words. (Mc, 79y, 06/24/2010)*

Not only does Marco feel that he waited a long time before receiving information about the medication, he feels that there is no guarantee about its effectiveness. He describes his basic understanding about its purpose and cost, but seems uncertain about why it is so important for his care. When I tried to clarify whether or not he felt like he received enough information in hospital, he changes the conversation and says that he feels "jaded". Marco was described during rounds in pejorative and unprofessional terms that did not reflect how reticent he actually was about the medication, or that he did not trust those who explained it to him. By pejorative labels I mean using words such as "cheap" or underlying comments that meant "difficult", or "ungrateful" for the medication that was obtained for him. Labelling patients can cause other health care professionals to adapt their voices and communicate differently with them due to an opinion that does not take into consideration the patients' individuality and their circumstances. As a result, there may be a misalignment between a patient's preferred voice and the health care professionals' voices, which might not have occurred if the patient had not been labelled as "difficult".

Receiving service "like a restaurant".

Unlike Jean's positive description of receiving health care as a service, Marco views service as a systemic issue within the hospital. He alludes to receiving care in a hospital similar to choosing a restaurant because some are "better than others", branding hospitals as good or bad.

> *And I will see which hospital they do better than the other, because some aren't so good. Like a restaurant. I don't know. But this is health, this is your life, it's more important than anything else. Personally I had a good service, in general I were I'm talking about (mumbling). I had a very good service. (Mc, 79y, 06/24/2010)*

Comparing the service of a hospital to that of a restaurant is an interesting analogy. A person may be less likely to return to a restaurant if he or she received a bad service the first time. However, Marco might have specifically chosen this academic hospital based on the good service he received here in the past, or because of bad service he received at another hospital and therefore chose this one by default. This liberal branding of hospitals may be due to the large number of hospitals that serve the Montreal population. I do wonder how Marco defines "good service", though. In the part of the interview where he discusses the new medication, he does not appear satisfied with the service, but in this excerpt he states that he is satisfied. Does a "bad service" in one aspect of his care then affect his overall opinion of the hospital service? Based on his feelings of being "jaded" regarding the new medication, it appears that he may be separating the professionals involved in his treatment, such as the doctors, from the professionals involved in his comfort, such as the nurses and orderlies. Therefore, the care that involved the medical treatment for his legs was under more scrutiny than the care that was provided to him for his daily needs.

Still, it appears that he is more satisfied by his hospital stay when he feels, or sees, tangible gains in his health.

> *Heidi: So do you feel like that is what has challenged you the most, the fact that you can to do as much as you wanted to?*
>
> *Marco: Well seems to be the, I don't know can say, they took samples of my skin and they didn't even know what it was. It took them such a long time. I've been coming for treatment here, I haven't walked ince, euh, two-three months I didn't walk. Now started walking because I had both legs, the right one, it was worst, it is healed now, but the left one is bad. Now it's better, much better. What can I say? (Mc, 79y, 06/24/2010)*

However, when he does not perceive any gains, he then appears dissatisfied with the service he received in hospital.

> *Heidi: So, if you look back on...because you've been here for quite a while so have much experience [Marco: (over my voice) I've been many times] how would you describe the difference between your condition today and when you were first admitted.*
>
> *Marco: A big difference, I'm a dead man today.*
>
> *Heidi: Today you're a dead man?*
>
> *Marco: Of all the years I've been here, instead of doing better I've been doing worst. Doing worst. Now is it my luck? There no seems to be understanding between doctors I don't know. (Mc, 79y, 06/24/2010)*

These excerpts are very different from each other even though he is describing care for the same medical problem in the same hospital admission. Here, Marco uses strong metaphors to describe his feelings of being a "dead man" today. He appears to be attributing this feeling to the fact that he does not trust the doctors, or health care team, because of a lack of understanding or communication they have with each other. How does a patient perceive a lack of team communication? I question whether one of the reasons he is so uncertain about the new medication is because he does not perceive any coherence between those who described the medication to him. This confusion may be due, in part, to the constant rotations within the medical team. Although more than one professional may individually visit the patient with the same information, on the receiving end the patient tries to put every piece of information together and draw a conclusion. If the information is different, even slightly, it may confuse or disorient patients to the point that they no longer trust the treatment, as one might infer from Marco's responses. I wonder, again, what type of information he received regarding the new medication and the types of voices the health care providers used in their interactions with him. Would he be more inclined to travel three times a week if the medication had been described in a way that was more attuned to his preferred *Fellow Human* voice? Although he describes himself only as a small business man, Marco provides the hospital with some practical advice to better the communication problem between the health professionals.

> *Marco: ...There's no vision no direction in this. The people are nice, but no vision no direction. There don't seems to be somebody really in charge.*
>
> *Heidi: Hum? What gave you that impression?*
>
> *Marco: Well I've been here a very well long. I've been in the hospital many times. And every time I come up here I come up with all different medications. Medications give you side effects...maybe I'm wrong...I've never been sick in my life and I've experienced now for four-five years being in and out of the hospital. [Heidi: Uhm] I've came here in the hospital a very strong man with a heart and (something inaudible) problem and I've deteriorated here. (Mc, 79y, 06/24/2010)*

One might ask: What is different about this admission that makes him feel like he deteriorated? Having worked in the service industry, Marco alludes to a variety of business systemic issues. He sees the lack of understanding of his situation stemming from a lack shared vision from the workers on the ward. Is he also referring to lack of vision within the entire hospital? How would Marco feel about the applicability "The Best Care for Life"? Again, he presents a dilemma with more than one complex problem which reflects back to his previous comment*"...he doesn't know who the doctor is."* In not knowing who his doctor is, he does not know who is in charge, and does not even feel that anyone is in charge. Who is ultimately responsible for the good service? Is it the manager, or the chef, like in a restaurant? If so, who is the chef of the ward?

Understanding Marco and Marco's Voice

Marco describes "being a patient" as needing to be treated as a human being by someone who is a human being. Above all, he appears to feel that it's important for health care professionals to speak to him using a *Fellow Human* voice. In order to adapt to the voices that were actually used during his discourses with the health care team, Marco uses *Apologizer* and *Challenger* voices. This led him to be labelled as a "difficult" patient, especially during discharge planning. The pending question is *who really owns this discharge problem*?

Mary: "Tell Me Plain and Simple, Don't Beat Around the Bush'"

Heidi: Do you feel like you received enough information in all the time you were here?

Mary: Yes, I found that they were good, very good at answering the questions I asked. Of course I say right up front: "I ask questions, please plain and simple, tell me plain and simple, don't beat around the bush, just tell me." You know? And they've been very

> *good. Any time I've asked anything, they've told me exactly what I wanted to know. (Mary, 72y, 06/30/ 2010)*

This excerpt emerged from my interview with 72-year old Mary who went to the emergency room at the request of her general practitioner, who found her haemoglobin to be suddenly very low. Here, she describes how she appreciates "plain and simple" answers to her questions, and does not want the health care professional to "beat around they bush" especially when it comes to her health.

Mary usually visits the hospital every couple of months for monitoring of her diabetes. On this admission, she was diagnosed with iron deficiency anaemia and found out she had colon cancer eight days after her admission to the ward. Mary has also been managing a past medical history of unstable angina, a cerebrovascular accident (CVA) in 1996 with no residual weaknesses, and a transient ischemic attack (TIA) in 2007.

> *And she sent me in here with papers to have me tested. To see what was happening because I wasn't bleeding anywhere. So, that's why I came in. […] They discovered that I have colon cancer, some colon cancer, not a lot they said, but some. (Mr, 72y, 06/30/ 2010)*

She is independent in all her daily activities, but reports an increased shortness of breath (SOB) when she walks. She lives alone, in the Montreal area. She remained on the internal medicine ward for 21 days before being transferred to the general surgery ward to prepare for colon surgery. I interviewed Mary on the ward five days before she was transferred.

Like Marco, she was in a large, white-walled hospital room with three other patients. Talking with Mary in this context once again presented me with conversational challenges in establishing participant privacy. We sat in front of each other in high-backed chairs. She appeared very comfortable throughout the entire conversation and was not hesitant to voice her opinions. She felt confident in her answers (*"I won't change my mind"*) and did not want to be interviewed again after discharge. She appears to be the type of person who is very decisive and likes direct and simple answers to her questions, which is reflected in her meaning of "being a patient": understanding everything!

It's important to know "what's happening and why".

At the start of the interview, Mary mentions that she's been through "a lot of tests" since her admission to the hospital. This sets the tone to understand her hospital experience since her admission. "Knowing what's happening" is what Mary feels is the most important part of being a patient, in order to anticipate the treatments and especially to remain calm.

> *Heidi: And when you were first admitted, say in the first couple days, did someone come in right away to help answer your questions or did you find it take a long time?*
>
> *Mary: No, no, they were very good. When, downstairs when they were starting to do the tests and there was no idea what was wrong with me, but they were very good. They explained. That was the important part. They said "We are going to do this and this is why we're going to do it". That's important. They told me, "This is what's going to happen, this is why we're going to do it, to see what's wrong here". That is good...'cause then you're not sitting there scared. Like "Oh my God..."*
>
> *Heidi: Yeah...what's gonna happen next? (Mr, 72y, 06/30/ 2010)*

In this excerpt, Mary uses "double voicing to intermingle her own utterances with the anonymous generalized voices" of the health care professionals working in the emergency room (Maguire, 2007; Maguire & Curdt-Christiansen, 2007, p. 57). Double voicing "refers to utterances or part of utterances that are attributable to two speakers at once" (Maguire & Curdt-Christiansen, 2007, p. 57), where the internal discourse of the two speakers is "half-ours and half-someone else's" (Bakhtin, 1981, p. 434). She briefly describes her stay "downstairs" in emergency where she felt her questions were well answered. Immediately, she notes that knowing what was happening meant not having to worry unnecessarily over tests she did not understand, or to be frightened by what would happen to her during her hospital stay. It appears that the health care team in the emergency room may have responded to Mary in the voices she prefers, a perfect combination of the *Educator* and *Fellow Human* voices. Mary could have also been the one to evoke these voices by prompting the health care professionals with her own questions to assure a constant understanding.

Cordella (2004) argues that a patient, like Mary, who initiates "questions to find out more information about their health problem and treatment" and who demonstrates an ability to manage their care, might prefer using *Initiator* and *Complier* voices (Cordella, 2004, p. 150). *Initiators* "seek information about their health condition [and] acknowledge that they lack the necessary knowledge to deal with their health problem" (Cordella, 2004, p. 171). Therefore, they call upon the doctor's expertise to answer their questions. *Compliers* demonstrate that they "understand the doctor's instructions and their own responsibilities and [are] able to report that they [have] successfully carried out" what was asked of them (Cordella, 2004, p. 157). *Initiators* and *Compliers* prompt *Educator* voices from health care professionals. The *Educator* voice "shares medical information with patients in order to help them better understand their health condition and appreciate the benefits of the recommended treatment" (Cordella, 2004, p. 87). The function of the *Educator* voice is mainly for *Communicating medical information* (Cordella, 2004, p. 87), which can be divided into three aspects of communication in clinical encounters: 1) communicating medical facts, 2) responding to patient discomfort, and 3) communicating medical treatment and management (Cordella, 2004, p. 87). In her interview, Mary appears to mainly evoke the *Educator* voice to instinctively respond to the discomforts and fears she feels as a patient. She continues:

> *[…] 'Cause I mean let's face it, when we come in for something and we don't know what it is...you're scared. And the first thought that goes into your head "Oh my God I've got cancer"...even if you haven't. That's, that's "Oh my God, why is that happening, I must have cancer". We all do it (giggles). (Mr, 72y, 06/30/ 2010)*

Here, she describes the fear she feels when she is left in the dark about her care. She is able to move from her own immediate experience to empathizing with other patients' feelings of vulnerability. Similar to the issues Jean raises in his conversation, patients can encounter situations when they appear to be unaware of which health care professional is responsible for specifics aspects of their care. Marco also raised a lack of awareness about who was in charge of his care. Mary is now adding that patients are also unaware of how the body functions and why they are ill, which draws them to automatically conclude the worst possible scenario, such as having cancer. Mary stresses the importance of an open communication between the health care team and the patient.

> *Heidi: You don't have to answer your own questions in your head.*
>
> *Mary: Yeah. It is true. It takes it away.*
>
> *Heidi: 'Cause when you start speculating a lot [Mary: Yep], your answers are worst than the actual answer.*
>
> *Mary: That's right. Yep but they explain it, it takes all that stress away. You're not laying there worrying about it. You can relax you know what they are doing, and you know why they are doing it, and...(pause)...that's me. I don't know about other people but I think it makes a big difference when they just tell you why they are doing it and what to expect. (Mr, 72y, 06/30/ 2010)*

Mary explains that knowing why she was ill made a "big difference" in her hospital stay. Since she knew what the health care professionals were doing, and why, she was able to "relax" and trust in the care they were providing her. If there is one concept health care providers could learn from Mary's experience as a patient, it is never to underestimate the patients' need for clear and constant information. In a few 'conversational moments' with the patient, the health care professional can increase rapport, confidence, and motivation for treatment and decrease stress and anxiety. No matter how simple or self-explanatory the test may appear to be, Mary is telling us not to assume the patient understands.

Listening to a patient's utterances and questions highlights the importance of understanding patient voices and the different voices they may or may not adopt. Here, Mary's voices appear to be in tune with the voices the health care professionals are using during medical discourses. However, such as was the case with Marco, not all patients receive treatment in their preferred medical voice. Even more complex issues arise when patients may not speak mainstream languages such as English or French. Noteworthy is the importance of speaking to the patient in their language of choice, or to make the effort to find a translator. Montreal hospitals in urban areas serve diverse populations and many may not speak or understand English or French. Although the hospitals within this academic hospital have translators at the health care professionals' disposal, not all have the occasion or time to use them, or there might not be a translator for a certain language. A translator can make the link or be the "linguistic broker" between the health professional and the patient and help both parties communicate with each other. Through Mary's description of the fear, anxiety, and worry she feels when she understands the language; one can only imagine how frightening being a patient can be when one does not. Understanding what is happening can make a "big difference" in a patient's hospital stay.

As Mary explains, patients may speculate the worst when they are ill. In her case, Mary did face the diagnosis of cancer.

> *Yep, now we just have to wait for the surgeon what he's going to do and how they're going to do it [colon surgery]. [...] He told me it was a very small section and as far as he's concerned, they've caught it early it can be taken care of well in here. (Mr, 72y, 06/30/ 2010)*

Having had explained how the surgery would go and how the cancer could be removed, the surgeon appears to reassure Mary. She details what the doctor said to make her at ease and double voices their conversation.

> *Yeah, but if you know what is, you know...like they know what's going to happen with the test so tell the person "This is what's going to happen" and the person isn't going to be asking all the time "What's wrong? What are you doing? Why are you doing it?" If you just take the time to beforehand to say: "We're going to do a colonoscopy this is what we're going do, this is why we're gonna do it" and, well in my case, you see what they're are doing. I say: "What is that, why is that different from that?" And was very good to me he said: "This one here, looks like nothing, it's just polyps. This one here looks like there might be something. So we're going to have to do further testing on that." I didn't worry about it then. I knew what they were doing and why. [...] He let me see the pictures of what they were doing which was great, you know, good for me. I like to know what's happening to me. They were very good. Yep, they were very good. (Mr, 72y, 06/30/ 2010)*

Here, Mary illustrates how she is trying to make sense of the discourse with the doctor. She comments on how the gastroenterologist provided her with concrete information about the findings of the tests. One can only image the fear Mary felt when the doctor said that in a section of her colon "might be something", yet she describes the conversation calmly. It could be inferred that his explanations on the findings and his confidence in doing the surgery might be reasons why Mary appeared to be no longer worried, and felt cared for. Unfortunately, there are patients who are not immediately reassured, as Mary was. For example, the physiotherapist, Anna, describes in her interview a scenario where a female patient thought she had cancer for 48 hours in hospital because did not receive information during or after a medical test.

> *Anna: [...] We had a woman that thought that they were, hiding recurrence of her cancer because no one went into the room for two days after she had had a test for, I think, I can't remember what exactly the test was, but she was sure that it could show that if there was malignancy.*
>
> *Heidi: So for two days she sat there thinking she had cancer.*
>
> *Anna: She had cancer and she didn't. Yeay. That was really awful. (Anna, 25y, 08/26/ 2010)*

A hospital admission is stressful enough, without imagining you have cancer when you do not. Such unnecessary fear could have been alleviated in a communication of less than five minutes! This raises a dilemma for health care professionals about deciding what to tell patients, when, and with how much detail. A patient like Jean appeared to be more passive and trusting about his care. A patient like Marco was also more passive, but appreciated obtaining clear and concise information as soon as it was available. A patient like Mary demonstrates a more pro-active role in her care.

Mary uses an *Initiator* voice and to describe the responsibility she has as a patient. In order to take to move from illness to wellness, she takes full advantage of her voice as she demonstrates a sense of agency.

> *Heidi: Would you say that (asking questions) was an important part of your recovery or stay here?*

Mary: It is, it is for me because as long as I know what's happening and why it's happening I don't fret about it, I don't lay and worry about it. I just know what's going to happen, I know why it's going to happen and that makes me feel better because I know, it's like I'm on top of the situation, I know (giggles). [Heidi: Yeah.] You know which sounds strange maybe, [Heidi: No no.] but that's how I feel. (Mr, 72y, 06/30/ 2010)

In her utterance, the concept of patient agency and empowerment resurfaces - something not all physicians may be used to or know how to respond to. As an experienced patient, Mary knows it is best to feel "on top" of her care with "some" control, rather than be a passive observer.

Heidi: And because of that (asking questions) did you feel like you had control over, what was happening?

Mary: Over my situation, yes. I had some control. Not all control, but I had some control over what was happening to my body. What they were doing and it made me feel better.

Heidi: And was that a feeling you had at your admission?

Mary: Uhm, I didn't come in with that feeling but after being here for a day and a half, that was in emergency, like I said I was told what was going on. And it didn't completely relax me but it relaxed me enough to trust what they were doing. You know, not be scared. (Mr, 72y, 06/30/ 2010)

But who is really in "control" when a person enters the hospital - the patient or the health professionals? Where does patient agency play a role in the patient-centered care rhetoric, where the patient should have the control? Mary explains that she understands that she may not have full control, but appreciates having "some" control. Patients and health care professionals can be in control in their own ways if both recognize a shared understanding of each others' roles.

Having “some” control might also be a question of personal preference. This raises an important patient education issue as the communication methods for passive and proactive patients are not the same. By asking questions, Mary assumed some control over her care which made her feel better about her role as a patient. Reciprocally, the health care professionals who responded to Mary allowed her to have that control by providing her with space in the patient-doctor relationship to freely express her voices. How much of this type of conversational expertise and mature understanding is actually taught to health care professional students and residents? However, when faced with a situation which she describes as “harassment”, she depicts a particular doctor who did not allow her that conversational space.

I felt “harassed”.

As I have illustrated in the previous section, Mary spent most of the interview describing how she felt it was important for her to ask many questions. This seemed to be her central preoccupation. However, within the first minute of the interview, she describes a situation with a particular doctor that affected her greatly, and negatively, during her stay on the internal medicine ward.

> *Heidi: And with the information that you got, or with the people that came in, did you find that there were any challenges or things that you found more difficult during your hospital stay?*
>
> *Mary: No...I found it...*
>
> *Heidi: Or...*
>
> *Mary: There is one thing that I found very annoying that made me very angry and that was doctor...I have her name written down there...*
>
> *Heidi: (giggles) To that point you have it written down?*

> *Mary: (giggles) Uhm...she, from the time I get up here, she kept telling me "You can't stay here to have the test, you should go out to out-patient clinic. You can't stay here. We need the beds; you know you've got to..." [Heidi: Uh hum]. Five times she (the doctor) come in and said the same thing and each time she'd come in, the (another) doctor sent me for another test, so I said to her, I said: "I'm not going anywhere until I get the results of the tests I've just done". But she was here every day, she…she made me so mad (laughing). I was, I was so angry at her that I was going to call the Ombudsman [Heidi: Uh um] and put in a complaint because that's harassment as far as I'm concern. (Mr, 72y, 06/30/ 2010)*

At first, it appears that Mary was contemplating my multi-faceted question. However, once she begins describing the event with the doctors, it appears that she might have been contemplating whether or not she wanted to disclose this unprofessional behaviour to me at all. Sharing this event with a neutral party might have been her motivation to participate in my study in the first place. By stating *"from the time I get up here"*, it appears that this event occurred early on in her admission to the ward. Since she received the diagnosis of the colon cancer only eight days after her admission, this event occurred either before or after the colonoscopy. On five separate occasions Mary reported the experiences she labels as "harassment". It is interesting how she relies on double-voicing to illustrate the conversation with the doctor, and how angry she is about the situation which still resonates in her memory. After she said she wanted to call the Ombudsman to submit a complaint, I told her she could call anyway. She answered:

> *I got over it, you know...But that's the only thing that really annoyed me. [Heidi: Hum] You know and I said, I said, if it was somebody that was really sick and in the bed, that is not going to help them, that kind of harassment is not going to help them get better.*

> *[Heidi: Uh hum]. It's just going to aggravate them all the more, you know, I mean at least I could talk back. (Mr, 72y, 06/30/ 2010)*

Had this been her first time in the hospital, it is debatable if Mary would have claimed such an assertive voice and "talked back" to the doctor. As she describes, had she been very ill or unaware of her right to stand up for herself in front of a doctor, this event may have gone unreported, not only to the Ombudsman, but to me. Unfortunately, as the days passed she says she "got over it". This makes me wonder about how many other patients "got over" feeling "harassed" in hospital. Mary appears to have fought for a bed on the ward, which may reveal her assertiveness and determination to keep hold of the little control she had left, and understanding of her rights for care as a patient. However, "letting it go" reinforces the power challenges that may exist between patients and doctors. Although I did not ask Mary why she would no longer report the incident, one might speculate that with time she no longer felt it was important, or she did not want to be labelled as a "difficult" patient, or questioned if reporting it would influence the quality of care she was entitled to receive.

What are the responsibilities of health care professionals when they hear that their fellow colleagues have been unprofessional? Mary describes this person as "the doctor", but there is a possibility that it was not the attending doctor on the ward, but a resident. If it was the resident, how can their supervisor reprimand their behaviour if it is never reported to a higher authority? If it was the attending doctor with their resident or student present, how does this example influence the practices of future doctors and their understandings of what it means to be "professional"? In either case, it does not excuse the act. This type of behaviour points to a variety of serious systemic issues. The superficial issue is the lack of hospital beds which force patients who are "not as sick" to be discharged earlier than they should. As a consequence, these patients may be forced to visit the emergency room on numerous occasions just to receive care.

This alludes to the external governmental pressures that are forced upon on hospitals and the power of politics on patient care. Considering the empty beds in Marco and Mary's rooms, there may simply be a lower capacity to admit patients to the ward due to a lack of health care professionals available to treat them. These systemic issues do not take into consideration the patients' need for care; they do not place the patient at the centre of care; they raise complex issues about patients' rights and health care delivery; and fall short of the best care for life. In this event, the needs of the hospital, and even government, were placed first and Mary was forced to stand up for herself, or she might have been discharged home.

When I met Mary, she had been on the ward for fourteen days. This long length of stay may have been the result of another important systemic issue: lack of interprofessional communication between those involved in the care of one patient.

> *Heidi: Is there anything else that greatly influenced your stay?*
>
> *Mary: I can say one thing, but I don't want to get nobody in trouble.*
>
> *Heidi: You don't need to mention names.*
>
> *Mary: It's just the instructions from the doctors don't seem to reach the nurses. [Heidi: Uhm]. It's like, I don't know how or why, but I had three tests cancelled because I wasn't, the nurses didn't know I was supposed to have certain things before those tests. And three times my tests were cancelled. It's somehow, it seems to me, I don't know if it's true, or what. It seems to me that it doesn't always filter down to the doctor to the floor. [Heidi: Hum?]. It's not their fault, I mean knock themselves out to, you know, make sure everything is ready, but somehow sometimes it doesn't get here.*
>
> *Heidi: Especially since the nurses are here so often. [Mary: Yep] The nurse is your number one side-kick.*

Mary: That's it, that's it. Yep yep. Like the first test, the nurse comes in and she's brought my tray and she's giving me my insulin and the doctors standing right there. And he sees her giving me the tray to have breakfast but he doesn't say: "She can't have breakfast because she's gonna have that test in an hour". So, I eat my breakfast. And then they come take me for the test. Well the nurse was mad, she said: "Well she just had her breakfast and the doctor was standing right there" (giggles). It just, it doesn't seem to connect. [Heidi: Hum]. But I don't blame the nurses for that. I don't know, maybe the...

Heidi: Communication

Mary: Yeah. But the service is good. They are good. I have no known complaints here.

(Mr, 72y, 06/30/ 2010)

Mary could have answered this question an infinite number of ways, but she chose to discuss this situation that she felt was unfair to her attending nurse. This particular situation was also discussed heatedly during rounds. The attending doctor was waiting for the results of a test that needed to be rescheduled on three different occasions because Mary had eaten breakfast when she was not supposed to. Although Mary does not blame the nurse, the nurse was blamed during rounds. In Mary's view, the doctor, who might have been a younger resident or a student, should have intervened and assumed the responsibility for the error because he observed the event, and not the nurses. This again alludes to the ongoing power relationships between health care professionals and the medical hierarchy. Who owns responsibility for the thousands of dollars that were lost for the extra days in hospital and the waiting time Mary had to endure? Did the nurse merit an apology?

As angry as she was when she felt “harassed”, and as upset as she was over this situation with the rescheduled medical tests, she differentiates both events from the totality of her hospital care and notes that she is still satisfied with the service she received. She says:

> *…but that was the only thing because the nurses here are great. Yeah, and so are the orderlies, they are very good. Yep, I have no complaints whatsoever about any treatments I’ve received or anybody I asked anything to, they were very forthcoming in telling me, explaining to me what I wanted to know. You know... (Mr, 72y, 06/30/ 2010)*

Overall, Mary was satisfied with her hospital stay and care. Like Marco, she does not fail to appreciate those who practice a more patient-centered care approach. Like Jean, Mary felt that she was well received by the professionals who were “very good” at providing her with medical service. Still, Mary notes that on occasions, she felt that her care was provided to her more like a chore. What differentiates a committed health care professional from one who may just be doing a perfunctory job?

Don’t treat patients “like a chore”.

As Mary moves on to a different subject, it is evident that her definition of “being a patient” is greatly influenced by those who were responsible for her care and what type of individual and professionals they appeared to be.

> *Heidi: How would you define “being a patient”?*
>
> *Mary: (10 second pause) I would, it would have to be, like I just said, coming in, being treated with respect and being spoken to...not sarcastically or anything like that...but being spoken to nicely...and that would be about it.*
>
> *Heidi: So is that in the sense that you’re experience depends a lot on the people...*
>
> *Mary: On the people who look out for you… (Mr, 72y, 06/30/ 2010)*

Here, she feels that it is important to explicitly state that she does not want to be spoken to sarcastically. Why does Mary feel the need to ask health care professionals to speak to her nicely? She concludes this small segment by reinforcing that her hospital experience depends a lot on the health care professionals who treat her, and on their empathy or lack of empathy, towards her as the patient. Although she states that she was satisfied with her care, this statement makes me wonder if, upon discharge, she still maintained some resentment towards the doctor who "harassed" her, and did not "let it go" after all. She continues:

> *Mary: …I understand it's a very busy place and they have had a bad day, you know but pass it on to the next patient [Heidi: Yeah]...sort of thing. Maybe that's not what your looking for but that's...*
>
> *Heidi: No, I'm not looking for anything, I have no...a clean slate. [Mary: Uh hum]. So if you could suggest to them [the staff who are having a bad day] how to fix that or give them some tips, what would you tell them?*
>
> *Mary: (pause) Take the time to reassure that you're working with and, like I said, take the time to explain. I know they are busy, very busy, but a little bit of explaining and a little bit of time makes everything a lot better and calms the person, you know that they're gonna help you that they know what they're doing, and I don't know, to me it helps just told, like I said, treated with respect and don't get angry at me because you had a bad day (laugh). But I think that they explaining part is the important part. Yep. (Mr, 72y, 06/30/ 2010)*

Here, Mary is exhuming a critical voice. In the first part of the utterance, she could be describing Epstein's concept of mindful practice, as I described it in Marco's understanding of "being a patient". Mary feels it is important to give patients each their own time, and not have a doctor who cannot listen to the patient because they are preoccupied by all the other patients they have to treat. She reminds health care professionals that no matter how busy they are, all patients need is *"a little bit of explaining and a little bit of time"* to decrease their anxiety and worries. Doing so also increases confidence in the medical team because the patients feel important as individuals, rather than a burden. Again, this may allude to demands that are made at a higher administrative level, which may force health care professionals to spend less time with each patient, thus appearing more stressed. As Mary describes, the health care professionals' state of mind has profound repercussions on the patient's care.

This excerpt also raises another important systemic issue. Why does Mary ask health care professionals not to get "angry" with her? Although Mary laughs it off, it is quite serious. This may be attributed to the fatigue health professionals experience and the surcharge of work they have to take on, in order to compensate for a lack of workers. It could also be simply a lack of awareness on how to communicate effectively with patients. It is not the patients' fault if the professional had a bad day, and they should in no way be the "punching" bag for the workers' frustrations. This type of lack of patient-centered care corresponds to Epstein's definition of mindless practice. Who is "they" Mary was referring to? Not surprisingly, Mary leaves this question unanswered, only giving high praise to the nursing team.

> *Heidi: And is there anything else? Anything you'd like to add concerning your experience as a patient?*
>
> *Mary: (pause) No, no. I think that takes care of everything. I'm treated well. And they (the nurses) respect me and I like that. And I respect them because they work hard. …They have how many patients they've got to look after? …They work too many hours you see it here when you're in for a week or two weeks and you see how hard they work and how hard they work. Yeah. (Mr, 72y, 06/30/ 2010)*

Mary describes being *"treated with respect"* as a two-way street. She respects the nurses because they worked hard to tend to her, and she felt respected in return. How does a health care professional earn a patient's respect? In older times, professionals needed a distinguished title to be respected, but that is no longer the case. To earn patient respect, Mary recommends that "they" should take a little bit of time to converse with patients and explain to them what they will experience while in hospital. When asked what she would recommend to future patients, she recognizes individual differences and continues to describe her recommendations for care.

> *Heidi: So if someone, say, was coming into the hospital […] what would you recommend to these people? If you knew them before they were about to be admitted...to help them.*
>
> *Mary: (long pause) I really don't know 'cause I think it's different for each person, you know, everybody comes in, it's…it's different. Ah, you're coming in you have no idea what is gonna happen...[raises her voice] just, just, just, treat the people with respect, like, uhm, don't rush them, like don't hurry them, to do things, you know...*
>
> *Heidi: You mean, you mean the patient hurry or the health professional?*
>
> *Mary: The health professional.*
>
> *Heidi: Ok!*
>
> *Mary: Being more, how do I want to say it, be...don't seem like it's a chore [Heidi: Hum]. "Get, get, do this fast" you know? Just, just go slower, a little slower***.** *Give the person time...a chance to (giggles). (Mr, 72y, 06/30/ 2010)*

In this excerpt, Mary reinforces the fear patients may have when they enter the hospital and the important role health care professionals play in alleviating that fear. In addition to being spoken to nicely and with respect, here she adds that she would have appreciated not to be "rushed" or "hurried". This alludes to the fast pace of hospitals and rotation of patients. Mary appears to question whether the patient needs to feel rushed. In other words, the pace of the hospital might not change, but perhaps the approach towards patients should change so that they feel less overwhelmed. In Mary's opinion, not treating patients "like a chore" would be the first step; the second step might be to take a few minutes to explain what they should anticipate, especially if a "rush" is needed. She concludes: "'*cause I mean let's face it, when we come in for something and we don't know what it is...you're scared…don't push so much"*, reiterating the importance of clear communication and the fear some patients may have when they do not understand their care, or are not assertive enough to ask. To conclude the interview, Mary comments on one last quality she appreciates from health care professionals: honesty.

> *Yep, they are very good here. Very good. They're very honest, that's what I like. They're very honest. They don't beat around the bush. If you ask, they tell you. Hum, that's important to me. Yep. (Mr, 72y, 06/30/ 2010)*

Mary appears to positively remember most of her stay on the ward positively and does not let the episode of "harassment" taint the good work that was done by the rest of the health care team. All she asks, as a patient, is to be treated with respect, spoken to nicely, and to receive honest care. The simplicity of her expectations is not unreasonable.

Understanding Mary and Mary's Voice

Mary describes "being a patient" as understanding every aspect of your care in order to know what to expect, reduce anxiety and fear, and perceive a certain control over your body. She describes the necessity of thorough information about all aspects of hospital care, indicating her personal preference for an *Educator* voice from the health care team. Although Mary experienced frustrating events during her stay on the ward, she still perceives that she received good care and service. She met many health care professionals who responded well to her *Initiator* and *Competence* voices, and clearly differentiates those who did not.

Chapter Summary

In this chapter, I interpreted the experiences of “being a patient” of Jean, Marco, and Mary, based on their personal narratives and utterances during their stay on the internal medicine ward. All three depicted unique and vastly different experiences as patients and exhibited different patient voices. Jean appeared to prefer a *Health-related Storytelling* voice in describing his view of hospital care as a service for sick people, the “un-enjoyable” difficulties of being a patient, his need for help and support especially from his wife, and needing to be well disposed when speaking. Marco appeared to prefer using a mixture of *Apologizer* and *Challenger* voices when describing his experience as a patient. Like Jean, Marco described hospital care like a service and emphasized his need for a *Fellow Human* voice from his health care providers, which he appears not to have received. Mary appeared to prefer using *Initiator* and *Complier* voices as a patient. Mary emphasized the absolute need for constant and thorough information throughout her hospital stay in order to feel reassured and in control. In chapter 5, I will to look at the emerging themes from the personal narrative of the participant Marie-Ange, whom I had the pleasure of conversing with on two occasions after her discharge from the ward.

Chapter 5. Rethinking the Voices of Health Professional Patients: Marie-Ange

> *J'étais arrivée à l'hôpital avec un texte sur la maladie de Wegener, trouvé sur Google le jour de mon hospitalisation. Le lendemain de mon arrivée, mon conjoint m'a apporté le texte sur le syndrome de Churg et Strauss. Je me suis servie de ces textes…pour comprendre la démarche évaluative des médecins.*

> *I had arrived at the hospital with a text on Wegener disease, found on Google the day of my hospital admission. The day after I arrived, my husband brought me a text on Churg Strauss Syndrome. I used these texts...to understand the doctors' differential diagnosis. (Marie-Ange, 65, Int 1, 09/03/2010)*

This excerpt emerged from my first interview with 65-year old Marie-Ange. Searching on the internet was her way of anticipating the medical tests and treatments she might experiences during her hospital stay. Marie-Ange raises four important issues in this qualitative inquiry of patient voice: 1) interviews and conversations are not the only ways to capture patient voices, especially for patients who are seriously ill; 2) the more one interacts with patients, the more one is able to understand their voices and appreciate and respect their perspectives; 3) patients post-discharge may have very vivid memories about their hospital experiences and see things more clearly that they did during their hospital stay; and 4) writing may be an important part in healing and understanding wellness, illness, and overall well-being. To understand Marie-Ange's experiences as a patient and her voices, I begin first by describing how we came into contact. Then I will describe how the information she obtained from the internet helped her understand her care and maintain a certain control over her body. I will then discuss the constraints and aggressions she experienced as a patient, the support system she developed and relied on, and her analysis of the care she received.

Since our first conversation, Marie-Ange impressed me time and time again with her clear articulation of her hospital experiences and determination to get better. I have never met a person so critically ill who still persists in helping others, notably me, a graduate student she has never met. Her willingness to participate supports the premise that patients do want their voices to be heard and recognized. I could not help but give her the name "Ange" which means "angel" in French.

I did not meet Marie-Ange in her hospital room as I did for the other participants. In her interview, she alludes to her sharing a hospital room with two other people. I infer that she was in a room like Marco's or Mary's, that is, a stereotypical large white-walled hospital room with four hospital beds and one bathroom.

J'ai été témoin involontaire d'un échange très intéressant entre mon colocataire de 94 ans et une intervenante. [...] J'ai été aussi témoin d'un échange plus pénible entre ma voisine de gauche et un soignant…	*I was an involuntary witness of a very interesting exchange between my 94-year old room-mate and a health care professional. [...] I was also a witness to a difficult exchange between my neighbour to my left and a health care professional...* *(M-A, 65y, Int 1, 09/03/2010)*

This excerpt demonstrates the difficulties of maintaining private and confidential conversations between the patient and the health care professional in a shared hospital room. It also reveals that patients observe much about their surrounding hospital environment and become involuntary witnesses to the health care of other patients. Although she was not directly involved in the conversation, Marie-Ange describes her room-mate's intimate scenarios. Her utterances point to the challenges and difficulties of actually capturing patients' voices in this type of environment in which other occupants of the room can become “third party listeners” in medical exchanges.

Near the end of my data collection process, Dr J, a doctor on the ward aware of my project, approached me to describe Marie-Ange and her willingness to participate in my project. They had discussed my project during a conversation. I contacted her four days after her discharge from the ward. She shared with me some information on her hospitalization during in a telephone conversation. I had not reviewed her medical chart, nor had any notion of how ill she really was prior to this conversation. When she described to her symptoms and the intensity of the treatments she was now receiving, I felt admiration and was overwhelmed by her resilience. She was diagnosed with a rare auto-immune disease called Churg Strauss Syndrome, which affects one in 100,000 people. Churg Strauss Syndrome is “characterized by inflammation of small to medium sized arteries, arterioles and venules” (Churg Strauss Syndrome Association, 2003). It also causes asthma, numbness or pain in the extremities, sinus problems, a lingering cough, a rash, stomach problems, or symptoms of cardiac involvement (Churg Strauss Syndrome Association, 2003). With early detection, close medical supervision and management of the symptoms, the people affected by this syndrome have a better chance at continuing their activities and maintaining a good quality of life (Churg Strauss Syndrome Association, 2003).

Among other treatments, she was receiving chemotherapy, cortisone, steroids, and required frequent blood tests. We scheduled a date and time to meet in person for the interview, but she cancelled it. She described to me that her body was very swollen and she did not feel like herself, or perhaps “well disposed”, as Jean described. Talking had become a tiring and arduous task. She proposed that I send her my questions by email. This willingness to help me with my thesis, even if she did not feel at her best, demonstrates her resilience and determination to share her story.

As a health care professional in her former life, she brings her professional analysis of the care she received, describes the camaraderie she developed with her room-mates and the respect as an individual she received from her attending physician. The excerpts also introduce thematic understandings of her efforts to maintain some control of her care through searching on the internet, and her own understanding of the health care system as a social worker.

Answering the questions in writing from her home provided Marie-Ange with ample time to reflect on how she wanted to answer them. She supplied very intimate, personal, and rich details about her hospital stay and experiences as a patient that might not have been elicited through a traditional interview. She provides methodological insights into the different ways that patient voices can be expressed and heard. Furthermore, through numerous email exchanges, Marie-Ange and I developed a close bond and rapport that I did not experience with the other participants.

Searching for Answers on "Google"

Marie-Ange lives with her husband in Ahuntsic by the back river (Rivière des Prairies). Her past medical history includes bilateral total hip replacements in 2001 and 2002, and 2009 and 2010 she suffered multiple respiratory difficulties such as asthma, bronchitis and a chronic cough, and multiple infections such as chronic rhinitis, sinusitis, ear infections, conjunctivitis, vaginitis. In July 2010, her physical symptoms increased suddenly and dramatically and included major sleeping difficulties, a sinusitis, numbness in both legs, arthritic and muscle pains all over her body, skin wounds, mouth ulcers, and throat pain. She began spitting blood on July 17th, 2010. She went to the Thoracic Institute's emergency room on July 18th where she was diagnosed with pulmonary haemorrhage due to an underlying vasculitis. She returned the next day to meet with the same doctor.

> *Quand j'ai rencontré le [doctor] à l'Institut Thoracique le 18 juillet, il m'a dit qu'il croyait que je souffrais d'une vasculite mais qu'il ne savait pas laquelle. Il croyait que c'était une vasculite rare, difficile à diagnostiquer car elle reliait tous les symptômes apparemment non reliés dont je souffrais. Je lui ai demandé si c'était une maladie grave. Il m'a répondu, après avoir gardé un moment de silence, que ça se soignait. J'ai insisté pour avoir une hypothèse de nom de maladie mais il a refusé de se prononcer, maintenant qu'il ne le savait pas.*

> *When I met the [doctor] at the Thoracic Institute on July 18th, he said he thought I was suffering from a vasculitis but he didn't know which one. He thought it was a rare vasculitis, difficult to diagnose because it tied together all the symptoms I presented which seemed unrelated. I asked him if it was a serious disease. He answered me, after keeping silent for a moment, that it was treatable. I insisted on having a hypothesis of names of diseases but he refused to say anything, since he didn't know. (M-A, 65y, Int 2, 10/14/2010)*

Marie-Ange's fervent search to understand her symptoms helps me understand her meanings of "being a patient". In this excerpt, she details her first conversation with a doctor where she realized the seriousness of what was happening to her. Marie-Ange asked the doctor for possible diseases, but he did not have enough information to provide a diagnosis. She recalls how he held his breath and weighed his words before answering. Could he have known how sick she was? He scheduled a CT-scan. When she returned home, her need for answers continued. She used the doctor's words to search on Google, but was unsuccessful. Her symptoms increased dramatically the next day.

> *Le lendemain, le 19 juillet, de nouveaux symptômes alarmants sont apparus: une constriction importante à mes deux jambes des genoux aux pieds, une douleur importante au mollet droit devenu chaud et rouge, une sensation de marcher sur un coussin épais sous le pied gauche. Je marchais difficilement, comme un canard, les jambes écartées, avec beaucoup de douleur. J'ai cherché de façon différente sur Google en écrivant la liste de tous mes symptômes: « vasculite, maladie rare, troubles pulmonaires, asthme, sinusite, troubles musculaires et articulaires » : je suis aboutie sur la maladie de Wegener.*

> *The next day, July 19th, new alarming symptoms appeared: a severe constriction of both my legs from my knees to my feet, a severe pain to my right calf which became hot and red, a feeling of walking on a thick cushion under my left foot. I had difficulty walking, like a duck, with my legs spread, with lots of pain. I searched differently on Google by writing all of my symptoms: "vasculitis, rare disease, pulmonary troubles, asthma, sinusitis, muscle and articular difficulties": I fell on Wegener's disease. (M-A, 65y, Int 2, 10/14/2010)*

She remembered how the doctor said he was searching for a diagnosis that included all her unrelated symptoms: *"I listened to what the pulmonologist told me..." ("J'ai écouté ce que m'a dit le pneumologue..."; M-A, 65y, Int 2, 10/14/2010)*. Although the doctor could not provide a conclusive diagnosis, she alludes to the attention she paid to each word, trying to decipher what he might have wanted to say. After her scheduled CT-scan on July 20th at 9h30 in the evening, she presented herself to the emergency room of the academic hospital with her Google document on Wegener's disease at hand.

> *J'ai alors nommé la maladie de Wegener à l'infirmière du triage à l'urgence. J'étais*

> *I told the triage nurse in the emergency room that I had Wegener's disease. I was*

> *gênée de le faire mais je trouvais la description de la maladie si semblable à ce qui m'arrivait que je l'ai dit. Elle l'a notée.*

> *shy to do so but I found the description of the disease to really resemble what was happening to me that I said it. She wrote it down. (M-A, 65y, Int 2, 10/14/2010)*

She was admitted to the internal medicine ward on July 21st and underwent a battery of evaluations and tests in pulmonology, dermatology for a skin biopsy, otolaryngology for a nasal tissue biopsy, rheumatology and internal medicine. The variety of health care professionals consulted in evaluating her medical condition illustrates the complexity of the diagnosis of patients who present with multiple complications.

> *[E]n me faisant passer toutes sortes de tests diagnostiques, les médecins m'ont dit que je souffrais d'une vasculite rare auto-immune mais qu'ils ne savaient pas encore laquelle. Ils devaient discriminer entre la maladie de Wegener ou le syndrome de Churg et Strauss. J'ai demandé à mon mari d'imprimer le texte du syndrome de Churg et Strauss. J'avais maintenant en ma possession les textes parlant des deux maladies. J'ai alors lu sur les deux maladies tout en suivant le processus médical en cours.*

> *[W]hile going through all sorts of diagnostic tests, the doctors told me that I was suffering from a rare vasculitis auto-immune disease but they didn't know which one yet. They needed to differentiate between Wegener's disease or Churg Strauss Syndrome. I asked my husband to print the text on Churg Strauss Syndrome. I now had in my possession the texts that described both diseases. So I read up on both of the disease while following the medical tests that were being done. (M-A, 65y, Int 2, 10/14/2010)*

This was the first time Marie-Ange heard of Churg Strauss Syndrome. She needed to know more. Once her husband brought her the information, she appeared to feel more comfortable and confident. She was able to use both documents as a guide to anticipate the medical tests, follow what the health professions were doing and keep up with the rapid pace of their ongoing evaluations and reasoning, which, she says, raised reactions from the residents.

Heidi: Quel type d'information vous a aidé le plus?	*Heidi: What type of information helped you the most?*
Marie-Ange: Les textes internet auxquels je me référais pour comprendre ce qui m'arrivait. [...] Je me suis servie de ces textes comme balises pour comprendre la démarche évaluative des médecins. Ce fonctionnement a suscité des réactions de la part des résidents.	*Marie-Ange: The internet texts that I was referring to to understand what was happening to me. [...] I used these texts as a base to understand the doctors' differential diagnosis. This method created some reactions from the residents.*
Heidi: Quels types de réactions avaient-ils?	*Heidi: What type of reactions did they have?*
Marie-Ange: Le Dr J m'a dit que les résidents avaient réagi à ma recherche sans me spécifier leur réaction. Lui, de son côté, semblait plutôt amusé et intéressé par le côté pro-actif de ma réaction devant la maladie.	*Marie-Ange: The Dr. J told me that the residents reacted to my research without specifying the reactions. On his side, he seemed rather amused and interested by the proactive side of my reaction faced with the disease. (M-A, 65y, Int 1, 09/03/2010; Int 2, 10/14/2010)*

As a social worker, Marie-Ange knows that self-diagnoses are not always accurate, or well viewed by health care providers. This may be why she was so shy to tell the triage nurse in the emergency room that she thought she had Wegener's disease. Although it is important for the patient to be well educated and the internet does provide useful resources, the information can mislead a person into thinking they are sicker than they are. The internet could become the patients' primary resource for medical information and cause them to ignore the doctor's advice, or the person may visit many doctors to find the one whose diagnosis corresponds to the internet information obtained. Some health care professionals may become sceptical towards the patients who value the internet over their university-acquired knowledge, but some may use the patients' proactive approach as a teaching opportunity, explaining what is true or false about the information that was found. Marie-Ange knows the medical databases that provide scientific documentation and the methods for evaluating the quality of scientific research. Ignoring her concerns might have been an insult to her knowledge and background as a health care provider. Validating the information that was found is an opportunity to validate the needs and concerns of the patient with a *Fellow Human* voice. Once the person feels listened to, the health care provider may then use their *Doctor* voice to investigate the symptoms further (Cordella, 2004).

When recalling the medical resident in charge of her case on the internal medicine ward, Marie-Ange remembers a *Fellow Human* voice, which she appears to favour the most. I ask her: "What was the most significant part of your hospital stay? Did someone say something to you that was a turning point in your hospital stay?" She answers by double voicing the dialogue she had with the resident.

Docteur: [Madame], j'ai une question importante à vous poser. Selon vous, comment ça se passe dans votre corps?	*Doctor: [Madam], I have an important question to ask you. What do you think is happening in your body?*
Marie-Ange: Je lui réponds que tout évolue bien. J'ai retrouvé l'usage de mes jambes mais je ne suis pas certaine du tout de la bonne évolution de mes poumons: je crache	*Marie-Ange: I answer her that everything is going well. I have the use of my legs again but I'm not sure about the good evolution of my lungs; I'm still spitting*

encore du sang, je ressens une impression de compression au niveau de mes poumons. Elle m'envoie passer une nouvelle radiographie pulmonaire dans les minutes qui suivent.	*blood, I feel a sensation of pressure at my lungs. In the next minute she sent me to get new x-rays of my lungs. (M-A, 65y, Int 1, 09/03/2010)*
Docteur: [Madame], que retenez-vous de ce que je viens de vous expliquer (après m'avoir expliqué que je suis très malade et les impacts de ma maladie sur ma vie quotidienne future)? *Marie-Ange: Je lui répète en mes propres mots ce que je comprends de ses explications. Elle peut alors vérifier ma propre compréhension et réajuster ses dires. Elle estime que je pense à trop long terme et que je dois me concentrer sur les décisions les plus immédiates plutôt que sur les impacts à plus long terme.*	*Doctor: [Madam], what do you recall from what I just explained to you (after explaining to me that I am very sick and the impacts of my disease on my future daily life)?* *Marie-Ange: I repeat in my own words what I understand from her explanations. She can then verify my comprehension and adjust what she wants to say. She feels that I am thinking too long term and that I need to concentrate on the immediate decisions rather than the long term impacts. (M-A, 65y, Int 1, 09/03/2010)*
Marie-Ange: Je demande: Est-ce que ma vie est en danger? Elle s'assoit sur le bord de mon lit, à côté de moi, et nous échangeons sur cette question un bon 15	*Marie-Ange: I ask her: Is my life in danger? She sits on the side of the bed, next to me, and we have an exchange about this question for a good 15 minutes in the*

minutes en présence d'une de mes amies, témoin important de cet échange.	*presence of my friend, an important witness to this exchange. (M-A, 65y, Int 1, 09/03/2010)*
Docteur: [Madame], quelles sont vos préoccupations majeures pour votre sortie de l'hôpital? *Marie-Ange: Elle m'encadre, me ramène à mes besoins immédiats. Elle me fait faire une discrimination entre des choses de base et des préoccupations plus lointaines*	*Doctor: [Madam], what are your biggest preoccupations about your discharge from hospital?* *Marie-Ange: She frames me, brings me back to my immediate needs. She makes me discriminate between the basic things and the long term preoccupations. (M-A, 65y, Int 1, 09/03/2010)*

This medical resident may have used a *Doctor* voice and then an *Educator* voice at some point in the dialogue however, Marie-Ange especially recalls the attention that was paid to her needs at the start of their conversations. The resident uses a *Fellow Human* voice to verify how she understands her care by asking *"According to you..."*, *"What do you remember..."*, *"What are your biggest preoccupations..."*, and by sitting on the side of Marie-Ange's bed to *"exchange"*, or devote herself to the conversation. This resident also respected Marie-Ange's knowledge and allowed her to have some control over her situation by providing her with conversational space to express how she felt. The type of questions she asked and the intuition she seemed to demonstrate toward Marie-Ange's psychological needs, demonstrate the patient-centered care approach this particular resident embraced with Marie-Ange. Not surprisingly, when I ask Marie-Ange to recall a significant moment in her hospital stay, she recalls the presence of this resident.

In being so tenacious in searching for her own answers on the internet and in the way she responds to the resident’s questions, Marie-Ange alludes to her preferred *Complier* and *Initiator* voices. Patients with the *Complier* voice demonstrate that they “understand the doctor’s instructions and their own responsibilities and [are] able to report that they [have] successfully carried out” what was asked of them (Cordella, 2004, p. 157). *Initiators* “seek information about their health condition [and] acknowledge that they lack the necessary knowledge to deal with their health problem” (Cordella, 2004, p. 171). They call upon the doctor’s expertise to answer their questions. However, Marie-Ange also appears to present a little *Social Communicator* voice. *Social Communicators* tend to describe their responsibilities as carers in the interview, or personal and emotional difficulties that are impinging on their physical health (Cordella, 2004, pp. 165, 170). A patient may “raise issues that relate to their social identities and experiences” in the course of the conversation (Cordella, 2004, p. 165). Marie-Ange’s *Social Communicator* voice does not disclose any difficulties in her family or a role as a caregiver, but frequently mentions her husband, children, and friends. With further investigation, one might wonder if Marie-Ange would have described any concerns she had towards her role in the family, how her illness might affect them, and how this may impact her capability to take time for herself.

Another voice Marie-Ange presents, which Cordella does not describe, is a voice I describe as that of *Knowledge* or *Reasoning*. Marie-Ange presents a deeper insight into and understanding of the questions that are asked that might be explained by her previous role as a health care professional. She appears to take in the information that is given to her, analyze it from various points of view, and then make a decision about what she understands the information to mean and how it applies to her. For example:

Dr J: Comment vous sentez-vous avec ce diagnostic (du Syndrôme Churg et	*Dr. J: How do you feel with this diagnosis (of Churg Strauss Syndrome)?*

Strauss)?	
Marie-Ange: Je sais que c'est une maladie grave mais qui donne une réponse à toutes mes questions.	*Marie-Ange: I know it's a serious disease but it gives me answers to all my questions. (M-A, 65y, Int 1, 09/03/2010)*

Here, Marie-Ange appears to separate the personal and clinical reasoning behind the final diagnosis. It is a serious disease which will affect her life, but at least she had been given the answers she has been searching for. Being a health care professional may not necessarily make a diagnosis any easier to understand, but might have quickened the reasoning behind the diagnosis and her acceptance of its implications.

After eight days of medical tests and life-changing news, Marie-Ange still uses a sophisticated *Knowledge* or *Reasoning* voice to describe her final analysis of her hospital stay. She comments to Dr. J: *"I told him that I felt very comfortable with the philosophy of the hospital that I had experienced during my stay" ("Je lui ai dit que je me sentais très à l'aise avec la philosophie de soin de l'hôpital telle que je l'avais vécue lors de mon séjour"; M-A, 65y, Int 1, 09/03/2010).* As a social worker training other social workers, Marie-Ange may have used her previous knowledge to clinically reason her diagnosis, and critically analyze the work of the health care team. Her professional background might have been a source of security for her to understand the functions of ward, and provide her with a certain sense of control over the unknown aspects of her condition, along with information from the internet.

The texts "provided me a certain control".

Marie-Ange used two distinct methods to help her regain control over her care and body: 1) information from the internet, and 2) encouragement from the medical resident and Dr. J.

Searching on the internet has become a popular way for people to obtain quick information about ailments or medical conditions. This was not only Marie-Ange's way of obtaining information, but a deliberate strategy she used to maintain a certain control over a situation she knew nothing about.

Une recherche sur Google me mène à la maladie de Wegener. Ce texte sera déterminant pour moi car il me permettra de devancer ce que me diront les médecins et de me procurer ***un certain contrôle*** *sur ce qui m'arrive.*	*A research on Google brought me to Wegener's disease. This text was determinant for me because it helped me to anticipate what the doctors were going to say and provide me with* ***a certain control*** *over what happening to me. (M-A, 65y, Int 1, 09/03/2010)*

Marie-Ange emphasizes "a certain control". As Mary also described, having information provided Marie-Ange with some control over her care, not all of it, but just enough. Prior to her admission and her search on the internet, she describes a complete loss of control over her body.

Heidi: Est-ce que vous vous sentiez en perte de contrôle (avant, durant ou après votre séjour)? Est-ce que vous sentez que vous avez repris contrôle?	*Heidi: Did you feel that you had lost control (before, during or after your stay)? Do you feel that you regained control?*
Marie-Ange: Je me sentais en perte de contrôle avant mon hospitalisation. Je trouvais que mes symptômes évoluaient de façon fulgurante et je ne comprenais pas ce qui m'arrivait tout en réalisant que ça semblait grave. J'ai tenté de retrouver un certain contrôle en m'informant sur ce qui m'arrivait, en lisant et en me réjouissant	*Marie-Ange: Before my admission I felt a loss of control. I found that my symptoms were progressing rapidly and I didn't understand what was happening to me while realizing that it seemed serious. I tried to regain a certain control by informing myself on what was happening to me, by reading and by rejoicing to find a possible disease hypothesis on the*

> *d'avoir identifié une hypothèse plausible de maladie sur internet…C'est très subjectif comme sentiment…Durant ma semaine d'hospitalisation, j'ai eu à gérer le choc de me découvrir très malade et même d'envisager un décès possible. J'ai essayé de conserver le contrôle de ce que je pouvais contrôler (surtout mes relations avec mon conjoint et mes enfants, avec le personnel soignant) et de lâcher prise sur le reste (l'évolution de la maladie et du traitement).*

> *internet...It is a very subjective feeling...During the week I was hospitalized, I had to manage the shock of discovering that I was very sick and even considering a possible death. I tried to keep the control on what I could control (especially my relations with my husband and my children, and the health care professionals) and to let go of the rest (progression of the disease and the treatment). (M-A, 65y, Int2, 10/14/2010)*

She used the internet to provide her with a sense of ownership over the symptoms was experiencing. She describes rejoicing when finding possible answers to her symptoms, recognizing this feeling as dubious in a sense. In shock, she contemplated her possible death. She might have used a stronger *Knowledge* or *Reasoning* voice which brought her to reason that the only thing she could really do was concentrate on her *Social Communicator* voice by focusing on her family and friends, and "let go" of the rest. She alludes to a deep understanding and reflected process of "letting go", which involves accepting what could happen to her. Was she at peace with her possible death?

Another important factor in regaining control over her care was the health care professionals who respectfully empowered her to take that control. By using a *Fellow Human* voice, the medical resident provides Marie-Ange with opportunities to lead her care, encouraging her to think about long-term goals and reorganizing her life after discharge. She warmly recalls her first encounter with Dr. J on the internal medicine ward as another important part of regaining control during her hospital stay.

> *Le Dr J est venu dans ma chambre pendant ma rencontre avec l'équipe de rhumatologie. Je l'ai salué et je lui ai demandé qui il était. Il s'est présenté comme étant le Dr J [sur] l'étage [de] médecine interne. Il m'a saluée, a salué mon mari et m'a dit: "Je viens rencontrer la personne qui est arrivée à l'urgence avec son diagnostic de maladie rare. Comment avez-vous fait?" J'ai souri.*

> *The Dr. J came into my room while I was meeting the rheumatology team. I greeted him and asked him who he was. He presented himself to me as being Dr. J [on the] internal medicine [ward]. He greeted me, greeted my husband and told me: "I come to meet the person who arrived at the emergency room with their diagnosis of a rare disease. How did you do it?" I smiled. (M-A, 65y, Int 1, 09/03/2010, Int 2, 10/14/2010)*

By using a *Fellow Human* voice in their first encounter, Dr. J appears to have created a line of trust with Marie-Ange. Instead of coldly answering her question of "Who are you?" with a *Doctor* voice, he chose to affirm his partnership in her care by admiring how she found her own diagnosis. She fondly recalls her encounters with Dr. J as important moments of her hospital stay, and appreciates how he respected her knowledge and capacity to understand.

> *Reconnaissance de ma compétence, d'un certain pouvoir que j'ai sur ce qui m'arrive. Il n'est pas condescendant, méprisant. Il reconnaît mon intelligence, ma capacité de comprendre, de faire du sens.*

> *Recognizing my competence, of a certain power I had over what was happening to me. He wasn't condescending, scornful. He recognized my intelligence, my capacity to understand, to make sense. (M-A, 65y, Int 1, 09/03/2010)*

Here, Marie-Ange describes Dr. J as being patient-centered. He "brings into focus the uniqueness of [Marie-Ange], respectful of what [she has] accomplished and compassionate to what [she has] endured (Kitwood, 1997, p. 135). Dr. J appears to be using a patient-centered care approach to make it possible for Marie-Ange to express herself in the medical diagnosis process as a person with a unique story and a health professional past (McWhinney, 2001, p. 15). Marie-Ange comments that Dr. J was surprisingly not "condescending" or "scornful". Recall that Mary similarly asked health professionals not to be sarcastic, although she refers specifically to the type of care she had received. Here, Marie-Ange does allude to health professionals who were scornful, but was perhaps was simply surprised by the positive responses she received towards her being so proactive. This depicts her understanding of how some professionals can be less patient-centered, especially when they face internet-savvy patients. She appreciated being given opportunity to show how she understood her care, and being respected for it.

Marie-Ange describes another encounter with Dr. J which empowered her control.

Dr J nous explique à mon mari et moi la gravité de mon état, les risques encourus, le traitement choisi et ses motifs, les conséquences possibles, sa possible impuissance. Il ne cache rien, est honnête et transparent, il me considère comme une personne à part entière responsable de mon propre corps.	*Dr. J explained to my husband and me the gravity of how sick I was, the possible risks, the treatment chosen and his motives, the possible consequences, his possible lack of power. He hides nothing, is honest and transparent, he considers me like a whole person responsible for my own body. (M-A, 65y, Int 1, 09/03/2010)*

Two months after this event, she still fondly remembers his disposition towards her and her husband, and feeling important and valued in the conversation. This dialogue appears to have led her to feel acknowledged, listened to, and empowered to continue to be proactive in her care, even if the information was difficult for her and her husband to hear. Dr. J appears to have used this occasion to educate and empower Marie-Ange with both the *Educator* and *Fellow Human* voices, a pattern he continues throughout her hospital stay. She adds:

Je me suis sentie considérée membre à part entière de l'équipe médicale. Je n'ai pas senti de condescendance de la part des médecins, j'ai senti au contraire beaucoup de respect pour la personne que j'étais.	*I felt that I was considered as a part of the medical team. I did not feel condescendence on behalf of the doctors, on the contrary I felt very respected for the person that I was. (M-A, 65y, Int 1, 09/03/2010)*

Although Jean and Mary also describe feeling respected, they never described themselves as part of the medical team. Marie-Ange appears to have been given a privileged position some patients only dream of: that of being the center of her care. Up to this point it could be inferred, that Marie-Ange lived the perfect patient-centered care approach. This makes me wonder how much she perceived herself as a patient and how much she perceived herself as a health care professional. Since Marie-Ange is used to working within a hospital environment, consulting doctors and participating in medical dialogues may have been natural to her, aside from being the one who was discussed. She does not appear to be intimated by health care professionals, is used to their ways of working and understands their roles.

Heidi: Quel type d'information vous a aidé le plus?	*Heidi: What type of information help you the most?*
Marie-Ange: J'ai beaucoup apprécié entendre les échanges entre les résidents et leur patron. On ne s'adressait pas directement à moi en tant que patiente mais	*Marie-Ange: I really appreciated hearing the exchanges between the residents and their boss. They weren't speaking directly to me as a patient but I could follow their*

je pouvais suivre leur processus évaluatif.

Heidi: Est-ce qu'ils parlaient de vous devant vous mais sans vous adressez la parole?

Marie-Ange: Les médecins s'adressaient à moi quand ils m'expliquaient leurs questionnements et leur démarche de recherche. Par contre, quand je passais un test, le résident en apprentissage s'adressait à son patron et l'échange se faisait entre eux. Ce n'est qu'à la fin des tests que le patron s'adressait à moi pour faire la synthèse.

differential diagnostic.

Heidi: Were they talking about you in front of you without speaking to you?

Marie-Ange: The doctors were speaking to me when they were explaining their thinking and research process. However, when I had a test, the resident in training would speak to their boss and the exchange would happen between the both of them. It was only at the end of the tests that the boss would speak to me to tell me the synthesis. (M-A, 65y, Int 1, 09/03/2010, Int 2, 10/14/2010)

An indication of her professional understanding of hospitals is how she refers to residents as “residents”. Not all patients know what a resident's role is. Another indication of her understanding is how she describes being spoken about but not directly to, yet following the discussion clearly. Rather than being insulted, she appreciated listening to the conversation as a spectator, but participant in some way. She felt privileged to take part in the doctors' reasoning processes, and observe how the resident was learning from her “boss”. Perhaps analyzing their communication style? Observing the way the physician was teaching the resident? She demonstrates a deep understanding about the hospital system and how comfortable she is within it.

Still, her professional experience could not prepare her for the challenges of “being a patient”. During her eight hospital days, Marie-Ange had to adapt to constraints and, as she describes, “aggressions” of hospital institutional life.

Moulding into “constraints and aggressions”.

Marie-Ange’s reflections on her hospital stay allude to various systemic issues. In her definition of “being a patient”, she makes reference to the challenges of having to adapt to the inadaptable environment that is characteristic of institutional cultures such as a hospital system.

> *Un patient: Celui qui reçoit des soins. De façon subjective: Une personne impatiente en détresse qui doit être très en bonne santé pour se mouler à toutes les contraintes et agressions du système hospitalier et en sortir guérie des maux qui l’affligent et l’inquiètent!!!*

> *A patient – the one who receives care. Subjectively – An impatient person in distress who needs to be in good health to mould to all the constraints and aggressions of the hospital system and to exit healed of the pains that afflict and worry them! (M-A, 65y, Int 1, 09/03/2010)*

Here, Marie-Ange first describes a patient very superficially as someone who receives care, similar to Marco’s definition. However, she elaborates the definition further, carefully selecting her words, alluding to the difficulties she experienced as a patient. First, she describes a patient as an *“impatient person”* wanting to get better sooner than later, in *“distress”* over what they are experiencing. Ironically, she continues that a patient *“needs to be in good health”* in the hospital. Being healthy while being ill is quite the oxymoron. However, she adds that a certain health is needed in order *“to mould into the many constraints and aggressions of the hospital system”*. By being a littler healthy, it is easier to “mould” into the hospital system and keep up with its fast pace and demands on patients. Marie-Ange might be making reference to the fact that she was too ill to “mould” and wishes she had, or she was able to “mould” and is making reference to the patients she witnessed who had to submit themselves to moulding. A patient must do this *"to exit without the pain that once afflicted and worried them"*. Her reference to discharge appears to be more of a plea to get out, to leave, and to rush home as soon as possible. She alludes to a difficult and rushed hospital stay where, in her view, a patient needs to get in, get treated, and get out as soon as possible. One might ask what kind of "constraints and aggressions" she experienced, which appear to have influenced this hard definition. In her texts, she details some of these difficult experiences.

Constraints.

She describes the constraints as situations in which the patient was required to accommodate the functions of the hospital system, rather than the hospital system adapting to the needs of patients.

Le patient est au service du roulement hospitalier et non l'inverse: horaires de travail, organisation des équipes de travail et des unités de soins, cédules des rendez-vous dans les différents départements, fonctionnement des brancardiers, etc.	*The patient is at the service of the hospital and not the other way around: working schedules, organizations of the working teams and the units of care, scheduling appointments in different departments, functions of the porters, etc. (M-A, 65y, Int 1, 09/03/2010)*

Here, she describes work functions that may not necessarily involved direct patient care, but certainly affect it. One might wonder how the work schedules and hours were ever created, and if they were originally planned with the patients in mind. She reiterates the importance of these functions:

Heidi: Si vous aviez à rencontrer un futur patient de l'hôpital, qu'est-ce que vous lui	*Heidi: If you were to meet future hospitalized patients, what would you tell*

diriez pour l'aider durant son séjour (vos « words of wisdom »)?	*them to help them during their stay (your "words of wisdom")?*
Marie-Ange: De l'information sur le fonctionnement de l'étage:	*Marie-Ange: Some information on the functions of the ward:*
• utilisation du téléphone: une ligne pour l'ensemble des trois patients (Qui répond? Pour qui?)	*• using the telephone: one line for a group of three patients (Who answers? Who is it for?)*
• horaires du personnel	*• the schedule of the personnel*
• roulement du personnel	*• the change of personnel*
• organisation concrète: cloches, lumières de lit, horaire des repas, services de bénévolat, etc.	*• concrete organization: the bell, bed lights, meal schedule, volunteer services, etc.*
• organisation centrée à partir des horaires du personnel et non du patient	*• organization centered on work schedules and not on the patient. (M-A, 65y, Int 1, 09/03/2010)*

Of all recommendations she could make to future patients, the simple day-to-day activities is what Marie-Ange believes is the most important information to know. In the last bullet, she repeats how the hospital is *"centered on the work schedules and not on the patient"*. In the first part of her interview Marie-Ange was describing patient-centered care examples in her interactions with the medical resident and Dr. J, but here she alludes to an entirely different aspect of what might be included in the broader definition of patient-centered care. Not the individual patient-professional relationships, but rather the functions of the work schedules and the organization of day-to-day activities of the hospital as an institution. She alludes to disconnects that may exist between the desire to be patient centred and the reality of how it is exerted in practice. Marie-Ange felt a patient-centered care approach on the ward, but also felt constrained by the functions of the hospital system that was not adapting to her needs as a patient. If the mission of the hospital is to provide a patient-centered care approach, the entire structure of it system should also be constructed on this approach. Although she does not elaborate, one might infer that other examples of such constraints would involve being woken up at all hours of the night for medical tests or being evaluated by the health care team at a time that suits their routine, rather than being related to how the patient feels.

The second constraint Marie-Ange alludes to is the vulnerability she has on the decisions the health care team takes on the direction for her care. Still involved in the decision-making process, she describes how she could receive contradictory messages from those who were in charge.

Heidi: Pouvez-vous me décrire comment vous receviez de l'information de l'équipe médicale: verbal ou par écrit?	*Heidi: Can you describe to me how you received information from the medical team: verbal or written?*
Marie-Ange: On me transmettait verbalement les résultats des différents tests: analyses sanguines, d'urine, taux d'éosinophiles dans mon sang, etc.	*Marie-Ange: The results of different tests were transmitted to me verbally: blood tests, urine, eosinophile levels in my blood, etc.*
Heidi: Est-ce que vous deviez attendre longtemps avant d'avoir des résultats? Est-ce que c'est Dr. J qui vous donnait la synthèse des résultats?	*Heidi: Did you have to wait long to get the results? Was it Dr. J who gave you the interpretation of the results?*
Marie-Ange: Chacun des médecins (et résidant) me transmettait sa propre	*Marie-Ange: Each doctor (and resident) would give me their own information day by day. I could receive different information in*

> *information au jour le jour. Je pouvais recevoir des informations différentes la même journée, de la part de deux spécialistes différents. (Par exemple, le vendredi, la pneumologue et le Dr Wiseman estimaient urgent que je reçoive un traitement de chimiothérapie le samedi alors que le rhumatologue me disait que ce traitement pouvait attendre au lundi). Je me sentais très impliquée dans le processus.*

> *the same day, from two different specialists. (For example, the Friday, the pulmonologist and Dr. J felt it was urgent that I get a chemotherapy treatment on Saturday whereas the rheumatologist was telling me that this treatment could wait until Monday). I felt really involved in the process. (M-A, 65y, Int 1, 09/03/2010, Int 2, 10/14/2010)*

Marie-Ange describes receiving the interpretations of her medical tests on a daily basis, whereas participants Marco and Mary described waiting a long time for results. Her experience could reflect the severity of her diagnosis where every day played a critical role. It could also reflect the philosophy of practice of those in charge of her care, since Marco and Mary were not treated by Dr. J, or the same medical resident. Marie-Ange then describes how she would receive different information from different health care professionals, often on the same day. Although she describes being really involved in her care as a result, receiving conflicting information can be very confusing for patients, especially if the decision involves a treatment such as chemotherapy. As seen with the participants Marco and Mary, receiving conflicting messages can be very frustrating because they do not know whom to believe or listen to, and ultimately feel like no one is in charge of their care. Marie-Ange also alludes to the lack of communication that can occur when more than one health care professional is involved in one patient's care. This issue connects to Marie-Ange's *Knowledge* or *Reasoning* voices and her ability to interpret the diverse perspectives of different professionals. Because of the line of trust that was initially developed between Marie-Ange, Dr. J and the medical resident, she had faith that the right decision for her care would be made, and trusted their decisions.

A third constraint Marie-Ange alludes to was having to communicate her symptoms in English, which is not her first language. Marco first described this constraint and the important power and authority issue language barriers involved. English is a powerful language, but when it is the only language used with linguistically diverse patients, they may feel even more vulnerable and unable to express their real patient voice.

> *Marco: [...] I've been fortunate, they [health care professionals] have been very cooperative with me, but I look at others.*
>
> *Heidi: And it's not the same?*
>
> *Marco: They forget a lot of people don't understand the language and have a problem with the language too. How you can cooperate with somebody that doesn't know the language? (Mc, 79y, 06/24/ 2010)*

During my year as a physiotherapy student - not on this ward - I observed a resident enter the room of a Chinese patient without an introduction, auscultate her lungs, move her at his will, and leave her distraught with her hospital gown unbuttoned and one breast exposed. Language barriers are present in Montreal for those who speak neither French nor English, or who are addressed in one of the majority languages but not the one that is their mother tongue. Marie-Ange is bilingual, but more experienced in French. She was admitted to this academic hospital which is purports to be a bilingual institution, but offers services primarily in English. Having to express herself repeatedly in English was a constraint during her stay, especially when she was not feeling at her best, or well disposed, as Jean phrased it.

She describes a language constraint on two different occasions for two different questions. Both involved the role of this academic hospital has a as teaching institution and its social accountability mission.

> *Heidi: Pouvez-vous me décrire comment vous avez vécu votre séjour à l'hôpital (vos impressions du travail de l'équipe)?*
>
> *Marie-Ange: Pour chaque discipline, je devais rencontrer le résident et son accompagnateur stagiaire et ensuite le patron [le docteur]. Ces rencontres furent très exigeantes pour moi: m'exprimer souvent en anglais (car la plupart de résidents ne parlaient qu'anglais), répéter l'histoire de l'apparition de mes symptômes et les relier à mon histoire médicale antérieure, passer de longs examens dans une position physique souvent inconfortable qui exacerbait mes symptômes, répéter pour le médecin principal qui heureusement parlait la plupart du temps ma langue et ce, sans avoir le temps de me reposer et de récupérer.*

> *Heidi: Can you describe to me your hospital stay (your impressions on the team work)?*
>
> *Marie-Ange: For each discipline, I needed to meet the resident and their medical student and then the boss [the doctor]. These meetings were really demanding for me: expressing myself frequently in English (because most resident only spoke English), repeat the story of how my symptoms appeared and relate them to my past medical history, go through long exams in a physical position that was often uncomfortable, exacerbating my symptoms, repeat this for the doctor who thankfully spoke my language most of the time, and this, without having the time to rest and recuperate. (M-A, 65y, Int 1, 09/03/2010)*

At this point, I had not asked Marie-Ange to describe a difficult moment. She describes having to linguistically accommodate the requests of the residents and medical students who only spoke English. As a person with a rare disease, Marie-Ange might have attracted students from various medical fields who wanted to observe her for themselves. A patient is usually visited by many professionals during a hospital stay; her diagnosis might have intrigued more medical visitors than usual. Even if her past medical history and symptoms were described in her medical chart, each student might have wanted to ask their own questions and make their own evaluations, which forced Marie-Ange to repeat herself in English on more occasions than usual. Although she could express herself in French to the attending doctor, the energy she needed to express herself in English to accommodate the bedside teaching of the medical groups left her exhausted.

In addition, she states being placed in physically uncomfortable positions for evaluations, and then sustaining these positions to accommodate the residents' teachings. As a teaching hospital, residents from various medical fields and medical students are placed on rotations to gain experience in different fields of medicine. When I ask her to recall a difficulty moment during her hospital stay, she chooses to reiterate this experience.

Heidi: Est-ce qu'il eu des situations, ou personnes, qui vous ont défiés plus que d'autres? C'est-à-dire, des moments plus difficiles à surpasser?	*Heidi: Was there a situation, or person, that challenged you more than others? That is, moments difficult for you to go through?*
Marie-Ange: La nécessité de devoir reprendre mon histoire [en anglais] avec chaque nouveau résident de chaque nouvelle équipe de soins, ensuite avec chacun des [docteur], entendre et attendre le [docteur] enseigner à son résident en ma	*Marie-Ange: The need to retell my story [in English] to each new resident from each new medical team, then with each [doctor], listen and wait for the [doctor] to teach his resident in my presence (a long process because I had to remain in the*

> *présence (processus long car je devais demeurer dans la position immobile requise pour le test sans qu'on se préoccupe de mon confort) et reprendre le même processus avec la résidente chargée de la synthèse le soir.*

> *fixed position needed for the test without anyone being concerned about my comfort) and go over the same process with the evening resident. (M-A, 65y, Int 1, 09/03/2010)*

Marie-Ange's physical discomfort alludes to the physical strain of being a patient in a teaching hospital. The patients do not want to be rude by refusing a student, but might be left to manage physical discomforts greater than prior to when student arrived. Ideally, patient-centered care should be modelled by the supervisor who should not have left Marie-Ange in uncomfortable positions, and demonstrated a concern for her comfort at all times.

These examples of constant re-evaluations and exacerbations of symptoms could have interchangeably been described as a physical and emotion aggression, of Marie-Ange provides further examples.

Aggressions.

In Marie-Ange's short and overall positive hospital stay, she describes instances that brought feelings of irritation to her experience of "being a patient". I ask her: *Was there a situation, or persons, which challenged more than others? That is, moments that were difficult to go through?"* She answers with a variety of hospital events which initially involves her first night in hospital.

> *Me faire réveiller à minuit et quart le soir du 21 juillet pour m'expliquer l'hypothèse retenue. Je dois cependant dire que cet événement a constitué à la fois un irritant et*

> *Being woken up at 12:15am the night of July 21st to have hypotheses explained. I have to say, though, that this event was both an irritant and a strong moment in my*

> *un temps fort de mon séjour à l'Hôpital.*

> *hospital stay. (M-A, 65y, Int 1, 09/03/2010)*

This utterance demonstrates the sacrifices patients have to make when they enter the hospital system. Unfortunately the medical team could not wait for Marie-Ange to get a good night of rest before speaking to her about the diagnosis. Marie-Ange appears to acknowledge this, even if it was difficult for her to take in the information at such a late time after an exhausting day.

Sleep, or rather the lack of sleep, is a frequent complaint and irritant for hospitalized patients. Marie-Ange describes one instance she felt was particularly disrespectful.

> *Les soignants qui arrivent à n'importe quelle heure du jour et de la nuit, ouvrent les lumières et parlent au patient sans se préoccuper des autres patients qui tentent de dormir.*

> *Health care providers that arrive at any hour of the day or night, turn on the lights and speak to the patient without being concerned about the other patients that are trying to sleep. (M-A, 65y, Int 1, 09/03/2010)*

IMAGINED SCENARIO: SLEEPING IN A HOSPITAL

You share a room with three other people you do not know, who need various levels of care. All that separates you and them is a curtain. Everyone is seen by approximately ten different professionals a day for their needs. You spend your days confined to a bed because you are too weak to get up on your own, so you are aware of what everyone in your room is saying and everyone can hear what you are saying. Night comes. You slowly doze off when the evening health care team wants to introduce themselves to you, so they wake you up. One of your room-mates needs to go for an MRI at two o'clock in the morning, so the attendees turn on the ceiling lights to wheel the hospital bed out of

> the room. At five o'clock your other neighbour is yelling for the nurse. An emergency is announced over the ward intercom at six o'clock. At seven, the day health care team begins their morning rounds and they want to assess how you are doing. At eight breakfast arrives and the day starts over again. Now imagine this every night for a week or more. Not to mention hospital beds are not comfortable, you are connected to various tubes that prevent you from moving, and you have not showered in two days. How irritable would you be? How do you think this affects your stay?

The health professionals who turned the ceiling lights on demonstrated a definite lack of consideration for others. It is questionable whether or not all three patients of the shared room needed to be awoken for the attendants to speak to one. This challenges the system of four beds in one room as a part of institutional life, and how little healing room it provides healing room for each person. Needless to say sleeping time is precious and rare. Marie-Ange provides another example in answering the same question:

> *Un brancardier avait la parole trop facile. Il était en guerre avec le fonctionnement du système hospitalier et documentait des erreurs médicales qu'il voulait dénoncer…Il me racontait ses commentaires personnels à ce sujet…Pas trop rassurant pour la patiente…Par contre, j'ai rencontré plusieurs brancardiers étudiants universitaires très intéressants.*

> *A porter who was too liberal with his words. He was at war with the medical system and was documenting medical errors he wanted to report...He was telling me his personal comments about the subject...Not too reassuring for the patient...However, I met many university student porters who were very interesting. (M-A, 65y, Int 1, 09/03/2010)*

Here, the porter displayed professional irresponsibility by sharing his personal opinion with patients who were at his mercy for transportation. One can only imagine the worry of a patient, already vulnerable by even being a patient, who is then forced listen to his comments about the hospital's medical mistakes. Even with her professional background, Marie-Ange found herself concerned by the porter's comments. With her *Reasoning* voice, Marie-Ange knew that this was just one porter and acknowledges that not all are the same. The cleaning team, the sitters, the porters, and the volunteers all come into contact with vulnerable patients and may not realize how their voices also have an impact on patient stay. They too have a role in the patient-centered care approach, just as much as the other professionals do.

Marie-Ange's final example, still in response to the same question, was on her last day on the ward when all her roommates had left and a new patient was admitted to the same room.

> *Le dernier jour de mon hospitalisation, j'ai perdu mes deux co-locs de chambre et accueilli une nouvelle personne dans le lit voisin du mien. J'ai dû jouer auprès de cette personne le rôle d'une initiatrice du fonctionnement de l'étage…Cette personne se servait de moi comme d'une dame de compagnie…J'étais d'une certaine façon volontaire à jouer ce rôle mais je devais mettre mes limites pour ne pas faire abuser de moi.*

> *The last day of my hospitalization, I lost both of my roommates and welcomed a new person in the bed next to mine. I had to play the role of initiator to the functions of the ward for this person…This person was using me like her "accompanier"…In a certain way I was voluntary to play this role but I had to set some limits so that I wouldn't be taken advantage of. (M-A, 65y, Int 1, 09/03/2010)*

Here, Marie-Ange was placed in a situation where her new room-mate relied on her to learn about the daily functions on the ward. Happy to help, Marie-Ange shared what she knew about the phone and the work schedules, but had to place a limit to this role so as not be used as a hospital worker. She alludes to the lack of preparedness patients might experience about the functions of a ward, or the difficulties in adapting to them. She also refers to the lack of information patients receive when they are first admitted to a ward and the necessity for them to fend, learn, and adapt on their own.

Aside from this new roommate, Marie-Ange shared a room with two other patients she describes as being a key part of her support system during her stay on the ward, along with her husband.

We “mutually supported” one another.

Marie-Ange relies on multiple people for support during her hospital stay. In her first description of her hospital stay, Marie-Ange details the personal interactive connections she develops with her room-mates during her stay on the ward. She writes:

> *Il s’est rapidement dégagé une dynamique d’entraide entre les trois patients de notre chambre: un homme de 94 ans bilingue gavé depuis quelques semaines et en attente d’une intervention chirurgicale risquée à la gorge, une dame d’origine Jamaïcaine anglophone de 80 ans avec un problème de circulation sanguine dans une jambe et moi. Nous vivions tous les trois des problèmes de santé vitaux et nous débattions avec des enjeux vie-mort. Nous possédions le même type de lucidité et d’intelligence consciente. Nous avons rapidement développé une communication allant à l’essentiel:*

> *A dynamic of mutual aid was quickly developed between the three patients in our room: a 94-year old bilingual man on feeds for the past couple week while waiting for a risky surgery at the throat, an 80-year old English lady from Jamaica with a blood circulation problem in one leg, and me. The three of us were living vital health problems and were fighting with situations of life and death. We possessed the same type of lucidity and conscious intelligence. We quickly developed a communication that went straight to the essentials: surviving, to*

> *survivre, nous soutenir mutuellement et favoriser les éléments positifs de notre situation.*

> *mutually support one another and to favour the positive elements of our situations. (M-A, 65y, Int 1, 09/03/2010)*

Connected through their illnesses, Marie-Ange describes a "mutual aid" that was developed between her and her room-mates. They develop their own support group and used one another to remain positive. She makes reference to the amazing human bond that can be created between people in times of need. She also makes reference to the importance of having a support system, whether it is through family or room-mates, in order to push through difficult moments such as a hospital admission. Considering patients can spend day and night lying next to each other displaying their bodies at their weakest, the people with whom patients share a room may make a big difference their overall hospital experience. Marie-Ange was fortunate to be in the same room as people she describes as exhibiting the same *"lucidity and intelligence"*. She was able to share and discuss her thoughts with her room-mates, which might have provided them with a distraction, rather than dwelling on being so ill. Having each other may have also provided them with extra support in times where family members were unavailable, or full support for those having no family.

The next person whom she describes receiving support from, and perhaps the most important, is her husband. Marie-Ange relies on her husband to bring her information from the internet and provide her support before, during, and after her hospital stay. She describes one particular instance with her husband and Dr. J.

> *Dr J nous explique à mon mari et moi la gravité de mon état […] Mon conjoint écoute attentivement les paroles du Dr J en cherchant à déceler le non-dit. Il réalise*

> *Dr. J explained to my husband and me the gravity of my state. […] My husband was listening carefully to the words of Dr. J looking for what he wasn't saying. He*

rapidement que le Dr J dit tout, et observe que je répète le discours du Dr J en l'adoucissant.	*quickly realizes that Dr. J was saying everything, and observes while I repeat what Dr. J said in softer words. (M-A, 65y, Int 1, 09/03/2010)*

Families and patients undergo a rollercoaster of emotions when they have a loved one sick in the hospital. This is the first excerpt from all the interviews where a participant describes the emotional reactions of a family member. Marie-Ange had six weeks to rethink her perceptions of this moment with her husband. The method in which she describes her husband's reactions of listening carefully, searching, and realizing what was happening to his wife, transports me to the hospital room where they both received the difficult news of Marie-Ange's diagnosis. I cannot even imagine the fear her husband must have experienced as he was trying to read between Dr. J's words; the surprise he had when his wife understood what Dr. J was saying; the shock when he realized how seriously ill she was. Perhaps Marie-Ange, knowing her husband, might have protected him by repeating what the doctor said in softer words for him to understand better.

Marie-Ange's awareness of her husband's feelings at the same time as she was listening to Dr. J's words could be interpreted in different ways. First, her background as a health care professional may have facilitated the exchange with Dr. J, stemming from her experience at sharing medical information with colleagues. Second, it could demonstrate her mental preparedness to receive this information, either through self-reflection, or from the help of the internet documents. Thirdly, she could have been in shock, simply listening and repeating Dr. J's words without fully processing the information. Fourth, she could have been presenting a strong facade in front of Dr. J to alleviate her husband's anxiety, masking her own worries.

Lastly, she could have presented a strong facade for Dr. J, hiding her own worries, only to have recourse to her husband once Dr. J left.

The importance of a good support system that included her husband, children, friends, hospital personnel and room-mates is evident throughout Marie-Ange's hospital stay. In one of the concluding statements of her interview, she details how she feels about the people who surrounded her during and after her hospital stay.

Je me sens privilégiée d'être si bien entourée et encadrée par mon réseau personnel très adéquat.	*I feel privileged to be so well surrounded and framed by my very adequate personal support system. (M-A, 65y, Int 1, 09/03/2010)*

The Personnel is "Very Adequate"

As an experienced social worker, Marie-Ange was trained in family and couples therapy and adapted her approach to train other social workers in hospital settings. Her knowledge of the hospital system was not only evident in the way she referred to health care professionals by their roles, such as knowing who the residents were, but also by the way she appears to analyze her hospital stay as a health care professional, and as a patient. Her first evaluation is of the emergency room, which she describes as *"rapid and efficient"*. Her subsequent evaluations arose listening to her room-mates' conversations with health care professionals. She describes the conversations that impact her, and adds her professional interpretation.

J'ai été témoin involontaire d'un échange très intéressant entre mon colocataire de 94 ans et une intervenante au sujet de sa réflexion sur sa décision d'être opéré dans son état critique. Il avait neuf risques à	*I was an involuntary witness of a very interesting exchange between my 94-year old room-mate and a health care professional about his reflection on a decision to be operated on in his critical*

affronter pour son opération: il risquait entre autres de mourir, de perdre la voix et le peu d'autonomie qui lui restait. Par contre, demeurer en gavage le menait à une mort certaine. Il a choisi de prolonger sa vie par une opération qui pouvait lui permettre de ne pas laisser sa femme seule. Il était parfaitement lucide et conscient des enjeux liés à sa décision. Il ne sollicitait l'opinion de son interlocutrice que pour vérifier le bon sens de sa décision.	*condition. There were nine risks involved for his operation: he could risk dying, to lose his voice and the little autonomy that remained. However, to remain on nasal feeds would bring him to a certain death. He decided to prolong his life with the operation which would permit him not to leave his wife alone. He was perfectly lucid and conscious of the risks involved in his decision. He solicited the opinion of his "interlocutrice" to verify if his decision made sense.*
J'ai été aussi témoin d'un échange plus pénible entre ma voisine de gauche et un soignant conflit autour d'une intervention médicale qui avait causé une aggravation de l'état de la jambe de la patiente. Elle refusait ce soin et devenait en conflit avec la soignante qui voulait imposer ce traitement.	*I was also a witness to a more difficult exchange between the neighbour to my left and a health care professional around a medical intervention that had aggravated the state of the patient's leg. She was refusing this treatment and began to argue with the health care professionals who wanted to impose this treatment.*
J'ai été témoin d'un échange qui m'a beaucoup impressionnée entre un résident	*I was witness to an exchange that really impressed me between a resident and my*

> *et ma nouvelle colocataire du dernier soir. Elle devait subir une colonoscopie le lendemain mais refusait car était alitée et ne voulait pas se préparer au test alitée. Elle devrait alors se salir et son fils arrivait de Rome le jour du test. Le résident a reconnu l'inconfort [...] a donné un quart d'heure de réflexion à la patiente pour s'entendre avec sa sœur. Il semble que cet encadrement ait réussi car la patiente a accepté de se préparer à son test. Le point central de cette entente m'a semblé la reconnaissance de l'inconfort lié à la préparation au test allié avec un encadrement sur la responsabilité propre à la patiente dans les conséquences de sa décision.*

> *new roommate on the last night. She needed to undergo a colonoscopy the next day but was refusing because she was bedridden and did not want to prepare for the test bedridden. She would have gotten dirty and her son was arriving from Rome the day of the test. The resident recognized the discomfort [...] gave her fifteen minutes to reflect by discussing with her sister. It seems that this framing worked because the patient accepted to get ready for the test. The central point to this agreement seems to be the acknowledgement of the discomfort tied to the preparation for the test with the framing of the patient's own responsibilities of the consequences of her decision. (M-A, 65y, Int 1, 09/03/2010)*

In listening to her room-mates' conversations, Marie-Ange appears to have been evaluating the quality of the health care professionals' answers to their inquiries. In the first excerpt, she tuned into one of her roommate's difficult decision to accept or reject the operation. Marie-Ange comments on how the health care professional allowed him to make his decision by being present only for questions and support. In the next excerpt, she tuned into the different viewpoints of her room-mate's and the health care professional regarding the treatment for her leg. Here, Marie-Ange interprets the health care professional as "arguing" and "imposing" the treatment. In the last excerpt, she tuned into her roommates' concern over her possible disposition when her son would arrive, rather than weighing the necessity of the test. Here, Marie-Ange is particularly impressed with the way the resident helped guide the patient and provide her direction to make her decision. She describes this particular patient and resident another time.

> *Marie-Ange: J'ai trouvé que ça demandait énormément de perspicacité, de formation, de patience, de savoir être et non pas juste du savoir faire de la part du personnel.*
>
> *Heidi: Je ne suis pas certaine dans quel contexte vous placez cette phrase. Est-ce que c'est face à l'éducation du patient?*
>
> *Marie-Ange: Je fais ce commentaire de façon générale en me souvenant de l'attitude du personnel face aux patients. Par exemple, une infirmière a démontré énormément de patience face à une nouvelle patiente anxieuse et très exigeante (de qui j'ai parlé ci-haut) qui réclamait énormément de temps et d'attention et contestait les orientations médicales. Face à cette même patiente, un résident a été capable d'entendre les arguments de la patiente, de reconnaître ses émotions mais*

> *Marie-Ange: I found that it took an enormous amount of perspicacity, of training, of patience, knowing how to be and not just knowing what to do from the personnel.*
>
> *Heidi: I'm not sure in what context you put this sentence. Is it in regards to patient education?*
>
> *Marie-Ange: I make this comment generally by remembering the attitude of the personnel towards patients. For example, a nurse demonstrated an enormous amount of patience toward a new anxious and very demanding patient (whom I spoke of earlier) who was requesting enormous amounts of time and attention and was contesting the medical decisions. When faced with the same patient, a resident was able to listen to her*

> *également de mettre une limite et de lui donner un temps de réflexion au bout duquel elle devait décider soit d'accepter l'examen requis et contesté par la patiente, soit de devoir retourner à la maison sans avoir réponse à ses questions sur son état de santé. Il a pu mener cet échange avec beaucoup de respect pour la patiente et beaucoup de patience.*

> *arguments, recognize her emotions, but also place a limit and provide her with a reflection time where by the end she had to decide to either accept the test needed and contested by the patient, or have to return home without having an answer to her questions on her state of health. He was able to guide this discussion with lots of respect for the patient and lots of patience. (M-A, 65y, Int1, 09/03/ 2010, Int 2, 10/14/2010)*

Marie-Ange believes this patient was very demanding of the team of the ward. Based on her professional experience, she compliments the way the resident and the nurse tended to this patient professionally by guiding, not forcing, her to make a decision. Marie-Ange appears to take advantage of her professional experience as an outsider looking at the experience of "being a patient" to understand her present state as an insider living the experience of "being a patient" (Geertz, 1983, p. 223). This heightens the critical interpretations of what she observes. She uses her analytical skills to evaluate the methods in which the health professionals are communicating with their patients, and the patients' reactions to the words of the health care professional. She alludes to the attunement patients have towards other patients and to health care professional voices. For health care professionals, this demonstrates the importance of protecting patient confidentiality in shared rooms, and the importance of exhibiting professional behaviour at all times, since all words and actions may be interpreted by the other patients sharing the room. She was very impressed with the quality of the interactions she experienced personally and observed from her room-mates' experiences. She adds:

Le personnel m'a semblé très adéquat: attentif aux besoins des patients, patient à leur égard, à l'écoute de leurs besoins, capable de se définir et d'expliquer les délais dans les soins.	*The personnel seems to me to be very adequate: attentive to the needs of patients, patient towards them, listening to their needs, capable at defining themselves and explaining delays in care. (M-A, 65y, Int 1, 09/03/2010)*

She compliments the personnel on the ward with the highest regard for attentiveness, patience, listening skills, and communication skills towards patients. Interestingly, Marie-Ange felt that the personnel were adequate at *"defining themselves and explaining delays in care"*. She alludes to long wait times between tests or before receiving care, which were also mentioned by participants Marco and Mary. However, the difference here is that Marie-Ange describes having the wait time explained, whereas the others described receiving no responses to their questions about the waiting time. This makes me wonder how different the personnel were with Marie-Ange, compared to the other participants. Did Marie-Ange approach the personnel differently to obtain answers? Did the personnel approach Marie-Ange differently because she was a social worker? Did Marie-Ange meet personnel who exhibited more patience and patient-centered than Marco or Mary?

Marie-Ange also presents her impressions about the coordination and quality of the care she receives from Dr. J and the medical resident. She describes:

Heidi: Pouvez-vous me décrire vos impressions sur le travail d'équipe?	*Heidi: Can you describe to me your impressions of the team?*
Marie-Ange: Le Dr J […] m'a semblé devoir coordonner les résultats des	*Marie-Ange: The Dr. J […] seemed to be coordinating the results of the different*

> *différents tests, en faire la synthèse et orienter le diagnostic et le traitement. Il a joué un rôle majeur dans la prise en compte de ma parole dans ce processus, et ce, de deux façons:*
>
> - *par des contacts directs et personnels avec moi et mon conjoint*
> - *par l'intermédiaire [de la] résidante affectée à mon dossier.*

> *tests, to be doing the synthesis and orienting the diagnosis and treatment. He played a major role in taking into consideration my voice in the process, and this, in two ways:*
>
> - *by direct and personal contacts with me and my husband*
> - *through the intermediary of [the] resident in charge of my case. (M-A, 65y, Int 1, 09/03/2010)*

Marie-Ange understood Dr. J and the resident's roles through the type of information and care each of them provided. She perceived Dr. J as playing the key role in the organization of her care and describes much appreciation for the attention he paid to her "voice". She makes reference to Dr. J's multiple voices through his practice of patient-centered care and his *Educator* and *Fellow Human* attentiveness towards his patients. Perhaps neither Mary nor Marco was treated by Dr. J since they did not perceive that their "voices" were listened to during their hospital stay. With Marie-Ange, Dr. J encouraged her self-expression and provided an invitational space for her voice to emerge within the patient-doctor relationship. This connects to Maguire's definition of voice as a speaking agency where the person believes he or she has the power to act (Maguire & Graves, 2001; Maguire, 2007; Maguire, 1999). Prior to her discharge, Marie-Ange met with Dr J to share her final perceptions of her overall hospital stay.

> *Le jour de ma sortie de l'hôpital, je suis allée saluer le Dr J au poste de l'étage. Je voulais le remercier de son attitude à mon*

> *The day of my hospital discharge, I went to see Dr. J at the nursing station of the ward. I wanted to thank him for his attitude*

> *égard et je lui ai partagé mes perceptions [de mon séjour en hôpital]. Je lui ai dit que je me sentais très à l'aise avec la philosophie de soin de l'hôpital telle que je l'avais vécue lors de mon séjour. Il m'a alors parlé de son souci du «helpnessness», de sa préoccupation face aux patients qui s'en remettent aux médecins sans être pro-actifs envers eux-mêmes.*

> *towards me and share my perceptions [about my hospital stay]. I told him I felt very comfortable with the philosophy of care of the hospital such as I had experienced during my stay. He then spoke to me about his concern for "helplessness", his preoccupation with patients who rely on the doctor without being proactive for themselves. (M-A, 65y, Int 2, 10/14/2010)*

By summarizing all her evaluations, Marie-Ange understood the "philosophy" of care of the ward. She alludes to a prior knowledge of what a philosophy of care is, which she may have compared, or been able to discern in the actions and words of the professionals on the ward. Reciprocally, Dr. J demonstrates his respect towards Marie-Ange as he shares his personal opinions and concerns about patients who are more passive towards their care. Evident here is the rapport Marie-Ange and Dr. J developed during her hospital stay. This highlights the profound understanding each had towards each other's knowledge and abilities to analyse and interpret complex hospital dynamics. Not long after this encounter with Dr. J, Marie-Ange was discharged home.

When I Got Home "I Didn't Know What to Do"

Marie-Ange remained on the ward for eight days and was discharged early to prevent possible infections.

> *En fait, je sortais de l'hôpital pour éviter le danger d'une contamination sur l'étage, suite au traitement massif de*

> *Actually, I was leaving the hospital to avoid the dangers of a contamination on the ward, following the massive treatments*

cyclophosphamide et de solumédrol qui détruisait mes anti-corps.	*of cyclophosphamide and solumedrol that were destroying my antibodies. (M-A, 65y, Int 2, 10/14/2010)*

Once home, Marie-Ange knew that she would no longer have as close a supervision of her symptoms as she had in hospital. She states: *"I knew that I would be left to myself at home" ("Je savais que je serais laissée à moi-même à la maison", M-A, 65y, Int 2, 10/14/2010).* Although she kept herself well informed in hospital, she felt a sort of abandoned at being "left" to fend for herself once she returned home. In fact, once she was home, she describes having difficulties tending to her basic needs.

Autant je me suis sentie en sécurité sur l'étage, autant je ne savais plus à quoi m'en tenir une fois sortie de l'hôpital. […] Je me suis retrouvée à la maison sans savoir comment répondre à mes besoins de base:	*As safe as I felt on the ward, I felt like I didn't know what to do with myself when I left the hospital. […] I found myself at home without knowing how to treat my basic needs:*
• Comment traiter mes ulcères buccaux, mon mal de gorge, mes troubles de sommeil.	*• How to treat my mouth ulcers, my throat ache, my sleeping difficulties.*
• […] Je me suis retrouvée avec une glycémie de 15.4 au bout d'une semaine.	*• […] I found myself with a glycemia level of 15.4 within a week.*
• Je n'ai pas reçu d'indications sur une diète appropriée à mes nouveaux besoins.	*• I didn't receive indications about a proper diet based on my new needs.*
• […] ça m'a pris toute une journée pour organiser ma dosette.	*• […] it took me a whole day to organize my pill box.*
• Insécurité liée à de nombreuses décisions	*• Insecurities tied to the many decisions I had to take without knowing the risks*

nouvelles à prendre sans connaître les enjeux liés à ces décisions.	*involved with these decisions.*
• Prise et annulation de rendez-vous par message téléphoniques sans savoir d'où provenaient ces appels.	*• Taking and annulling appointments through telephone messages not knowing where the calls were coming from. (M-A, 65y, Int 2, 10/14/2010)*

In this excerpt, Marie-Ange does not appear to feel that she was well prepared to manage her symptoms at home. She describes the organization that is required by patients to effectively continue the management of their care at home. In addition to these post-discharge needs, in a separate utterance she describes the violent reaction she sustained three weeks after her discharge following an intensive treatment of cortisone and solumedrol. She became "logorrhéique" and could no longer verbally interact without losing control of her words. Physically, felt like she was becoming "fused" (*"je me suis sentie devenir fusée", M-A, 65y, Int1, 09/03/2010*). This highlights the extremely contextualized information patients need to know before they are discharged home. This lack of practical preparedness gave her the impression a "gap" between the hospital and going home.

C'est à ma sortie de l'hôpital que j'ai réalisé le grand vide entre le suivi de l'hospitalisation et le moment de la prise en charge en clinique externe.	*It is at my discharge from the hospital that I realized the large gap between the follow-up of a hospitalization and the time care is continued in an external clinic. (M-A, 65y, Int 2, 10/14/2010)*

How can patients be better prepared to go home? How much time is allotted to discharge preparation in hospital? Who can patients turn to if they are unable to control their symptoms? One possible option, as was described in Chapter 3 of this manuscript, is the existence of the Navigator Project on the ward. Dr. J had discussed the project with Marie-Ange prior to her discharge. She was the only participant to make note of the Navigator Project and provide comments for its improvement.

> *C'est à ce moment que le Dr J m'a parlé du projet de navigateur. [...] Je réalise rapidement la non pertinence de ce projet de navigateur avec la situation concrète du patient qui sort de l'hôpital avec des besoins et inquiétudes dans l'immédiat. Je n'ai d'ailleurs jamais reçu d'appel du navigateur.*

> *It's at that moment that Dr. J talked to me about the navigator project. [...] I realized quickly the lack of pertinence of this project of navigators with the concrete situation of a patient being discharged from the hospital with immediate worries and needs. Actually I never got a phone call from the navigator. (M-A, 65y, Int 2, 10/14/2010)*

Marie-Ange notes that she does not feel that this project was able to satisfy her discharge needs in the way that she was hoping it would, such as being able to contact the person herself if she has questions, concerns or is experiencing adverse effects. This makes reference to the importance of clear discharge teachings that are adapted to the needs of each patient. This also highlights the importance of more resources available for patients to contact after their discharge from the hospital in order to discuss medications, talk about how to orient and mange their condition at home, provide a liaison between the hospital and external care, and simply answer their questions. A simple phone call could alleviate the patients' worry about their symptoms and even avoid a trip to the emergency room.

Life One Month After Discharge

Since her discharge and the time she and I were in contact, Marie-Ange feels much better. She visits the hospital three times a month for medical follow-ups, no longer coughs, and breathes better. She controls the side effects of the cortisone by doing Tai Chi, resting, and expressing herself. She feels she has regained the capacity to organize her thoughts and her life.

Nonetheless, she is still tired, vulnerable to the illness, and remains in *"a state of shock"* concerning her diagnosis. She has difficulty perceiving the gravity of her illness and feels well physically. The most difficult part of her diagnosis has been the physical contact she was forced to withhold from her grandchildren due to the fragility of her condition. Still, she is disciplined to respect the needs of her body and the doctors' recommendations. She is taking full advantage of the present to hopefully influence the unknown future of the disease, and educate her doctors about living with Churg Strauss Syndrome. Lastly:

> *Je me sens également privilégiée d'avoir su organiser les échanges par écrit plutôt que verbalement. Ça me procure une distance psychologique aidante. Repos et calme autour de moi, pas trop de téléphones épuisants.*

> *I also feel privileged to have been able to organize the exchanges in writing rather than verbally. It provides me with a helpful psychological distance. Rest and calm around me, not too many tiring phone calls. (M-A, 65y, Int 2, 10/14/2010)*

Marie-Ange describes the psychological help she experienced in writing me her story. In adapting the interview process for her needs, she was able to feel calmer and able to gather her thoughts to express herself like she wanted to, rather than feel pressure to answer me immediately over the phone or in person. This makes reference to the importance of sharing and expressing personal opinions and needs, and the special importance of having some who will listen.

Understanding Marie-Ange and Marie-Ange's voices

Marie-Ange describes "being a patient" as a need to be able to take some control of the aspects of care through information and knowledge, and to allow the health care professionals to manage the rest. She also describes how moulding into the constraints and aggressions of a hospital system is physically and mentally exhausting for patients. As a retired health care professional, Marie-Ange's knowledge of the hospital system provided her with a foundation to critically observe patient-doctor interactions and interpret the philosophy of care of the ward. Her utterances demonstrated her preferred *Complier*, *Initiator*, and *Social Communicator* voices, but also gave rise to a deeper *Knowledge* or *Reasoning* voice as a health care professional.

Chapter Summary

In this chapter, I presented my conversational exchanges with the participant Marie-Ange. Our exchanges through emails shed light on the importance of adapting interview styles to the needs of patients as a therapeutic exchange, especially those who are critically ill. Marie-Ange presented her preferred *Complier*, *Initiator*, and *Social Communicator* voices, along with a voice of *Reasoning* or *Knowledge* which depicted her voice as a health care professional. Our post-discharge conversations brought forth a different experience of "being a patient" that might not have been as detailed had we met during her hospital stay or in person. Marie-Ange described the importance of written documentation in order to anticipate the doctors' treatment plan and maintain a certain control over her care. She described the constraints and aggressions a patients can experience during their hospital stay and the importance of a support system, notably the one she developed with her hospital room-mates.

In chapter 6, I detail my critical interpretations of "being a patient", based on my theoretical framework of patient voice and patient-centered care. I also provide implications for patient care, implications for physiotherapists and health care professionals, and implications for future health care qualitative research on patient voice.

Chapter 6. Reflecting on the Meanings of Patient Voices in Health Care

Throughout this text, I tried to provide some insights into the perspectives of four participants about their experiences of “being a patient” on an internal medicine ward in an urban academic teaching hospital. In reflecting on the implications of my inquiry, I return to my three research objectives: 1) knowing more about the experiences of “being a patient” on an internal medicine ward from the patients’ perspectives, 2) recognizing patients’ recommendations to future hospitalized patients, and 3) determining the information these patients would have liked to receive during their hospital stay.

Dialoguing with these four participants has made me reflect on my own practice and how I can positively influence the hospital stay of my future patients. I discuss the implications of these participants’ utterances about their experiences as patients for medical educators, patient health educators, health administrators, physiotherapists, all health care professionals, and for future qualitative researchers on patient voice.

Implications for Medical Education

The CanMeds Physician Competency Framework identifies “patient education” under a section called **Scholar** and expects doctors, as teachers, to facilitate the “translation of medical knowledge” to their patients (Royal College of Physicians and Surgeons of Canada, 2005, p. 7). However “educating” patients is more than a translation of information from a doctor to a patient. Education should be a dialogic, collaborative partnership between the health care professional and the patient. A starting point is to first understand the patients as a unique individuals so as to hear and understand their particular voice, context and needs. The four participants’ utterances suggest that “patient education”, or an “exchange of information”, might be absent from routine patient care, let alone realized in a dialogic, collaborative partnership with the patient. Where is the concept of shared partnership in the CanMeds definition? Where is patient voice? If a concept is not present in a competency framework, nor taught in a medical curriculum, nor explicitly evaluated, will physicians, residents, and medical students use this concept in clinical practice?

My initial impression of the free expression of patients' voices in a hospital setting was that it was not common practice among patients to explicitly voice their concerns. I now realize that some patients do feel the importance of expressing and sharing their needs or concerns with those involved in their care. My key interpretive understandings from this inquiry suggest that whether or not patients are comfortable with expressing their voices depends on the health care professional with whom they are speaking. Participant Marco expressed that none of the voices his health care professionals were using during medical discourses reflected his preferred *Fellow Human* being voice. Would Marco have offered different perceptions about his experiences of "being a patient" if the health care professionals had used different voices in their interactions with him? How can voice be used as a form of expression and agency, if no one is listening to patients' utterances and their meanings? Could this feeling of "being ignored" be a result of a conflict between the types of voices that are being used at the time of the clinical encounter? If health professional students are not taught how to listen to patient voices, and do not see it in their clerkships or in their mentors' behaviours, it may be unlikely that they will appropriate this concept into their own clinical practices.

I came into contact with many critical incidents, which made me further reflect on the socialization of medical students, or residents, discovering their unique attitudes towards and beliefs about patients, and their attunement to them as human beings. I recall a very emotional incident during the discussion of Marco's treatment plan in rounds when a social worker labelled him "cheap" for not wanting to pay a taxi for his medical visits. Ron Epstein, author of *Mindful Practice*, notes:

> "Self-knowledge is essential to the expression of core values in medicine, such as empathy, compassion, and altruism. To be empathic, I must witness and understand the patient's suffering and my reactions to the patient's suffering to distinguish the patient's experience from my own" (Epstein, 1999, p. 836).

How does labelling Marco as "cheap" teach students and residents to be empathic and to distinguish their own emotions from the needs of their patients?

Other consequential labels are those given to patients who are elderly, or to people with cognitive or mental challenges or difficulties. They may be "assumed" not to understand, or if their words appear to be incoherent, patients may be "assumed" as not able to voice their needs. Anna, the physiotherapist on the ward, notes from her experience: *"[...] Or some of them [health professionals] think that just because they're elderly [patients] that they, that they are mis...like misunderstood as someone who cannot talk for themselves and that's the worst" (Anna, 26y, 08/06/2010).* Marie-Ange repeatedly emphasized the importance of patients being given time and opportunity to express their voices and feel valued for the human beings they are. Health educators should ask themselves how they are listening to the voices of the patients who cannot verbally express themselves, and how they are showing their students how to listen to and for these voices.

Ultimately, labelling needs to be labelled as such, and openly discussed among medical learners and supervisors as it can negatively taint the clinical education of students and residents. When supervisors and other clinicians use labels such as non-compliant, difficult, not listening, rude, or other pejorative descriptors, this affects the way students learn about patient-centered care and makes it is socially acceptable to dismiss patients. It also reinforces and promotes cynical behaviours of young health care professionals, who may consequentially develop a division between their own humanity and the humanity of the patient. Not ignoring what may appear to be a harmless comment may be a fleeting opportunity for learners to be brought on to reflect on their own patient-centered behaviour and cynicism. Conversely, medical students need opportunities and invitational spaces to express their voices and feel valued for the health professionals they want to be. In an environment where cynical behaviours are reinforced, students may not feel confident in advocating against injustice towards patients. Students who are inherently more patient-centered and empathetic may feel drowned out without the strong presence and support of a supervisor who shares similar values. This raises complex authority, power, and control issues in health care for patients, and also for the socialization of medical students into the medical profession.

On more than one occasion during rounds, I heard about a particular resident whose trademark was to be patient-centered because he spent lots of time listening and being with the patients.

> *Anna: [...] Like in the last team there was a resident that took a lot of time to do that [thorough discharge teachings]. And it was really nice and I didn't really him having...you know...much crazier schedule that the others. So...*
>
> *Heidi: So it seemed to be more of his personal value than...*
>
> *Anna: Yeay. It was more like a personal thing that...and he was known for it [...] It ends up being really more, it depends on how you see, like how each member of the team, the whole team...medical, nursing, everyone. How you see yourself and your patients care. (Anna, 26y, 08/06/2010)*

Would this resident be rewarded by his peers for being proactively patient-centered? Would referring patients to him become just another cynical comment when "needy" patients need someone to talk to? Yet other health care workers see, recognize and value the residents and students who exhibit patient-centeredness, yet have no explicit role in their formative or summative evaluations. In order to promote patient-centeredness among student and residents, clinical curricula need to explicitly describe patient-centered competencies and evaluation criteria that patients, and other health care workers, could understand and judge. There should be explicit roles for other health care workers and patients in the formative evaluation of students' and residents' patient-centeredness. There is a need for the creation of a low-stakes method for representing and presenting such formative evaluations to medical learners, such that it is "safe" to hear the students' voice and promote more opportunities to learn from their actions and interactions. Lastly, the creation of a higher, more summative method for representing the medical learners' aggregate patient-centeredness over many months, as a teaching tool to show them their personal growth and change within their individual experiences, is needed. This way, students and supervisors could track the medical learners' response to feedback over time and any single negative evaluation cannot by itself necessarily effect learners' summative evaluations. Students and residents, whether in their first or senior year, are still learning to grow and develop their own voices as professionals. They need to learn how to adapt themselves to different situations and teachers should encourage them to develop, or show them situations in which their behaviour did not play in their favour.

The important message for medical educators is that students and residents need to be taught and shown how to become and be attuned with their patients' voices and how to interpret these voices and respond appropriately. Perhaps personal values and character traits as an empathetic human may be more of a determinant if a health care professional really learns how to listen to and for their patient's voices. Even Marie-Ange, a health care professional, wrote:

[…] Je ne sais pas si je réponds bien à votre demande de précision car je ne suis pas très familière avec le concept	*[…] I don't know if I'm answering your questions well with the precision your ask, because I'm not too familiar with the*

«d'éducation du patient».	*concept of "patient education". (M-A, 65y, Int 2, 10/14/2010)*

Patients may not understand what "patient education" means and each person may bring their own values and assumptions to what "patient education" means to them. In addition, that particular patient's illness contexts may not present opportune or readiness times at particular moments in an illness trajectory for patients to learn and even interpret information, let alone act on it. Some, like Marie-Anne, may prefer to express themselves in writing in addition to live conversation. Other patients may be unable or unready to learn because of sleeplessness, fear, scepticism, feelings of "being broken", pain, or the complexities of leaving hospital and getting back to life, in addition to coordinating new appointments, medication schedules and tests.

Supervisors who would teach patient-centeredness must help medical learners learn how to anticipate the optimal time, the time needed, the preferred communication methods, educational beliefs, and past illness experiences of patients. Perhaps, certain sections of the CanMeds Framework should be developed further and explicitly explain more clearly the concepts and definitions of patient voice and patient-centered care, especially when teaching future health professionals about "patient education".

Implications for Patient Health Education

In patient-centered care, students and residents need to understand where and when to situate their care between the two poles of "one size fits all", and "just in time, just for you" for each patient in each context. During my conversations with these four patients, I asked them what they wish they had known prior to their admission to the hospital, and what they would recommend to future hospitalized patients about being a patient. All four participants provided unique and highly individual responses, in hopes that other patients would benefit from their experiences. Although varied, these responses may provide future hospitalized patients some comfort and guidance to traverse their hospital stay.

Jean recalls being very "skeptical" and "suspicious" at his hospital admission. These feelings dissolved when he received information about his tests and trusted his health care providers who would "*would always come ask [him] questions about this or that"* (J, 72y, Int 1, 06/17/2010). He recommends for future patients "*…to be persistent, not to lose courage, that the hospital personnel are there to help…the best days are to come and that you can't let yourself down for this"* (J, 72y, Int 2, 09/06/2010). For health care professionals, this recommendation reinforces the sense of security newly admitted patients require when they first arrive on the ward. By initially providing patients with more one-on-one contact, health care professionals could help allay their anxieties of the unknown. Encouraging patients to enunciate shared short and long-term goals may encourage them to actively participate and assume a sense of agency in their care.

Marco highlights the importance being treated by a health care professional who values "being present" in doctor-patient relationships. Again, relating to establishing treatment goals with patients, Marco's experience depicted a misalignment in the treatment goals that were established around an expensive medication, resulting in feelings of "lack of hope" and *"instead of getting better it coming worst" (Mc, 79y, 06/24/2010).* His hospital experience also reinforces the importance of health care professionals using a *Fellow Human* voices and trying to understand their patients' needs, especially when the patient feels "broken". It also requires medical learners to be taught how to anticipate and invite the expression of feelings of skepticism or mistrust a patient may feel in a given health care context.

Mary recommends that all patients should ask *"What is happening? Why it's happening? What to expect to happen?"* throughout every step of their hospital stay. Why? Simply because *"then you're not sitting there scared"* (Mr, 72y, 06/30/ 2010). Although some information such as the medical tests could have been detailed on paper, Mary emphasizes the importance of verbal communication because *"[she] can't read it [because she] can't see the print"* (Mr, 72y, 07/30/2010). Mary's experience reinforces the importance of good and constant patient-professional communication about everything that involves her care.

Marie-Ange recommends that patients should first inform themselves about the functions of the ward, such as:

• *utilisation du téléphone: une ligne pour l'ensemble des trois patients*	• *using the telephone: one line for all three patients*
• *horaires et roulement du personnel*	• *schedules and changes of the personnel*
• *organisation concrète: cloches, lumières de lit, horaire des repas, services de bénévolat, etc.*	• *concrete organization: the bell, bed lights, schedule of the meals, volunteers services, etc. (M-A, 65y, Int 1, 09/03/2010)*

Although Mary seemed to have no use for written information, Marie-Ange was greatly comforted by paper documents because of the help they provided her in anticipating what would happen during her hospital stay. Marie-Ange's experience also makes reference to the heightened importance of thorough discharge teaching as patients are discharged earlier from the hospital, and must continue their care independently at home. Despite being a health care professional, she notes: *"I didn't know what to do with myself when I left the hospital...I found myself at home without knowing how to treat my basic needs"* (M-A, 65y, Int 2, 10/14/2010). Marie-Ange's experience reinforces the necessity for health care providers to be present for their patients to provide answers to all their questions, or anticipate what they will need after discharge. This can prevent not knowing what to do in case of any adverse reactions to medications, or avoid unnecessary readmissions to the emergency room.

In addition to the four participants' suggestions, Anna provides further information on the admission teachings she provides to the patients, specific to this ward and hospital. These are offered to other health care providers as suggestions to better prepare their patients for their hospital stay. Regarding a diagnosis, Anna recommends that future patients should ask: "*What is that? What does that mean? Is this permanent? Am I going to recover? Am I going to get better?" (Anna, 26y, 08/06/2010).* For patients who are experiencing their first hospital stay, this information may include describing or explaining hospital routines, that it is a teaching hospital, that more than one doctor will be involved in their care, that the nurses rotate, that everything is written in their medical chart, and that they can ask to speak to specific people if they have questions. She states that she tells the patient that they are expected to do everything they do at home, unless told otherwise. Importantly, she tells patients that they are not expected to stay in the hospital for long and that they may not feel completely better when they are discharged. She describes the discharge procedure and that certain discharge locations, like rehabilitation, have admission criteria that the patient may not qualify for. But if the patient needs post-discharge help, their ward health care professionals will prepare the necessary documents for the patients, or guide them on how to do it themselves once they get home.

It is worthy to note that the participants in my inquiry had no cognitive or communication difficulties. Patients with hearing difficulties, cognitive limitations, or who do not speak English or French may require adapted information, such as written documents for their family member to translate, explain, or read for them at a later time. The information these participants, based on their own experiences as patients and what they wish they had known, prior to hospitalization, may be used as a guideline to facilitate the hospital stay of future patients.

Ultimately, preparing future patients for a hospital stay is highly individualized and varies depending on the patients' needs, as well as social, and cultural backgrounds. This requires health care providers to listen and be attuned to their patients' individual and diverse voices.

Implications for Health Administrators

> *J'ai trouvé que ça demandait énormément de perspicacité, de formation, de patience, de savoir être et non pas juste du savoir faire de la part du personnel.*

> *I found that it took an enormous amount of perspicacity, of training, of patience, knowing how to be and not just knowing what to do from the personnel. (M-A, 65 y, Int 1, 09/03/2010)*

Working in health care is very demanding physically and emotionally. I believe the devotion provided by health care professionals to sick people is remarkable. Unfortunately, the underfunding and understaffing of Quebec hospitals have left countless professionals struggling to provide "good enough" patient care to make ends meet in busy and overcrowded hospitals, despite their best intentions to be more present for their patients.

Prior to the start of the interviews I was expecting to hear many negative comments from the patient participants because of the negative media representation of health care. I was surprised to find that, for the most part, these participants were content and overall well-care for during their stay on the ward. Still, the participants were not immune to various systemic issues that they personally experienced or witnessed with other patients. However, they are aware of and understand the systemic issues very well.

> *Marco: ...there are wonderful people but the vision and direction of the hospital, they don't know where it's going. [...] There is a lot of waste in a hospital. A lot of waste. And it seems to be that nobody's happy. Nurses aren't happy. Doctors aren't happy... (Mc, 79y, 06/24/2010)*

> *Mary: ...Well it's important for the nurses too. They have how many patients they've got to look after? [...] They work too many hours you see it here when you're in for a week or two weeks and you see how hard they work... (Mr, 72y, 06/30/ 2010)*

What kind of support is offered to front line health care professionals who are forced to adapt to business governmental business decisions? Are decision-makers aware that wards are so understaffed that patients must wait to go to the bathroom, to eat, or be bathed?

> *Anna: They [the patients] don't go to the bathroom exactly when they ring the bell. Sometimes they [orderly] don't come to answer the bell. [...] And the tray is left on the window sill, and... [the patients] haven't been able to get out of bed for a week. [...] They [the patients] want to go back to bed and they're left if the chair for...hours...like someone was left in a chair for eight hours; someone that has, like, raw ulcers [on their behind]. (Anna, 26y, 08/06/2010)*

> *Lili: Ben laisser quelqu'un…il y a une madame qui est ici pis elle est rendu elle a plein de crasse dans ses bourlets mais c'est tellement crasseux que c'est carrément, sa peau est morte, c'est noir. Parce que je ne sais même pas si elle est lavée. Pis elle est laissée souvent dans ses excréments.*

> *Lili: Well leaving someone...there is a lady who is here and it's to a point where she has filth in her fat rolls but it is so filthy that it's literally, her skin is dead, it's black. Because I don't even know if she is washed. And she is often left in her feces. (Lili, 25y, 07/30/2010)*

How can patient-centered care in a medical system really be implemented when the system is so understaffed and health care professionals are so overworked that patients must soil themselves for attention?

Conversely, health administrators also need to be concerned about the behaviours and actions of health care professionals who do not practice patient-centered care and even diminish patient dignity. When I review the instances I observed and heard that depict an absence of patient voice and lack of patient-centered care towards patients, I question how the future generations of professionals are being trained. For example, should patients be left to wonder if they have cancer because they were not approached to discuss the results of a test? Why do patients have such little contact with their doctor that they are afraid to leave their hospital room, afraid of missing them if they pass? Does being in a teaching hospital mean that patients have no choice but to endure repeated and painful physical evaluations, when the information is already in the medical chart? Another example of lack of patient-centered care occurs when health care professionals proceed with evaluating a patient without introducing themselves beforehand.

> *Anna: [...] Patients are always telling me, they're like...sometimes they're like: 'I don't know who that was', because they've never seen them [the doctor who entered the room]. They've only seen their resident, or their medical student. [...] When they don't know who people are and they're not sure what people do, and there's ten people that go into their room in a day and you don't even introduce yourself, that's the worst thing. [...] And they're just getting bombarded with all these people... [...] And they don't even know 'Who is this, now?' [...] (Anna, 26y, 08/06/2010)*

This lack of consideration for the patient's well-being leaves patients vulnerable and frustrated in having to answer the same questions, redo uncomfortable evaluations, and comply with the needs of the professional without knowing why, or who they are. This raises a power relationship question that connects to the authority figure the professional represents.

With these examples of lack of patient-centered care and attention to patient voice listed here and in other locations in this inquiry, I invite health care administrators to reflect on how they can better represent the best interests of their health care professionals and the provision of patient care. The examples I describe are easily avoidable if health care professionals spent a few more minutes with patients and listened more carefully to what they need.

Implications for Physiotherapists

I began my inquiry with various questions about patient-centered physiotherapy care. However, I had to readjust these questions and include them only if the patient chose to discuss them, as not all patients were treated by a physiotherapist. However, the participants Lili and Marco reflect on physiotherapy treatment plans and the misunderstanding patients may have of its purpose. I asked Lili how patients respond to functional help while in hospital.

Lili: ...Il en a qui vont refuser carrément. Eux-autres ils étaient indépendants avant fac qu'aujourd'hui ils sont encore indépendants et ils refusent toutes aides. Mais il en a qui vont prendre toutes l'aides possible aussi.	*Lili: ...Some will completely refuse. They were the type of be independent before so today they are they still independent and refuse all help. But some will take all available care. (Lili, 25y, 07/30/2010)*

Offering "help" to a patient in terms of physiotherapy services can include maintaining walking endurance, bed and transfer mobility, maintaining their physical strength and articular range, and preparing the patient for discharge. Patients may refuse physiotherapy treatment because they do not wish to receive physical help. They may not feel that being physically active is a part of or a responsibility they need to assume as part of "being a patient", as Marco describes in his interview.

> *Heidi: When you say about your health, is it about just the medications, or is it about exercise, or is it about other things?*
>
> *Marco: No, exercise I don't need it. I do it myself. No it's ok. Where in the hospital not in a hotel. I understand that too. Seems to be fine. (Mc, 79y, 06/24/2010)*

Marco divulges that he was not independent physically prior to his admission, yet here refuses physical help on the ward. He appears to perceive that physical activity is not part of hospital care, and more of a hotel luxury. It can be confusing and overwhelming for patients to have multiple professionals enter their room to perform a treatment, if they do not understand who they are or how their medical problem relates to the treatment. Misunderstandings can make it difficult to provide functional care to patients, such as walking; this which might create confrontations and even result in labelling patients as non-compliant.

I recommend physiotherapists meet the patient and discuss their hospital and discharge goals, and help patients identify if function, or returning to function, is part of their personal objective. This may make the integration of physiotherapy into the treatment plan easier.

Implications for All Health Care Providers

Ideally, a dialogue of sharing should exist between a patients and their health care providers. Listening to the patients' voices may reassure them that they are being heard and not forgotten in the busy institutional life of a hospital setting. Maguire sees the importance of creating a shared dialogue with the patient to understand and respond to their voices in a timely manner so as to decrease anxieties. In other words, "not to leave [the patient] hanging in an ambiguous state and [to] provide [them with] a timely response" (Maguire, 2009, p. 5). Lili comments how a shared dialogue between the health professionals and the patients would help the patient *"maybe freak out a little less" ("ils capoteraient peut-être un peu moins"; Lili, 25y, 07/30/2010*). Anna discusses how she encounters some of her patients who are so uninvolved in the medical dialogue that *"...sometimes they don't want to leave the room 'cause they don't want to miss out on any information [...]" (Anna, 26y, 08/06/2010).*

A shared dialogue between the patient and their health care provider can range from discussion about the meanings and interpretation of medical tests and their results, even if they are negative; the functions of the ward, as Marie-Ange suggests; who is involved in the patient's care; and the treatment plan and the team's goals for the patient. Participant Mary explains: *"I think a lot of the worrying is not knowing..." (Mr, 72y, 07/30/2010).*

Similarly, a shared dialogue must exist from health professional to health professional. Even though patients are not directly involved in inter-professional communications, health care providers should be in tune with the voices their fellow health care professionals use with each other during their clinical encounters with one another. Anna describes how there is a difference between the dynamics of the health care team on the ward when they are more multidisciplinary, that is working alongside each other without working with each other, than when they are interdisciplinary, where there is a shared partnership of care.

> *Anna: [...] the more discussion you hear [during rounds] and the more searching of opinions and stuff, you know that...everyone medical, nursing, whoever's there at that time during that period, is really, kind of, searching out the best for the patient. Almost like the less you hear from the [allied health and nursing] team [...] usually means that everyone is kind of doing their own thing. Like multidisciplinary instead of interdisciplinary. (Anna, 26y, 08/06/2010)*

Difference in patients' perceptions of, and lived hospital experiences of "being a patient" might be attributed to disconnects among team members, or lack of harmony in professional relationships when a health care team is not functioning as a cohesive unit. This lack of harmony appears to have a ripple effect on patient care, among those who do not feel as valued and listened to from the health care team.

> *Anna: The patients either they want to leave [the hospital] because they either just don't want to be in a place where they don't feel like they are being helped or they...or they'll*

> *kind of just, they won't feel as comfortable, they won't feel as comfortable voicing complaints because they feel like its falling on depth ears… (Anna, 26y, 08/06/2010)*

Patients are not the only ones affected by the types of voices health care professionals choose to use. For example, Anna noticed that when there was a lack of harmony among team members, she needed to provide more psychological support and reassurance to her patients, rather than focus on her role as a physiotherapist.

> *Anna: [...] when the patients know what's going, when they really feel like they know 'Ok...the doctor told me I can't go home 'cause I'm not safe' you know? Then I'm really able to just do...my therapy time instead of constantly having to tell them 'It's ok. Don't worry. […] You don't have to be afraid. No one is kicking you out'...even the patient, the moral, is so different [when the team works together] [...]. (Anna, 26y, 08/06/2010)*

Even though patients are not directly involved in inter-professional communications and work dynamics, they appear to be much attuned to and aware of the changes that occur in clinical encounters and the voices health care professionals use with each other. This suggests that there might be a chink in the way health care professionals work cohesively together. I wonder if health care professionals are aware of the impact of their dynamics and voices on the hospital stay of patients, and on the workload of their colleagues. I recommend that administrators of a ward critically reflect on moments where patients seemed to be expressing a greater discontent with their care, and review the dynamic of the team members present on the ward at that a time. This could not only affect patient-centered care, but also create a healthy and satisfying work environment.

Implications for Future Health Qualitative Researchers

Reflecting back on my qualitative inquiry, there are research steps I would have taken differently, about which I would like to forwarn other qualitative researchers who may wish to understand patient voices and patient-centered care.

First, I should have been more flexible and adapted to the needs of hospitalized patients. The first four weeks of my data collection process I spent identifying the appropriate hours and days to meet patients. The primary reason I chose to meet patients at the end of the day was so that I would not interfere with their medical tests and health professional visits. I occurred to me at the end of the data collection process that these reasons might have been more selfish than practical. I did not consider that patients might be exhausted after a day of medical tests and that some might have preferred to meet me in the morning. Without the deadlines of graduate studies, I would have met with the patients more frequently in person, or in writing, in hospital and after discharge. Jean was the only participant who agreed to converse with me after discharge and had I not done so, I would have missed very rich information about his perception of his experience as a patient. I would also extend the data collection time, and meet with more patients, and adapt conversations to meet with patients who are nonverbal, do not speak English or French, have cognitive limitations, and patients who come from diverse cultural backgrounds.

Second, it is respectful to provide patients opportunities to review my interpretations of their utterances. Marie-Ange was the only participant who actually reflected on my presentation and discussion of her perspectives derived from her interview responses. She corrected some dates and changed some words, but states that she felt well represented within the text.

Globalement, je me sens bien entendue et respectée dans ce chapitre. Je trouve très intéressante l'analyse que vous faites de	*Globally, I feel well heard and respected in this chapter [5]. I find it really interesting the analysis that you did on my utterances*

> *mes propos et l'analyse que vous faites autour du vécu des patients et du système hospitalier. Vous ne trichez pas mes mots! Je me sens bien comprise et bien interprétée. Je me reconnais tout à fait.*

> *and the analysis you did around the experiences of patients and of the hospital system. You are not tricking my words! I feel well understood and well interpreted. I recognize myself. (M-A, 02/20/2011)*

Although Marie-Ange was a "sophisticated patient", in the sense that she is also a health care provider, health care qualitative researchers should explicitly offer and provide their participants with full access to their interpretations of their utterances, not just to small selected excerpts that are not contextualized. Publishing patient experiences without verifying with the patient about interpretations of their experiences or perspectives can result in "othering" and misrepresentation of patients as homogenized groups, and lead authors to state what the researcher wants to say rather than what the patients actually experienced.

Third, one of the realities of conducting research on a clinical ward of a busy hospital ward is the lack of private space. The ideal arrangement would have been to provide an invitational and safe space for the patients to talk freely and uninterrupted. Although I used as much discretion as possible, the patient and I knew that others might be listening which might have restrained them in the way way they chose to express themselves. Patients may overhear conversations and observe behaviours that may not directly impact on their own health situation. However, their reflective comments provide insights about patients' awareness of institutional ways of being and doing.

Fourth, prior to starting my inquiry I knew it would be tricky to obtain consent from patients, but I did not anticipate the difficulties I would have, especially with gaining access to patients and systemic gate-keeping. I would have conducted the interviews earlier in the week and hopefully increased the number of participants. However, I knew from my previous research and physiotherapy experience that I was too demanding of a hospital ward, and volunteer recruiter. I had to abandon my desired schedule, place my confidence in the recruiter, Emily, and allow all the time necessary to meet with patients, even if it meant later in the week, or not at all. I selected a total of 18 patients for Emily to approach. Due to her busy work schedule, discharges and the instability of patients' illnesses, I only met seven patients during the three months. Of these, four volunteered to be interviewed. The others refused when I met them in hospital, or could not be formally interviewed because they had not signed or understood the consent form due to communication barriers. For example, one participant spoke more Italian than French and the other patient had hearing difficulties. Looking back, these patients did seem interested in participating and answered as many questions as they could "off the record". I limited their participation because of my research criteria, not because of they refused. I could have adapted the consent form. I could have asked them to write me their answers. Marie-Ange provided me with this methodological insight into the different ways patient voices can be expressed and represented and how I needed to adapt to them, rather than having them adapt to me. Recall, she had challenges in verbally responding, so she took agency of her situation to communicate with me via e-mail, a mode of communication that worked very effectively.

Based on my experience in both quantitative and qualitative research, I believe that some qualitative research in health care is highly problematic. Qualitative research has many complex traditions and methodologies that have evolved over the decades. Some researchers in health care misuse and overly simplify qualitative research through mixed methods approaches. There appears to be a growing trend in health care research to use focus groups and interviews to justify a "qualitative" research approach. In this type of research, qualitative research can be compromised, theoretical framework is frequently absent or simplified and patient utterances and the complexities of their contexts are misrepresented.

Yanchar describes mixed methods as methodological eclecticism and methodologically flawed (Yanchar & Williams, 2006, p. 3). Methodological eclecticism “holds that methods are essentially disengaged from paradigms and able to be mixed any way that researchers desire without theoretical incompatibility, contradiction, or implication [with an] absence of transcendent truth and a sufficient method” where the researchers uses “whatever combination of methods seems appropriate” (Yanchar & Williams, 2006, p. 3). Without a critical theoretical reflection on qualitative methodologies, results have been shown to be faulty assumptions that “generally give rise to faulty or harmful interpretations, arguments, and practices” (Yanchar & Williams, 2006, p. 7). A coherent theoretical framework and epistemology are crucial aspects of qualitative inquiry. If strangers were to look at my data, they would obviously see something completely different and have different interpretations. Appreciating multiple perspectives in understanding human inquiry is an epistemological assumption of qualitative research. Every utterance and text is always an interpretive act. Had I used a more reductionist or positivistic methodological approach with multiple reviewers to verify my data, the patients’ voices would have been lost and not fully appreciated. I understand that a quantitative reader might challenge this “subjective” methodology and look for truth, but post-modern qualitative research approaches do not ask researchers to tabulate the frequency of words and themes, and triangulate the analysis for intra-rater reliability to conclude with a definition or “truth” that everyone must adopt. This Cartesian way of thinking can lead to one-size-fits-all philosophy of patient-centered care.

Similarly, I also recommend qualitative researchers in health care should not treat all patients as essentialized or homogenous groups of people called “patients”. I got caught in that trap when I was writing my ethics proposal and realized that it was not important for all patients to have the same admission diagnosis. More important was to understand their perspectives.

Drawing on phenomenological research, I viewed patients as human beings, regardless of their medical admission diagnosis or co-morbidities.

Yanchar argues that researchers should stop using mixed methods as a “fallback”, and advises them “to accept the existence of theoretical frameworks underlying both methods and research practices, and to take them seriously in the development of questions, use of methods, and interpretation of data, is to abandon eclecticism as it is usually understood” (Yanchar & Williams, 2006, p. 7). I recommend health care qualitative researchers critically review the logical justification of using mixed methods and epistemological assumptions, and follow Yanchar’s recommendations for contextual sensitivity, creativity, conceptual awareness, coherence, and critical reflection (Yanchar & Williams, 2006, pp. 8-9).

Researcher Reflexivity

My view of qualitative research changed significantly during the course of this inquiry. At first I was clinging to the theory, like a cane, for extra support. Although I still consider myself a novice, I now have a deeper appreciation of the complexities and sensitivities in conducting, meaningful, ecologically valid research in health care. During the course of this inquiry, I immersed myself in my participants’ lives and reflected on what it meant for them to be patients. Being a patient is scary! Svanaeus explains: “When we are ill, life is often penetrated by feeling of meaninglessness, helplessness, pain, nausea, fear, dizziness, or disability” (p. 88). One’s life is placed in the care of total strangers and one has no choice but to trust that they know what they are doing. One can lose all the comforts of home and be placed in a busy, depersonalized ward with other sick people. Jean stated “if you have the choice, it is better not to be sick”. Unfortunately, being ill is not a choice for the millions of people who go in a hospital’s doors hoping to exit better than when they entered.

My impressions of the meaning of "being a patient" were too narrow prior to the start of this inquiry. I had some hunches of how demanding it was and imagined what it would be like, but it was just an imagined idea. Now I see the meaning of "being a patient" much differently. The utterances of the patients I met on the ward, whether or not they participated in this inquiry, brought me into their worlds and lived experiences. Being a patient is a challenge of self-control, self-motivation, self-restraint, and support. Being a patient means being able to constantly search within yourself to keep pushing forward and to return to a state of wellness and well-being.

Meeting with the physiotherapy participants, Anna and Lili, helped me understand more about the environment of this internal medicine ward. Their conversations provided more contexts to some of the patients' utterances. They also helped me to determine if health care professionals were attuned with the ways patients felt about their hospital experiences. Anna shared a similar passion for geriatric and hospital care as I do as she defines "being a patient":

> *It's so...so many things. It's hard for me to say. Like a lot of times fearful...euh...anxious, worried, seeking answers. That's what they're here for most of the time. Helpless at times. [...] But, at the same time...euhm...strong, ready to go ahead, seeing...seeing the other side. Not all of them are motivated but some of them. But yeay. Euhm...wanting answers in a big one. In terms of treatment or... day to day care, but a lot of it is, is wanting answers and usually quick, and wanting to...get rid of whatever they came in for. Surmount, you know? (Anna, 26y, 08/06/2010)*

Here, Anna is reiterating how some of the participants defined "being a patient" as *"fearful, anxious, worried and seeking answers"*, *"helpless at times"*, and the importance of *"seeing the other side"* of an illness. Lili's ideal definition involves better patient-doctor communication and full transparency towards a patient's care, which are both concepts that Mary and Marie-Ange emphasized in their utterances.

In my personal ideal definition of "being a patient", patients would also have access to full transparency over what was happening in their care, with minimal wait times to receive care or results. Patients would be at the center of their care and feel comfortable at expressing their voices in whatever form. Simply put, "being a patient" would reflect the ideal definition of patient-centered care, and would not be such a difficult experience.

I offer some last advice for my fellow physiotherapists and health care professionals on the concept of voice: reflect on your own voices; accept that patients have multiple voices and that they might not be your preferred voices; reflect on the patients' world before labelling them; accept that your patients' voices and needs can take over your agenda; and take an extra five minutes to understand, listen, and speak to your patients.

In this inquiry, I described how voice remains an abstract, absent, and ill defined concept in both medical and physiotherapy literature. I argued that patient voice should be at the centre of patient-centered care as I see these sensitizing concepts as intertwined. With the help of key theorists and authors who work within a post modern epistemology, I argued that the medical treatment plan and entire approach towards patients should be tailored to their unique needs. With the help of four generous people, I was able to describe what it was like to be a patient from the lived experiences of these patients, and learn how to better prepare future patients for their hospital stay. I hope this inquiry sheds light on the importance of patient voice, patient-centered care, and the powerful positive influence we can have on the lives of others when we understand ourselves as human beings.

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Appendix B

Sample of Interview Transcript

Heidi: Do you feel like you received enough information in all the time you were here?
Mary: Yes, I found that they were good, very good at answering the questions I asked. Of course I say right up front: “I ask questions, please plain and simple, tell me plain and simple, don’t beat around the bush, just tell me” You know? And they’ve been very good. Any time I’ve asked anything, they’ve told me exactly what I wanted to know.
Heidi: And with the information that you got, or with the people that came in, did you find that there were any challenges or things that you found more difficult during your hospital stay?
Mary: No...I found it...
Heidi: Or...
Mary: There is one thing that I found very annoying that made me very angry and that was doctor...I have her name written down there...
Heidi: (giggles) To that point you have it written down?
Mary: (giggles) Uhm...she, from the time I get up here, she kept telling me “You can’t stay here to have the test, you should go out to out-patient clinic. You can’t stay here. We need the beds, you know you’ve got to...” [Heidi: Uh hum]. Five times she come in and send the same thing and each time she’d come in, the doctor sent me for another test, so I said to her, I said: “I’m not going anywhere until I get the results of the tests I’ve just done”. But she was here every day, she she made me so mad (laughing). I was, I was so angry, at her, that I was going to call the Ombudsman [Heidi: uh um] and put in a complaint because that’s harassment as far as I’m concern. That’s, you know, that’s ridiculous. Just because I’m not vomiting on the floor or something, I’ve got a problem.
Heidi: You can call anyways...
Mary: I got over it, you know... [Heidi: Yah...] But that’s the only thing that really annoyed me. [Heidi: Hum] You know and I said, I said. (coughs) Excuse me. If it was somebody that was really sick and in the bed, that is not going to help them, that kind of harassment is not going to help them get better. [Heidi: Uh hum]. It’s just going to aggravate them all the more, you know, I mean at least I could talk back, but that was the only thing because the nurses here are great. [Heidi: Ok]. Yeah, and so are the orderlies, they are very good. Yep, I have no complaints whatsoever about any treatments I’ve received or anybody I asked anything to, they were very forthcoming in telling me, explaining to me what I wanted to know. You know...
Heidi: Would you say that that was an important part of your recovery or stay here?
Mary: It is, it is for me because as long what’s happening and why it’s happening I don’t fret about it, I don’t lay and worry about it. I just know what’s going to happen, I know why it’s going to happen and that makes me feel better because I know, it’s like I’m on top of the situation, I know (giggles).
Heidi: Yeah.
Mary: You know which sounds strange maybe [Heidi: No no] but that’s how I feel.
Heidi: But you felt that way.
Mary: That’s how I felt, yeah.

Notes:
Commas were used for short pauses. Long pauses are indicated with (...).